

A thick blue wavy line that spans the width of the slide, starting from the left edge and ending at the right edge, positioned above the title.

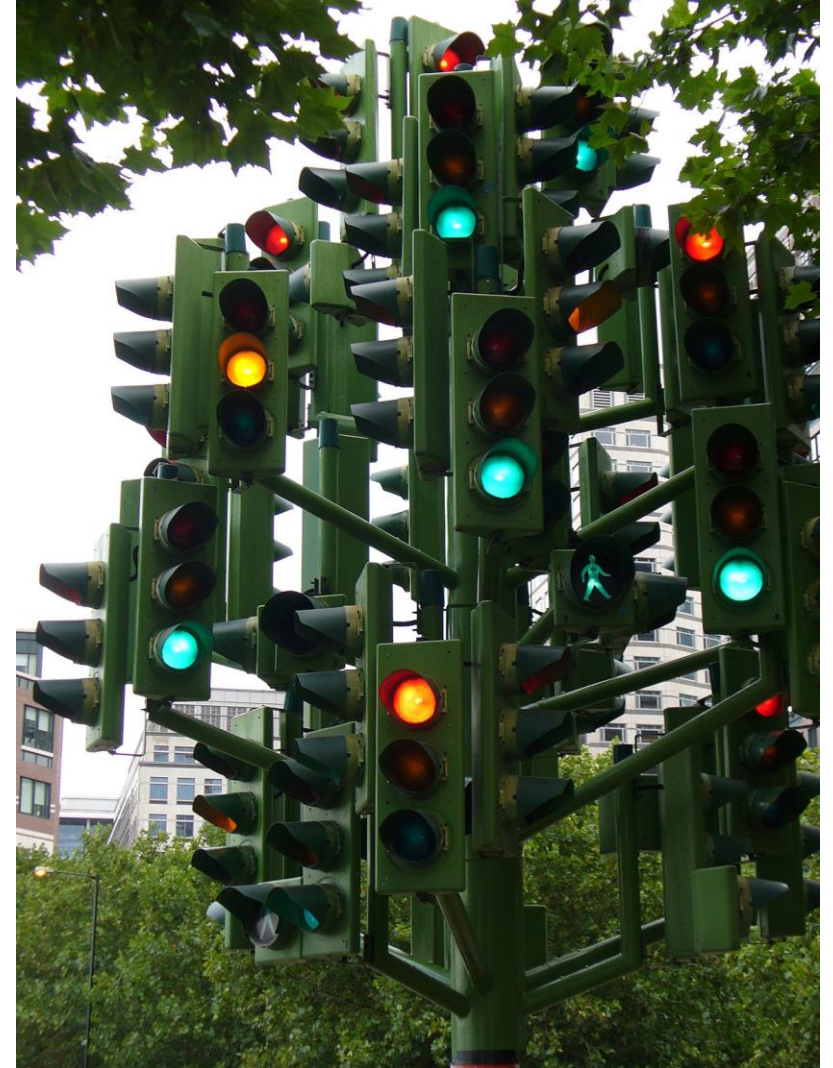
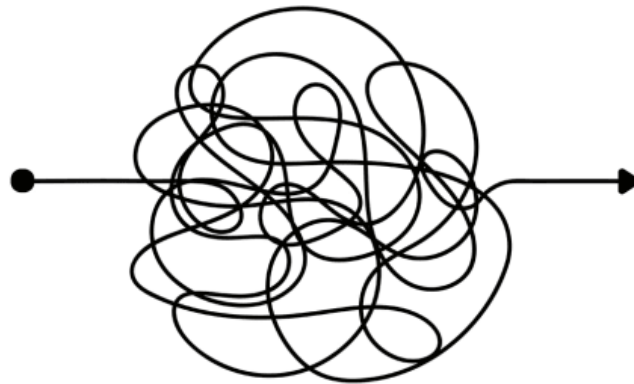
# Travel for Transplantation – UK Matters Arising

Lisa Burnapp

Consultant Nurse

Associate Medical Director - Living Donation and Transplantation

# Lessons Learned



# 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*



# 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\* (but Modern Slavery Act may also apply)

- **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 are National Focal Points?

- Council of Europe

- Human rights organisation that includes 46 member states, 27 of which are members of the European Union

- Resolution CM/Res (2013)55 on establishing procedures for the collection and dissemination of data on transplantation activities outside a domestic transplant system

- designate a contact person in charge of data collection on illicit transplantation activities. This contact person should be based at the existing national transplantation body or, alternatively, at the ministry of health in those member States where a national transplantation body does not exist or is not in charge of following-up on transplantation activities;

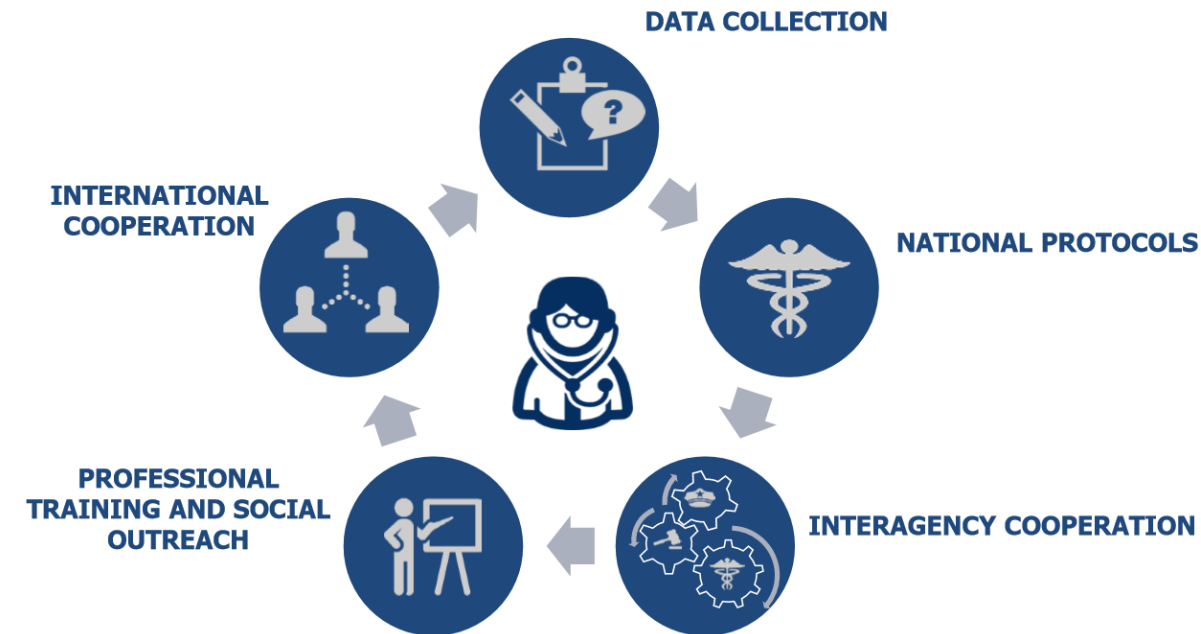


**NFP**

# What are National Focal Points?

- First meeting in 2016
- Role\*
- **Audit data collection** - Registry of International Travel for Transplantation Activity (RITTA), Council of Europe

The data collected will be used by our national authorities to analyse the phenomenon of travel for transplantation and to design appropriate measures and policies.



*\*Marta Lopez Fraga, Technical Meeting for NFPs 2019*



# Types of Travel for Transplant\*

- **TTA – Patients who travelled for transplantation abroad** and returned to their country after the transplantation procedure
- **NRP – Non-resident recipients** who received an organ transplant from a non-resident living donor
- **NRD – Resident recipients** who received an organ transplant from a non-resident living donor
- **NRR – Non-resident recipients** who received an organ transplant from a resident living donor
- **KEP – Transnational living kidney exchange programmes** where donors and/or recipient travels to your country

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

# Real Life Stories



# Real Life Stories 1

*Potential non-resident living donor, still in country of residence, offers to donate to a recipient under your care. The relationship with the recipient is unclear and/or cannot be substantiated and/or appears 'unequal' (e.g. by socio-economic status, age and/or power/influence).*

- Genuine relationship or potential trafficking?
- Who makes 'the call' and on what grounds?
- What are the consequences for donor, recipient and clinician?



*Potential non-resident living donor arrives in the UK, appears 'clinically' suitable but has limited understanding of the donation procedure and their relationship with the recipient seems superficial and/or the story is inconsistent. Clinician declines the donor due to concerns about potential donor vulnerability.*

- If trafficking, is there a risk that the donor will be exploited elsewhere?
- What is the impact on the donor and their relationship with the recipient?
- Where does it leave the clinician?
- What is the impact on public confidence if illicit activity is unearthed?



# Real Life Stories 3

*Your patient expresses the intention to travel abroad for a transplant and you counsel against it. They ask for their HLA type and go anyway, returning to your clinic with a functioning transplant, brief discharge summary and no donor details.*

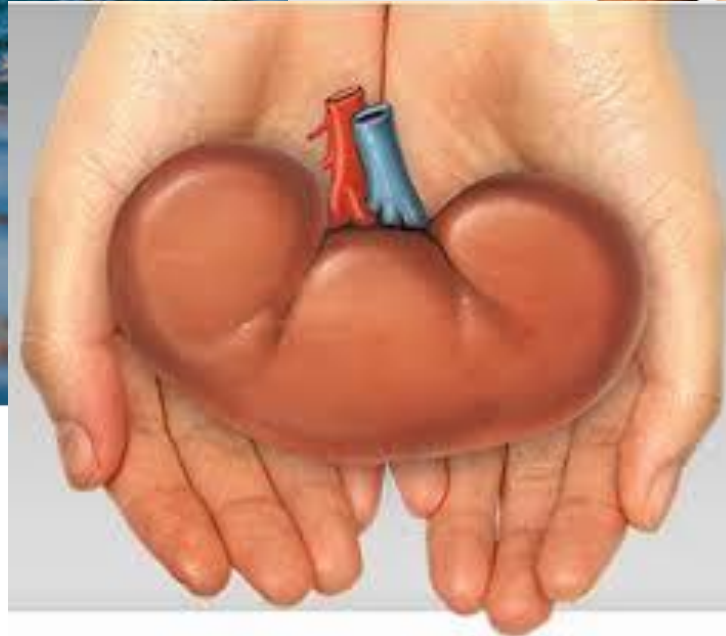
- Legal or not?
- Is the recipient the perpetrator or the victim?
- What is the role of the clinician?





# Matters Arising





# 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

## ■ Don't do enough

- 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 to improve safeguards and support legitimate travel for transplantation**
  - Review of 'end to end' processes
  - Revised policies and guidance
  - Engagement with and support for patients and clinicians



# So, what can you do?





# Be appropriately cautious



## Professional Skepticism

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

# 1. What do you do if.....

The relationship between a recipient under your care and their non-resident living donor is described to you as a friend of the family.

The donor is still in their country of residence but plans to travel as soon as possible.

They need a letter of support from you to apply for a UK Entry Visa.



## Potential non-resident living donor where the relationship is unclear and/or cannot be substantiated

1. Check Immigration Rules V 8.1 to V.8. 4. for requirements.
  - Crucially these require that the “the applicant must satisfy the decision maker that they genuinely intend to donate an organ to, or be assessed as a potential organ donor for, an identified recipient in the UK with **whom they have a genetic or close personal relationship**”
2. Do not write letter of support for the visa unless you are absolutely satisfied there is a genetic or close personal relationship
  - Question motivation and be less trusting- **use your professional scepticism**
  - Request to see all documents that will be submitted at the point of visa application so you can **assure yourself of the relationship** and be **content to support the application**

## Potential non-resident living donor where the relationship is unclear and/or cannot be substantiated

3. **Contact HTA for advice – [transplants@hta.gov.uk](mailto:transplants@hta.gov.uk) or 0207 269 1900 and ask to speak to a member of the LOD team.**
  - If a case of this nature does come to the HTA, we will need sufficient time to review and make decisions – please do not assume you will have a decision within normal timeframes, there will be clarifications we will need to seek
4. **Read [HTA guidance](#)**

## 2. What do you do if.....

You see a non-resident living donor in your clinic who is planning to donate to a recipient under the care of one of your colleagues.

You are concerned that they have a superficial understanding of what is involved in the donation process and they are not very forthcoming about the nature of their relationship with the recipient.





## Potential non-resident living donor has arrived in the UK, is potentially vulnerable and a decision is made that they are not suitable to proceed to donation

1. **Keep safeguarding concerns in mind** – could they have been trafficked?
  - Signs to look for include lack of understanding about why they are in the UK
  - Concerns about age / education / wealth disparity between donor and recipient
  - Concerns that relationship is not as claimed
2. **Consult hospital safeguarding team** if you have any of these concerns and contact HTA if you need further advice.
  - If any immediate safeguarding concerns (if a person may be in danger of harm) contact the Police

### 3. What do you do if.....

A recipient under your care expresses a wish to travel abroad to receive a transplant and asks you for a record of their HLA type.

They have no suitable living donors in the UK and they tell you that they do not want to wait any longer for a kidney here and they can get one much quicker in the country they plan to travel to.



## **Patient who has expressed a wish to travel abroad for a transplant, has been counselled against doing so but still requests HLA typing**

- 1. Information on the HTA website [for patients](#) and [professionals](#) on travelling overseas**
- 2. Provide [Leaflet on Declaration of Istanbul](#) to patients**
- 3. Be clear with patients not only about the **quality and safety risks** of seeking an organ transplant overseas, but also that they are **opening themselves up to prosecution****
- 4. Red flags include anxiety from patient about being listed in the UK**

## Patient who has expressed a wish to travel abroad for a transplant, has been counselled against doing so but still requests HLA typing

5. **Under Article 15 of the GDPR**, patients have a right to access, and receive copies of, their health records and this includes H&I data.
  - It is unlikely that a transplant team would be committing a criminal offence by providing the patient with their medical H&I data
  - Consult with your Information Governance Team
6. **The change made to the law in July 2022** means that the offences related to commercial dealings that already existed (had they taken place in the UK) **e.g. giving, offering, receiving, initiating or negotiating a reward, now apply if they are committed anywhere in the world**
7. **Until reporting processes are clarified**, please notify HTA of any cases of concern via [transplants@hta.gov.uk](mailto:transplants@hta.gov.uk)

## Case 3: Potential non-resident living donor has arrived in the UK, is potentially vulnerable and a decision is made that they are not suitable to proceed to donation

1. **Keep safeguarding concerns in mind** – could they have been trafficked?
  - Signs to look for include lack of understanding about why they are in the UK
  - Concerns about age / education / wealth disparity between donor and recipient
  - Concerns that relationship is not as claimed
2. **Consult hospital safeguarding team** if you have any of these concerns and contact HTA if you need further advice.
  - If any immediate safeguarding concerns (if a person may be in danger of harm) contact the Police



## 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

- Matthew Robb - Principal Statistician, fellow NFP representative
- Derek Manas – OTDT Medical Director

## ■ Human Tissue Authority

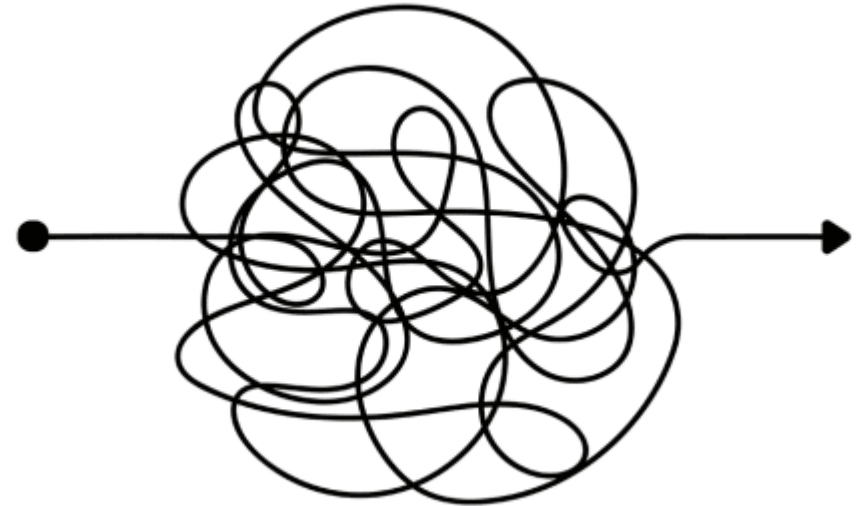
- Jess Porter - Head of Regulation

## ■ Clinical colleagues

- In transplant centres

## ■ Others

- Dept. of Health and Social Care (DHSC)
- UK Visas and Immigration
- National Crime Agency
- Police





**Thank you.**

[lisa.burnapp@nhsbt.nhs.uk](mailto:lisa.burnapp@nhsbt.nhs.uk)