

# Travel for Transplantation

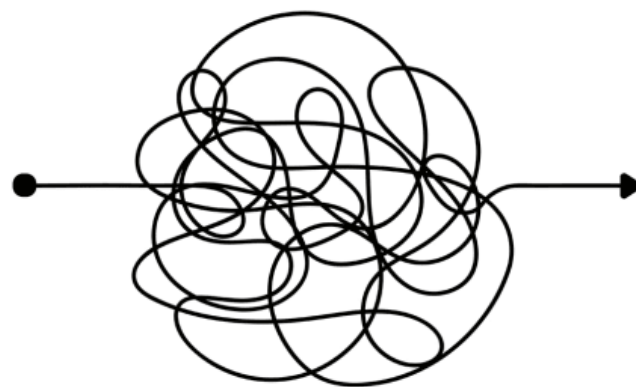
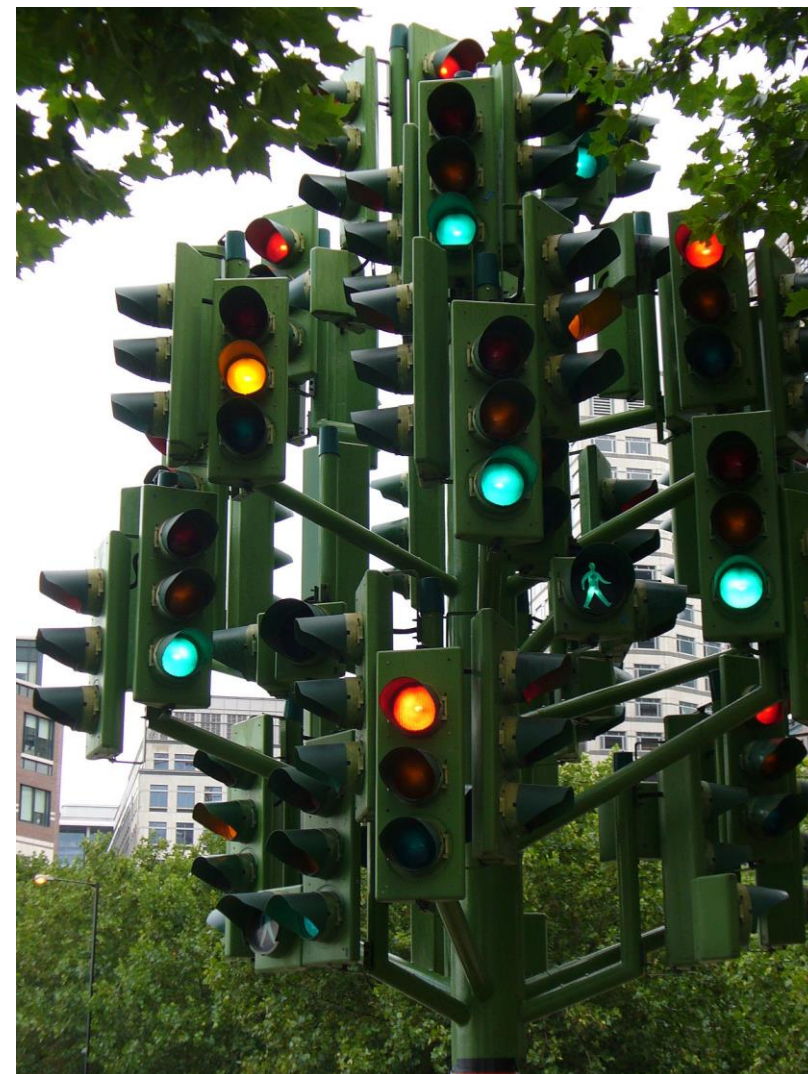
**Lisa Burnapp**

Consultant Nurse

Associate Medical Director - Living Donation and Transplantation

UK LKD Network Meeting, April 2024

# Background



# Back to Basics

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

# The Perfect Storm

- **Law changes**
  - Modern Slavery Act (2015)
  - Human Tissue Acts (July 2022)
- Organ trafficking case prosecuted, May 2023
- NFP\* audit and improved clinical awareness
- Transplant waiting lists going up post-pandemic
- Lifting of travel restrictions



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

# Existing Legislation

- **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



# 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



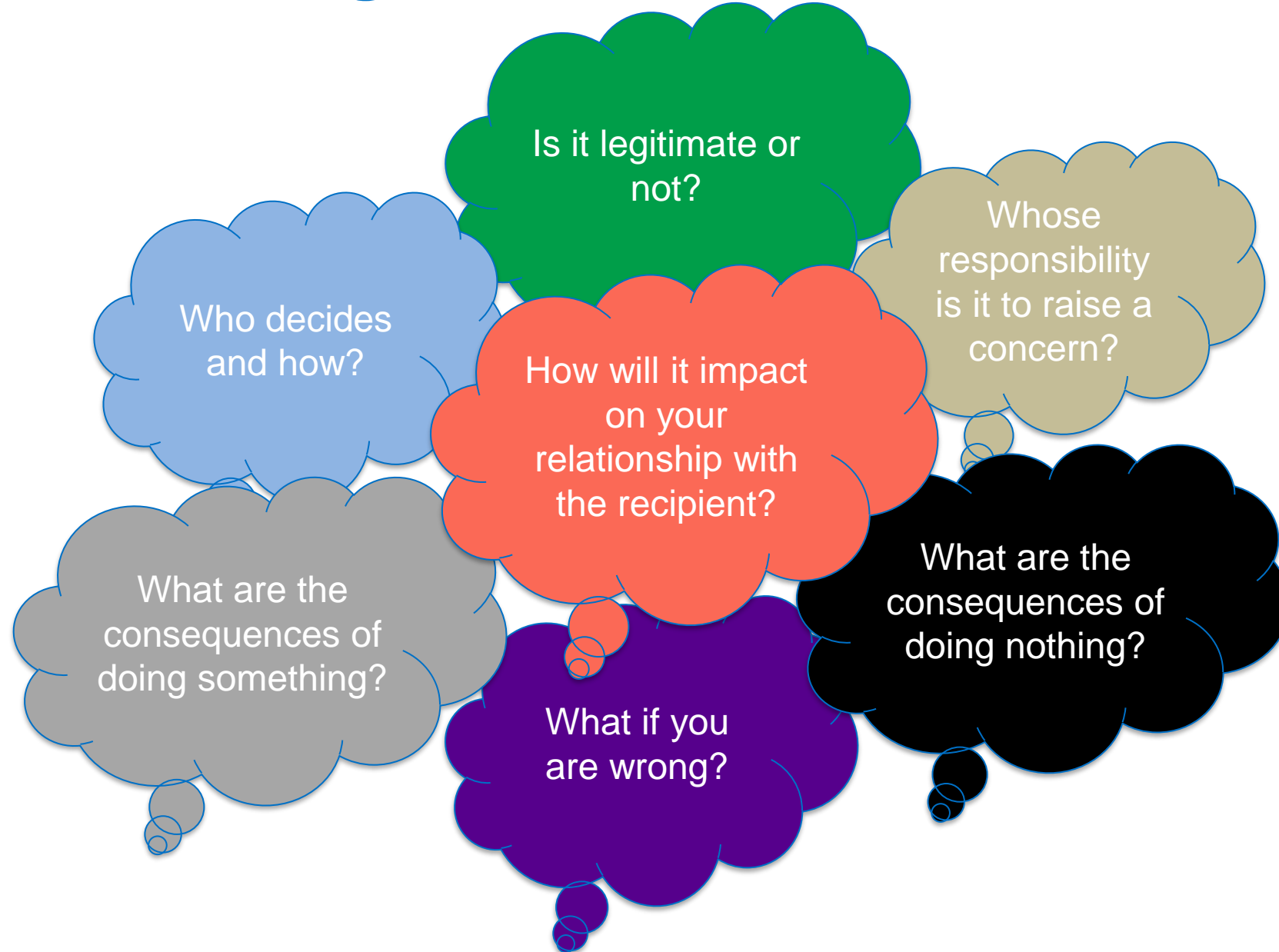
*\*Network of National Focal Points on Travel for Transplantation (NETTA), Council of Europe*

# What is Travel for Transplant?\*

- **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*

# Matters Arising





# 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



# Interim Guidance

## If in doubt.....

- **Early consultation with the HTA, when**
  - There is little or no evidence of relationship
  - You had any other concerns

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



# What are the statistics?

## Since October 2022\*

- 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
- 1 case received under the new Regulations
- Multiple enquiries to HTA for advice and guidance on complex issues



# 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

\* <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**
- **Engage** with your **Trust information governance** and **safeguarding** teams
- **The HTA** cannot divulge information to you that may compromise a police investigation

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



# What do you say to patients?\*

- **Be clear** in your discussions with patients about
  - **The quality, safety and health issues** that may be associated with unlawful organ donation and transplant activity
  - **That you 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>



## Further Resources

### 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 \(hta.gov.uk\)](#)



## Further Resources

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

### Coming soon

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



**Be appropriately cautious**



## **Professional Skepticism**

Professional skepticism is an attitude that includes a questioning mind and a critical assessment of audit evidence.

## If in Doubt...

- **Early consultation with the HTA, when**
  - There is little or no evidence of relationship
  - You have any other concerns

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





# 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 centres

- **Others**

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





**Lisa Burnapp**  
**Jess Porter**