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**PARLIAMENT OF UGANDA**



**REPORT OF THE COMMITTEE ON HEALTH ON A  
BENCHMARKING VISIT TO ISTANBUL, TURKEY ON THE  
UGANDA HUMAN ORGAN DONATION AND TRANSPLANT BILL,  
2021**

**(19<sup>TH</sup> -24<sup>TH</sup> SEPTEMBER, 2022)**

SEPTEMBER, 2022

OFFICE OF THE CLERK TO PARLIAMENT

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## 1.0 INTRODUCTION

The Uganda Human Organ Donation and Transplant Bill, 2021 was read for the First Time on 5<sup>th</sup> July, 2022 and referred to the Committee on Health for expeditious consideration and report back to the House.

The object of the Bill is to establish a legal framework for the regulation of organ, cell and tissue donation and transplantation in Uganda.

While scrutinising the Bill, the Committee held physical and online meetings with the public and other relevant stakeholders, reviewed relevant documents, received written memoranda and held a workshop with medical specialists in various fields directly related to organ, tissue and cell donation and transplantation.

The Committee did not get information from other countries, yet the medical field of organ, tissue and cell donation and transplantation is of a global magnitude.

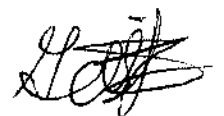
This report is being presented in accordance with Rule 33 of the Rules of Procedure of Parliament.

## 2.0 BACKGROUND

Surgical transplantation of human organs, tissues and cells from living and deceased donors to sick and dying patients has become a worldwide practice, which has greatly enhanced the quality of and saved thousands of lives following the World Health Organisation (WHO) Director General's report to the Executive Board at its 79<sup>th</sup> session on human organ transplantation in 2010.

Creating an enabling national policy, legal and regulatory framework to improving equitable access to safe and efficacious human organ, tissue and cell services for those in need is a basic right that governments and partners across the world have to progressively realise.

Uganda is one of the countries that does not have any legal and regulatory framework governing human organ, tissue and cell donation and transplantation which is increasingly becoming an essential package of health care that is used to treat organ, tissue and cell malfunction caused by communicable and non-communicable diseases, including injuries.





### **Rationale for the benchmarking mission to Turkey**

The first successful renal transplant in Turkey was performed at Hacettepe University by Dr. Mehmet Haberal and his colleagues in 1975, which involved a transplant from a mother to her child. This was followed by the first deceased-donor kidney transplantation in 1978, using an organ supplied by Eurotransplant. The law on harvesting, storage and transplantation of organs and tissues was enacted in 1979. Later that year, the first local deceased-donor kidney transplantation was performed. In 2001, the Turkish Ministry of Health established the National Coordination Center to promote transplantation activities and deceased-donor organ procurement. Currently, the Organ Transplantation Regulatory Unit is a subdivision of the Ministry of Health. The 1979 law on organ and tissue donation and transplantation has been amended several times to suit emerging best practices in the industry.

Today, Turkey is the leader in Europe in living donor transplantation and ranks among the first three countries in live transplants in the world. This is due to a positive attitude towards donation by citizens, advanced health care system, high success rates and enforcement of quality assurance and control mechanisms. According to the most recent reports from the International Organ Registry in Organ Donation and Transplantation, Turkey ranked first globally for the overall living-donor transplant rate (53.02 per million population [pmp]) and for living-donor renal transplant activity (36.64 pmp).

In recent years, Turkey has been investing heavily in the health care system and the development of medical tourism. Organ transplantation is one of the most popular reasons for people from abroad to travel to Turkey. In Turkish hospitals, they are attracted by the high quality of medical industry, the use of innovative surgical methods and the low price, in comparison with other developed countries.


It is against the background above that the Committee on Health conducted a benchmarking trip to Istanbul, Turkey on the Uganda Human Organ Donation and Transplant Bill, 2021.

### **3.0 OBJECTIVES OF THE STUDY VISIT**

The overall objective of the field trip was to study the legal and regulatory framework governing organ and tissue donation and transplantation in Turkey so as to find out best practices and lessons for Uganda.



The specific objectives include:



- (i) To find out the legal regime and national governance structure of organ, tissue and cell donation and transplantation;
- (ii) To ascertain the funding mechanism for organ, tissue and cell donation and transplantation;
- (iii) To find out the donor consent systems in place in regard to organ, tissue and cell donation and transplantation;
- (iv) To find out mechanisms for controlling and preventing trafficking in human organs;
- (v) To establish how the national waiting list is managed;
- (vi) To establish the accreditation and licensing requirements for hospitals and specialists offering organ, tissue and cell transplantation;
- (vii) To find out how brain death donation is managed;
- (viii) To establish how storage of organs, tissues and cells is done;
- (ix) To establish the data management systems in place;
- (x) To examine any other matters, incidental there to.

#### **4.0 METHODOLOGY**

The benchmarking mission used a mix of approaches that included but were not limited to:

##### **Document review**

The Committee reviewed key documents on legal, regulatory, policy and practices related to human organ, tissue and cell donation, storage, distribution, transplant and post-transplant care.



## **Meetings**

The Committee held meetings with key policy and practice stakeholders in the host country and entities of focus. The meetings were held with officials of Medipol Mega Hospital, Medical Park Hospital and Basaksehir City Hospital.

## **Key informant interviews**

The Committee held key informant interviews with legislators, policy makers, executives, practitioners and clients. These included a member of the scientific board and regional coordinator of human organ donation and transplant services in Basaksahir City Hospital Complex.

## **Site visits**

The Committee conducted guided tours to selected government and private hospitals providing organ donation and transplant services to interact with facility leaders, managers and providers.

## **Checklist**

The delegation had a check list developed to guide and direct discussions during the meetings and interviews.

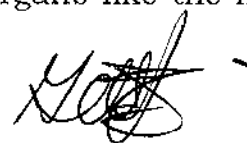
## **5.0 FINDINGS**

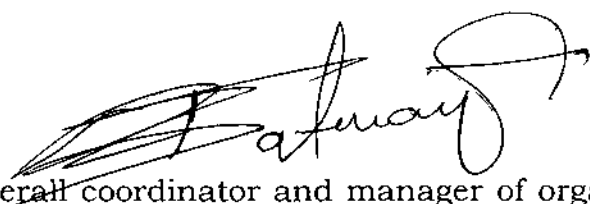
### **Legal framework and national governance structure for organ, tissue and cell donation and transplantation**

Turkey has a national law on human organ and tissue donation and transplant services first enacted in 1997 and severally amended to suit emerging best practices in the industry.

There is a national policy and strategic plan to guide the government in planning, programming and financing human organ and donation in the country.

Turkey is divided into regions for organ donation and transplantation. This geographical division is aimed at achieving real-time organ harvesting and transplantation in the event of cadaveric donation since organs like the heart have a short lifespan after harvesting.





The Ministry of Health is the overall coordinator and manager of organ, tissue and cells donation and transplantation activities in the country. The Division of Organ Transplantation has five advisors one of whom is an organ transplant surgeon. Every region has a regional coordinator for organ donation and transplant services responsible for coordinating the planning ,programming ,provision ,supervision ,monitoring and reporting on human organ donation and transplant services in accredited and licensed public and private hospitals providing transplant services in his/her region of jurisdiction .

There is a coordinator/manager for each organ type. Each organ has a scientific advisory board which gathers data annually and analyses it. The board handles medical-legal issues of organ donation and reports to the Ministry of Health. Every city has a transplantation committee.

There is a national scientific advisory board consisting of eminent multidisciplinary specialists who advise the ministry of health on policy and practice issues on organ donation and transplant.

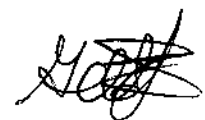
Human organ donation and transplant services are provided in both public and private hospitals in the country for both nationals and foreign patients.

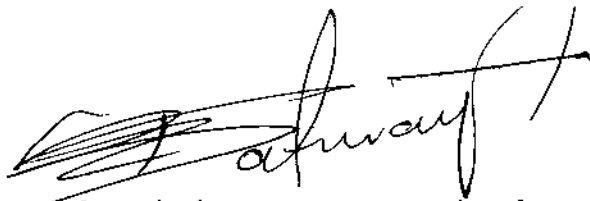
### **Accreditation and licensing requirements for hospitals and specialists**

The scientific Advisory Board collaborates with Turkey Medical Council and Medical Association to manage training, accreditation, licensure and medical professional practice in the country without duplication of roles and responsibilities. The transplant hospitals are licensed for quality and adequacy of infrastructure and the surgeons who carry out transplantation are given a licence based on the adequacy of their training. For urologists, they should have carried out at least 40 surgeons in another facility.

Every specialist is accredited and attached to a transplant hospital in which he/she practices. The exceptions are for academic purposes and personal social relations like fiends which are approved by the transplant hospital where the specialist works.

There are no provisions for dual practice in both government and private hospital by specialist; one either works for government or private hospital; not both.





Specialists working for government hospitals are not permitted to open and operate private clinics and surgeries in Turkey.

### **Financing mechanism for organ, tissue and cell donations and transplantation**

The national patients in need of organ donation and transplant services are paid for by the government through a health insurance. If Turkish nationals prefer private hospitals, they can top up on what the Government provides.

Foreign patients are paid for by the individuals privately or companies or governments.

The cost of transplant in government transplant facilities is generally lower than in the private hospitals.

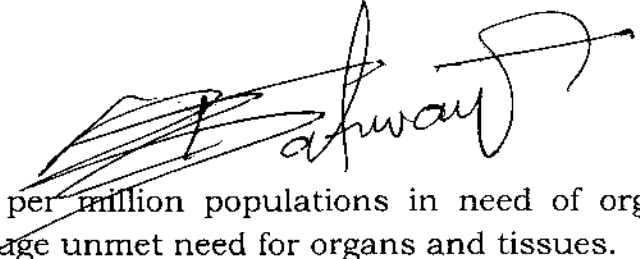
### **Donor consent systems in place**

The human organ donation and transplant program started with living donor organs and tissues from relatives up to the fourth generation in a bid to prevent commercialisation of organ, tissue and cell donation. However, this restriction has not prevented commercialisation even if the donations are from relatives. Donors always expect a token of appreciation. The Ministry of Health has a Central Ethics Committee whose members are an anonymous group of specialists in medical, law enforcement and other relevant fields. The Committee ascertains whether a potential donor is a relative or not by interviewing the person. However, cases of 'false' relatives are discovered and such people are usually trained to answer questions with the hope that the Committee will be convinced.

Turkey is a leader in living donor transplantations worldwide. This is due to a positive attitude towards donation, high success rates, excellent medical facilities and highly trained and specialised medical personnel. For kidney transplants, 85% are from live donors while 15% are from cadaveric donors.

Turkey uses an opt out policy on organ donation; with informed consent being required before any person above 18 years can donate any organ or tissue. Persons below 18 years cannot be living donors.





There is a low person per million populations in need of organ transplant services resulting in a huge unmet need for organs and tissues.

There is international collaboration with other European countries like Italy and Spain to share tissues on a reciprocal basis. .

Since the demand for organs exceeds the available supply, there is no donation of organs to foreigners. Turkish nationals receive organs from Turkish donors. Foreigners are only admitted for transplant if they come with their own donors. These donors are also subjected to the Turkish law to establish that they are related to the recipients and there isn't any financial incentive. The documents of the patients are approved by the Turkish Consulates in their respective countries. Citizens of conflict areas like Syria, Russia cannot donate organs in Turkey.

### **Management of brain death/cadaveric donations**

The issue of brain death determination and consent for donation is one of the areas which has been amended in the Turkish law. Currently, the medical team certifying brain death comprises an intensive care physician, neurologist and anaesthesiologist/cardiologist. However, there is a shortage of intensive care physicians.

The team diagnosing for brain death is different from the harvesting team and transplantation team.

Annually, there are over 2,000 brain deaths in Turkey and consent has to be provided by the families (first relatives) of the deceased. Unfortunately, the family approval rates are very low (about 500); making Turkey one of the poor performers in cadaveric donations in comparison with other countries in Europe like Spain which rank highly in cadaveric donations. The low family approval rates are due to cultural beliefs which make families hold back from approving organ donations from their departed ones.

The Ministry of Health has clear guidelines for diagnosis of brain death.

### **Harvesting and storage of organs, tissues and cells**

Solid organs are harvested instantly and transplanted into the recipients. This is aimed at maximising the quality of the organs since the quality of harvested





organs deteriorates with time if it is not given to a potential recipient. The Ministry of Health pays for the harvesting of organs.

Banks for tissues exist and are set up by private hospitals. This has made them very expensive. Government facilities do not have banks for tissues. In Turkey, there are no banks for solid organs.

### **Management of the national waiting list**

All organs belong to the country. The Ministry of Health documents all available organs and allocation is done from the centre. Every hospital has a transplant coordinator who works with the Ministry of Health. The distribution of organs is done on a rotational basis. The top 5 chronically ill Turkish patients in a hospital are given priority in the event of availability of cadaveric organs. Patients who are not nationals can be given a cadaveric organ after reaching a certain limit like 50 patients and such cases are usually emergencies.

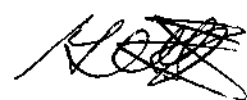
Distribution of the organs is transparent and this has won public trust.


There are about 30,000 patients on the national waiting list. Sadly, every day, 10-20 pass away due to inability to get a life-saving organ. Of the 30,000 patients on the waiting list, 2,000 are children.

Organs belonging to Turkish nationals are not exported to another country nor shared with another country.

### **Data management systems in place**

The Ministry of Health maintains a highly sophisticated electronic central data base where all legal documents pertaining to donors and recipients are uploaded onto the system. The Division of Organ Transplantation manages the data base. Part of the information in the system includes the date of the operation/transplant, outcome, medical team, bio data of the recipient and others.





## **Mechanisms for prevention and control of trafficking**

In order to control trafficking of persons for organs, tissues and cells, the Government of Turkey works with Interpol. However, Turkish nationals who deal in trafficking of persons go to Turkish hospitals who may have no idea that the donor is an illegal one. That's the major stumbling block to control of trafficking in Turkey.

There is a very stringent law on human organ trafficking with deterrent penalties for breach of the laws.

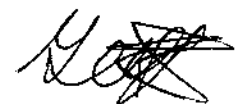
## **6.0 LESSONS FOR UGANDA/RECOMMENDATIONS**

### **Phased roll-out/approach to organ, tissue and cell donation and transplantation**

When a country is beginning transplantation, it is better to start with a few organs, tissue and cells and proceed gradually to the others. Turkey started with kidney transplants and has moved on to transplantation of more complex organs like heart and lungs. The heart and lungs can only be provided by cadaveric donors. The Uganda Human Organ Donation and Transplant Bill has a provision of starting with living donors and imported organs. Uganda can start with kidney, cornea and skin which are not very complicated and move on to expand the range of transplant services provided with time and experience gained from the pioneered organs, tissues and cells. During meetings to consider the Uganda Human Organ Donation and Transplant Bill, the Committee was informed that Joint Clinical Research Centre (JCRC) is ready to conduct the first bone marrow transplant this November.

### **Regional collaboration arrangements**

Turkey is part of the European Committee on Organ Donation and Transplant Programme. Under the arrangement, members share organs and tissues on the principle of reciprocity.





## **Human Resources for Health**

There is need to have enough human resources for organ, tissue and cell donation and transplantation. Turkey which has made big strides in the field of organ, tissue and cell donation and transplantation has a shortage of intensive care specialists.

## **Need for sufficient financial resources**

For organ donation and transplantation, there is need to allocate sufficient and necessary resources to finance human organ donation and transplant services as part of the comprehensive package of health services to be provided at national and regional hospital levels.

## **Need to attain public trust and confidence**

Public trust is very important in organ, tissue and cell donation and transplantation system. The distribution of cadaveric organs to the national waiting list recipients should be fair so that more people sign up for their organs to be donated after their death. Justice must be done and seen to be done. The distribution criteria should be followed.

## **Information, Education and Communication strategy**

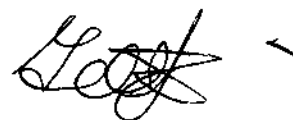
Public trust goes hand in hand with popularising donation. In Turkey, families who approve donation of organs belonging to their departed loved ones are recognised annually. There are runs which are conducted to popularise donation. Sports competitions are held to popularise donation and transplantation. There is an art book distributed worldwide depicting and popularising organ, tissue and cell donation.

## **Commercialisation of organs**

This is a very delicate area to regulate. There should be tight controls and a special committee set up to handle and interrogate such cases.

## **Establishment of the National Health Insurance Scheme**

Establishment of the National Health Insurance Scheme is long overdue. In Turkey, citizens are able to get organ, tissue or cell transplants using their





national health insurance scheme. This saves thousands of lives. Uganda should fastrack the process of enacting a law on national health insurance.

### **Need for a policy national policy framework for private sector investment in human organ and tissue transplant services**

The Ministry of Health should develop a national policy framework for private sector investment in human organ and tissue transplant services.

### **Collaboration opportunities for Uganda**

All the health facilities visited expressed willingness to cooperate with Uganda in the area of capacity building/training for its medical personnel. The Ministry of Health therefore, should develop memoranda of cooperation/cooperation agreements with the respective transplant hospitals in order to enable the country's medical personnel attain more skills.

The capacity of national and regional hospitals needs to be boosted to enable them provide appropriate organ and tissue transplant services in the 4 regions of the country.

There is need to strengthen strategic partnerships, networking and collaboration with Turkey for technical assistance, capacity building trainings, technology transfer and patient referral services, inter alia.

### **Inter-university collaboration**

There is need to explore possibilities of Makerere University Medical School and other universities collaborating with universities in Turkey for knowledge and technology transfer purposes.


### **Low cost in Government facilities compared to private hospitals**

The cost of transplantation services in public hospitals is far much cheaper compared to private facilities, yet the quality of service is similar. This option can be explored by Ugandans who may not be able to afford the cost in private facilities.

## **ANY OTHER MATTERS INCIDENTAL THERE TO**

### **Increased volume of trade between Turkey and Uganda**

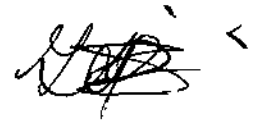




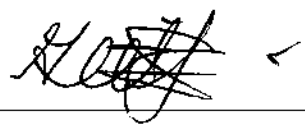
The delegation found out that Turkey is a preferred business destination for Ugandan traders and the volume of trade keeps on increasing. This is a business opportunity which can be exploited by Uganda Airlines.

## **7.0 CONCLUSION**

The life-saving and life-prolonging medical procedures of organ, tissue and cell transplantation are a universal health requirement which call for international collaboration, continuous professional development and continuous research and development. If Uganda adopts the aforementioned lessons from Turkey, some challenges likely to be faced while implementing the law on organ, tissue and cell donation and transplant will be reduced.



**SIGNATURE SHEET FOR A REPORT ON THE COMMITTEE ON HEALTH ON  
A BENCHMARKING VISIT TO TRUKEY**

S/NO	NAME	SIGNATURE
1.	Hon. Dr Didi George Bhoka - Leader of Delegation	
2.	Hon. Esther Mbayo	
3.	Hon. Batuwa Timothy Lusala	