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# Travel for Transplantation

**Lisa Burnapp**

Consultant Nurse

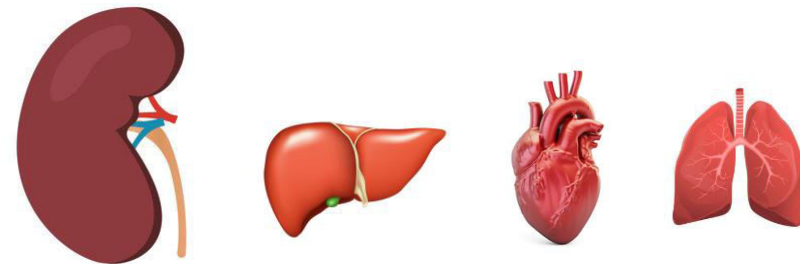
Associate Medical Director - Living Donation and Transplantation

# Overview

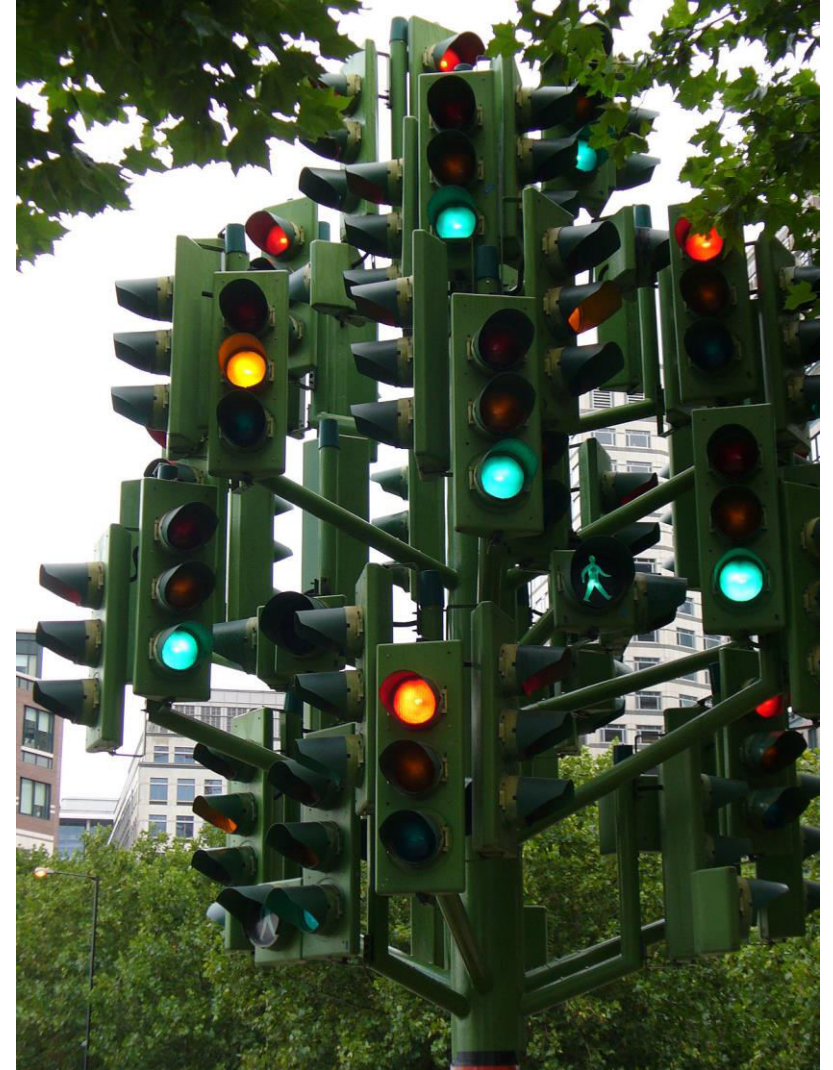
- **Background**
- **Travel for Transplantation**
- **Change in Legislation- Duty to Report**
- **Resources**
- **Work in progress**
- **Asks of KAG**



# Background



# Background



# Relevant Legislation - Pre April 2024

## ■ Modern Slavery Act (2015)

- Human trafficking for the purposes of organ donation

## ■ Human Tissue Acts – (Amendments, July 2022)

- Jurisdiction **within and outside the UK** for transplantation associated with criminal activity\*

## ■ Other considerations

- General Data Protection Regulations (GDPR)
- Consent law

\*Except Northern Ireland



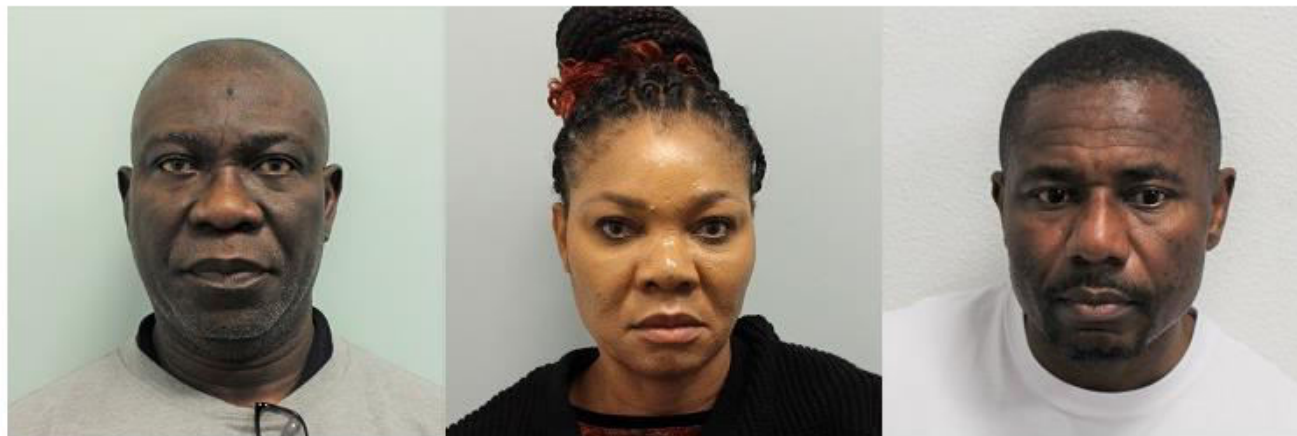
# May 2023

## Updated with sentence: Senior Nigerian politician jailed over illegal UK organ-harvesting plot

— 05 May 2023 | *News, International and organised crime, Fraud and economic crime*

A senior Nigerian senator, his wife and a doctor have been imprisoned today (5 May 2023) for exploiting a vulnerable victim for illegal organ harvesting.

Ike Ekweremadu, 60, Beatrice Ekweremadu, 56 and Dr Obinna Obeta, 51, have been imprisoned for nine years and eight months, four years and six months, and 10 years respectively at the Old Bailey for conspiring to arrange the travel of a man for the purpose of harvesting his organs.



*Left to right: Ike Ekweremadu, Beatrice Ekweremadu, Obinna Obeta*

# Learning

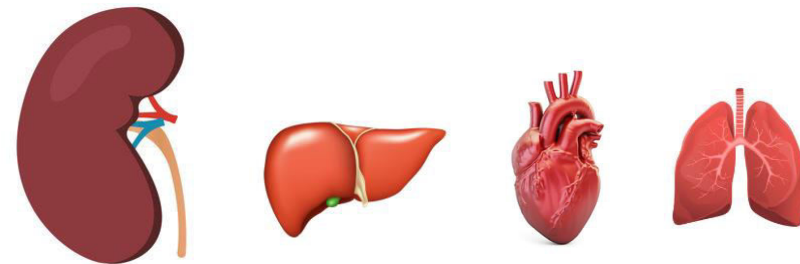


# Questions.....





# Travel for Transplantation



# What is Travel for Transplantation?\*

- **Patients who travel for transplantation abroad** and return to their country after the transplant
- **Resident recipients** who receive an organ transplant from a **non-resident living donor** (e.g. NHS recipient)
- **Non-resident recipients** who receive an organ transplant from a **non-resident living donor** (e.g. Private Sector)
- **Non-resident recipients** who receive an organ transplant from a **resident living donor** (e.g. Private Sector)
- **Transnational living kidney exchange programmes** where donors and/or recipient travels to participate in a KEP

\* *Registry of International Travel for Transplantation Activity (RITTA), Council of Europe*

# In Context

- **Not all travel for transplantation is illicit or criminal (i.e. involving payment)**
  - People can and do travel legitimately for organ donation and transplantation
- **Low level of travel for transplantation in UK but reported activity has increased**
  - Mostly living kidney donation and transplantation
  - Few deceased donor transplantation cases (returning to the UK)

# Statistics (1)


## October 2022- March 2024\*



- 20 cases referred to HTA
- 15/20 cases referred to police
  - Majority for travel outside the UK to receive an organ but includes cases where there was concern about a donor who travelled to the UK to donate
  - Mostly kidney
- 2 cases yet to be determined for police referral
- Multiple enquiries to HTA for advice and guidance on complex issues



# Multiple Agencies - Roles and Responsibilities

- **Human Tissue Authority**- Regulator 
- **Department of Health** - Policy setting; Ministerial liaison
- **NHS Blood and Transplant** - National Focal Point\*; clinical liaison and support
- **Other agencies**
  - Visas and Immigration
  - National Crime Agency
  - Police



*\*Network of National Focal Points on Travel for Transplantation (NETTA), Council of Europe*

# Balancing the Risk



## ■ Do too much

- Stop legitimate donation and transplantation activity
- Limit access to transplantation for people who are already disadvantaged
- Encourage (different) risky behaviours by those who feel 'disempowered'
- Loss of trust – professional v patient v 'targeted' communities

## ■ Do too little

- Illicit activity goes unchecked; vulnerable people are exploited/harmed
- Mission creep- discriminatory behaviours become habitual
- Loss of trust and public confidence in donation, transplantation, professionals (everyone loses out)

# Multi-agency Collaboration

- **Engage** with clinicians and patients
- **Improve** safeguards
- **Support** legitimate transplantation
- **Update** policies and guidance
- **Introduce** new legislation



# Statistics (2)- since 1<sup>st</sup> April 2024



## Since April 2024\*

- 9 cases reported under the new regulations



*\*Data courtesy of HTA*



# Duty to Report

**Human Tissue Act 2004 (Supply of Information about Transplants)  
Regulations 2024**



# About the 2024 Regulations\*

- Came into force on 1 April
- Introduced under section 34 of the Human Tissue Act 2004
- Apply to England, Wales and Northern Ireland (Parallel legislation is being developed in Scotland)
- Failing to report under the Regulations is an offence

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## What is the requirement?\*

- **Relevant clinicians** who work closely with patients that need, or have received, an organ transplant are required to report to the HTA:
  - If they have a **reasonable suspicion** that an **organ donation and transplantation related offence may have been committed** under the Human Tissue Act or Modern Slavery legislation, or
  - If they **are made aware** that a patient has received an organ transplant outside the UK

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## Are there penalties?\*

- **Failing to report** under the Regulations is an offence
- **Clinicians risk**
  - **Criminal charges** amounting to a fine for failing to report or
  - **An unlimited fine** for providing false or misleading information
- **Report cases** (as soon as reasonably practicable) or contact the HTA at: [report@hta.gov.uk](mailto:report@hta.gov.uk)

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## Who are relevant clinicians?\*

- **Relevant clinicians** who work closely with patients that need, or have received, an organ transplant (in a transplant or non-transplant centre) include:
  - a specialist nurse involved in living donor care
  - a specialist nurse involved in recipient care
  - a transplant surgeon
  - a physician involved in living donor care
  - a physician involved in recipient care

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## What constitutes ‘reasonable suspicion’?\*

- You can report even **if you are not certain** that an offence has been committed
- When reporting a reasonable suspicion, clinicians **must not alert the donor or recipient**
- Grounds for ‘reasonable suspicion’ may include:
  - a. Where the work up of a living donor is **not progressed** for **non-clinical reasons** (e.g. due to suspicion that a donor has, or will be, rewarded for their donation)
  - b. If the donor has a **changing or conflicting account** about their reasons for donating
  - c. If a recipient states a **clear intent** to seek a transplant outside the UK in circumstances where there is concern that an offence may take place

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## Important to Note\*

- The legislation **does not apply retrospectively**
- The **Duty to Report** applies to
  - **All cases** where a patient receives an organ transplant outside the UK
  - **Any case within or outside the UK** where there is concern that an offence may have been caused under the **Human Tissue Act 2004** or **Modern Slavery Act 2015**
  - **Does not conflict with any professional advice (e.g.; General Medical Council)**

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



## Important to Note\*

- **Engage** with your **hospital information governance** and **safeguarding** teams for additional support
- **The HTA** cannot divulge information to clinicians that may compromise a police investigation
- **Early consultation** with the HTA if in doubt
  - There is little or no evidence of relationship
  - You have any other concerns

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>





# What do patients need to know?\*

- **Be clear** in discussions with patients about
  - **The quality, safety and health issues** that may be associated with unlawful organ donation and transplant activity
  - **That professionals are obliged to share information and personal data** with the HTA if they travel outside the UK for an organ transplant
  - **The risk of opening themselves up to prosecution** and being reported to the HTA for possible police referral where an offence may have been committed
  - **The requirement to notify the HTA** of any transplant that has taken place outside the UK

\*<https://www.hta.gov.uk/news/supply-information-about-transplants-regulations-2024>



**HTA Resources** [transplants@hta.gov.uk](mailto:transplants@hta.gov.uk) or **0207 269 1900**

## **General information:**

- [Supply of Information about Transplants Regulations 2024 | Events | Human Tissue Authority \(hta.gov.uk\)](#)

## **The Regulations:**

- [The Human Tissue Act 2004 \(Supply of Information about Transplants\) Regulations 2024 \(legislation.gov.uk\)](#)

## **Guidance document for clinicians:**

- [The Human Tissue Act 2004 \(Supply of Information about Transplants\) Regulations 2024.pdf \(hta.gov.uk\)](#)



## Other Resources

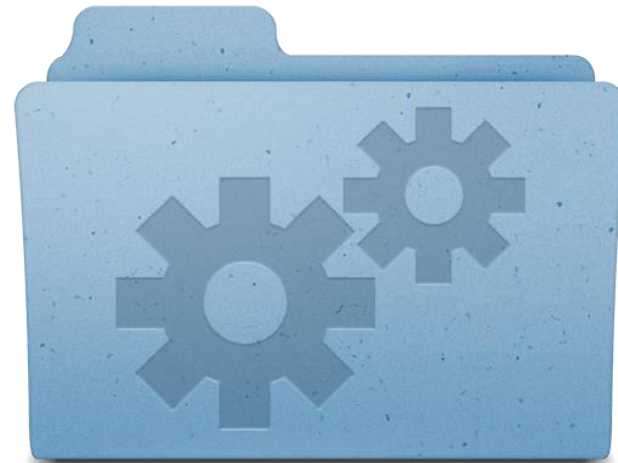
**Declaration of Istanbul leaflet** [Leaflet on Declaration of Istanbul](#)

### Coming soon

- Updated information for donors and recipients- NHSBT website
- Co-Ordinator training (HTA/Met.Police/NHSBT)



# Work in Progress



## Work in Progress

- **On-going engagement/briefings with professionals and patient representatives**
- **Updates to donor-recipient information and UK LD Guidelines**
- **Co-Ordinator training (NHSBT/HTA/Police)**
- **Data sharing agreements between HTA and NHSBT for NFP audit**
- **Multi-agency discussions re UK Entry Visa provisions to support living donor transplantation**

## Asks

- **Familiarise yourself with the changes**
- **Cascade this information to your teams**
- **Register all non-resident living donors with NHSBT with country of resident addresses (not UK temporary addresses)**
- **Consult with HTA early about matters of concern**
- **Engage with your safeguarding and information governance teams**
- **Let us know how we can best support you**

# Acknowledgements

## ▪ NHSBT

- Derek Manas – OTDT Medical Director
- Bruce Willan- External Affairs

## ▪ Human Tissue Authority

- Jess Porter - Head of Regulation,
- Sumrah Chohan
- Anjeli Kara

## ▪ Clinical colleagues

- In transplant and non-transplant centres

## ▪ Others

- Dept. of Health and Social Care (DHSC)- Dylan Parrin, Jackie Cooper
- UK Visas and Immigration
- National Crime Agency
- Police

