

# Living Donor Kidney Transplantation Update

Lisa Burnapp  
Clinical Lead- Living Donation

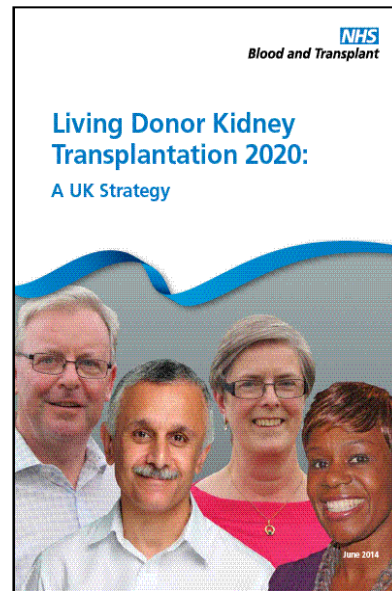
KAG Kidney Patient Group, July 2021



**Caring Expert Quality**  
Three small words, one big difference

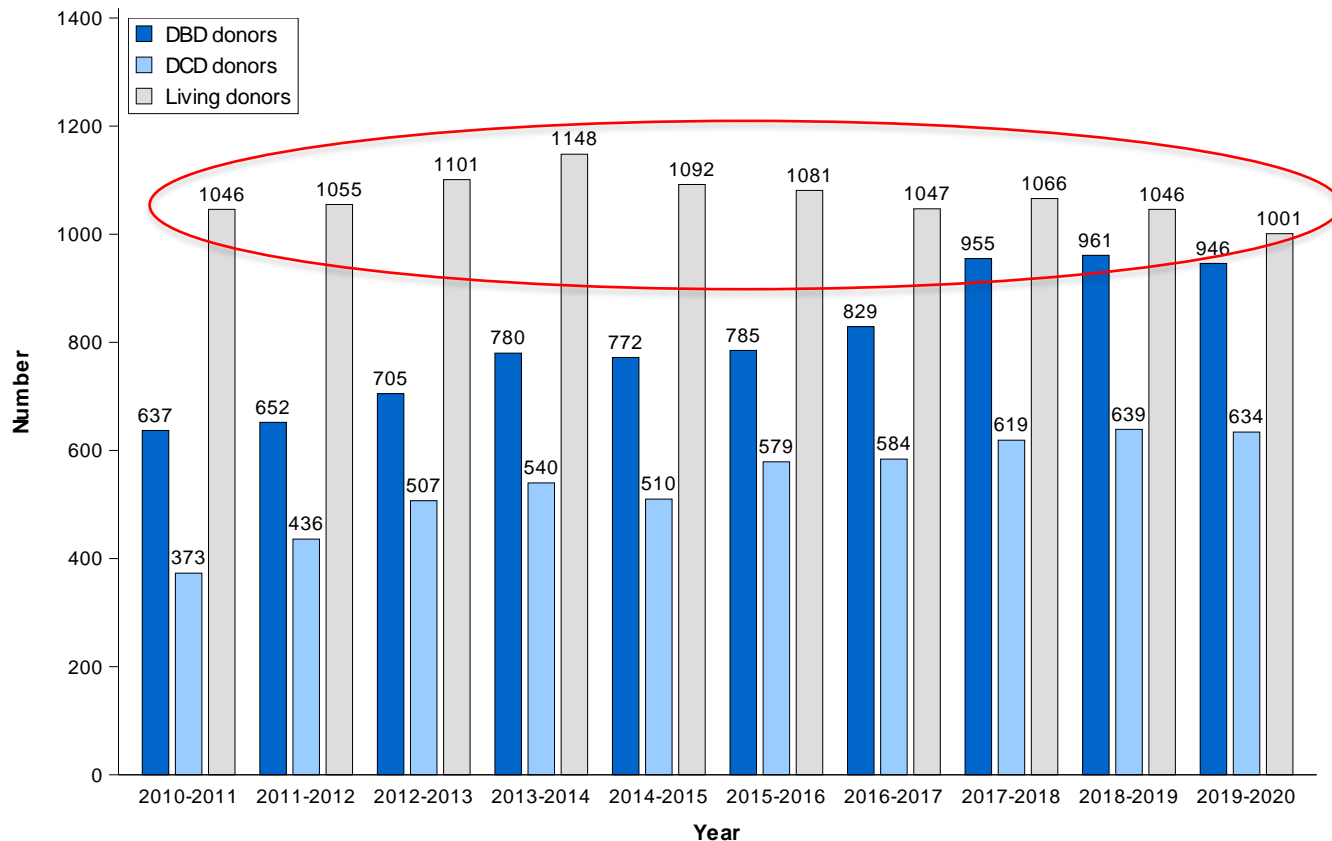
# Our Ambitions: 2010-2020

- Increase living donor kidney transplantation (LDKT)
  - Address unwarranted variation
  - More options for LDKT
  - More living donors
- Improve recipient outcomes
  - Increase pre-emptive (before dialysis) LDKT
  - Maximise UK living kidney sharing scheme (UKLKSS)
  - Disincentivise travel outside UK for a transplant
- Look after donors
  - Remove unwarranted barriers to donation
  - Ensure the best outcomes and donor experience



*"To match world class performance in living donor kidney transplantation"*

# Number of deceased and living donors in the UK, 1 April 2010 - 31 March 2020



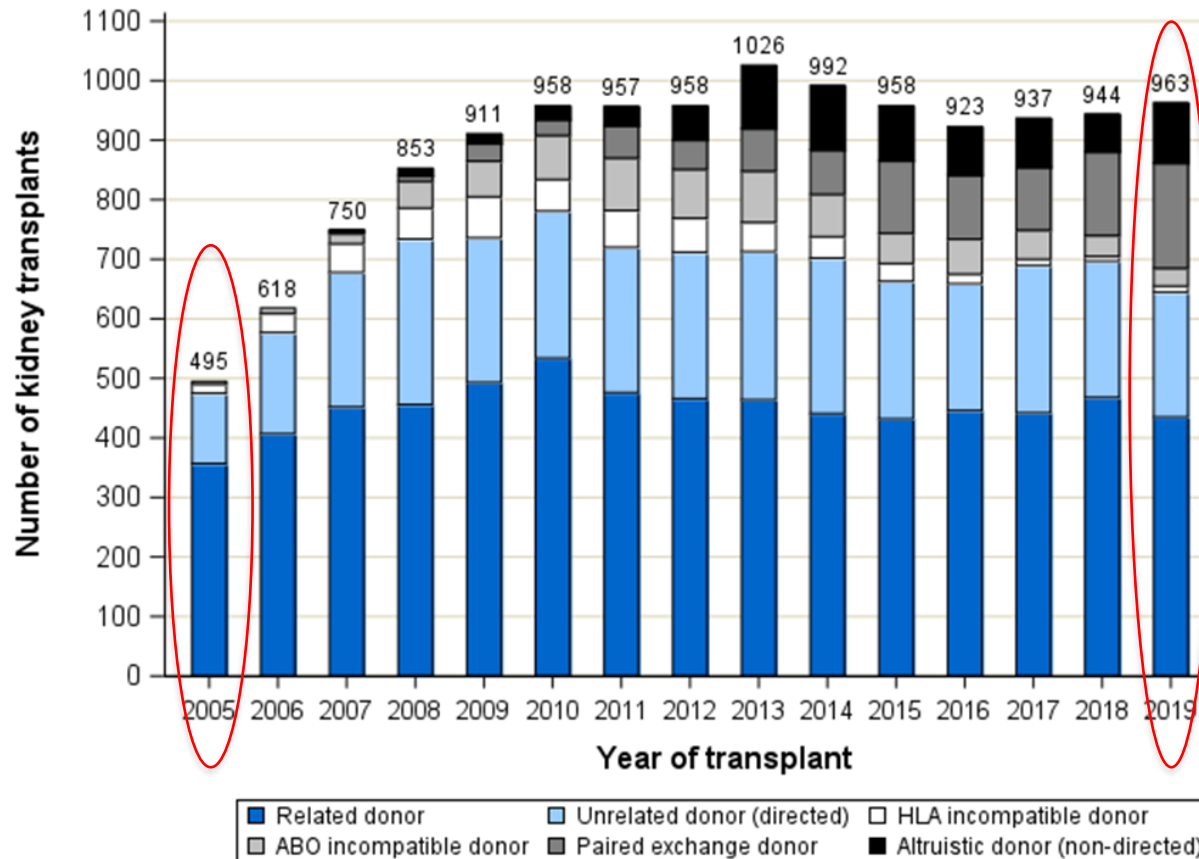
**2019/20**

**39% of all donors were living donors**

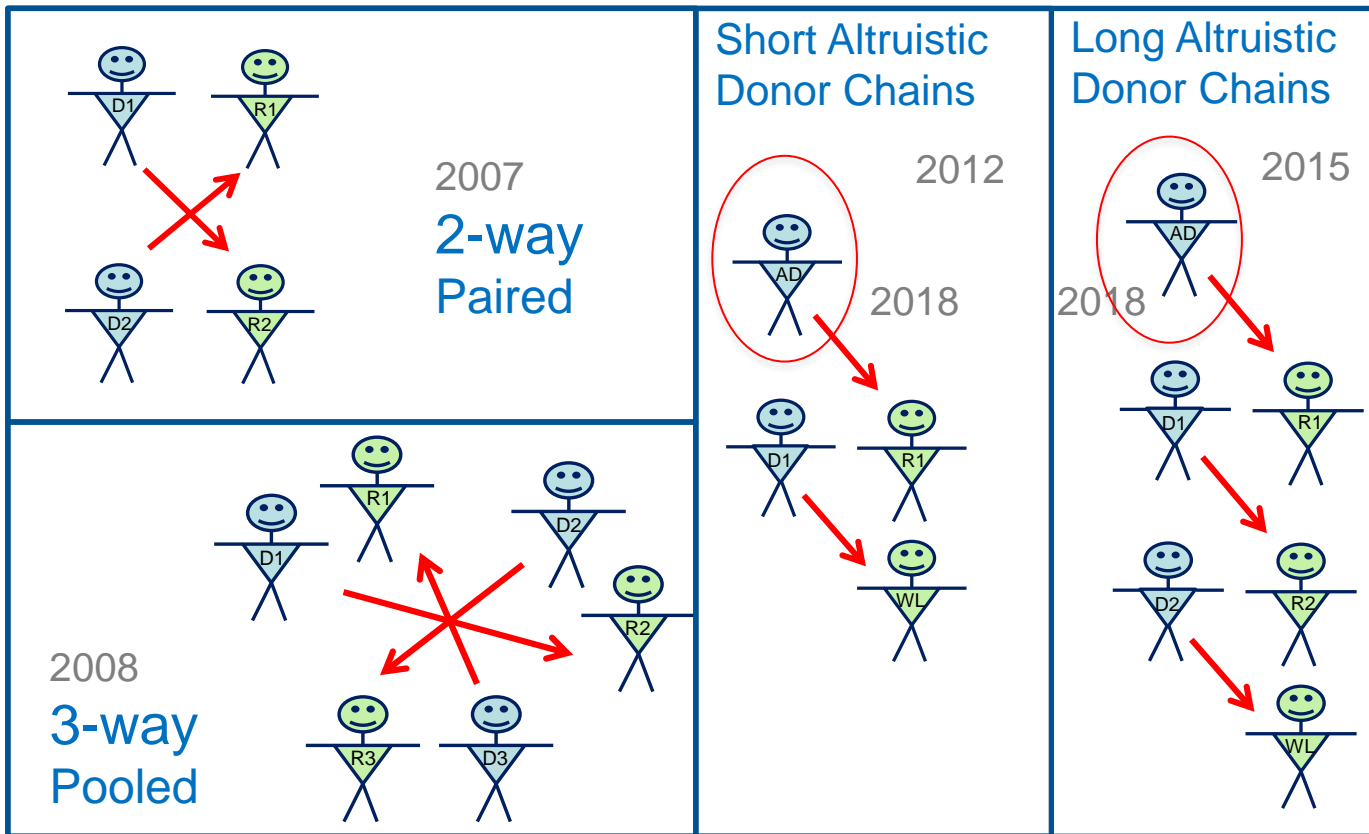
**28% of all kidney transplants were from living donors**

**2% of all liver transplants were from a living donor**

# Adult living donor kidney transplants



# The scheme today - matching runs identify....

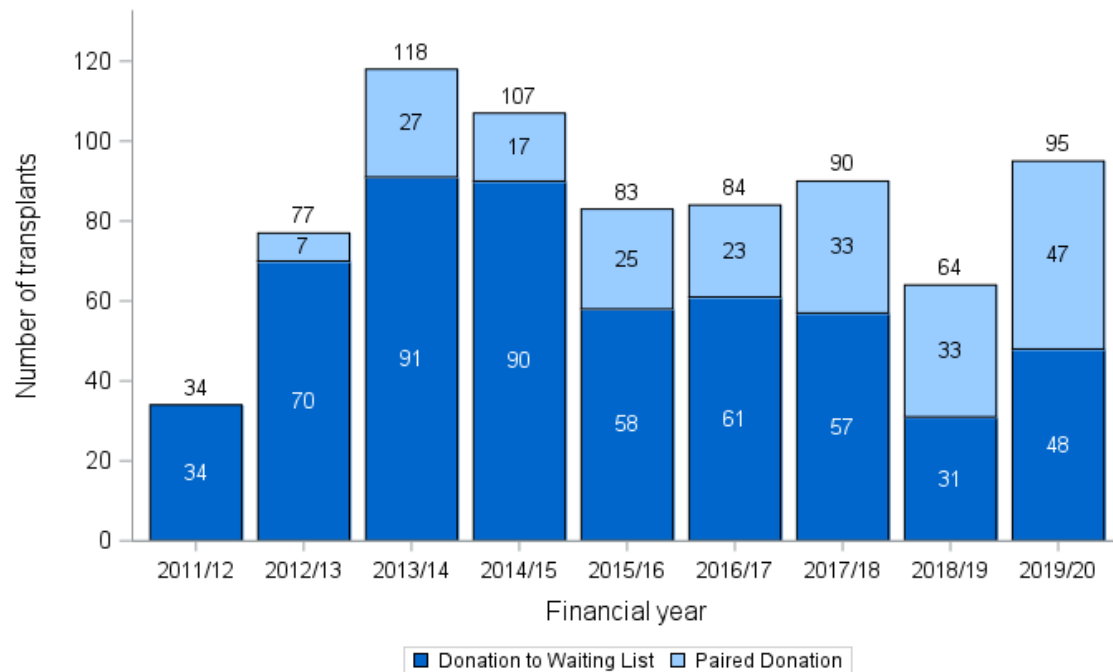


# The Generosity of Strangers



Blood and Transplant

**Figure 4.8** Non-directed altruistic donor kidney transplants in the UK by type,  
1 April 2011 - 31 March 2020

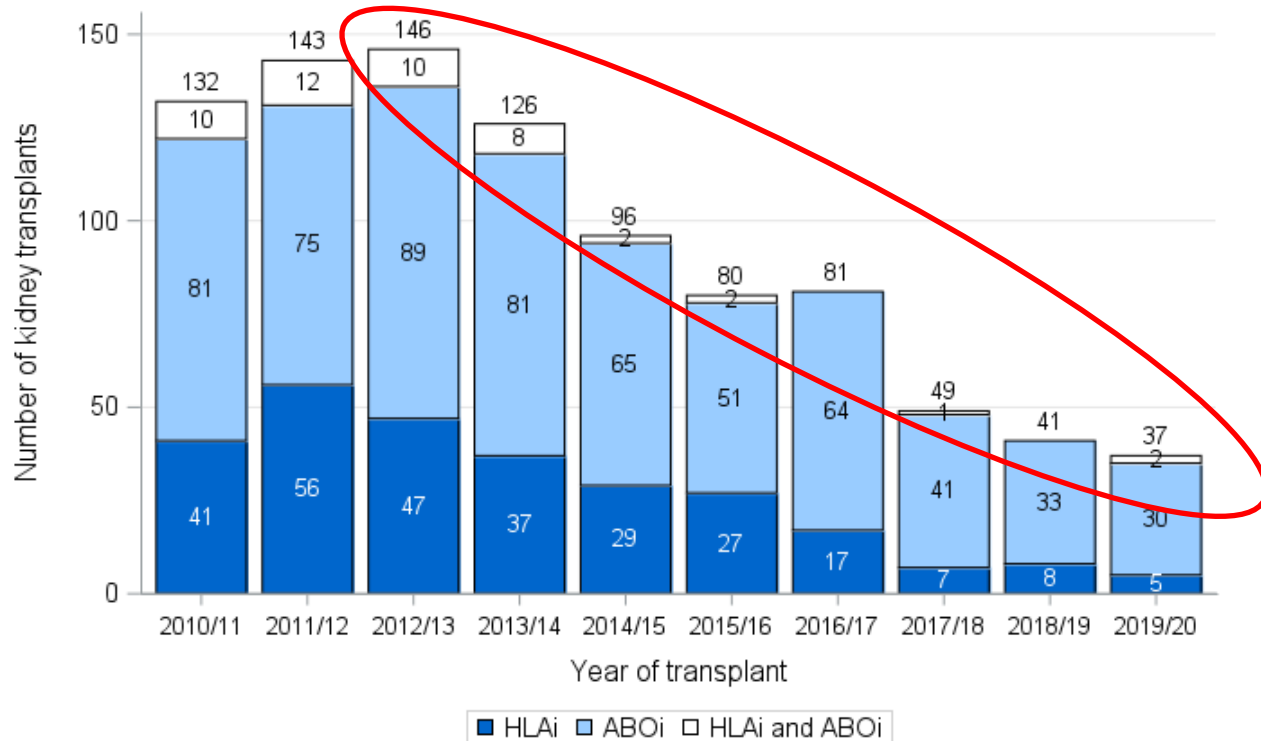


**31<sup>st</sup> March 2021**

**847 donors**  
**1177 transplants**

- **610 direct to list**
- **237 into a chain (567 Txs.)**

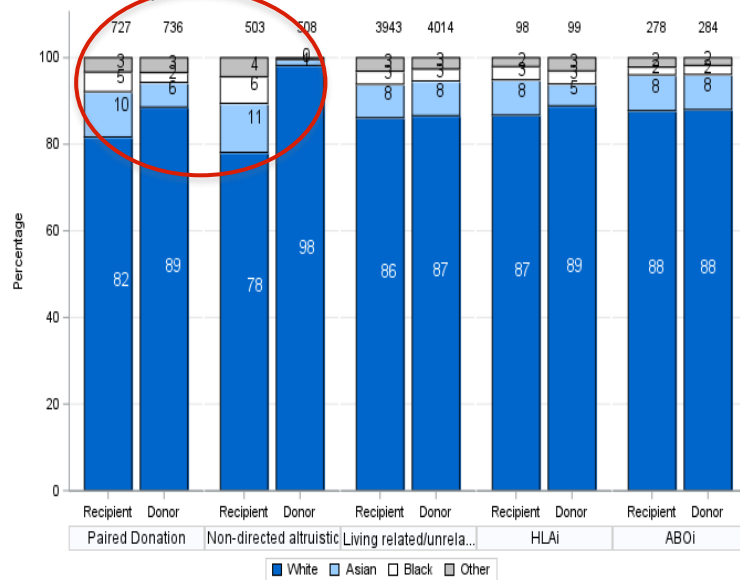
**Figure 5.2 Adult living donor antibody incompatible kidney transplants in the UK, 1 April 2010 - 31 March 2020**



# Recipient Ethnicity

## Adults

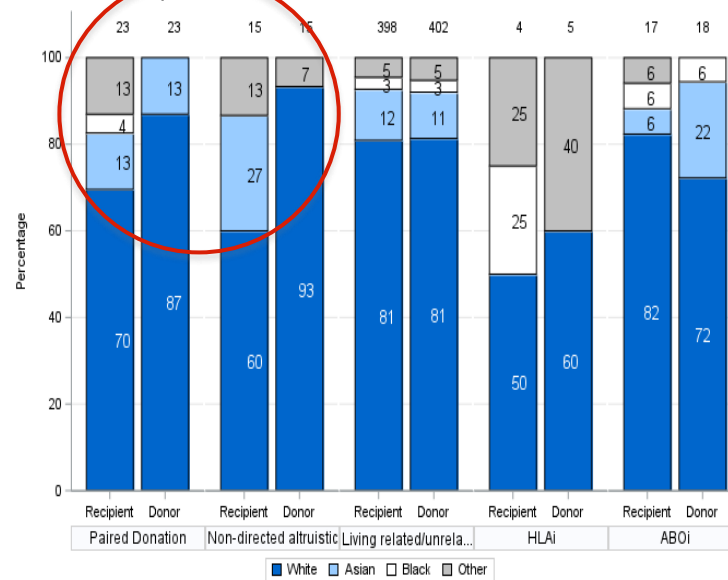
Figure 3.2 Ethnicity of recipient and donor by adult transplant type, 1 April 2014 - 31 March 2020



Source: Annual Report on Living Donor Kidney Transplantation 2019/20, NHS Blood and Transplant

## Children

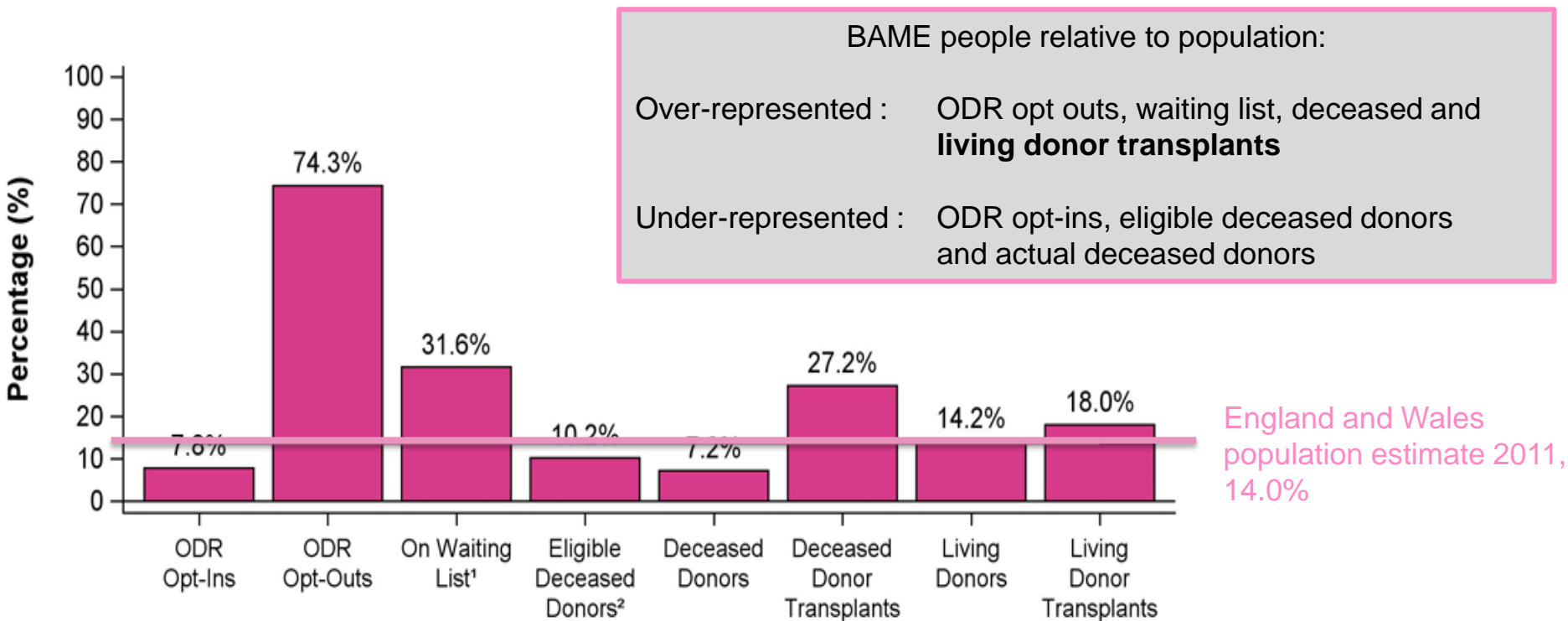
Figure 3.10 Ethnicity of recipient and donor by paediatric transplant type, 1 April 2014 - 31 March 2020



Source: Annual Report on Living Donor Kidney Transplantation 2019/20, NHS Blood and Transplant



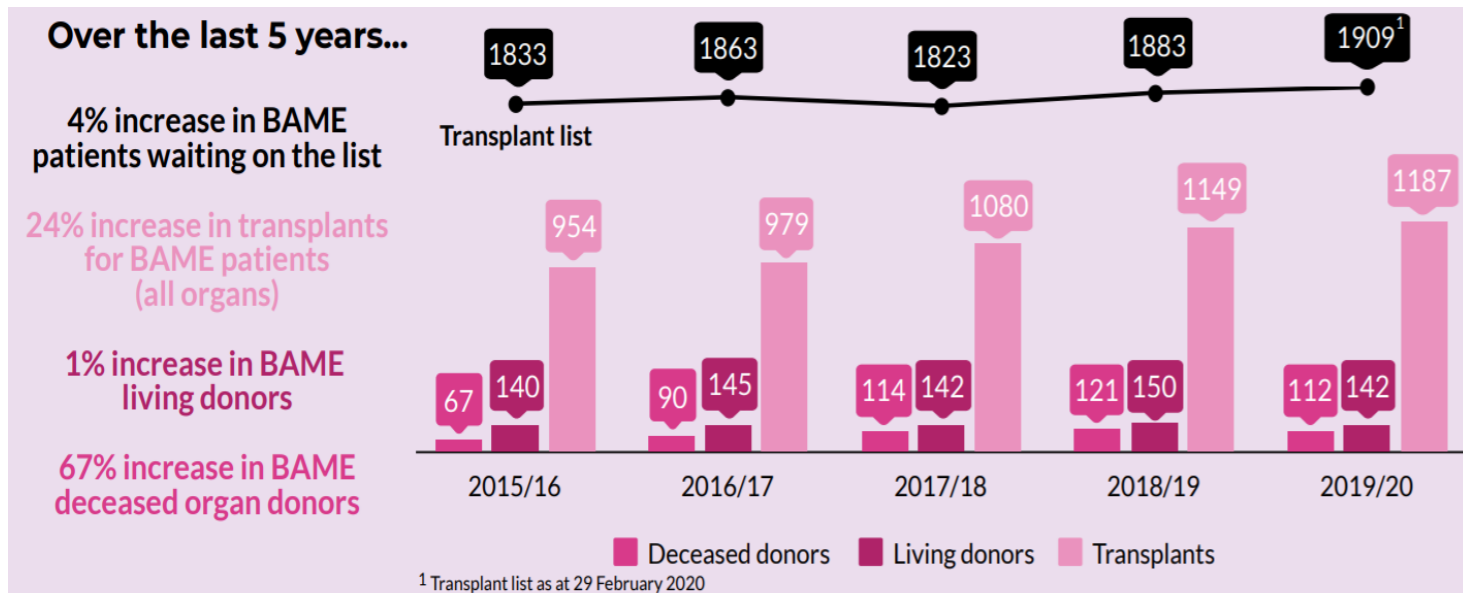
# BAME summary, 2019-20



¹ Waiting list as at 29 February 2020

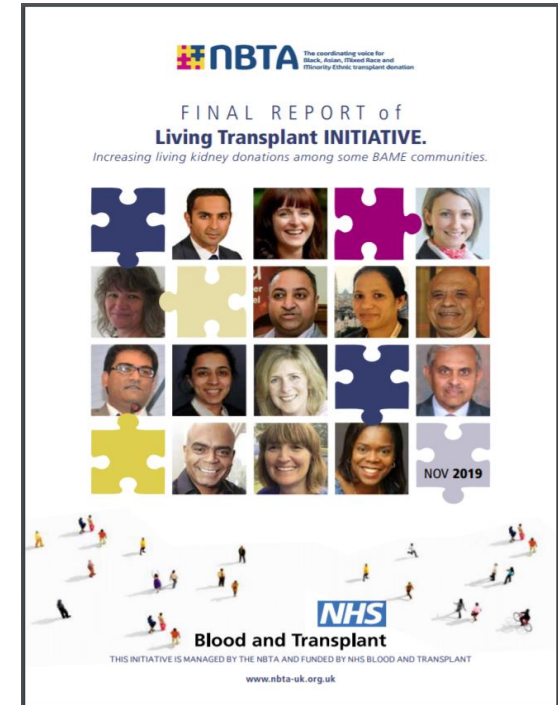
² 1 April 2019 to 29 February 2020 due to COVID-19 pandemic

# Increase in BAME Living Donors



# The Living Transplant Initiative- Phase 1&2

- Tailored, faith-based educational materials are a valuable and important resource
- Community events are helpful to raise awareness, improve understanding and encourage interest in living donation
- Of those who expressed interest in donating a kidney, very few proceeded to assessment or donation within the lifetime of the LTI
- Fostered positive collaborations between community project leaders and transplant professionals
- Targeted education is likely to be more successful in increasing uptake of living donation from BAME people



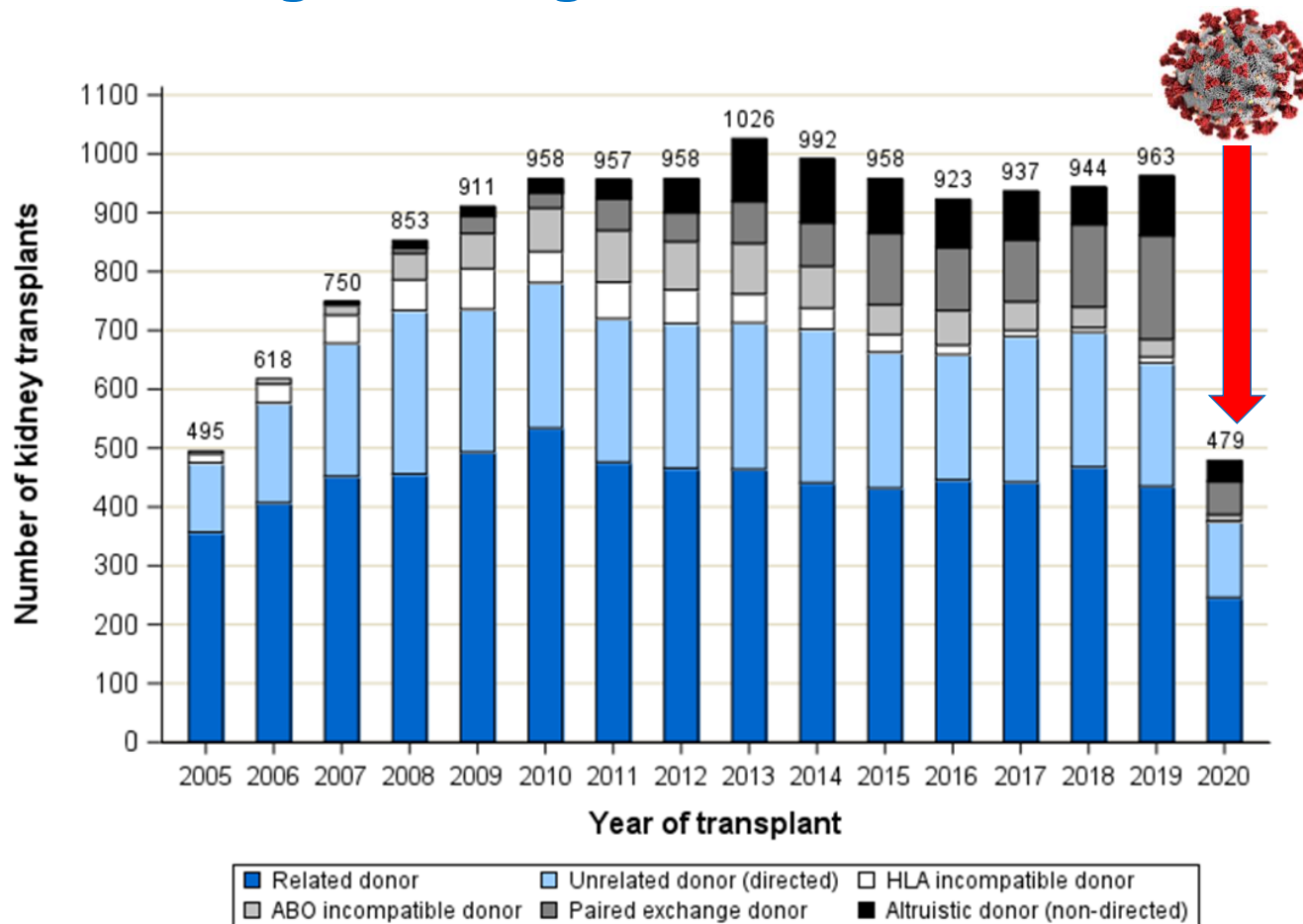
# LTI: Phase 3- Learning

- **Early engagement and education** about living donor kidney transplantation for everyone
- **Information and interventions need to be tailored** to individuals and/or groups of people dependent on faith, ethnicity and circumstances in order to be effective
- **Annual funding cycles, without recurrent funding opportunities, are ineffective** in supporting or sustaining interventional projects
- **Collaboration between transplant professionals and community representatives** from the same BAME background are the most effective strategies
- **Community representative outreach, peer volunteer support and advocacy** were effective to support transplant professional-led educational programmes for people from a BAME background
- **Home education is effective in delivering tailored transplant education to anyone in need of a transplant.** Access to the home environment is easier to achieve for a healthcare professional than for a peer volunteer

# Looking Ahead



# Re-building the Programme



In 2020

Living donor kidney  
transplants at 50%  
compared to 2019

2/4 UKLKSS matching  
runs performed

# Our Greatest Opportunity

One strategy

Living donation

Deceased donation

Organ Utilisation

## Organ Donation and Transplantation 2030: Meeting the Need

A ten-year vision for organ donation and transplantation in the United Kingdom



# For the person sitting in front of us....

Receiving the right kidney at the right time.





Living Donation will become an expected part of care, where clinically appropriate, for all in society

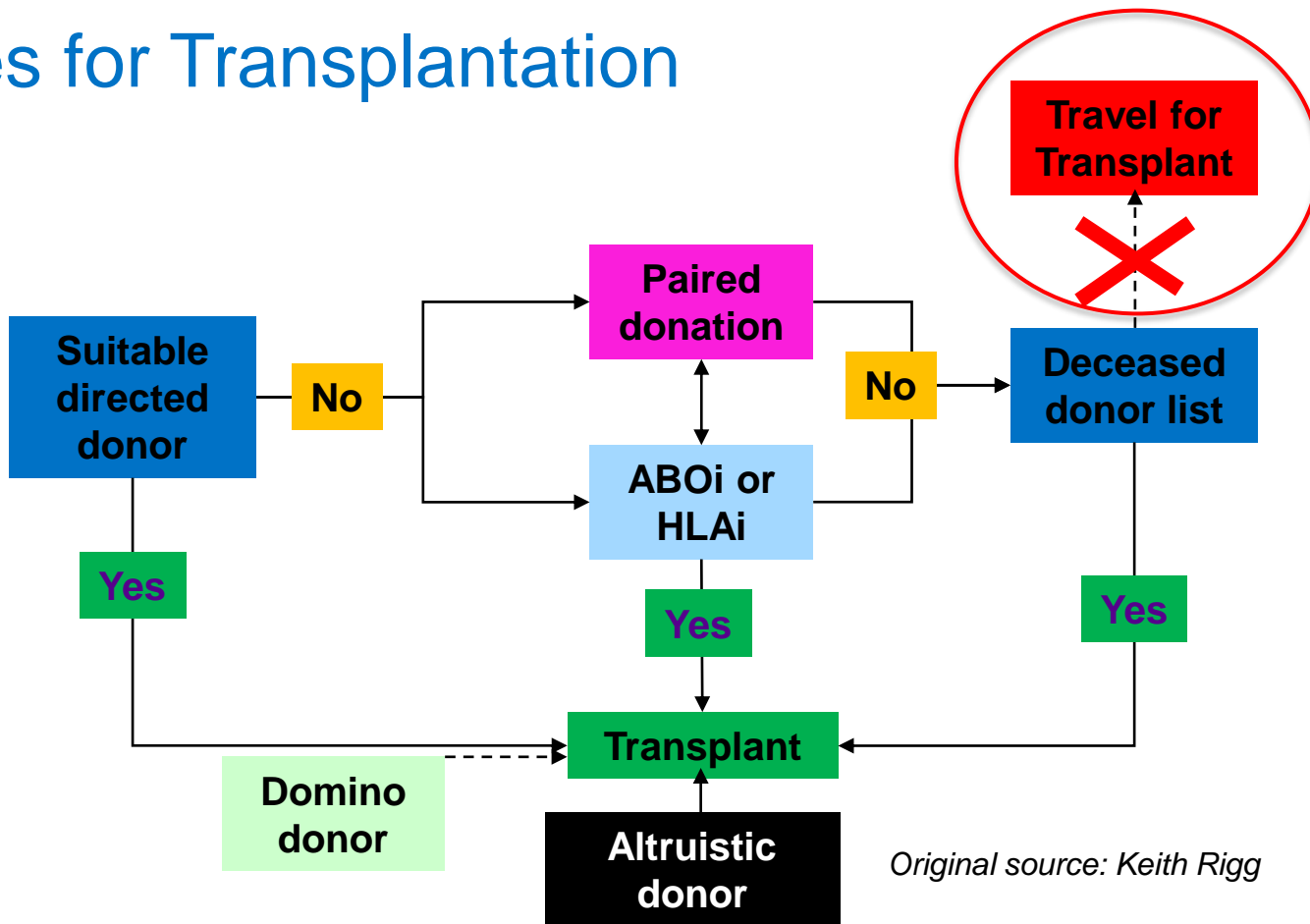


*Silver donor pin sent to every living organ donor in recognition of the gift of donation.*

# Living Donation

	Action
1.	Maximise <b>transplant opportunities</b> in the UK through the <b>UKLKSS</b>
2.	Ensure that the option of ' <b>transplant first</b> ' is considered for <b>all</b> suitable kidney recipients, especially <b>pre-emptive transplantation</b>
3.	Make it <b>as easy as possible to give or receive</b> a living donor kidney or lobe of liver by <b>removing unwarranted barriers</b> to donation
4.	Promote <b>public and patient awareness and engagement</b> in living donation across all sectors of society and <b>develop the 'Living Transplant Initiative'</b>
5.	Address <b>unwarranted variation</b> in clinical practice by <b>strengthening leadership</b> and providing <b>clear policies and guidelines</b>
6.	Ensure that the <b>experience, safety and welfare of living donor transplantation is the best it can be</b> for all donors and recipients and that donors are <b>recognised for their gift of donation</b>
7.	Use <b>innovative solutions</b> to offer more recipients the option of a living donor transplant ( <b>e.g. antibody depletion techniques</b> )

# Choices for Transplantation



Original source: Keith Rigg

# We can all do something about ‘transplant tourism’



**Protect your health**  
**Follow your conscience**  
**Do not break the law**

**The Declaration of Istanbul**  
In 2008, a group of leading medical experts from around the world met in Istanbul, Turkey to develop strategies to prevent organ trafficking and transplant tourism.

The group well appreciates the desperation felt by many patients in need of a transplant. It put forth a number of principles and proposals designed to promote both deceased and living donor transplantation around the world in a manner that protects the health and welfare of both recipients and donors while ending exploitation. They developed a policy document called **The Declaration of Istanbul**.

In 2010, the **Declaration of Istanbul Custodian Group (DICG)** was formed to promote the principles of the Declaration internationally. The DICG is sponsored by two major international professional organizations, **The Transplantation Society (TTS)** and the **International Society of Nephrology (ISN)**. More than 80 international professional societies and governmental agencies have endorsed the Declaration of Istanbul.

**THE DECLARATION OF ISTANBUL**  
AND THE TRANSPLANTATION SOCIETY

For more information:  
**DECLARATION OF ISTANBUL  
CUSTODIAN GROUP**  
[www.declarationofistanbul.org](http://www.declarationofistanbul.org)

**THINKING OF  
BUYING  
A KIDNEY?**

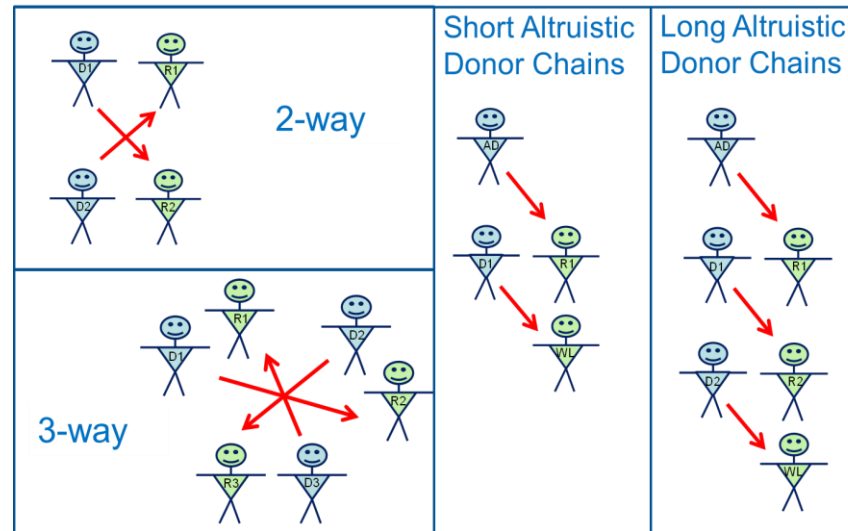
**STOP**

**WHAT YOU NEED TO KNOW**

- Be Aware
  - Legal Frameworks
  - Role of other agencies
  - Tools and Resources
  - Reporting mechanisms
- Inform Choices
  - Recipients
  - Donors
  - Family members
- Collect the Evidence
  - Detection
  - Reporting

# Increasing Opportunity and Choice in LDKT

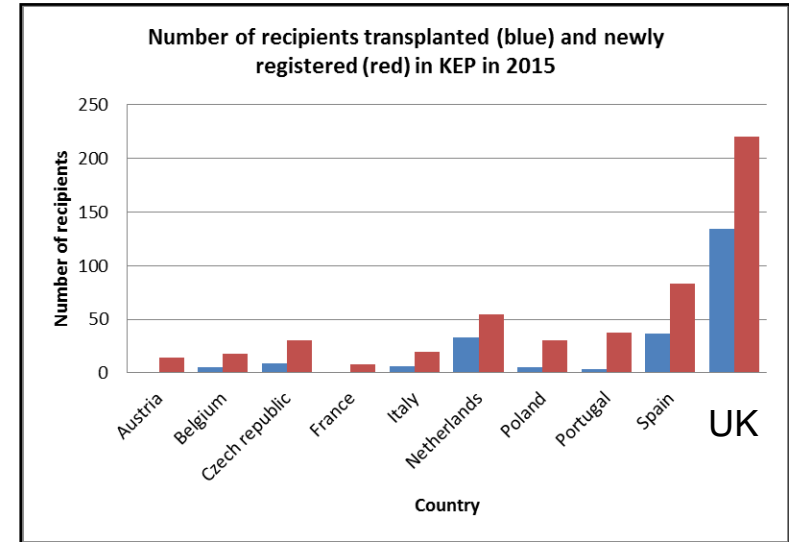
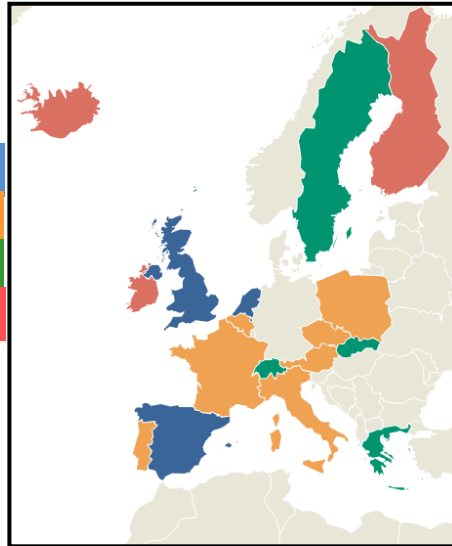
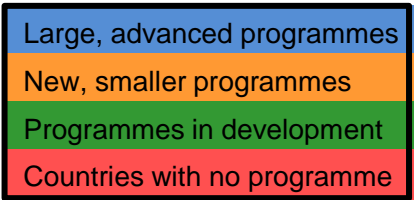
- **Maximise transplant opportunities** in the UKLKSS
- **Use innovative antibody depletion** solutions to facilitate transplants for recipients who are not transplanted through the UKLKSS



# International Collaborations



## European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)



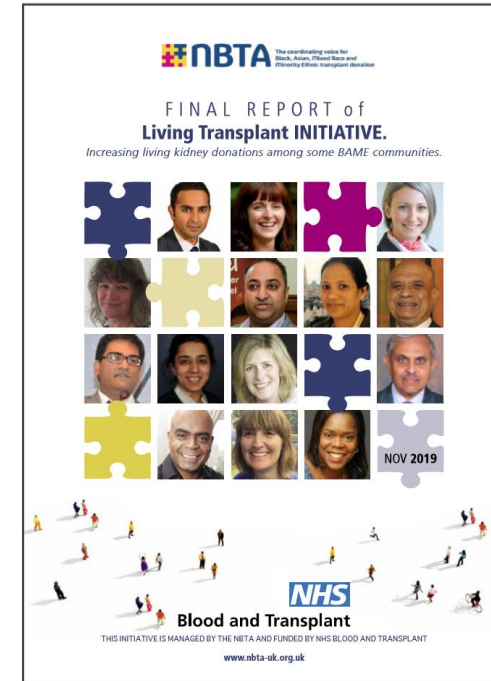
## Transplantation

Building kidney exchange programmes in Europe - An overview of exchange practice and activities

Biró, P. et al. (2018) Building kidney exchange programmes in Europe - An overview of exchange practice and activities. [Transplantation](#), (doi:[10.1097/TP.0000000000002432](#)) (PMID:[30247314](#)) (Early Online Publication)

# Addressing Health Inequalities

- **Promote public and patient awareness and engagement** in living donation across all sectors of society and develop the Living Transplant Initiative



# Community Investment Scheme: LDKT

- To improve equity in living kidney donation
- Due to launch later this summer
- Steering group appointed
- £100k over 18 months
- Invited bids
- Projects start January 2022



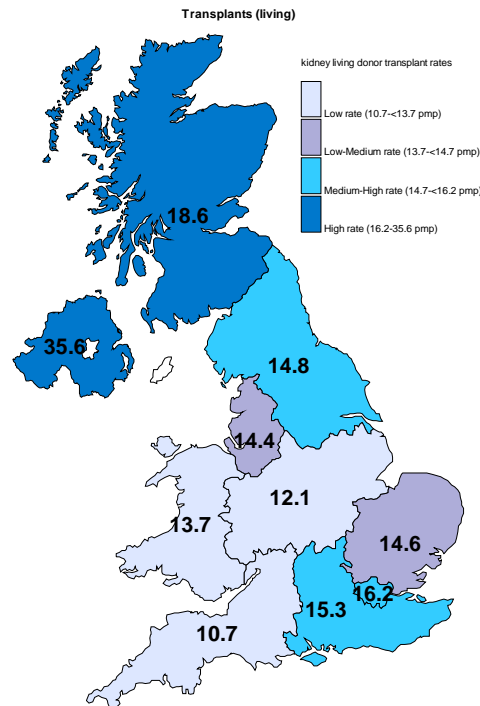
A living donor can donate to someone they know, such as a family member or someone they don't know.



# Unwarranted variation in LDKT

Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/NHS region of residence

- Addressing unexplained variation
- Removing unwarranted barriers to living donation
  - Clinical, Financial, Logistical
- Making it easy for people to donate and receive a kidney

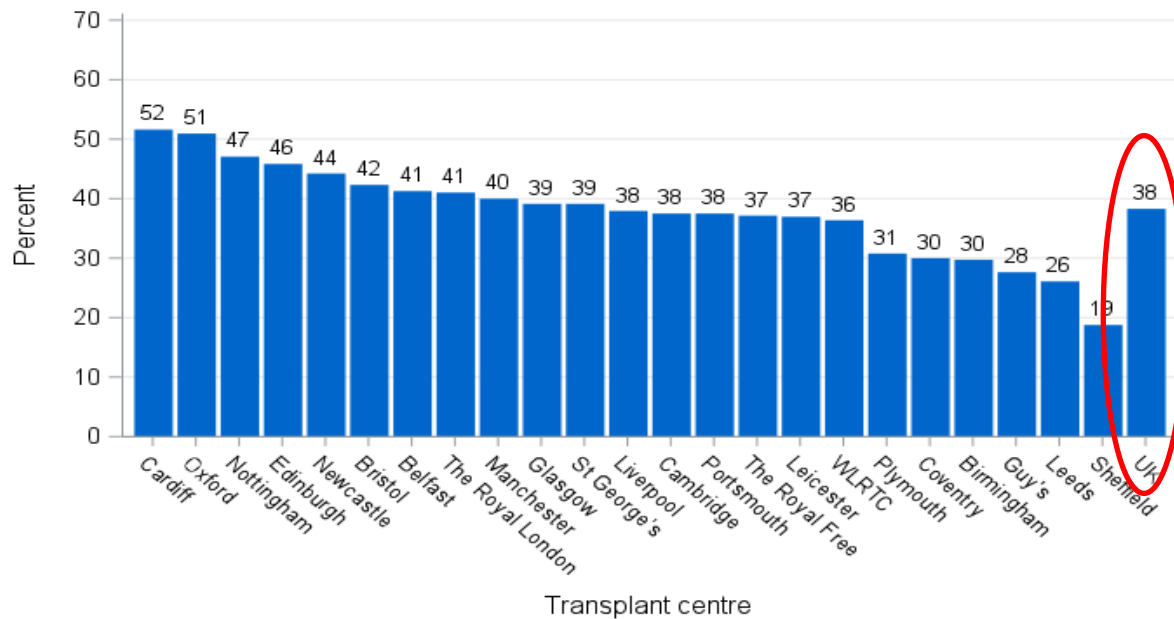


# 'Transplant First' for Suitable Recipients



Blood and Transplant

**Figure 3.8** Adult living donor pre-emptive transplant rates by centre,  
1 April 2019 - 31 March 2020



Source: Annual Report on Living Donor Kidney Transplantation 2019/20, NHS Blood and Transplant

# UK LKD Network

- Established in October 2017 to
  - Strengthen regional multi-disciplinary clinical leadership in living donor kidney transplantation (LDKT)
  - Engage transplant and non-transplant centres
  - Share learning and best practice
  - Reduce variance in LDKT practice across the UK
  - Potential to do more



# Increasing Opportunity and Choice in Liver Transplantation

- Addressing unexplained variation
- Removing unwarranted barriers
- Making it easy for people to donate and receive a lobe of liver



## Understanding Donor Experience and Outcome

Scenario	Section 3
<p>"very poor" and 10 is "excellent"?</p>	
<p>was 1 is "almost all the time" and 10 is "no more as I expect"?</p>	
<p>scale of 1-10 where 1 is "poor" and 10 is "great"?</p>	
<p>all family or social life on a scale of 1-10 where 1 is "significant effect"</p>	
<p>was 1 is "not at all" and 10 is "very positive"?</p>	
<p>or decision to donate, on a scale of 1-10 where 1 is "They think very</p>	
<p>as 1 is "poor" and 10 is "excellent"?</p>	
<p>Stage on a scale of 1-10 where 1 is "poor" and 10 is "excellent"?</p>	
<p>was 1 is "poor" and 10 is "excellent"?</p>	
<p>activities such as working, housekeeping or travelling on a scale of</p>	

RUEY		
		Section 2
ordinators?		
5 - 9 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
uration team?		
8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
assessment process?		
to help you understand the process and the timeframes involved?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
ut the assessment process?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
- 7 - 8 - 9 - 10 Extremely		
Don't know	<input type="checkbox"/> Not applicable	
essment?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
part of your assessment?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
- 7 - 8 - 9 - 10 Extremely		
Don't know	<input type="checkbox"/> Not applicable	
obated through the process?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
g assessment?		
9 - 7 - 8 - 9 - 10 Extremely	Don't know	<input type="checkbox"/> Not applicable
ation provided to you?		

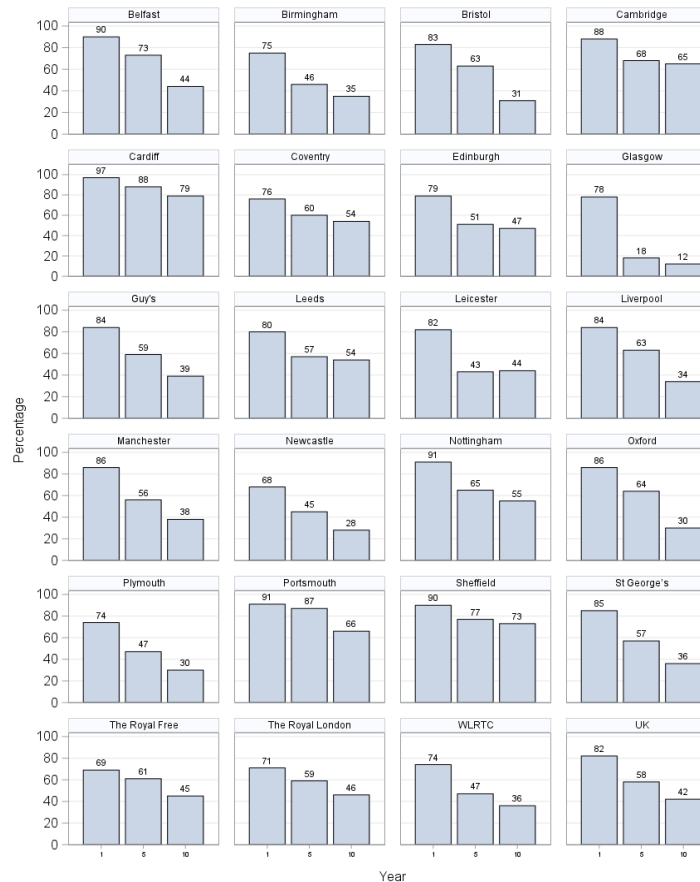
- Self-reported **experience**
  - **Assessment**
  - **Hospital stay**
  - **After donation**
- Collected in UK Living Donor Registry

# Donor Follow-up by Centre

➤ 1, 5, & 10 years (kidney)

No donor follow-up for living liver donors

Figure 6.5 Percentage of donors with lifetime follow-up reported, by centre



# Paper-Based Manual Processes



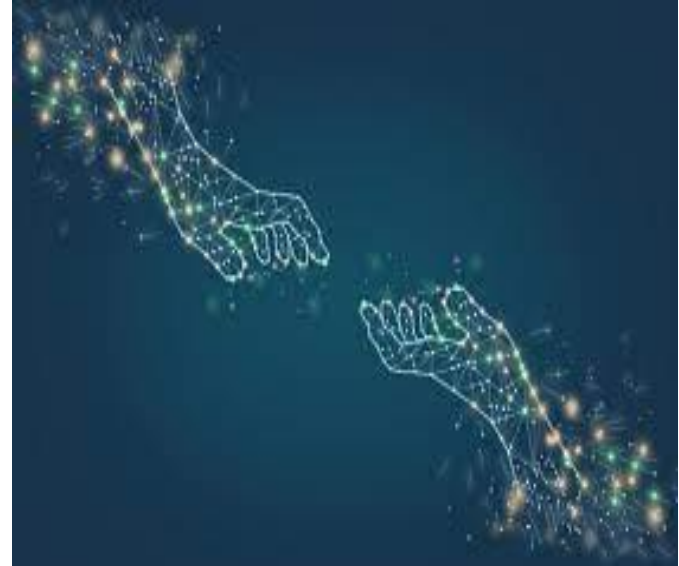
# 'End-to-End' Digital Transformation

All donor registration

UKLKSS

Donor follow-up

Self-reported measures





# Saying 'Thank You' to Living Donors

- Aim to create on-line resources to support recipients of anonymous living donations to say 'Thank you'
  - Team 'Thank you' (Sheffield 'Daisy Chain' initiative)
  - Recipient to donor 'Thank you'
- Fixed Time Working Group
  - Representation from living donors, recipients, coordinators, NHSBT
- Deliver Summer 2021



# The Future is Optimistic



# Thank you.

## Everyone



<https://www.organdonation.nhs.uk/become-a-living-donor/>  
<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/#living>

# Any Questions?

