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HEALTH WORKER'S PRACTICES AND PERSPECTIVES ON THE ALLOCATION OF SOLID ORGANS BASED ON THE GOVIND PERSAD ET AL. CRITERIA: A CASE OF MULAGO HOSPITAL

BY:

MWEBAZA DEBORAH BETTY.

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A RESEARCH DISSERTATION SUBMITTED TO THE DIRECTORATE OF RESEARCH AND GRADUATE TRAINING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF A MASTERS OF HEALTH SCIENCES IN BIOETHICS DEGREE OF MAKERERE UNIVERSITY.

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DECLARATION

I, MWEBAZA DEBORAH BETTY, declare that to the best of my knowledge, this dissertation has not been presented to this university or any other institution of learning for an academic award.

Sign……………………………………… **Date**……04/02/2026……………………

This dissertation has been submitted with approval from the supervisors:

Dr. Fredrick Nelson Nakwagala (MBChB, MSc, M.MED, MA. BIOETHICS)

Department of Anatomy

School of Biomedical Sciences

Makerere University, College of Health Sciences

Sign: …………………………………………… **Date:** ……4/2/2026……………

Prof. Ibingira Charles (MBChB, M.MEB)

Department of Anatomy

School of Biomedical Sciences

Makerere University, College of Health Sciences

Sign…………………………………………… **Date**……4/2/2026……………

Dr. Haruna Kiryowa (MBUnB, MMED)

Department of Anatomy

School of Biomedical Sciences

Makerere University, College of Health Sciences

Sign…………………………………………… **Date**……04/02/2026……………

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OPERATIONAL DEFINITIONS

Perspectives: Describes a specific method of thinking about something that varies depending on the individual.

Practices: The practical implementation of a concept, theory, or approach, as opposed to its theoretical underpinnings.

Solid organ: A type of organ that is not hollow and has a dense, compact structure. Examples include liver, kidneys, heart, pancreas, spleen, lungs.

Organ allocation: The procedure for deciding the distribution of organs. Allocation comprises the set of rules and regulations that guarantee the fair, moral, and medically sound distribution of organs.

Organ donation: Donation is the giving of an organ and tissue to help someone who needs a transplant.

Organ Transplantation: Refers to the process in which an organ, tissue, or collection of cells is surgically removed from one person (the donor) and placed into another during a transplant.

Equity: Equity in health is the absence of systematic disparities in health (or in the major social determinants of health) between groups with different levels of underlying social advantage/disadvantage is, wealth, power, or prestige.

Equality: Refers to the right of different groups of people to have a similar social position and receive the same treatment.

Criteria: A principle or standard by which something may be judged or decided.

Healthcare worker: A healthcare worker delivers care and services to the sick and ailing either directly as doctors and nurses or indirectly as aides, helpers, laboratory technicians, or even medical waste handlers.

Attitude: Refers to the positive/negative evaluations by an individual toward a given practice or behaviour

Behavior: Pertains to the (aggregate of) acts or reactions that an individual produces in response to a particular circumstance.

List of Abbreviations

DALY	Disability-Adjusted Life-Years
ESRD	End Stage Renal Disease
ETKAS	Euro transplant Kidney Allocation System
GoU	Government of Uganda
HIV	Human Immunodeficiency Virus
HLA	High Level Architecture
ICESCR	International Covenant on Economic, Social, and Cultural Rights
KII	Key Informant Interviews
LDT	Living Donor Transplantation
LMICs	Low- and Middle-Income Countries
NGOs.	Non-Government Organizations
PI	Principal Investigato
QALY	Quality-Adjusted Life-Years
SSA	Sub-Saharan Africa
UHODTA	Uganda Human Organ Donation and Transplantation Act
UNOS	United Network for Organ Sharing
UK	United Kingdom.
USA	United States of America
WHO	World Health Organization

ABSTRACT

Background: Allocation of solid human organs is complex due to global scarcity amidst high demand necessitating transparent, equitable and efficient allocation policies. In Uganda, the absence of a formal organ distribution framework raises concerns about fairness and consistency in decision-making. This study explored the practices and perspectives of health workers in Uganda regarding organ allocation, guided by Govind Persad's ethical criteria.

Methods: A qualitative cross-sectional study was conducted with 15 health workers involved in organ transplant services at Mulago National Referral Hospital, Kampala. Key-informant interviews were audio-recorded, transcribed verbatim, and analyzed by two independent coders. Analysis was primarily deductive, guided by Ajzen's Theory of Planned Behaviour and Persad et al.'s multi-principle framework, complemented by inductive analysis to capture emergent themes. NVIVO 14 software supported data management and organization.

Results: Four themes emerged: practices for organ transplant scheduling, attitudes towards organ allocation based on Persad's ethical principles, perceived control and ethical dilemmas encountered. Current practices at Mulago Hospital are largely influenced by an institutional culture that prioritizes first-degree relatives identified by patients. Compatibility screening and psychosocial support are provided and standard operating procedures emphasize voluntarism, informed consent, and respect for religious values. Health workers expressed positive attitudes toward adopting global organ allocation models but emphasized the need for contextual adaptation. Perceived control over transplant scheduling was limited due to systemic constraints, including resource scarcity and infrastructure limitations, which negatively affect equity. Ethical dilemmas commonly arose from challenges in identifying familial coercion and managing emotional distress linked to transplant disqualifications or delays.

Conclusion: Formal organ allocation frameworks are essential for promoting equity and transparency in transplant scheduling. Adjusting global allocation models to align with the resource, cultural, and systemic constraints represents a pragmatic approach to strengthening organ allocation practices at Mulago National Referral Hospital and similar resource-limited settings.

1.1 CHAPTER ONE: INTRODUCTION

The ethics of organ transplantation can be broadly divided into three key areas: determining when a person is considered dead, establishing when it is ethically acceptable to procure organs, and deciding how organs should be allocated (Veatch & Ross, 2015). The ethics of organ allocation in particular, represents a specific application of ethical principles to social practices (HRSA, June 2015). Allocation becomes necessary whenever the demand for scarce medical resources, such as solid organs, exceeds the available supply. Given that solid organs are particularly limited and irreplaceable, allocation decisions made by stakeholders especially health workers are both critical and highly valuable (Govind Persad, January 31, 2009). In this context, ethical principles provide the essential framework that guides and justifies these decisions. As general prescriptive norms, they guide the evaluation of actions and practices by identifying characteristics that render them morally acceptable (HRSA, June 2015).

Organ allocation lies at the intersection of clinical ethics and public health ethics. At the clinical level, health workers are guided by duties to individual patients, including beneficence, non-maleficence, and professional responsibility, and therefore consider factors such as medical urgency, prognosis, and treatment adherence when recommending candidates for transplantation (Beauchamp & Childress, 2019). At the same time, organ allocation is a public health concern, as it involves distributing scarce, life-saving resources across populations in a manner that promotes equity, transparency, and efficient use of limited organs (National Research Council, 2022). National and international allocation systems institutionalize these public health values through standardized policies that prioritize utility, urgency, and fairness, thereby shaping individual clinical decision-making (Health & Human Services, 2013; Oedingen et al., 2020). Ethical tension arises when clinicians must balance advocacy for individual patients with system-level obligations to maximize overall benefit and ensure equitable access Multi-principle frameworks, such as those proposed by Persad, Wertheimer, and Emanuel, reflect this intersection by integrating individual-focused and population-level ethical considerations (Govind Persad, January 31, 2009). In contexts such as Uganda, where formal allocation systems are still evolving, understanding how health workers navigate this intersection is essential for developing ethically robust and equitable organ Four ethical principles underlie allocation according to medical ethicists: maximizing benefits, treating people equally, prioritizing the most vulnerable, and promoting social usefulness (Yeung et al., 2022). These can be broadly categorized into three overarching approaches: need-based principles, maximizing principles, and egalitarian principles (Cookson & Dolan, 2000).

For many patients with organ failure, transplantation offers the only chance of survival, making allocation decisions ethically sensitive (Stegall, 2005). Robert Veatch argues that these difficult decisions should not rest solely with physicians, as they extend beyond individual clinical judgment. Instead, they represent a collective societal responsibility, entrusted to governments, courts, and organ procurement organizations, and guided by diverse stakeholders (Veatch & Ross, 2015). Allocation policies are therefore essential for fair rationing of scarce resources, with ethical principles providing the normative framework for local, regional, and national decisions.

No single principle, however, offers a universally accepted standard, which makes fairness ethically complex (Govind Persad, January 31, 2009). Consequently, a fair system often integrates several of these principles to reduce disparities and improve access based on objective evidence (Latt et al., 2022; Lee et al., 2019). Balancing and rank-ordering these principles is a key responsibility of stakeholders, including health workers (Childress, 2022). Evidence suggests that resolving conflicts between principles requires weighing their relative importance and examining stakeholder perspectives (Elalouf & Pliskin, 2022).

Persad et al. proposed eight allocation principles: lottery, first-come-first-served, sickest first, youngest first, number of lives saved, prognosis, reciprocity, and instrumental value, grouped into four categories: equality, prioritizing the least fortunate, maximizing benefits, and social usefulness. Multi-principle frameworks, such as the Quality Adjusted Life Years, (QALYs), the Disability-Adjusted Life Years (DALYs), and the United Network for Organ Sharing (UNOS), better capture allocation complexities (Govind Persad, January 31, 2009).

A major strength of the Persad et al. framework is its pluralistic and non-absolutist approach. Unlike single-principle models, it accommodates the ethical reality that fairness in organ allocation requires balancing competing values rather than rigid adherence to one moral rule. The framework's flexibility makes it particularly relevant to national and institutional allocation systems such as UNOS, Euro- transplant, and the UK allocation model, which demonstrably combine principles of utility, equity, and urgency rather than privileging one exclusively.

Another strength is the framework's normative clarity. By distinguishing morally defensible principles from ethically weak ones such as rejecting first-come-first-served as arbitrary in life-saving contexts Persad et al. provide policymakers and practitioners with ethical guidance rather than merely descriptive criteria. This is particularly important in contexts where health workers function as gatekeepers, shaping both access to waiting lists and ultimate allocation outcomes.

Importantly, the framework has high relevance for emerging transplant systems, such as Uganda's. In the absence of operational allocation policies and regulatory bodies, Persad et al.'s principles offer a structured ethical vocabulary that can guide early policy development, professional deliberation, and stakeholder engagement. Their adaptability allows for contextual weighting of principles in resource-constrained settings where equity, feasibility, and public trust are critical concerns.

Despite its strengths, the Persad, Wertheimer, and Emanuel framework has several limitations some principles within the framework particularly reciprocity and social usefulness raise ethical concerns regarding Uganda fairness and discrimination. While reciprocity-based policies, such as those in Israel and UNOS donor-priority systems, have been shown to increase donation rates, they risk excluding individuals who face structural or cultural barriers to donation. Similarly, instrumental value, though defended during public health emergencies, challenges commitments to equal moral worth and may be difficult to justify for solid organ allocation outside exceptional circumstances.

Health workers serve as gatekeepers, evaluating needs, initiating procedures, and ensuring fairness in allocation (Oedingen et al., 2020). Their role extends beyond clinical care to influencing institutional practices and ethical decision-making related to organ allocation (Alameer, 2024).

In HICs, Euro transplant, UNOS, and Hong Kong's registry illustrate structured systems that integrate ethical principles into national allocation practices (Davison, Kromm et al. 2010; Alagoz 2008; Yeung, Coates et al. 2022).
Africa faces rising cases of non-communicable diseases, which contribute to organ failure and make transplantation a standard treatment option (Nyirenda, 2018). Yet most African countries lack legal frameworks, infrastructure, and skilled personnel for transplantation, creating risks for organ trafficking and transplant (Loua, 2020).

South Africa has an organ Donor Foundation (ODF). The Organ Donor Foundation assists with organ and tissue referrals whereby solid organs such as lungs, live, kidneys, heart and pancreas are donated if a loved one is diagnosed with brain death and is on ventilator in hospital. In which case a family member calls the ODF and the ODF passes the information to the nearest transplant centre and soon thereafter a transplant coordinator coordinates the person (ORGAN DONOR FOUNDATION, 2022). The ODF however does not have or use an organ allocation algorithm; their role is awareness, education, and facilitating donor registration, while the actual allocation is managed by medical professionals and transplant coordinators based on clinical criteria (optima). In Uganda, despite a growing need, there is no established allocation system. Although the Uganda Human Organ Donation and Transplant Act, 2023 enshrines fairness (Parliament of Uganda, 30th June, 2023), its regulatory body is not operational, and local adaptation of global principles remains. As Uganda progresses toward establishing systems to support deceased donor organ donation, the need for formal organ allocation mechanisms will inevitably arise. At that point, clear and contextually appropriate ethical principles will be essential to guide allocation decisions and ensure equitable access to scarce organs. In anticipation of this development, the present study examines health workers' perspectives on organ allocation ethics using Persad et al.'s framework, with a specific focus on kidney transplantation at Mulago National Referral Hospital. Given that many ethical and practical challenges associated with other solid organs are also evident in kidney transplantation, insights from this setting may help anticipate broader allocation challenges across organ types (Simmons et al., 1987).

There is limited evidence on Ugandan health workers' perspectives, particularly their understanding of ethical frameworks and their moral reasoning in the absence of formal guidelines. This study addresses that gap by exploring their views on organ allocation, guided by Persad et al.'s principles of allocation ethics.

1.2 PROBLEM STATEMENT

There is limited empirical evidence on how health workers in Mulago referral hospital understand, interpret, and apply ethical principles in organ allocation, particularly in the absence of formalized systems. Their moral reasoning, prioritization of competing principles, and practical decision-making processes remain underexplored. This knowledge gap constrains efforts to develop contextually appropriate, fair, and ethically robust allocation policies. Therefore, there is a need to explore health workers' perspectives on organ allocation ethics at

Mulago National Referral Hospital, focusing on kidney transplantation, to inform the development of locally and institutionally relevant and ethically grounded allocation frameworks.

Furthermore, there is no available knowledge as to whether criteria established elsewhere is appropriate in Mulago's context in regards to organ allocation/transplantation. Therefore, this study sets out to fulfil this knowledge gap and find a clear description of the current modus operandi in the allocation/transplantation of organs. The scope of this study is to substantially contribute to this ethical discussion based on Persad et al.'s positions. This study therefore builds mainly on the substantial set of ethical principles/criteria described by Persad and colleagues on allocation of scarce resources.

1.3 GENERAL OBJECTIVE:

The study aims to explore healthcare workers' practices and perspectives on the allocation of organs as a scarce resource based on Govind Persad et AL's criteria for the allocation of scarce resources.

1.4 SPECIFIC OBJECTIVES:

(i) To describe the current modus operandi/practice in the allocation of solid organs in Mulago National Referral Hospital.

(ii) To determine the perspectives of healthcare workers on the allocation of solid organs based on Govind Persad's criteria for allocation of scarce resources.

1.5 RATIONALE/ JUSTIFICATION

Health workers make decisions at the micro level of the healthcare system, which makes them key stakeholders whose opinions are essential. Their perspectives are crucial for developing effective interventions and improving patient care hence the need to understand their views. Further more, their perspectives could be incorporated into the forthcoming regulations, which may indirectly contribute to the improvement of health system performance (Michelle Irving, 2013).

Exploring stakeholder's perspectives of internationally recognized ethical criteria for organ allocation, as well as their moral decision-making processes in the absence of formal guidelines, can generate valuable evidence that may inform and guide the development of regulations by the council.

This study represents a timely and essential contribution to the discourse on organ allocation, particularly in light of the recent enactment of the Uganda Human Organ Donation and Transplantation Act 2023. Furthermore, there is a lack of empirical studies examining the allocation criteria preferred by health workers, which could inform the development of regulatory frameworks in Uganda. And this study has potential to contribute to ethical decision making in our health system and to promote equitable resource allocation.

This study will therefore contribute to the body of scholarly knowledge specific to the Ugandan context regarding of organ allocation.

Additionally, research assessing the applicability and effectiveness of allocation criteria established in other contexts is necessary to determine their relevance and potential impact within the Ugandan context. This gap in knowledge thus underscores the necessity for this study.

1.6 SIGNIFICANCE OF THE STUDY

This study will contribute to the existing body of literature on organ allocation particularly within the Ugandan context, through the dissemination of its findings.

This study will further establish a basis for subsequent research on organ allocation by offering a platform upon which future investigations may be done to build upon or extend its findings and address its identified limitations.

1.7 THEORETICAL FRAMEWORK

Theory of planned behaviour

Ajzen's Theory of Planned Behavior (TPB) was the basis of data collection and analysis. It is a social psychology framework that describes how attitudes, perceived behavioral control, and subjective norms all affect people's actions. That one’s behavior is a function of the three factors which together shape an individual’s intentions and ultimately guide behavior. The model predicts human social behavior and focuses on organizational behavior and human decision-making processes in the health domain (Ajzen, 2020). Attitude refers to an individual’s evaluation of engaging in specific behaviour and the resulting consequences what do I think. Subjective norms refer to social pressure from friends, colleagues or superiors. The three factors lead to an intention; your desire to perform the behaviour. Social norms represent and individual’s beliefs on how his referents or significant others expect him to act regarding a given behaviour. This theory aided exploration of health workers perspectives on the different ethical principles as aligned with their moral judgement on potential course of action in the face of dilemmas to allocate organs.

In this study, the Theory of Planned Behavior functioned as an interpretive lens to understand health workers' practices and ethical reasoning around organ allocation.

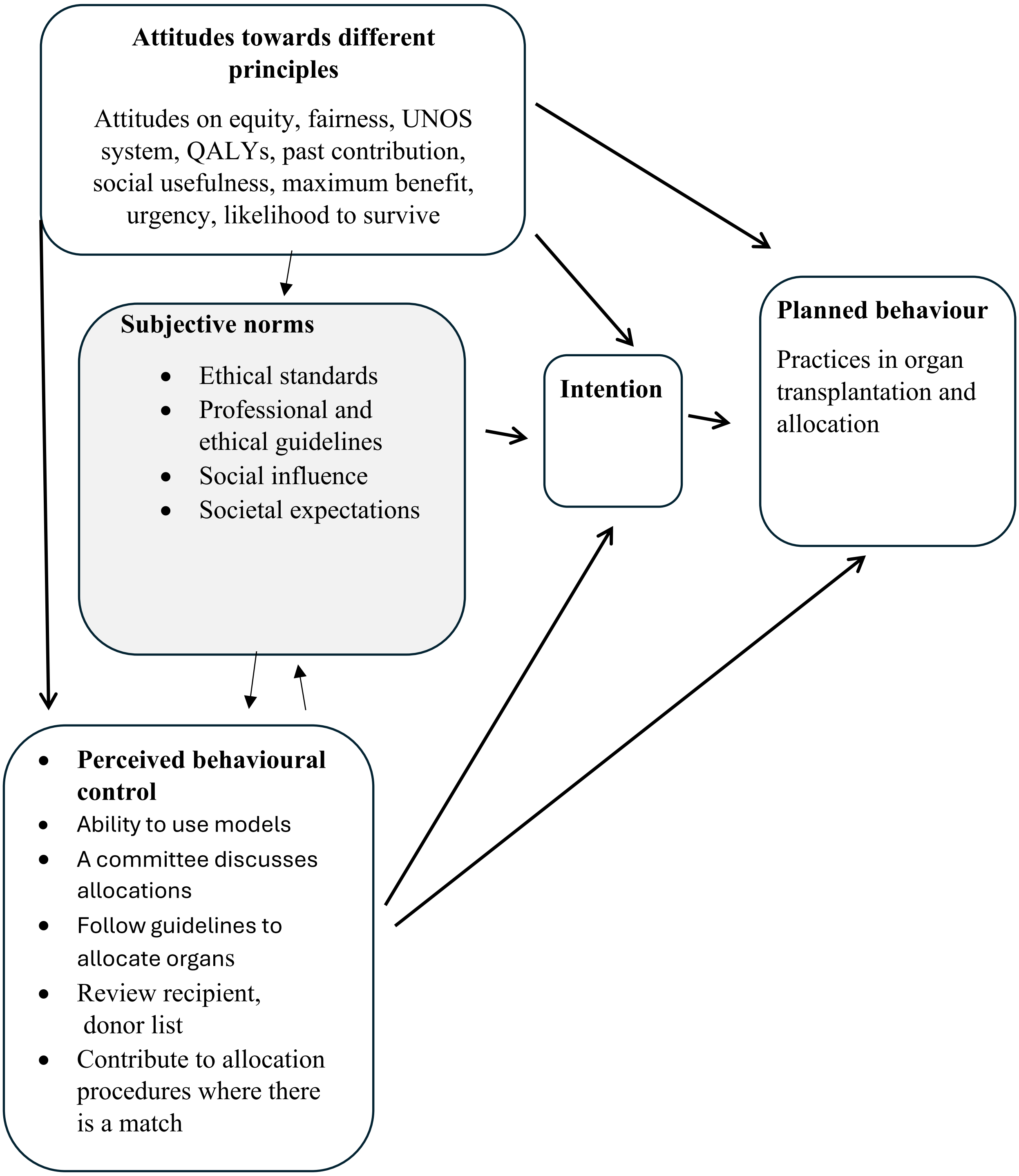
1. TPB helped explain why health worker's stated ethical ideals such as equity, fairness, patient-centeredness did not always align with their actual practices;

- Attitudes*:* Health workers generally valued saving life and maximizing transplant success.
- Subjective norms*:* Professional expectations, peer practices, and family pressures shaped what was considered appropriate or acceptable.
- Perceived behavioural control*:* Severe resource constraints, lack of national guidelines, and financial barriers limited what clinicians felt able to do.

2.Understanding the gap between policy ideals and real-world behavior; TPB illuminated how structural constraints reduced perceived behavioural control, leading health workers to prioritize patients who were financially prepared, had family support, or had readily available donors even when this conflicted with equity-based principles.

3. Interpreting family and affordability influences
Family involvement and patients' financial capacity functioned as subjective norms and control factors**.** Health workers perceived strong family backing and affordability as enabling conditions that made transplantation possible, thereby influencing their willingness to proceed.

Theoretical Framework



This chapter introduced the study by outlining the background to organ allocation practices, the problem statement, study objectives, research questions, and the ethical and contextual justification for examining health workers' perspectives at Mulago National Referral Hospital. It also presented the scope, significance, and methodological overview of the study.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 BACKGROUND

2.1 Introduction

Organ transplantation is a life-saving medical intervention for patients with end-stage organ failure and represents a critical component of modern healthcare systems worldwide. Despite advances in transplant medicine, the demand for solid organs continues to far exceed supply, resulting in persistent global scarcity and difficult decisions regarding allocation. This shortage has significant ethical, clinical, and public health implications, as healthcare systems must determine how limited organs can be distributed fairly and effectively. Globally, disparities in organ donation rates, healthcare infrastructure, and regulatory frameworks further complicate transplantation practices. In low- and middle-income countries, including those in Sub-Saharan Africa and Uganda specifically, these challenges are intensified by resource constraints, limited transplant programs, and sociocultural factors influencing organ donation.

This chapter reviews existing literature on the ethics of organ allocation, with a particular focus on ethical principles, allocation frameworks, and the role of health workers in allocation decision-making. The review situates the study within both normative ethical theory and empirical evidence from clinical practice, drawing on global experiences to inform understanding in low- and middle-income country contexts, particularly Uganda. Emphasis is placed on consequentialist, egalitarian, and need-based approaches to allocation, as well as multi-principle frameworks such as those proposed by Persad, Wertheimer, and Emanuel.

Scope of the Review; The scope of this review encompasses peer-reviewed empirical studies, ethical analyses, and policy documents related to organ allocation and transplantation. It covers both high-income and resource-constrained settings, examining how ethical principles are translated into practice at individual, institutional, and national levels. Particular attention is given to kidney transplantation as a model for understanding allocation challenges, while also drawing insights applicable to other solid organs. The review explores health workers' perspectives, allocation criteria, decision-making practices, and system-level influences on ethical judgment.

Sources of Data; The literature reviewed was drawn from multiple sources, including peer-reviewed journal articles, ethical and philosophical texts, international guidelines, and policy documents. Key sources included biomedical and social science databases such as PubMed, Scopus, and Google Scholar, as well as publications from organizations involved in transplantation and health policy, including the World Health Organization, the Health Resources and Services Administration, and the United Network for Organ Sharing. Contemporary empirical studies were included to ensure both theoretical depth and practical relevance.

Limitations of the Review Process; Several limitations should be acknowledged. First, the review relied primarily on published English-language literature, which may have excluded relevant studies published in other languages. Second, there is a relative scarcity of empirical research from low- and middle-income countries, particularly from sub-Saharan Africa, limiting the availability of context-specific evidence. Consequently, findings from high-income countries were used to inform discussion, which may not fully capture the realities of resource-constrained settings. Finally, as this was a narrative rather than a systematic review, the selection of literature may be subject to publication bias and may not represent all available evidence on the topic. Despite these limitations, the reviewed literature provides a robust conceptual and empirical foundation for examining health workers' perspectives on organ allocation ethics in Uganda.

2.2 Perspectives of Healthcare workers on the allocation of organs.

In the United Kingdom, McMillan and Briggs surveyed 190 nephrologists and transplant surgeons and found that patients were substantially more likely to be selected for transplantation if an adequate supply of donor kidneys existed, emphasizing the principle of maximizing total benefit, particularly the "save the most lives" criterion (McMillan, 1995). Similar findings were reported by Tong et al., who noted that nephrologists from 15 Australian transplant and nephrology clinics endorsed the incorporation of age compatibility in allocation policies to ensure younger candidates receive younger and higher-quality kidneys (Tong et al., 2010).

A study conducted in Australia examined the views of both the general public and healthcare professionals regarding organ allocation principles. Participants were asked to rank various allocation criteria based on perceived importance (Sypek, 2022). The authors concluded that policymakers should recognize significant divergences between the priorities of healthcare professionals and those of the general public concerning the allocation of deceased donor kidneys (Sypek, 2022). Among healthcare professionals, the highest-ranked principles related to utility, and included allocating higher-quality organs to those with the best predicted survival or to the young. These findings suggest that health professionals prefer allocation based on utility (Howard et al., 2015).

In the United States, Thamer et al. explored the relative importance of clinical and non-clinical factors in transplant recommendations. Their results demonstrated that nephrologists frequently relied on a combination of clinical, social, and demographic variables when assessing hypothetical patient scenarios. Notably, older patients were significantly less likely to be recommended for transplantation compared to younger individuals (Thamer, 2001). A separate survey conducted by the Patient Care and Education Committee of the American Society of Transplant Physicians revealed variability in candidate acceptance criteria across centres participating in the UNOS (Ramos, 1994.).

Moss and Siegler reported that liver transplant candidates who developed end-stage liver disease through no personal fault were often prioritized over those whose disease resulted from alcohol-related behavior, reflecting societal concerns about fairness and public support for transplantation programs (Moss, 1991).

Tong et al. highlighted the tension between maximizing efficiency and ensuring equity in organ allocation. Behavioral factors such as substance abuse, treatment adherence, and self-harm history were frequently invoked to justify allocation decisions aimed at improving therapeutic outcomes. These considerations were framed within the context of treatment prognosis and anticipated social benefits (Michelle Irving, 2013). Oedingen et al. outlined a discrete choice experiment designed to investigate how different stakeholders including medical professionals weigh key principles such as equity or equal access, likely benefit, and medical urgency in organ allocation decisions, reflecting an empirical and data-driven approach to understanding decision criteria in transplantation (Carina Oedingen, 2018).

In Qatar, Alsaied et al. assessed the knowledge and attitudes of health-care professionals regarding organ donation and transplantation and found that, although most physicians and nurses supported organ donation in principle, nurses were more likely than physicians to report insufficient knowledge and a desire for more training in identifying potential donors.

Participants generally did not view organ donation as conflicting with their religious beliefs, and religious objections were minimal, but many respondents held misconceptions about aspects such as organ sale and donation practices (Alsaied, 2012).

2.3 Practices of Health Care Workers in the Allocation of Organs.

Access to the waiting list for an organ transplant is the fundamental prerequisite to organ allocation. Appropriate referral for transplant evaluation is in the province of those caring for the patient with organ failure such as the end stage renal disease networks in the case of kidney disease. Both geographic and socioeconomic challenges may impact referral for transplantation (HRSA, June 2015). The UNOS lung allocation policy, now incorporates medical urgency and transplant benefit. This model has been adopted by Germany, the Netherlands, and the broader Euro transplant community for cross-border organ distribution (Egan T. M, 2018). The final rule requires UNOS and or the Organ Procurement and Transplantation Network (OPTN) to develop allocation policies that are equitable and to promote the efficient management of organ placement with consideration of the ethical principles of utility, equity, transparency, and autonomy (HRSA, June 2015). Australia has a fully nationalized kidney transplant system that operates across the country almost exclusively through the public hospital system. The main goals are; improving access to transplant for highly sensitized patients; improving utility of donor organs; and improving accessibility for HLA matching for younger patients and homozygous recipients (Yeung et al., 2022).

South Africa has an organ Donor Foundation. (ODF). The Organ Donor Foundation assists with organ and tissue referrals whereby solid organs such as lungs, live, kidneys, heart and pancreas are donated if a loved one is diagnosed with brain death and is on ventilator in hospital. In which case a family member calls the ODF and the ODF passes the information to the nearest transplant centre and soon thereafter a transplant coordinator coordinates the person (ORGAN DONOR FOUNDATION, 2022). The ODF however does not have or use an organ allocation algorithm; their role is awareness, education, and facilitating donor registration, while the actual allocation is managed by medical professionals and transplant coordinators based on clinical criteria (optima).

In high income countries (HICs) like Europe, organ-sharing networks such as Euro transplant are used and they prioritize utility, aiming to optimize graft matching across participating countries (Davison, 2010). The United Kingdom’s allocation system similarly emphasizes maximizing transplant benefit, while North American approaches often value egalitarian principles such as waitlist time.

The United States permits private and organizational initiatives, such as UNOS's priority system favoring registered organ donors in kidney transplantation, reflecting ethical considerations of reciprocity without resorting to financial incentives (Trotter, 2008). The UNOS lung allocation policy, originally based on waiting time, now incorporates medical urgency and transplant benefit. This model has been adopted by Germany, the Netherlands, and the broader Euro transplant community for cross-border organ distribution (Egan T. M, 2018).

Israel’s 2008 Organ Transplant Law incorporated reciprocal altruism by granting allocation priority to individuals who, or whose family members, consented to organ donation posthumously. This policy significantly improved national donation rates by reinforcing the moral value of reciprocity (Ashkenazi, 2015). During the COVID-19 pandemic, European countries adopted allocation strategies prioritizing frontline healthcare workers and elderly care residents for vaccination, based on their instrumental societal value; a principle that could similarly influence solid organ allocation (Cylus, 2021).

In another study, healthcare professionals emphasized that maximizing expected long-term transplant success should take precedence over urgency that is, the immediate risk of death—when determining organ allocation priorities (Tobiasch, 2015).

In a study exploring factors influencing nephrologists’ decision-making regarding patient eligibility for kidney transplantation, respondents including both practicing nephrologists and trainees were more likely to recommend transplantation for hypothetical candidates who were younger, of normal weight, and adherent to treatment. In contrast, candidates who smoked or had comorbidities such as diabetes or cardiovascular disease were less likely to be recommended for transplantation. Notably, no significant differences in recommendations were observed based on patient sex or ethnicity (Cass, 2007).

In conclusion, the reviewed literature provides substantial insight into healthcare workers’ perspectives and practices in organ allocation. Across diverse contexts, studies consistently demonstrate a strong preference among healthcare professionals for utility-based principles, especially maximizing survival benefit and graft longevity, often operationalized through age, prognosis, and medical suitability. Equity, urgency, and fairness are acknowledged as important ethical considerations, but they are frequently subordinated to utility in practice.

This reflects a persistent ethical tension between efficiency and justice that remains unresolved in both policy and clinical decision-making.

However, several critical gaps emerge from the literature. First, there is a geographical and contextual gap**,** as the majority of empirical studies originate from HICs such as the United Kingdom, Australia, the United States, and Europe. These settings are characterized by deceased-donor programs, national registries, and formalized allocation systems, which limit the applicability of their findings to low- and middle-income countries (LMICs), where transplantation often relies heavily on living donors and informal, patient-driven processes.

Second, while healthcare workers' ethical preferences are well documented, there is a disconnect between stated ethical principles and actual allocation practices**.** Many studies rely on surveys and hypothetical scenarios, offering limited insight into how decisions are made in real-world, resource-constrained clinical environments. The influence of socioeconomic status, health system capacity, and institutional constraints on allocation decisions is often underexplored.

Third, the literature gives insufficient attention to the role of healthcare workers as gatekeepers in the absence of national allocation frameworks. Although variability in decision-making across centers is acknowledged, few studies examine how informal norms, and institutional cultures shape allocation outcomes, particularly in decentralized or weakly regulated systems.

Finally**,** living-donor specific ethical challenges such as familial coercion, gendered patterns of donation, informed consent, and moral distress among health workers are inadequately addressed. Most allocation frameworks and empirical studies are grounded in deceased-donor models, leaving a significant gap in understanding ethical decision-making where living donation predominates.

In summary, the literature reveals a strong emphasis on utility-driven allocation principles among healthcare workers but highlights important gaps regarding context, practice, and lived ethical complexity. These gaps underscore the need for context-sensitive empirical research that examines healthcare workers' practices and perspectives within LMIC settings, particularly where living donation, informal allocation mechanisms, and resource constraints fundamentally shape ethical decision-making.

This chapter reviewed relevant literature on organ allocation ethics, including clinical and public health perspectives, theoretical frameworks, and empirical studies, to situate the current research within existing knowledge.

3.0 CHAPTER THREE: METHODOLOGY

3.1 STUDY DESIGN

This was a qualitative study that used a cross-sectional design to explore practices and perspectives of health workers on Organ allocation criteria in Mulago hospital. Key informant interviews were conducted to gather in-depth insights into their experiences and ethical perspectives regarding organ allocation.

3.2 Research Team and reflexivity

The interviews were conducted by the principal investigator assisted by an experienced research assistant with a Master's degree in Bioethics and training in qualitative interviewing techniques. They had no prior relationship with the participants. Their professional training reduces bias, and reflexivity was maintained throughout data collection and analysis. The researchers' professional backgrounds in health ethics and clinical practice meant that they entered the study with certain preconceptions, including the assumption that ethical principles such as fairness and maximisation of benefit are valued but inconsistently applied in practice. Reflexivity was actively maintained throughout data collection and analysis. Prior to data collection, these assumptions were explicitly discussed within the research team to heighten awareness of their potential influence on questioning and interpretation. During interviews, open-ended and neutral probes were used to minimise leading participants toward these expectations. Throughout analysis, emerging themes were continuously checked against the raw data to ensure they were grounded in participants' narratives rather than researchers' prior beliefs.

3.3 Study Setting

The study was conducted at Mulago National Referral Hospital (MNRH) at the transplant ward on ward 6A which also houses the kidney dialysis unit. MNRH is a national tertiary-level healthcare facility in the Kampala established in 1913. It provides services in internal medicine, pediatrics, and surgery, along with all of their subspecialties (Mulago National Referral Hospital, 2024).

3.4 Study Population

The study participants were doctors, nurses, and laboratory technicians. These were selected because they are directly involved in organ transplantation activities.

3.5 Participant Sampling and sample size

The study participants where purposively selected following after the Snowball (Chain) Sampling. This was done with the help of the unit in-charge, who recommended the initial team for interview, after which the remaining participants were recruited through purposive snowball sampling and we set appointments with them. Participants were then asked to recommend other individuals from their network who also fit the study's requirements. Creating a chain Reaction whereby new participants are added, and they, in turn, provide more referrals, expanding the sample organically. And this process continued until the desired sample size was reached and no new relevant contacts could be found.

We hoped to get data saturation if all cadres were represented and no new study information was generated. Accordingly, 15 participants were recruited and the interview process was concluded at that time because we had reached saturation.

3.6 ELIGIBILITY CRITERIA

3.6.1 Inclusion criteria

- Health workers who were Willing to participate in the study
- Health workers involved in organ transplantation or allocation at Mulago National Referral Hospital.

3.6.2 Exclusion criteria

- Health workers unavailable during the study period

3.7 Data collection methods

A key informant interview guide was used to collect the data. This guide was developed by the principal investigator based on the study objectives and approved by a team of research supervisors. The guide comprised of questions and probes on; 1) health worker perspectives which sought for respondents' opinions about engaging in specific behaviour and the resulting consequences. 2) Subjective norms which included social pressure from friends, colleagues or superiors, institutional culture, professional guidelines, ethical standards which influence the different decisions made on organ allocation, and 3) Perceived behavioural control in terms of ability of health workers to make allocation decision and the related barriers that exist to decision making on allocation of organs. Respondents were identified by the ward in charge who both recommended and helped introduce me to the participants who were relevant to achieve the goal at hand. Appointments were made with them via phone call, and a convenient and quiet place was chosen to conduct a physical interview. This approach enabled the data to be collected in a comfortable and less distractive environment. Data were recorded on a secure password protected device, and notes were written to make note of observed nonverbal communication. A socio-demographic form was used to collect descriptive data on the participants. All interviews were conducted in the English language. The average length of the interviews was 35 minutes.

3.8 Data management

All study data were securely stored to ensure confidentiality and data integrity. Hard copy materials, including informed consent forms and socio-demographic data collection forms, were kept in lockable cabinets accessible only to the PI. Electronic data, including audio recordings and verbatim transcripts, were stored on password-protected devices and encrypted folders throughout the research process. Access to both physical and electronic data was restricted to study-delegated personnel, specifically the Principal Investigator, the research assistant, and the data analyst.

Data sharing was limited to authorized members of the research team and conducted solely for purposes related to data analysis and reporting. No identifiable data were shared with external parties. Following completion of the study and dissemination of findings, hard copy documents will be securely destroyed through shredding, while electronic files will be permanently deleted from all storage devices in accordance with institutional and ethical review guidelines.

3.9 DATA QUALITY CONTROL

Several measures were undertaken to ensure scientific rigour, credibility, and reliability of the data collected. Credibility was enhanced through the use of a well-structured, pre-tested interview guide that was informed by existing literature and ethical frameworks on organ allocation. Interviews were conducted by trained research personnel to ensure consistency in data collection and to minimize interviewer bias. Probing and follow-up questions were used to obtain in-depth and accurate responses, allowing participants to clarify and expand on their views.

To ensure reliability, audio recordings were used to ensure accurate capture of participants' responses, and interviews were transcribed verbatim to preserve the original meaning of the data. Transcripts were reviewed alongside audio recordings to confirm accuracy.

To enhance trustworthiness, data analysis was conducted systematically using an agreed coding framework, and emerging themes were discussed among the research team to ensure consistency and reduce subjective interpretation. Reflexivity was maintained throughout the study, with the researchers acknowledging and reflecting on their assumptions and potential influence on data interpretation. These measures collectively ensured the credibility, reliability, and overall rigour of the study findings.

3.10 Data analysis

Analysis was carried out by two coders, the principle investigator and a seasoned qualitative researcher and data analyst at the IDI who offered guidance during this rigorous process as the PI ensured that all coding answered study objectives throughout the process and also shared codes and other findings. A deductive analytic approach was employed, guided by Ajzen's Theory of Planned Behaviour (TPB) and the criteria proposed by Govind Persad et al., alongside an inductive process through which additional themes emerged during data analysis. Three transcripts from respondents in the categories of Nurse, Nephrologist, and Lab Technician were selected for data familiarization. This involved reading the transcripts and creating annotations from excerpts of statements by the respondents that addressed the study objectives. These were mapped onto the different aspects of the planned behaviour theory; after consensus was reached between the coders, the initial coding framework was formed. All transcripts were coded using the framework that was entered in NVivo 14 software, enhancing data organization and management of codes. New codes identified during the process were added onto the existing framework, and after analysis, a final codebook was populated. Themes and subthemes were identified from the various aspects of the theory, these include; Current practices on Organ Allocation in Mulago Hospital, perspectives/ attitudes towards the allocation of organs, based on Govind Persad et Al's Criteria, ethical dilemmas encountered and Health worker perceived control over organ transplant scheduling.

Coding frequencies and a matrix coding query were used to recognize patterns in the data and inform study results, which are illustrated with respondent quotes.

3.11 Ethical consideration

Ethical approval and clearance were obtained from the Department of Anatomy and the Makerere University School of Biomedical Sciences Research and Ethics Committee under REF: SBS-2025-719. Respect for study participants was upheld by ensuring voluntary participation, informed consent, and protection of participants' rights throughout the research process. All participants received clear and adequate information about the study's purpose, procedures, potential risks and benefits, and their right to decline or withdraw from the study at any time without any consequences. Privacy and confidentiality were strictly maintained during data collection, storage, and reporting. Interviews were conducted at times and locations convenient to participants, and in a manner that promoted comfort, dignity, and open expression of views. Participants were treated with professionalism and cultural sensitivity, and no form of coercion or undue influence was applied at any stage of the study.

Voluntariness was ensured by clearly informing participants that participation was optional and based on informed consent. Participants were free to decline or withdraw at any time without penalty or adverse consequences. Adequate information was provided before consent was obtained, and no incentives or coercion were used.

Data anonymity was ensured through the removal of all personal identifiers from study materials at the point of transcription and analysis. Participants were assigned unique identification codes, which were used on audio files, transcripts, and data extraction documents instead of names or personal details. Any information that could potentially reveal participants' identities, was omitted or generalized during transcription. The linking file that connected participant identities to identification codes was stored separately from the study data in a location accessible only to the Principal Investigator. These measures ensured that individual participants could not be identified in any reports, publications, or presentations arising from the study.

The study findings will be disseminated through academic channels, including a thesis, conference presentations, and submission to peer-reviewed journals. Study participants will be informed of the findings through a brief summary shared via email or during departmental meetings, ensuring that results are communicated in an accessible and non-identifiable manner.

This chapter described the methodological approach adopted to explore health workers' perspectives on organ allocation practices at Mulago National Referral Hospital. It outlined the qualitative cross-sectional study design, study setting, target population, sampling strategy, data collection methods, and analytical framework. Ethical considerations, measures to ensure trustworthiness, and study limitations were also discussed. This methodological foundation informed the systematic presentation of findings in the subsequent chapter.

4.0 CHAPTER FOUR: RESULTS

This chapter presents and interprets study's findings. The research conducted in July 2025 at Mulago ward 6A examined the health workers' practices and perspectives on criteria used for solid human organ allocation. MNRH is a national tertiary-level healthcare facility in the Kampala established in 1913. It provides services in internal medicine, pediatrics, and surgery, along with all of their subspecialties (Mulago National Referral Hospital, 2024). The study site was designated as Uganda's pioneer transplant center for Organ transplantation according to the UHODT Act, 2023. Furthermore, it possesses a substantial pool of medical professionals. By July 2025, 9 kidney transplants had been done in Mulago Hospital.

4.1 SOCIO-DEMOGRAPHIC INFORMATION OF PARTICIPANTS

A total of 15 respondents doctors, nurses and laboratory technicians were interviewed of which the majority of the respondents were male (10/15) and 13/15 were aged between 30-53 years. Five respondents were specialized nurses. Most respondents had a working experience of more than 6 years.

4.1.2 Table 1: Socio-demographics of participants

Characteristic	**Frequency**
SEX	
Female	5
Male	10
Total	15
AGE	
20-29	1
30-39	7
40-49	5
50-59	2
Total	15
N0. OF YEARS OF EXPERIENCE	
0-5	2
6-10	4
11-15	3
16-20	6

Total	15
AREA OF SPECIALIZATION	
Nursing	9
Doctors	2
Urologist	1
Nephrologists	1
Laboratory	2
Total	15

4.2 THEMES THAT EMERGED FROM THE INTERVIEWS

The results are organized around four major themes that emerged from the interviews, namely:

1. Practices for organ transplant scheduling,
2. Attitudes towards organ allocation based on Persad's ethical principles,
3. Perceived control and
4. Ethical dilemmas with the allocation process.

Table 2: THEME TABLE

Theme	**Subtheme/Codes**
1. Current practices on Organ Allocation in Mulago Hospital	**Subjective norms** Sub theme 1: Institutional culture • First blood relatives who are identified by patients are the main consideration for transplant • Screening to test compatibility • Psychosocial support, pre- and post-operative care are offered to the pair. Sub-theme 2: Professional guidelines • Follow Standard operating procedures Sub-theme 3: Ethical standards • Guided by religious values

	• Voluntarism and consent Autonomy is prioritized • Shared decision making
1. Attitudes towards the allocation of organs, based on Govind Persad et AL's Criteria	Sub-theme 1: Perception on the priority consideration of the different principles of allocation Sub-theme 2: Cultural appropriateness of global models to Uganda • Foreign models can be adopted with modification to suit the local context
2. Health worker perceived control over organ transplant scheduling.	Sub-theme 1: Systems versus Individuals Sub-theme 2: Contextual constraints • Limited infrastructure to increase organ transplants done • Lack of formal systems and models to guide organ allocation • Limited resources limit equity and fairness
4. Ethical dilemmas and considerations arising from current organ transplantation practices	• It is difficult to detect coercion in families • Emotional distress caused by disqualified pairs or postponed organ transplants • Structural injustice • Affordability was another dominant ethical issue. • Prioritization emerged as a central ethical concern • Tension between respecting donor autonomy and ensuring non-maleficence in clinical decision-making.

Theme 1: Current Practices on Organ Allocation in Mulago Hospital

Sub theme 1: Institutional culture

First blood relatives who are identified by patients are the main consideration for transplant

When asked to explain the current process through which patients receive organs, health workers reported that transplantation is currently limited to patients who have identified donors within their own families, such as siblings, parents, or cousins. They stressed that the term 'allocation of organs' is more suitable for the extraction of organs from cadavers in relation to the current practices at the hospital. Most of the information shared focused on how some of these ethical principles are applied to ensure that patients are given priority for a transplant schedule after they have identified their donors.

"…there would really be no allocation in terms of us, because the patient comes with their donor and the donor gives to the recipient. So, the maybe umm only area where we might talk about allocation is in maybe who gets surgery and who doesn't. Umm… Because surgery is beneficial in that it takes a patient off dialysis..." -KII-01

"So, in terms of who gets surgery and who doesn't, it would be, we usually look for the healthiest patient, patient and donor pair. That's number one. But also, number two, we have a first come- first serve criteria, in that if you don't, are not able to be transplanted during this camp, this medical camp, then the subsequent camp, you might be, you get your priority. for transplant" -KII 01.

"*If you're saying how organs are allocated, we are not, we're not allocating organs now. Patients who are sick with end stage kidney disease are asked to get to donors, and these donors must be one, be relatives*." –KII 09.

Screening to test compatibility

Majority of the respondents stated that another criterion they are using now is carrying out screening tests to ensure compatible matches. They take samples from the donors and recipients to ensure that they are in recommended health to undergo the transplant process and that they are medically compatible. These tests ensure that both the donor and patient have higher chances of survival after the operation.

"*From that one a suitable donor, the one that matches perfectly is selected by the medical team with the help of the results sent from the laboratory and the health status of the patient. So that's how it is allocated.*" –Male Nurse

"We are directly involved because we have to make sure that we assess the donor and make sure that it's a perfect fit for the recipient. Because it makes no sense getting a donor, and the the organ does not work for the patient. So, we are involved in each and every step, make sure the the donor is compatible with the recipient…" KII 05.

Psychosocial support and pre- and post-operative care is given

The health team, led by social workers, provides counselling to both the donor and patient in preparation for the possible outcomes of the screening process. Pre-operation and post-operation care are done to ensure that patients and donors are ready for the transplant, recover well, and maintain the organ after the procedure.

"Part of the preparation that we do preoperatively is a detailed psychosocial assessment."-KII 06.

"*We counsel them to prepare their minds psychologically so that they can go through this and then when they bring, when they identify donors so we bring the donors on board and also take them through the same criteria of investigations, counselling and then preparing them to be fit.*" –Male nurse

"Despite there and then patients are looking at receiving an organ, they think they will be fine but we are supposed to counsel them in accordance to what they are going to take post the operation. That is why we are involved into family counselling; we are involved in home visits. To see how the donor is going to cope up with his previous life compared with to the life he's going to live right now." -KII 03.

Sub-theme 2: Professional guidelines

Follow Standard operating procedures

The respondents also us informed that in their medical practices, the standard operating procedures are followed

"Whenever you are having guidelines in place, they really help a lot. Consistency, reliability, accuracy of whatever you're going to get out of the whole process, transparency, then cost effectiveness of implementation of the project…We treat, but we also know on the other part of the story that we give according to the standard practices, but we may not predict the survival rate." -KII 15.

Sub-theme 3: Ethical standards

Moral standards –everyone has a right to live

Health workers felt that every person has a right to live, and only God decides who should not live. This was strongly expressed when they were asked about principles of urgency, maximum benefit, and QALYs.

"To be fair enough, everyone needs a life. It's God only who takes life. So, I would look at, like, everyone has a right to life. So, giving someone an organ can be at random. You can give to anyone. But as I just told you, there are some things that you have to look into. But God gives life. So, I'm not saying I will kill someone of 100 years." –KII O4.

Voluntarism and consent

The respondents also emphasized that donors and patients must consent and that they are only operated if they express voluntarism and further sign informed consent forms to confirm that they were not coerced into the organ donation.

"*And on top of that, uh you must also consent, and part of your consent is you are not selling. Like, you are not giving anybody a debt."* -Male, doctor

"And this is aimed at ensuring this, uh whoever is donating the kidney has not been coerced, okay, into doing so, has not been paid." -KII 06.

Autonomy is prioritized

People who donate organs must be of sound mind and considered to make independent decisions. Respondents emphasized that younger donors below 18 years of age are rejected as their ability to make sound decision is not confirmed according the Ugandan context.

"*If we don't think you can make decision on your own, especially under age. That person will not be a donor, will not be accepted to donate. Yeah. So that means that, um, if a patient cannot* *make a decision, let me say is mentally whatever, then that person cannot be a donor because his decision will not, they will consider it non-informed decision*."—Male nurse

Shared decision making

With the transplant team exercising constrained/ limited discretion. Health workers described situations where they played a role of determining stable donors and doing test and had to ensure the donors voluntarily chose to donate without coercion. Patients and families' involvement included; finding a suitable donor, consent and logistical discussions

"*...they look at stable patients, and you need to be a close relative. So usually, we prefer the primary ones. So here I mean, it could be your brother, it could be your sister, it could be your dad. So, basically, if you are fit, don't have any other comorbidities, of course, there are those investigations they have to do, the baseline. Like, they'll get off the blood. They find out if you are compatible. Then they also do other serological tests. Once they realize you are fit and you have passed all those investigations, that's the time they can do the organ, organ transplant*". -KII 012

"*...the practice here is that, uh, a recipient gets a willing donor, and they come to the hospital"* -KII-015

Theme 2: Health Workers' Views on Organ Allocation in Relation to Govind Persad et al.'s Ethical Framework

Sub theme 1: Competing principles and their priority consideration

Respondents shared principles they would give priority consideration when allocating organs. Maximum benefit/ utility ranked highest, equity was second, followed by urgency. Fairness was selected with reservation that it cuts across all principles and social usefulness and past contribution were considered controversial with arguments that each individual is useful in their own way. QALYs was discussed with reservation and barely ranked, however, perceptions are shared.

Survival or maximum benefit consideration

Many respondents identified this as an important principle since the goal of health care is to save lives. They shared that every principle must work hand in hand to ensure that more lives are saved and maintained. They highlighted that it is important to maximize the chances of survival in each decision.

“*Maximizing overall, yes. Who can get the best out of this kidney? A transplanted kidney from living donors should live about 20, 25, sometimes 30. From the deceased donor, you're talking about seven to 10 years. So, who can pull out 10 years out of this kidney as opposed to seven or five? Or two or maybe one month. That's why the issue of can they afford anti-rejection medication, you know? So yes, maximizing the benefits to me is very important.”* -KII O9.

Perspectives on the Equity principle

This was considered the second-best principle to consider because of its limitations. They felt that equity is applicable when people have the same condition and more so when compatibility with the donor of an organ has been met. “*First come, first serve does not matter, whatever. Closeness in compatibility is what would matter, they talk about not equal distribution, but equitable. meaning that they give it where it is necessary.*” –KII O2.

They also shared that much as first-come, first-serve is a very important principle in regards to equality, it is limited by the fact that people have different needs at a given time hence it serves as a final decision maker incase people have the same condition. And that we cannot consider equality but equity in regards to organ allocation matters.

“But it falls short when you come to the actual distribution, you cannot have equality because, um. If, for instance, in, in, in the, in the row of the next 10 organs I'm getting, they're all blood A type A, it means the guide of part B of type B will not benefit. Then I may be looking as if I am being, I'm not practicing equality. So, equality cannot be sustained throughout the whole process”. -KII O9..

“*Yes. Might have come first, but after the transplant, what what next? Because it doesn't make any sense. I give you an organ and in two weeks or in two months. It dies off because you can't look after it.”* -KII O5.

They alluded to a case of poor patients, who cannot be prioritized if they have no means of maintaining an organ post-operation, since they will damage the organ, yet someone donated it, hence wasting organs and opportunity to save other people.

“It is really a good one because We are seeing these patients after their transplant, they have a line of so many medications of which they are going to put in their money. So, if someone

with a poor social background has gotten this organ, it will just be a waste."—Female Nurse

Urgency

This ranked third and was rated highly over QALYs and fairness more so if the goal is to save lives. Limitations and strengths are discussed below:

Urgency is considerable if it saves a life

Nevertheless, there were thoughts expressing that urgency was important depending on the situation; for instance, if it is a health emergency requiring the transplant for survival.

"*I think those who needs it urgently should be the priority*." – KII 13.

"*Usually, in medical setup, that is you have to first go for the emergency test. If the one who is the sickest, who is in dying point, that becomes emergency and you have to prioritize.*" --KII 14.

There is no urgency in the transplant process

This was a highly controversial principle based on the inferences made. One of the respondents highlighted that there is no urgency in organ allocation, more so in their current practice, since these are patients who have long been prepared and identified their potential donor. Worse still, precaution needs to be taken during screening to save the life by ensuring compatibility between donor and recipient for the best match and best survival.

"*Because it takes time to prepare. You cannot just tell me that it's urgent to transplant this person and has not yet gone the criteria of being screened…You have to take go through the screening and be able or your findings should be in line with what is required for someone to undertake a transplant. So, no urgency*." – KII 04.

Sickest person first may risk wasting organs

Other sentiments included that there is no point in attending to the sickest person first when it comes to organ allocation, because of other situations such as organ rejection by their body, hence wasting organs and tarnishing the goal for maximum survival. They preferred to first stabilize such patients then consider allocating organs or conducting procedures.

"*If I know your chances of surviving are very low. Okay? Why should I leave one who has I think that's where we talk of benefit*." _ KII-06.

Fairness perspective

They indicated that fairness cuts across all principles and should be considered in application. They referenced being nonjudgmental towards people with lifestyle challenges, such as smokers or drunkards, during the allocation of organs or prioritization for transplants. They argued that the priority is to save a life; therefore, they should be fairly considered since lifestyle choices can be modified after receiving advice or behavioural change counselling.

"*Every patient, as you said, is equal. So, you treat them equally. What we can do, we can counsel them and tell them what to do. Yes. But we can't ignore them because they have been misbehaving*." -- KII-08.

Social usefulness and past contribution

Respondents intimated that every individual is important in their capacity. As such, these principles were looked at as a basis for violating equality and fairness hence they were not much of a priority according to respondents.

"*I would consider, provided the patient or someone is fit. It's what I would really consider. I wouldn't really mind which role you play in the society. There are those people who play their role silently*." -- KII-12.

However, there was some leniency towards people who have ever donated an organ. Participants expressed preference for these ones, informing that if their life was endangered, priority should be given to them.

"*Definitely. That one, I'll give him chance because already has saved a life. So, I really will take him as a priority*."— KII-12..

QALYs principle

The majority thought that prioritizing the youngest first would be beneficial in our setting as such people are more productive and have less complications when compared to the elderly. And also because of life expectancy in Uganda and considering the youth are more than the older in Uganda in comparison to countries like the UK. However, some thought that an organ could be donated by a close relative who sees a social benefit to the individual considered elderly, which warrants justification. Others thought that life expectancy is an estimate and life span cannot be guaranteed, hence it cannot be the only consideration for allocation.

"I was in the UA, UK, and I saw them transplant an eighty or something year. And to them, their life expectancy is high. And when you look at Uganda, so those are the things that we shall be a country will be base on. You just don't do because others are doing it. You also look to your country. Is this beneficial to us? For them, they have the highest the they have as in in their graphs, they have more aged people than the young. But if you come to our country, you have the young more than the elderly." -KII O6.

"*You have met that criteria. It is now age which is what? Which is now limiting us. You are, the other person is 100 years, you're 25 or maybe even 30. This is a productive age. And we know once this person is, transplanted, he will be useful to the country. But, the one of a hundred years will be still taken care of and the government has to spend on this person, medication and all those things*." --Female, Nurse

Sub-theme 2: Cultural appropriateness of global models to Uganda

<u>Global models can be adopted but modified to suit the local context</u>

Most respondents strongly believed that foreign models for organ allocation can be adopted. They felt that these nations had researched these models and that they applied to any human being, and only resource constraints could be a barrier. They continued to emphasize that for aspects of the model that do not fit our context, modifications can be made after a series of lessons and local research.

"*I think the benefit of the benefit of being a developing country is that, we don't have to re-invent the will. So, we can see what works, in different settings and see how to modify it to fit in our settings, because we are different. But at the end of the day, we are still human beings. With the same emotions, with the same resource limitations in terms of availability of organs, and so many sick patients and the demand and supply problems, so some problems are the same*." –KII O1, Female.

Theme 3: Health worker perceived control over organ transplant scheduling.

Sub theme 1: Individual and systems control

Health workers contribute to allocation prioritization decisions. Most of the health workers believed in their contribution to decisions made when scheduling priority for the organ transplants. They contributed to these through populating and reviewing the donor and patient lists, and following guidelines and criteria to support decisions made.

"*We developed a register. We need, like, maybe 10 people to be worked on. And out of the 10 people from number one to 50, these numbers can be transplanted. We go back to our list according to their registration and say, who was the first? is the first in our number? then we develop according to the list of registration*." -- KII 04.

Sub-theme 2: Contextual constraints

Limited infrastructure to increase organ transfers done

They informed us that they have two theatres where organ transplants are performed, which limits their capacity to accept many patients at a given time because the limited space could lead to organ mismatch or misallocation. *Transplant has theatres inside. They are two. Plus, the ICU, the other side. So, for we have the two theatres are active at the same time. One theatre has a donor, and then one theatre has a recipient. Within the unit, we have not had so many, but, of course, with other hospitals who are carrying out transplant operations, surgeries. uh... Where what you have told, misallocation. Okay? Improper allocation, which comes from multiple transplants at the same time. We have we have had, issues mainly our issues which we have had, which I've seen in multiple transplant operations or surgeries which are being carried out in other areas, misallocation of the organ."*

--KII O7, Male.

Lack of formal systems and models to guide organ allocation

Health workers thought that the lack of formal systems to guide organ allocation is a barrier to the practice. They share that formal models are systemic and give clear guidance for allocation of donated organs.

"*No, we don't have the formal model. Informal models are very… it can turn to be problematic, and actually cannot give you, you can't work so much on it. You can't make a work plan for it. Formal model of things are better. Because you have something to rely on always*."—KII 02.

Limited resources limit equity and fairness

Respondents stated that the limited resources in our country affect observation of some principles, an example was that of equity because if the patient cannot afford post-transplant care, they cease to qualify in Uganda but in western countries, this care can be afforded for citizens by the government.

"I would wish they should, to choose the young one, to choose the young one with less complications, and because I have a feeling that if at all this person, like, in our probably, I don't know. I may not say what is abroad or for them, they have a lot of resources. But, as for my country, we still have limited resources, medically, like, things of care is not good, provision of medication, what is, like, available. Somebody may be having money, mmm? can be sustaining himself." –KII 011.

Theme 4: Ethical dilemmas arising from current organ transplantation practices

Emotional distress caused by disqualified pairs or postponed organ transplants

Health workers expressed feelings of empathy and emotional distress that comes when patients who have had several trials on being transplanted fail to make it to the operation due to compatibility issues, failure to make it to the list and other issues that contribute to the disqualification. This situation underscores the ethical and emotional tension faced by health workers, who must balance clinical safety with the disappointment and suffering of patients and families who have invested significant hope and effort in reaching the point of surgery.

"*So that, becomes very emotional cause they have come a long way, and then, the final bit is the patient and the donor have passed all the hurdles of, of telling the donor, identifying a donor, they've passed the hurdle of the screening and then the day of surgery comes and then the patient may for example get an infection and therefore you cannot donate them, I mean, you cannot do surgery because they have an infection*." –KII O1.

It is difficult to detect coercion in families

"*We had, a 19-year-old going to give his brother, and we were wondering if he could have been coerced? Yes. There was no question that he was a brother. He was a brother. But could he have been coerced by the parents? You know, give your brother, give your brother. Fortunately, or unfortunately for them, again, this patient was found to have, we call them donor specific antigens. So, there was going to be a bit of rejection."* -KII 09.

The quotation illustrates the ethical challenge of assessing voluntarism in familial donation, where family dynamics may subtly compromise genuine consent. Despite a legitimate donor–recipient relationship, the health worker questioned whether the young donor's decision was autonomous or influenced by parental pressure. This reflects how moral obligation and familial expectations can act as implicit coercion, making it difficult for health workers to distinguish voluntary altruism from socially imposed obligation.

Structural injustice

The exclusive reliance on living-related donation creates an ethical dilemma of structural injustice**,** as patients without biologically compatible or willing family members are automatically excluded from transplantation, regardless of clinical need.

"*...the legal framework encourages that we encourage more of, uh related donors. Okay. As opposed to other people outside the family as friends and distant. So, we usually take close relatives".* -KII 06

"*...the donor had some physical abnormalities, she's using, walking on clutches. She had spinal problems, but she's a donor. Then she was counselled that it could, is not easy. It and it will be difficult to harvest an organ from her. And it will leave, put her life at risk. But she insisted. Actually, all of them were not happy, and we I also felt touched because they were right, in their family they can't get any other donor because she was the only one willing and had committed to donate her kidney. But surely, she was disappointed, and I myself, I was disappointed, but nothing would be done because this is a person. Her herself is needy. She's really, if you could see her physically, she was not physically fit to donate an organ. So, it was kind of a dilemma*". - KII 08

Affordability as another dominant ethical issue.

Affordability was another dominant ethical issue. Health workers repeatedly linked transplantation decisions to patients' ability to meet the financial demands of transplantation, including investigations, immunosuppressive therapy, and post-transplant follow-up. In practice, patients who could not afford these costs were less likely to be considered viable candidates.

"*..., patients who are transplanted have got to get immunosuppressive medication. And it's not free. It's not free. It's not about to be free, and we cannot be seen to be hiding our heads in the sun. An advocate that should be given on the essential drug list. It's very expensive. 5,000 US dollars per patient per year. It's a lot. They'll drain the budget. So one of the criteria is that someone must show ability to afford costs, operative and rejection medication. So unfortunately, socioeconomic status has got to support his life after transplant. If transplant was an end in itself, then you could give it to everyone, but unfortunately it must be factored in".* - KII 09

Prioritization emerges as a central ethical concern

Prioritization emerged as a central ethical concern. Participants described informal criteria such as likelihood of transplant success, and availability of a compatible donor. These criteria reflect implicit utilitarian reasoning—maximizing survival and efficient use of scarce organs.

"...Who are most likely because what we look at, we check for so many things, blood level, age, and other thing. But there is what we call a compatibility". -KIII 07

"...*also looks at your ability to survive. There's no point I should take a kidney from her to give it to you when I know even when I give it to you, your ability to survive is minimal. Actually, what happens in such instances, we are advised against*". - KII06

Tension between respecting donor autonomy and ensuring non-maleficence in clinical decision-making.

Living donation presents an inherent ethical dilemma between respecting donor autonomy and upholding the principle of nonmaleficence. Health workers must approve procedures that expose healthy individuals to medical and psychosocial risks for the benefit of another.

"*...the brother he had selected who had also taken a dead year. From his senior six, I think also because our assessments take about six months, come take this and they were coming* *from very far. So, the guy had taken in a dead year, and he was found to have donor specific antigens Antibodies. So, the, the donor was rejected. So, we said we can't carry on with that. Now he got a younger brother, okay? Now, unfortunately, the younger brother also developed, was found to have specific antigen and I was feeling bad because he has been here twice. So, he is going to go and look for another relative. ...again, he had come with a brother and the brother was found to have, to have had TB. So, you do all these tests, you do all these tests, and you know, you think you've covered the ground, but later on as you, as you assess and ask questions and find that, oh, he has had a cough"* -KII09.

The findings of this study are largely consistent with existing literature on organ allocation ethics, particularly regarding the prioritization of medical urgency, prognosis, and anticipated benefit. Similar to studies from high-income settings, health workers in this study emphasized outcome-oriented considerations such as graft survival and likelihood of post-transplant adherence, reflecting utilitarian and benefit-maximization principles commonly embedded in formal allocation systems. However, unlike contexts with established national allocation frameworks, participants in this study described relying heavily on informal clinical judgment and team consensus, highlighting the absence of standardized allocation protocols in Uganda. This contrasts with reports from countries with mature transplant systems, where allocation decisions are more strongly governed by transparent, algorithm-based policies. Additionally, the prominent role of family involvement and affordability considerations observed in this study is less emphasized in the international literature, underscoring the contextual influence of resource constraints and sociocultural norms in low-income settings. These similarities and divergences illustrate how global ethical principles are selectively adapted within MNRH's evolving transplant landscape

This chapter presented the findings of the study, organized around key themes that emerged from the qualitative data. The results highlighted health workers' experiences with organ transplantation, perspectives on criteria for patient prioritization, ethical challenges, and systemic constraints influencing decision-making. These findings reflect the realities of organ allocation in a resource-limited setting and provide the empirical basis for interpretation and discussion in the next chapter.

5.0 CHAPTER FIVE: DISCUSSION

5.1 INTRODUCTION.

This study explored the ethical and practical dimensions of organ allocation in Uganda, focusing on health workers' perspectives on the ethical criteria used in situations of resource scarcity. Respondents explained how patients currently access organs and highlighted the stage at which Mulago Hospital stands in terms of organ transplantation. Uganda is still in the early stages of establishing an organ transplantation system. The regulatory council responsible for developing and overseeing organ allocation policies has not yet been established by the relevant ministry, resulting in a legal and policy vacuum in this area (ULII, 2023). Accordingly, the practice of cadaveric organ retrieval from brain dead donors, as provided for under Section 53 of the UHODT Act has not yet been legalized, thereby eliminating the possibility of posthumous donations (ULII, 2023). As a result, Uganda does not have a national organ bank or a structured allocation system yet, and transplantation practices are restricted to living donations from close family members.

Philosopher John Locke, in his work on the two treaties of Government emphasizes the superiority of individual rights and the necessity of the consent of the governed (Locke, 1988). This position implies that policies should be subject to deliberation and collective agreement prior to their implementation, thereby ensuring both legitimacy and the safeguarding of fundamental rights. Drawing on this principle, the present study sought to examine the perspectives of health workers regarding the ethical principles that should inform organ allocation once Uganda advances to the stage of nationwide distribution to patients on waiting lists, and to generate recommendations for policy development.

These ethical principles play a central role in guiding the allocation of scarce medical resources and are incorporated into organ allocation algorithms across different countries to promote fairness and equity among patients on waiting lists. As outlined by Govind Persad and colleagues, these principles include urgency, first-come-first-served, utility, priority for previous donors, social usefulness, the UNOS points system, quality-adjusted life years (QALY), and survival predictability (Govind Persad, January 31, 2009).

In the United States, for example, the UNOS system uses points and a continuous distribution system for organ allocation in the USA, where candidates receive a composite allocation score (CAS) for lung transplantation based on: the urgency of the candidate's medical need, the likelihood of post-transplant survival, the presence of biological factors that may complicate donor–recipient matching (e.g., blood type incompatibility, immune sensitization), the candidate's age (with priority for individuals under 18), prior living organ donor status, and the logistical efficiency of transporting lungs from the donor to the transplant centre with higher scores indicating greater priority for an organ (HRSA, June 2015).

5.2 Practices of Health workers in Mulago hospital

The findings from this study suggest that organ transplantation in Uganda currently relies exclusively on living donors, primarily first-degree relatives. Living-donor kidney transplantation is generally the preferred choice because it offers several advantages: quicker access to a transplant, less time spent on dialysis, higher chances of immediate kidney function, and better graft survival compared to kidneys from deceased donors. Still, for patients with end-stage kidney disease (ESKD) who do not have a living donor, receiving a kidney from a deceased donor provides a greater survival benefit than continuing dialysis (Foley, 2020).

The study also found that organ donation and transplantation is largely patient-driven, depending on individuals identifying suitable family donors. Health workers complement the process by managing the scheduling of the transplants, preparing and doing medical tests to ensure compatibility match. The practice which relies on familial donors excludes patients without suitable family members, an issue highlighted in global debates on transplant ethics (Tong et al., 2010; Venter, 2012).

Studies find that Living Donation has great advantages because it can be planned i.e., scheduled, wait-time is reduced, and organ ischemic time is reduced, leading to better recipient outcomes (Habbous, 2018). However, heavy reliance on familial donation not only limits the pool of potential organs but also delays the country's progression toward an equitable, systematized model of organ allocation for patients in need.

This patient-centered model naturally reflects disparities, since individuals' and families' willingness to donate organs is shaped by various factors, such as existing consent policies, beliefs about the body, interpretations of death, and altruistic or cultural values tied to solidarity and reciprocity, among others (María Victoria Martínez-López, November 2023). Trust is another factor which plays a major role in contemporary organ transplant policies and in differential rational attitudes toward donation (Almassi, 2014). Distrust in the healthcare system often discourages living donors, fueled by the belief that doctors might not make every effort to save a potential donor's life (María Victoria Martínez-López, November 2023). Public trust not only legitimizes the operations of the healthcare system but also fosters public engagement in health-related activities. This trust is shaped by multiple factors both within and beyond the healthcare system, including political dynamics and the state of infrastructure (Gille et al., 2021). Consequently, such dynamics often discourage participation in familial donation, as evidenced by existing studies, thereby underscoring the need for the country to expedite cadaveric donations and establish systematic organ allocation mechanisms.

The absence of a formal national system means that decision-making often rests with individual health workers, who act as "key gatekeepers." This informal process can lead to subjectivity and inconsistency, a concern echoed in studies from other contexts (Machin et al., 2022).

This patient-driven model perpetuates disparities by favoring individuals with greater knowledge, resources, or networks. Evidence shows gender and relational inequalities in transplantation: women are more likely to donate kidneys but less likely to receive them, reflecting gendered caregiving norms and altruistic behaviours that disadvantage female recipients (Daw et al., 2024).

Health workers also face emotional strain and ethical dilemmas, such as ensuring genuine informed consent and detecting coercion of donors within families, a persistent challenge in living donation globally (Abboud et al., 2008). Living donation challenges the principle of nonmaleficence by exposing healthy individuals to medical, psychosocial, and uncertain risks. Thus, ensuring adequate informed consent is ethically essential, both to respect donor autonomy and to safeguard their well-being (Gordon, 2012).

Findings of this study also suggest that the principles of voluntarism and autonomy are paramount, as emphasized by health workers. This principle asserts that individuals should be able to exercise personal determinations (Yeung et al., 2022). However, the familial context can complicate these principles, as donors may feel a moral or social obligation to donate, even if not explicitly coerced. The WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation explicitly state that donors should be voluntary and unpaid, a standard that is challenged by the complex family dynamics at play in such systems(Sixty-Third World Health Assembly, 2010).

The results highlight how family relationships and associated duties strongly shape decisions around living organ donation. Participants' accounts suggest that emotional bonds within families often intensify the sense of moral obligation to donate, particularly because living related donors are typically also emotionally related to recipients. This dual relationship can create ethical tension, as the desire to help a loved one may blur the line between voluntary consent and subtle forms of undue influence, emotional pressure, or coercion. Such concerns were frequently raised in relation to living related donation, where expectations linked to kinship and caregiving roles may compromise donor autonomy (National Academies of Sciences, 2006.).

Although health workers emphasized principles of fairness and equity, the findings indicate that a patient’s ability to afford post-transplant care and lifelong immunosuppressive therapy significantly shapes prioritization decisions. This reflects an ethical tension between maximizing graft survival and overall utility, and the obligation to avoid discrimination against economically disadvantaged patients (Govind Persad, January 31, 2009). Consequently, poverty operates as an implicit exclusion criterion, undermining distributive justice and equity in access to transplantation, particularly in resource-constrained health systems (Ministry of Health Uganda, 2010). The findings also indicate that living donation presents a fundamental ethical tension between respecting donor autonomy and upholding the principle of non-maleficence, as health workers are required to sanction procedures that expose healthy individuals to medical and psychosocial risks for the benefit of another (Beauchamp & Childress, 2019)

While health workers valued equity and fairness, the study found that socioeconomic status significantly influenced decisions, particularly concerning a patient's ability to afford post-operative care thus undermining their authority over the allocation processes. This is a common hurdle in low and middle-income countries, where a lack of financial resources can be a significant barrier to receiving care, even if a donor is available (Olawade et al., 2025).

The study found that the Ugandan health workers' approach, also prioritizes the ethical principle of maximum benefit (survival), reflecting a pragmatic utilitarianism common in limited-resource settings (Govind Persad, January 31, 2009). This means that priority is given to patients most likely to have a successful and long-lasting transplant, a principle also seen in Western allocation systems, where factors like post-transplant survival are heavily weighed (Lee et al., 2019).

The current approach emphasizes medical compatibility through screening, particularly HLA matching, to enhance graft longevity and patient outcomes, reflecting the principle of utility. Additionally, longevity-matching is increasingly prioritized as an important consideration in preserving a scarce resource (Dyer et al., 2001). Systematic pre-allocation compatibility checks reduce unexpected positive cross-matches, particularly in highly sensitized patients, thereby improving allocation fairness and overall process efficiency (Formica Jr, 2017).

5.3 Perspectives of Health workers on allocation of organs based on Govind Persad et al criteria.

A key challenge for healthcare systems is balancing priority setting which is a matter of determining the most valuable use of limited resources with efficiency. This study explored health workers' perspectives on ethical principles guiding resource allocation, focusing on four core values: maximizing benefits, treating individuals equally, prioritizing the worst-off, and promoting social usefulness (Govind Persad, January 31, 2009; Williams, 1985).

The rejection of controversial criteria like QALYs and social usefulness aligns with community preferences documented in other studies, where there is a general reluctance to use criteria that assign different values to individuals based on their societal roles or potential productivity (Tong et al., 2010; Sypek et al., 2022). However, they expressed preference for younger patients due to perceived productivity and recovery potential subtly reintroduces age-based prioritization, a criterion that has been a subject of ethical debate in allocation policies worldwide (Ryynänen et al., 1999; Elalouf & Pliskin, 2022). QALYs are a metric used to evaluate the benefits of organ transplantation within utility-based allocation frameworks, aiming to maximize overall health and life-years. However, as noted in QALYfying the Value of Life*,* QALYs are flawed for healthcare prioritization: they can discriminate against people with disabilities, ignore non-health outcomes such as social participation, and undervalue those with fewer potential years or preexisting conditions (Harris, 1987).

Health workers perceived that global organ allocation models are applicable to the Ugandan context and considered computerized systems, such as the UNOS point-score system, advantageous in reducing inequality and corruption if prioritization principles are agreed upon. However, given local resource constraints, they emphasized the need for ongoing research and contextual adaptation to ensure these models align fully with Uganda's healthcare realities. Some studies argue that organ allocation systems should incorporate societal value judgments such as prioritizing younger individuals or those with dependents to reflect local ethical priorities in scoring frameworks (Browning & Thomas, 2001).

Another study suggests that what is considered an acceptable system in one context may not be suitable elsewhere, as the moral and ethical values of each society shape the relative importance of different principles (Yeung et al., 2022).

Health workers emphasized the importance of equity and fairness, particularly when patients share the same condition and meet donor compatibility criteria. They noted, however, that equity is limited by varying individual needs at a given time hence it serves as a final decision maker when patients have similar conditions. Fairness was selected with reservation that it cuts across all principles. It was seen as important for treating everyone equally in organ allocation, including those with lifestyle challenges like smoking or drinking. They argued that the main goal is to save lives, using factors like medical need and waiting time. A study suggests that due to disagreement on fairness principles, a transparent and fair process is essential to achieve equitable outcomes (Dyer et al., 2001).

Health workers rejected the principle of strict equality, favoring equity in practice. Equality in transplantation emphasizes equal access for all eligible patients, and its often operationalized through random allocation by lotteries or first-come, first-served models. While lotteries reduce bias and corruption, they ignore prognostic differences, potentially misallocating organs. Similarly, first-come, first-served appears fair but advantages patients with greater resources and system knowledge, as shown in the United States, where it historically created disparities by privileging early referrals and rapid evaluations (Bunnik, 2023 Feb; Yeung et al., 2022).

Resolving ethical dilemmas in allocation requires balancing and rank-ordering of principles, a responsibility entrusted to key stakeholders such as health workers (Childress, 2022). Respondents thus ranked competing allocation principles, and they prioritized maximum benefit/ utility, followed by equity and urgency. Fairness was acknowledged as a cross-cutting value, while social usefulness and past contribution were viewed as controversial, given that all individuals are considered useful. These findings resonate with previous studies suggesting that health workers prefer allocation based on maximizing principles. In an Australian study, a group of healthcare professionals were asked to rank allocation principles in order of importance. And the highest-ranked principles related to utility, and included allocating higher-quality organs to those with the best predicted survival or to the young (Howard et al., 2015; Sypek et al., 2022). This also provides evidence for the claim that healthcare professionals attach different weights to the principles of equity and utility.

Consequentialism and its dominant healthcare expression, utilitarianism, evaluate the moral rightness of actions based on their outcomes (Savulescu et al., 2020). In the context of organ allocation, this translates into prioritizing decisions that maximize overall benefit, such as saving the greatest number of lives, achieving the longest graft survival, or optimizing post-transplant quality of life (Bunnik, 2023). The empirical evidence demonstrates that both approaches function as practical and rational ethical frameworks both preferred and also routinely employed by clinicians and embedded within allocation systems (Oedingen et al., 2020)

The study found that health workers prioritized younger patients, reflecting utilitarian ethical principles. This supports the work of Govind Persad et al. who emphasize maximizing benefit and prioritizing those with more potential life years in organ allocation frameworks (Persad et al., 2009). Many respondents emphasized survival and utility as central principles, aligning with healthcare's overarching goal of saving lives. They stressed that principles should operate hand in hand to maximize survival outcomes. They highlighted that it is important to maximize the chances of survival in each decision. The principle of utility seeks to maximize the benefit to the greatest number of individuals (Persad et al., 2009). To many people, however, it seems intuitively unfair to abandon precisely those patients who are most severely ill or those with poorer prognoses. This is the dilemma at the heart of the discussion on the ethics of allocation of donor organs: how can a balance be struck between utility and justice or between efficiency and equity (Bunnik, 2023 Feb; Yeung et al., 2022).

Urgency was ranked third, above QALYs and fairness, especially when saving lives. Respondents viewed it as situational, relevant in emergencies, and best combined with other principles contrasting studies where urgency was prioritized. German legislation and Eurotransplant initially prioritized urgency in liver allocation. However, it was later deemed counterproductive due to higher post-transplant mortality rates (Bobbert & Ganten, 2013). This reflects respondents' views that precaution during screening is essential ensuring donor–recipient compatibility and survival prospects before considering urgency. Evidence shows participants often favoured younger recipients and those with greater clinical urgency and that urgency is only one factor among others shaping allocation preferences (Tobiasch et al., 2015). This finding also supports evidence elsewhere that urgency must be combined with another principle to be prioritized. A German study found lay audiences could not choose between maximizing success and prioritizing urgent patients, supporting combination of the two principles (Tong et al., 2010).

Respondents regarded social usefulness and past contribution as less important, emphasizing that all individuals are valuable and that such principles risk undermining equality and fairness. Similarly, another study reported that allocation preferences were influenced by efficiency, social value, and moral considerations, with some participants supporting the idea that recipients' deservingness should be judged based on their social status and lifestyle choices (Tong et al., 2010).

5.4 Study Strengths

This study had several strengths; it provides valuable qualitative insights into the attitudes of Ugandan health workers regarding organ allocation, filling a critical knowledge gap in a context where formal guidelines are absent. A key strength is its focus on the local context, which is essential for developing culturally and practically appropriate policies. The study's findings directly inform the potential direction for setting national guidelines, ensuring they are shaped by the on-the-ground realities of a living-donor-based system. By capturing the perspectives of the key "gatekeepers" of the current system, the research offers a rich understanding of the ethical dilemmas and practical considerations that guide decision-making.

Policy implication and future direction

The findings highlight the need for a system that balances ethical principles with local realities and addresses the unique challenges of a living donor-based program. The transition to a cadaveric program, if it occurs, would require addressing significant legal, logistical, and cultural hurdles, similar to those faced by health institutions in other nations in Africa and Asia (Ieoma Ulasi et al., 2020; Mettu et al., 2025). The establishment of a centralized national registry and transparent allocation criteria, guided by principles that align with local values, would be a critical step forward to guide MNRH (Lavee et al., 2010; Delmonico, 2013).

5.5 Study Limitations

A significant limitation is the discrepancy between the research topic and the scope of responses. While the study aimed to understand "organ allocation" in a broad sense, the responses were largely confined to patient prioritization for living-donor transplants. This is because the transplant ward is in its early stages and operates exclusively with family-based donations. Nevertheless, health workers used their understanding of ethical principles and experience in scheduling patients to share information on prevalent complexities of allocating organs from a diverse donor pool, for instance, cadaveric extractions, to inform their views on the latter.

Additionally, the findings of this study have limited generalizability due to several factors. First, the study was conducted in a single national referral hospital, which may have unique organizational structures, resources, and patient populations not representative of other hospitals in Uganda or other low- and middle-income countries. Second, the study employed a qualitative cross-sectional design with purposive sampling, focusing on health workers directly involved in organ transplantation. This approach provides rich, context-specific insights but does not capture broader perspectives from other stakeholders, such as patients, policymakers, or health workers in peripheral facilities. Third, cultural, socioeconomic, and institutional factors influencing organ donation and allocation in Mulago Hospital may differ from other settings, limiting the applicability of the findings to different regions or healthcare systems.

Despite these limitations, the study provides valuable, in-depth insights into health worker perspectives on organ allocation and highlights areas for policy development and future research. The findings should be interpreted within the context of the study setting, and caution should be exercised in extrapolating them to other populations or national contexts.

Another acknowledged limitation is the potential for social desirability bias. Respondents, aware that their input could inform future guidelines, may have presented their views in a way they believed would be seen as ethically sound or aligned with professional norms. The research team mitigated this by employing reflexivity and creating an open, non-judgmental environment to encourage honest sharing. Throughout data collection, the researchers continuously reflected on their own professional positions, attitudes, and potential influence on participants' responses. This involved: Monitoring verbal and non-verbal cues during interviews to avoid affirming or signalling approval for socially desirable answers. And maintaining neutral body language and tone, and carefully phrasing follow-up questions to encourage participants to share their authentic experiences rather than "expected" responses.

Nonetheless, the inherent power dynamics in the interview setting could still have influenced the participants' responses.

5.6 Recommendations for Future Research

The following recommendations for future research are proposed to strengthen evidence on organ allocation practices and ethics in similar contexts:

1. Adopt longitudinal and multi-site study designs
   Longitudinal studies across multiple hospitals would provide deeper insight into how allocation practices and ethical perspectives evolve over time, particularly as transplant programs mature and national frameworks are developed.
2. Incorporate mixed-methods approaches
   Combining qualitative interviews with quantitative methods, such as surveys or analysis of transplant records, would help triangulate findings and reduce reliance on self-reported perspectives, thereby addressing social desirability bias.
3. Include additional stakeholder perspectives
   Future research should include patients, donors, family members, policymakers, and transplant coordinators to capture a broader range of experiences and ethical concerns influencing allocation decisions.
4. Examine real-time decision-making processes
   Observational studies or case-based analyses of actual allocation decisions could provide insight into how ethical principles are applied in practice, helping to bridge the gap between stated values and real-world actions.
5. Investigate mechanisms to minimize coercion in living donation
   Given the dominance of family-based donation, future studies should focus on assessing tools and interventions for detecting subtle coercion and strengthening voluntarism and informed consent among living donors.
6. Contextualize ethical frameworks to local realities
   Research is needed to adapt global allocation frameworks, such as those proposed by Govind Persad et al., to local cultural, economic, and health system contexts, ensuring their relevance and feasibility in low- and middle-income countries.

This chapter interpreted the study findings in relation to existing literature, ethical frameworks, and the Ugandan healthcare context. It discussed the implications of informal organ allocation practices, health worker discretion, and equity concerns for clinical and public health ethics. The chapter concluded by summarizing the key insights of the study and offering recommendations for policy, practice, and future research aimed at strengthening organ allocation systems in Uganda.

6.0 CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

This study explored the practices and perspectives of health workers on organ allocation in Mulago national referral hospital, providing insight into the ethical, and practical challenges in this context. The findings highlight current practices, priorities, and gaps in the organ allocation process, including reliance on living-family donors, prioritization of younger patients, and the absence of formal regulatory frameworks. These results contribute to a deeper understanding of the factors influencing equitable organ allocation and provide evidence to inform policy development, clinical practice, and future research. From the study's results, we can conclude that these are the practices in regards to organ allocation/transplantation at Mulago Hospital;

- The practices are currently patient-driven, with transplantation dependent on living, related donors.
- Health workers act as key gatekeepers, ensuring compatibility, informed consent, and psychosocial support, while navigating significant ethical dilemmas such as coercion within families and inequities tied to patients' socioeconomic status.
- The ethical principle of maximum benefit/ survival is prioritized reflecting pragmatic adaptation to Uganda's limited resources, though it inadvertently disadvantages those unable to afford post-transplant care.
- Other ethical safeguards such as informed consent, voluntarism, shared decision making and donor autonomy are prioritized.
- The process is further constrained by limited infrastructure, resource shortages and absence of a formal national allocation system which has left decisions highly subjective and context-dependent thus compromising equity and consistency.
- Health workers therefore operate within an informal allocation framework heavily dependant on available resources and special committee meeting decisions.

Additionally, the study found these perspectives among health workers, and it can be concluded that although they supported the underlying ethical principles, they differed in the degree to which they prioritized them;

- Maximum benefit/ survival emerged as the most important consideration, followed by equity and urgency**,** though the latter was debated due to the long preparation period for transplants.
- Fairness was seen as a cross-cutting value, while social usefulness and past contribution were largely dismissed as discriminatory.
- The QALYs principle received mixed views: some favoured prioritizing younger patients for productivity and recovery potential, while others rejected age-based bias.
- Importantly, participants believed that global allocation models can be adapted to Uganda, provided modifications are made to account for local realities such as limited resources, cultural dynamics, life expectancy and patient affordability of post-operative care.

Overall, the study highlights that while Ugandan health workers are committed to ethical practice, the absence of formalized national allocation systems and the dependence on family donors generate inequities, emotional dilemmas, and ethical tensions.

6.2 RECOMMENDATIONS

The following recommendations can be drawn from our findings and conclusions:

Promote structured reflection on ethical principles currently used in practice;

Although the study applied Govind Persad et al.'s framework as an analytical lens, findings showed that healthcare workers already value principles such as fairness, equity, and maximizing benefit, albeit implicitly. Institutions should therefore encourage structured reflection and discussion on these ethical principles as they are currently understood and applied in practice, rather than introducing new external models.

Strengthen institutional guidance on organ allocation within Mulago National Referral Hospital;

Based on the finding that organ allocation practices are largely informal and dependent on individual health worker discretion, there is a need for clear, institution-level guidelines to support consistent and ethically defensible decision-making. Such guidance could outline agreed-upon principles for prioritization, documentation, and management of ethical dilemmas such as donor coercion.

Strengthen ethical competence in scarce resource allocation;
Healthcare workers involved in transplantation, particularly those in leadership and decision-making roles related to organ transplantation should receive continuous ethics training focused on balancing utility, equity, and urgency in organ allocation, drawing explicitly on Govind Persad et al.'s framework. This will ensure more ethical, consistent, transparent decision-making in the absence of a formal national system.

Support ethical reflection and address moral distress among health workers;
The institution should facilitate regular ethics discussions, debriefings, or moral distress support forums for health workers involved in transplantation. This can help staff navigate ethical dilemmas arising from scarcity, familial pressure, and competing allocation principles.

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APPENDICES

APPENDIX 1: GOVIND PERSAD ET.AL. CRITERIA OF ALLOCATION OF SCARCE RESOURCES.

There are eight basic ethical guidelines for allocation I. e. Depending on their fundamental ethical principles, lottery, first come, first served, sickest first, youngest first, number of lives saved, prognosis/life years saved, reciprocity, and instrumental value can be divided into four groups: treating people fairly, giving preference to those who are less fortunate, maximizing overall benefits, and encouraging and rewarding social usefulness (Persad, 2009).
Equality of treatment: A lot of limited medical procedures, like organ transplants, are indivisible. Benefiting people equally for indivisible goods means giving them equal access to the limited intervention—equality of opportunity—rather than equal quantities of it. Lottery and first come, first served are two principles that aim to exemplify this value. Lotteries have a number of appeals, including the fact that they are difficult to tamper with and require little recipient information. Its disregard for other pertinent principles is a drawback. First-come, first-served; minimal recipient information is required; preserves current doctor-patient relationships. A disadvantage is that it benefits the powerful, well-connected, and wealthy.

2. Prioritarianism: favouring those who are less fortunate. There are two principles at play. The four Mult principle UNOS points systems for organ allocation in the United States are prognosis, sickest-first, and first-come, first-served. Benefits include flexibility and the ability to integrate all conceivable principles. The following are some of its drawbacks: it is susceptible to bias and manipulation, such as being listed on multiple transplantation lists and misrepresenting health status; it permits multiple organ transplants, saving fewer lives; it incorporates the least justifiable principles of first-come, first-served, and sickest-first; and it places little importance on prognosis. Principles included; prognosis; excludes save the most lives; QALY allocation.
Benefits: Optimizes future gains; takes quality of life into account; utilized in numerous quantitatively complex frameworks currently in use. Drawbacks: The outcome measure disadvantages people with disabilities; it misunderstands equality by emphasizing equality of QALYs rather than equality of persons; it ignores many important DALY allocation principles; it includes prognosis; it has instrumental value; it excludes people who save the most lives. Benefits include maximizing future gains and saving individuals whose

productivity is essential to a thriving society. The definition of instrumental value is overly focused on economic worth, which could justify bias towards heads of household and other "traditional" social positions; it is devoid of many pertinent principles; the drawbacks of utilizing outcome measures impact disadvantaged individuals with disabilities; it's observed that age plays a role in assigning significance to an individual's life years, not from a perspective of fair distribution.

The principles of prioritizing the youngest first, predicting prognoses, saving the maximum number of lives, employing a lottery system, and valuing life based on instrumental worth – although limited to public health crises – are tenets of the complete lives framework. Benefits include: incorporating the greatest number of pertinent principles; resisting corruption; and aligning with the intuition that adolescent deaths are worse than those of infants or the elderly.

Drawbacks: The significance of life-years in health care assessment is questionable; they fail to account for global differences in life expectancy; they necessitate linguistic precedence over equilibrium, rather than balance; the all-encompassing lives method is unsuitable for distributing health care resources equitably across the populace and people who have lived for a long time have fewer opportunities. (Persad et al., 2009).

The UNOS points systems are used for organ allocation. They combine three principles: sickest-first (current medical condition); first-come, first-served (waiting time); and prognosis (antigen, antibody, and blood type matching between recipient and donor). UNOS weights principles differently depending on the organ distributed. Kidney and pancreas allocation is mainly by waiting time, with some weight given to sickest-first and prognosis. The systems are easily revisable to weight one principle more heavily than others. The UNOS systems are also vulnerable to additional exploitation. Taking advantage of the first-come, first-served principle, well-off patients place themselves on multiple waiting lists. Exploiting the sickest-first element, some transplant centres temporarily alter or misrepresent their patients' health state to get them scarce organs, making sickest-first both practically and inherently flawed.

Allocation systems based on quality-adjusted life-years (QALY) have two parts. One is an outcome measure that considers the quality of life-years. The other part of QALY allocation is a maximising assumption: that justice requires total QALYs to be maximised without consideration of their distribution. QALYs are a valuable tool for assessing the effectiveness of medical interventions, but they have limitations when applied to solid organ allocation. Specifically, QALYs can disadvantage older and sicker patients, potentially leading to unfair allocation decisions. Additionally, QALYs may not adequately capture the nuances of quality of life, particularly for those with mental health conditions or disabilities, and can be influenced by subjective perceptions of health.

APPENDIX 2: INFORMED CONSENT FORM

Title of the Study: HEALTH WORKER'S PRACTICES AND PERSPECTIVES ON THE ALLOCATION OF SOLID ORGANS BASED ON THE GOVIND PERSAD ET AL. CRITERIA: A CASE OF MULAGO HOSPITAL

Principal Investigator: Ms. Betty Deborah Mwebaza (Tel: +256-773733608), Makerere University, College of Health Sciences, School of Biomedical Sciences, Department of Anatomy.

Background and purpose of the Study: In Uganda, there are various medical conditions like diabetes, hypertension, polycystic kidney disease among other conditions which may necessitate solid organ transplantation. However, solid organs are particularly scarce and irreplaceable making allocation decisions by stakeholders, especially health workers, crucial. Without criteria, allocation decisions could potentially lead to unfair or unjust outcomes. Persad et al. proposed ethical principles which fall into four categories: treating people equally, favoring the least fortunate, maximizing benefits, and promoting social usefulness. There is limited evidence available on health worker's perspectives on allocation criteria or internationally recognized ethical frameworks for allocation. Therefore, this study sets out to fill this knowledge gap and to find a clear description of the current modus operandi regarding the allocation of organs, and to contribute to the ongoing ethical debate on equity in solid organ allocation, and to shed more light on the ethical dilemma surrounding organ allocation drawing upon the writings and insights of Persad et al. of allocation. Therefore, this study sets out to fill this knowledge gap and to find a clear description of the current modus operandi regarding the allocation of organs, to contribute to the ongoing ethical debate on equity in solid organ allocation, and to shed more light on the ethical dilemma surrounding organ allocation drawing upon the writings and insights of Persad et al.

Purpose of the Study: Once you consent to participate in this study, you will be asked to complete an informed consent form. You will then be asked to participate in an interview guided by the researcher. The study aims to evaluate heath worker's practices and perspectives on the criteria for equitable allocation of organs.

Duration of Participation: You will be expected to answer some questions, in the form of a questionnaire, and this will take about 25-35 minutes.

Procedures: If you agree to participate in this study, the principal investigator or the research assistant will ask you to answer a few questions, in form of a questionnaire about health worker's practices and perspectives on criteria for allocation of solid organs.

Subject Participation: The study will include clinicians involved in the process of allocation of solid organs for transplant at Mulago National Referral Hospital.

Potential Risks and Discomfort: There are no major risks involved in this study. The study however poses a minimal risk, primarily related to the time commitment required for participation in the interviews. We intend to mitigate this by focusing on the task at hand and keeping to the estimated time which is 25-35minutes.

Potential Benefits: There are no direct financial benefits to you by participating in this study. It is designed to generate knowledge that can inform policy development and improve practice in the area of solid organ allocation. By addressing the existing gap, in understanding and providing evidence-based insights, the study has potential to contribute to the enhancement of health systems, support ethical decision making and promote equitable resource allocation. Ultimately, the findings may lead to improved service delivery, better health outcomes, thereby benefitting society at large.

Additionally, by involving relevant stakeholders, the research fosters inclusivity and responsiveness to societal needs ensuring that outcomes are socially relevant and ethically sound.

Confidentiality: The results of this study will be kept strictly confidential and used only for research purposes. Your identity will be fully protected and your name will not be revealed anywhere on the forms, instead only codes will be used to identify your name. Your responses are completely anonymous. All records will be kept in a locked, secure location and once the audio recordings have been fully analyzed, they will be destroyed.

Voluntary Participation and Authorization: Your participation in this study is voluntary, and you are free to withdraw from participating in this study at any time you wish, without prejudice, penalty, or loss of benefits to which you are otherwise entitled.

Costs: You will not incur any costs in the study.

Compensation: Each participant will receive fifty thousand Uganda shillings (50,000) at the conclusion of the study.

Reimbursement: As participants will be found at their stations of duty, there will be no reimbursement of transportation.

Questions about the Study: In case of any questions related to the study, please contact the principal investigator Ms.Betty.D. Mwebaza, **Tel:** +256-773733608, **Email:** mwebwabetsy@gmail.com

Questions about Participants' Rights: For any queries related to the study participants' rights, please address them to the Chairperson School of Biomedical Sciences Research Ethics Committee, Dr. Ochan Moses, **Tel:** +256-782-355-302. Makerere University, College of Health Sciences, P.O. Box 6062, Kampala; or contact Uganda National Council for Science and Technology on plot 6, Kimera Road, Ntinda, Kampala, Tel: 041470550

Statement of Voluntariness: Your participation in this study is voluntary and you have the right to withdraw from the study at any time without penalty. You will be expected to sign at the end of this document for your approval to participate.

Dissemination of Results: You will get feedback on findings and progress of the study and any new information that affects you or the data that has relevance will be made available to you and/or other health care providers.

Ethical Approval: The study has been approved by the School of Biomedical Sciences Research and Ethics Committee College of Health Sciences, Biomedical Science Research Ethics Committee.

Statement of Consent

I………………….. agree to participate in the research project titled**:** HEALTH WORKER'S PRACTICES AND PERSPECTIVES ON THE ALLOCATION OF SOLID ORGANS BASED ON THE GOVIND PERSAD ET AL.

CRITERIA: A CASE OF MULAGO HOSPITAL, conducted by Mwebaza Betty Deborah who has discussed the research project with me. I consent to participate in the research project and the following has been explained to me; the research may be of direct benefit to me, my participation is completely voluntary, I have a right to withdraw at any time and my right to withdraw at any time has no implications on me, what is going to be done has been described to me to have risks and benefits involved and I'm aware of my rights regarding this study. In the use of this information, my identity will be concealed and as such confidentiality of my personal information is guaranteed. Publication of results from this study is on condition that my identity will be not be revealed.

I understand that by signing this form, I do not waive any of my legal rights to which I am entitled, but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

☐ In addition, by ticking this checkbox, I consent to; Audio recording of all of the interview activities.

Name of Participant…………………………....................**Signature** …………….........

Date………………………………

Name of Interviewer……………………….......................**Signature.**..................................

Date………………………………..

APPENDIX 3: KII GUIDE.

Tittle of the Study: HEALTH WORKER'S PRACTICES AND PERSPECTIVES ON THE ALLOCATION OF SOLID ORGANS BASED ON THE GOVIND PERSAD ET AL. CRITERIA: A CASE OF MULAGO HOSPITAL

Principal Investigator: Ms. Deborah. B. Mwebaza (Tel: +256-773733608), Makerere University, College of Health Sciences, School of Biomedical Sciences, Department of Anatomy.

Date of data collection……………………………......
Study ID…………………………………**Participant's initials**…..

SECTION 1: SOCIAL DEMOGRAPHIC CHARACTERISTICS (CIRCLE ANSWER)

1. Gender of respondent.
   a) Male b) Female

2. How old are you?...

3. Level of education of respondent.
   a) Diploma c) Masters' Degree
   b) Bachelors' Degree d) PhD e) Others (specify)…………………………

4. Work experience of respondent.
   a) 2-5 years c) 11-15 years
   b) 6-10 years d) 16 years and above

5. Cadre of respondent.
   a) Nurse b) Doctor c) Others (specify)………………………….

6. Religion of respondent.
   a) Christian b) Muslim c) Others (specify)………………………

7. Marital status of respondent.

    a) Single b) Married c) Divorced/separated d) Widow/Widower

SECTION 2. PRACTICES AND PERSPECTIVES OF HEALTH WORKERS

1.(a) How is the process for allocation organized or what steps are taken by health workers in your facility when allocating solid organs to recipients?

(c) Have you personally been involved in the allocation process? In what ways have you been involved?

2.(a) Describe a scenario you went through in regard to allocation of organs. (Probe for ethical dilemmas, and the emotions they went through)

(b) How should we handle situations where one principle (like fairness) conflicts with another (like saving the most lives)? Which should take priority in such cases?

3. How do you approach decisions when comparing patients with complex medical conditions to those whose conditions may worsen over time? (Probe for factors that guide decisions)

4. (a) Should people who are more likely to survive the transplant and recover well be given priority, even if others may need it more urgently?

(b) Some argue that everyone should have an equal chance, like using a lottery or a first-come-first-served system. What are your thoughts on these methods?

(c) Do you think the main goal should be to save as many lives as possible with the available organs? Why or why not?

5. How do you think personal responsibility such as lifestyle choices like smoking or alcohol use should influence organ allocation decisions?

6. What is your view or perspective on the use of formal models rather than informal models?

7. According to Govind Persad et al.'s criteria, please rank the following principles as the most, second, and third important when allocating organs:

(a) treating everyone equally;

(b) favouring the least fortunate;

(c) maximizing overall benefits; and

(d) Encouraging and rewarding social usefulness.

8. Should we prioritize patients who are the sickest or most disadvantaged, even if their chance of surviving the transplant is low?

9. What do you think about giving priority to people who play key roles in society such as health workers or caregivers because they might help more people if they recover?

10. Should someone's past contributions, like being a former organ donor, influence whether they get priority for a transplant?

11. The UNOS system tries to balance urgency, compatibility, and predicted survival. How do you view this kind of combined scoring approach for deciding who should receive an organ?

12. (a) QALYs are sometimes used to estimate how much good a treatment does by combining life expectancy with quality of life. How appropriate do you think this is in deciding who gets a transplant?

(b) Do you think the values used in global or Western organ allocation systems (like QALYs or UNOS) are appropriate in the Ugandan context? Why or why not?

Signature of study
representative……………………………Date…………………….

THANK YOU VERY MUCH FOR YOUR TIME.

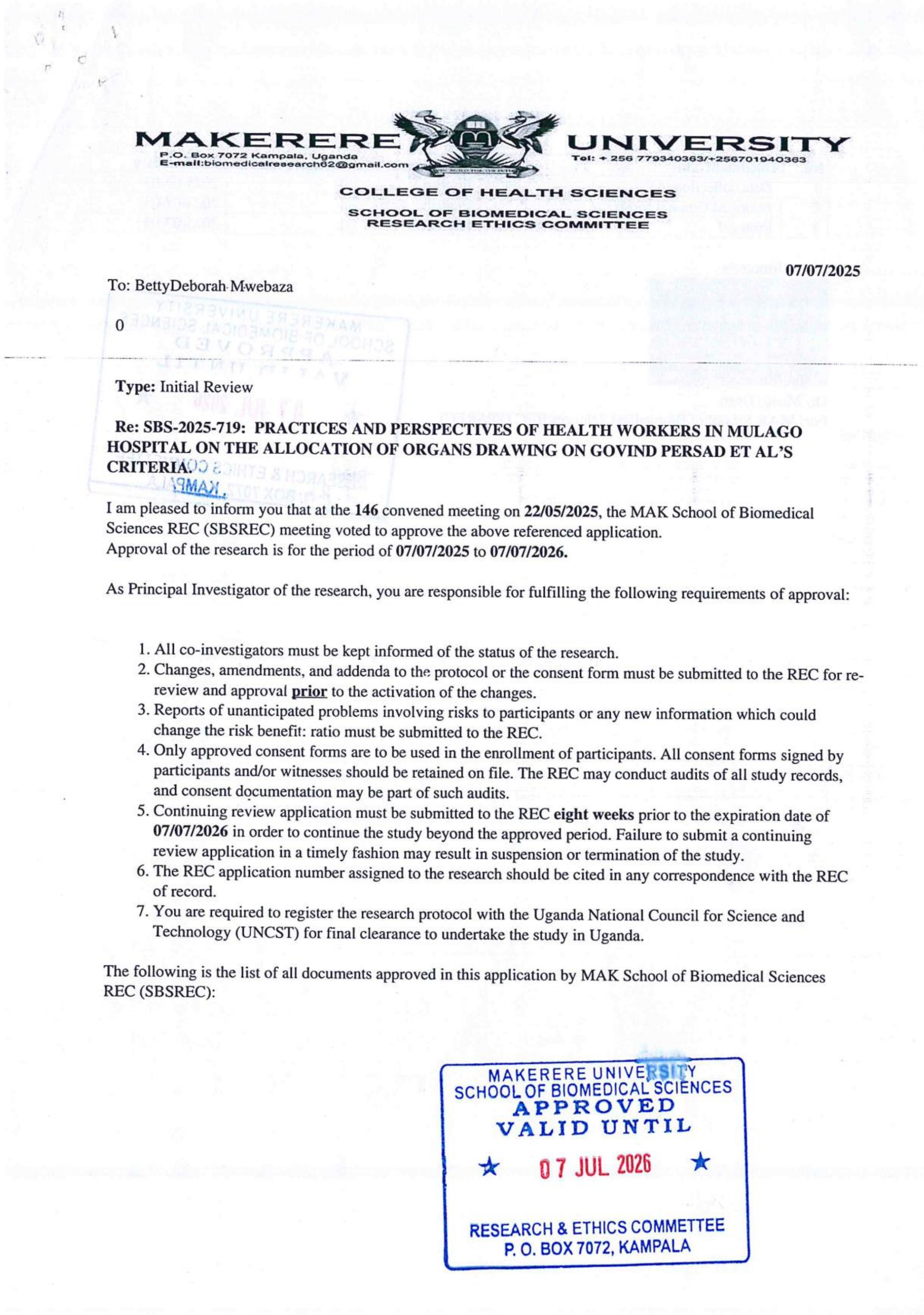
APPENDIX 4

APPENDIX 4: RESEARCH BUDGET

TITLE OF STUDY: HEALTH WORKER'S PRACTICES AND PERSPECTIVES ON THE ALLOCATION OF SOLID ORGANS BASED ON THE GOVIND PERSAD ET AL. CRITERIA: A CASE OF MULAGO HOSPITAL

NO	ITEM	Unit price	Quantity	AMOUNT (UGX)
1	Voice recorder	330,000	1	330,000
2	Materials: Stationary, photocopying and printing, binding, secretarial.			300,000
3	REC fee	100,000	1	100,000
4	Compensation for research participants		20	1,000,000
5	Airtime	50,000		50,000
6	Research assistants	3,000,000	2	3,000,000
7	Results dissemination	400,000		400,000
8	Computer software (BitLocker)	350,000	1	350,000
	TOTAL			**5,530,000**

APPENDIX 5: REC CLEARANCE LETTER



MAKERERE UNIVERSITY
P.O. Box 7072 Kampala, Uganda
E-mail:biomedicalresearch62@gmail.com
Tel: + 256 779340363/+256701940363

COLLEGE OF HEALTH SCIENCES

SCHOOL OF BIOMEDICAL SCIENCES
RESEARCH ETHICS COMMITTEE

07/07/2025

To: BettyDeborah Mwebaza

0

Type: Initial Review

Re: SBS-2025-719: PRACTICES AND PERSPECTIVES OF HEALTH WORKERS IN MULAGO HOSPITAL ON THE ALLOCATION OF ORGANS DRAWING ON GOVIND PERSAD ET AL'S CRITERIA.

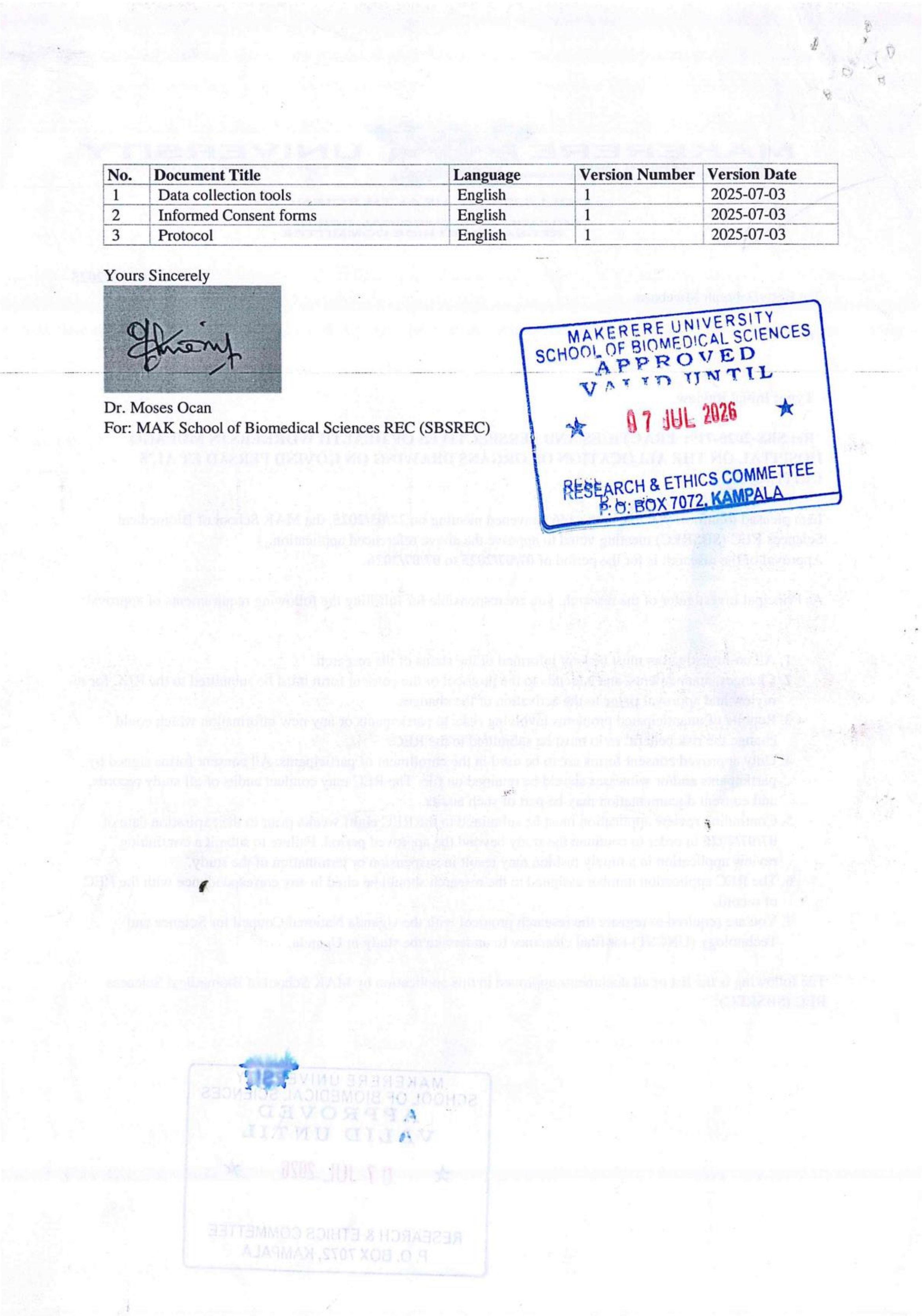
I am pleased to inform you that at the **146** convened meeting on **22/05/2025**, the MAK School of Biomedical Sciences REC (SBSREC) meeting voted to approve the above referenced application.
Approval of the research is for the period of **07/07/2025** to **07/07/2026.**

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **07/07/2026** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by MAK School of Biomedical Sciences REC (SBSREC):

MAKERERE UNIVERSITY
SCHOOL OF BIOMEDICAL SCIENCES
APPROVED
VALID UNTIL
★ 07 JUL 2026 ★
RESEARCH & ETHICS COMMETTEE
P. O. BOX 7072, KAMPALA



No.	Document Title	Language	Version Number	Version Date
1	Data collection tools	English	1	2025-07-03
2	Informed Consent forms	English	1	2025-07-03
3	Protocol	English	1	2025-07-03

Yours Sincerely

Dr. Moses Ocan
For: MAK School of Biomedical Sciences REC (SBSREC)

MAKERERE UNIVERSITY
SCHOOL OF BIOMEDICAL SCIENCES
APPROVED
VALID UNTIL
07 JUL 2026
RESEARCH & ETHICS COMMETTEE
P. O. BOX 7072, KAMPALA