

Living Donation

Thursday 29th April 2021

Community Investment Scheme Cohort Three



Housekeeping

- Please keep yourselves on **mute**. This helps us avoid background noise.
- Please submit any questions through the **chat feature**. Any we don't cover will be answered in the wrap up email.
- Please note, this workshop will be recorded.
- This slide deck, along with any resources, will be emailed out after the event and added to our [new CIS webpage](#).



Agenda

- **12.00 – 12.05** Welcome and Objectives – *Charlotte Silver, Senior Marketing and Campaigns Officer – Organ Donation Marketing*
- **12.05 – 12.35** Living Donor Transplantation in Context – *Lisa Burnapp, Clinical Lead Living Donation*
 - » What is Living Donation and why we do it?
 - » How has Living Donation changed over the years?
 - » What contribution has it made for people from BAME communities?
 - » What have we learnt from the Living Transplant Initiative?
- **12.35 – 12.45** – First -hand account of Living Transplant Initiatives – *Guest speaker, Dela Idowu, Founder, Gift of Living Donation*
- **12.45- 13.00** – Q&A and Next Steps - *Charlotte Silver, Senior Marketing and Campaigns Officer – Organ Donation Marketing*

Objectives

1. To provide you with an understanding of what Living Donation is, why we do it and how it has changed over the years.
2. To learn about the contribution Living Donation has made for people from black, Asian and Minority Ethnic communities.
3. To hear what we (NHSBT) have learnt from the Living Transplant Initiative and very importantly hear from our guest speaker Dela Idowu as to the work she has carried out to raise awareness of Living Donation within Black communities and hear what Dela has learnt and her advice.
4. Learn about what Living Donation Resources already exist and how to find and use them.
5. Ultimately we would like you to feel equipped to talk about and promote Living Donation within your community and your CIS project where appropriate for example as part of a wider health and wellbeing session.

Living Donor Transplantation in Context

Lisa Burnapp, *Clinical Lead Living Donation*

Community Investment Scheme Cohort Three

Living Donation

- What is it and why do we do it?
- How has living donation changed over the years?
- What contribution has it made to people from Black, Asian, Mixed-Race and Minority Ethnic (BAME) backgrounds?
- What have we learnt from the Living Transplant Initiative?



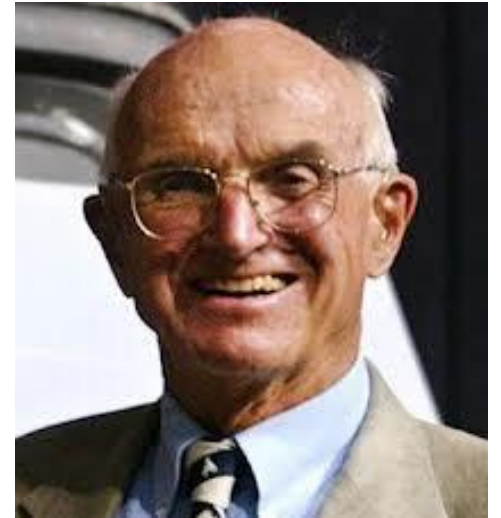
1954: The Herrick Twins



Sir Joseph Murray 1919-2012

“Kidney transplants seem so routine now,” Murray told The New York Times after he won the Nobel. “But the first one was like Lindbergh’s flight across the ocean.”

Some people “felt that we were playing God and that we shouldn’t be doing all of these, quote, experiments on human beings”

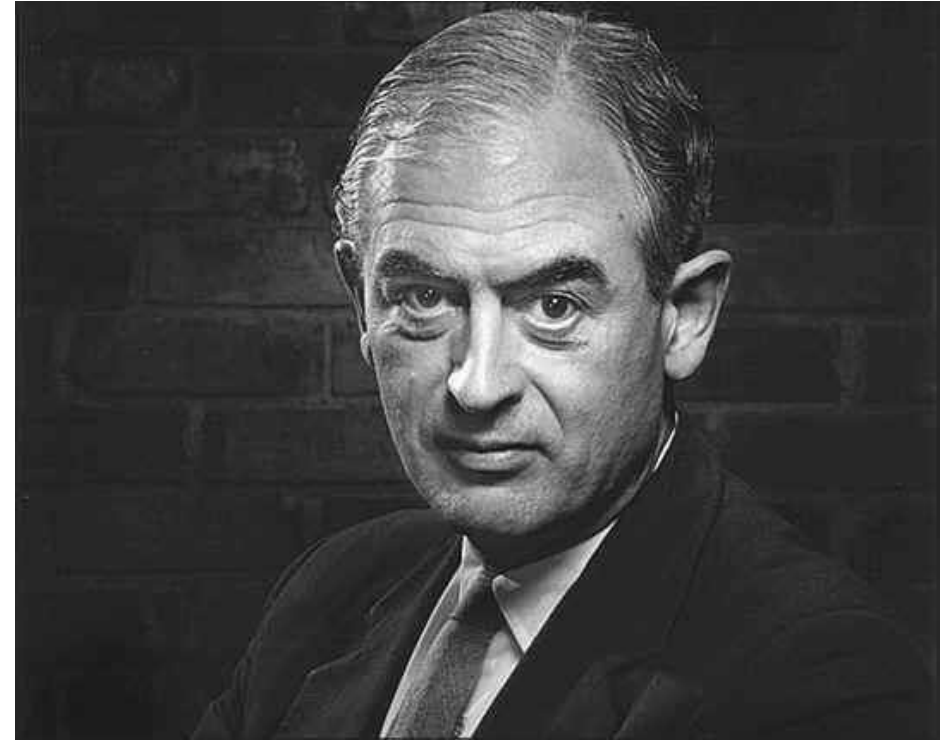


Nobel Prize Winner: Physiology and Medicine

“Is kidney transplantation ethical for patients with kidney failure?”

*“That’s very simple.
People would rather
live than die.”*

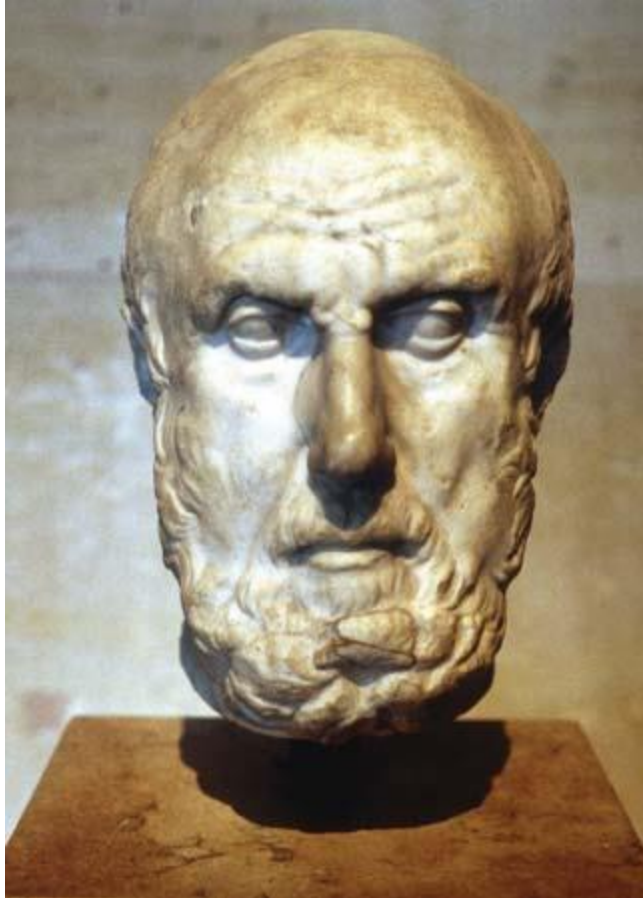
Sir Peter Medawar
1915-1987



*Dr. Clyde F. Barker, Philadelphia, on ‘Health-Related Quality
of Life After Different Types of Solid Organ Transplantation’,
C. Wright Pinson et al, Annals of Surgery, Vol. 232, no4, 597-607, October 2000.*

What is success in 2021?



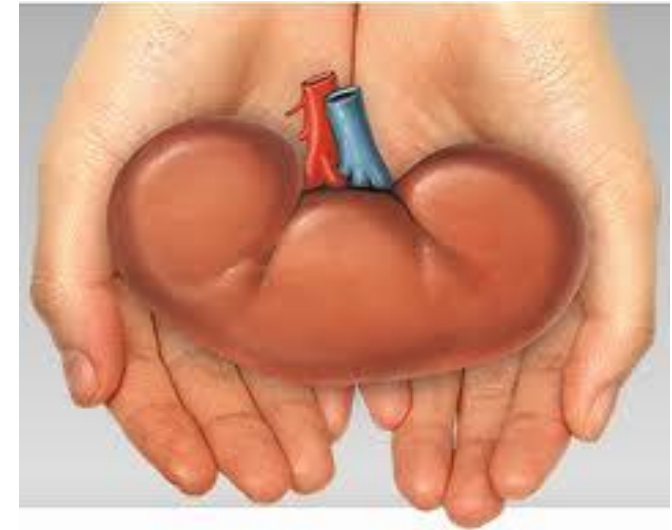


“First do no harm.”
Hippocratic Oath

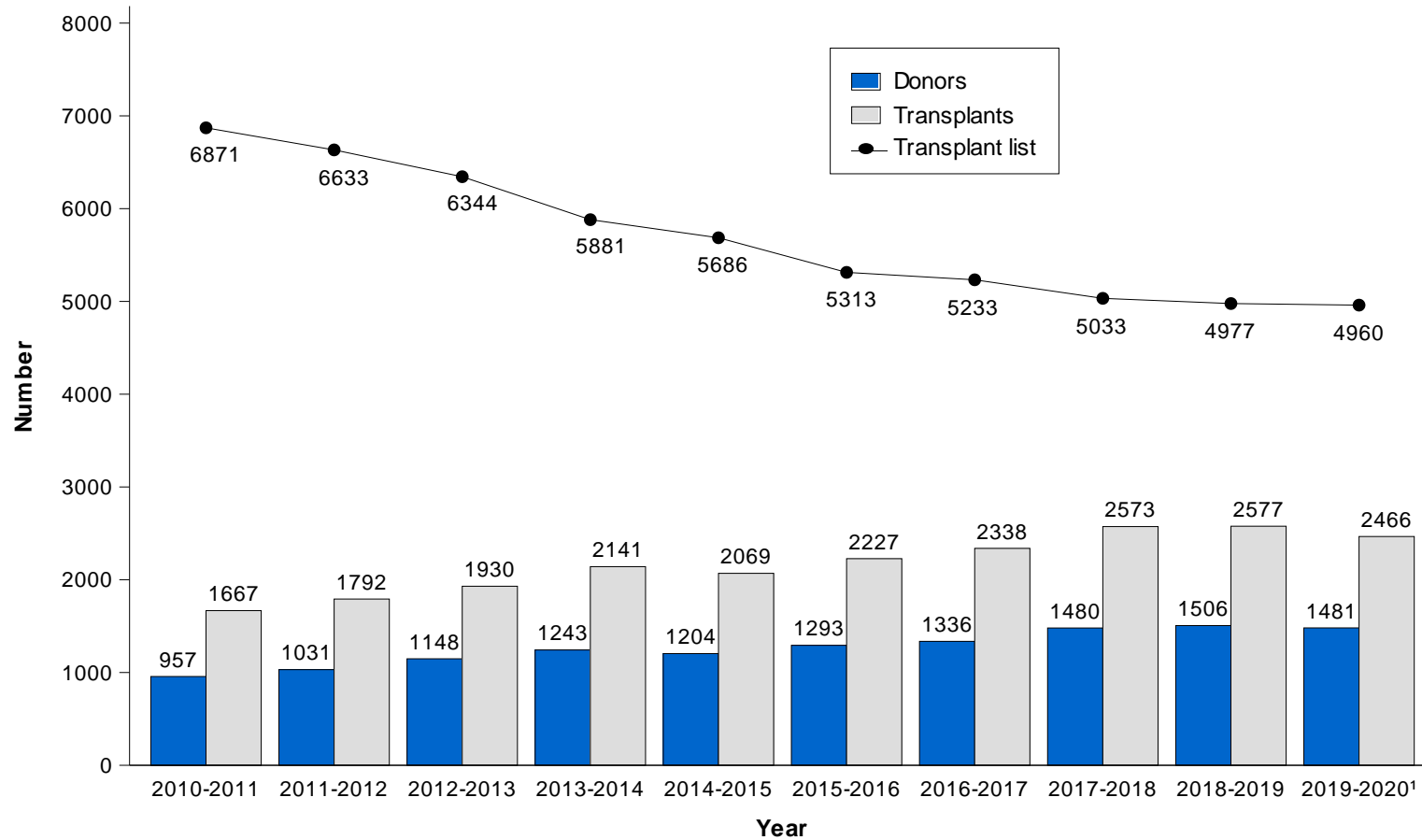
Our Responsibility

Maximise opportunities for organ transplantation that are

- Legal
- Moral
- Deliver the best outcomes
 - Recipient
 - Donor
 - Health economy
 - Donation and transplantation programmes



Deceased donor kidney programme in the UK, 1 April 2010 - 31 March 2020,
Number of donors, transplants and patients on the active transplant list at 31 March



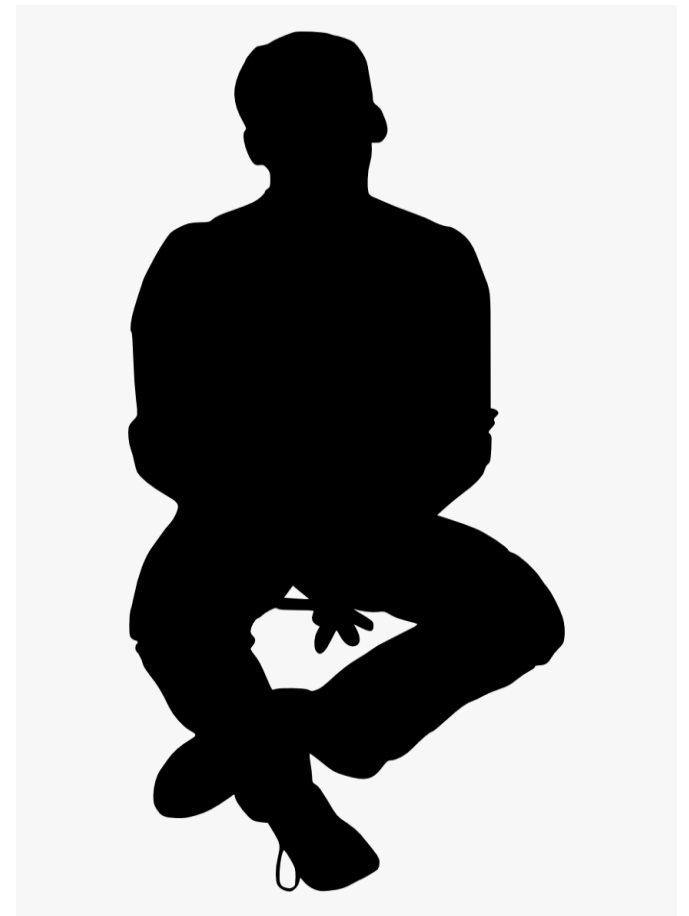
¹ Waiting list as at 29 February 2020

2008-2019
98% increase in
donors since Organ
Donation Task Force

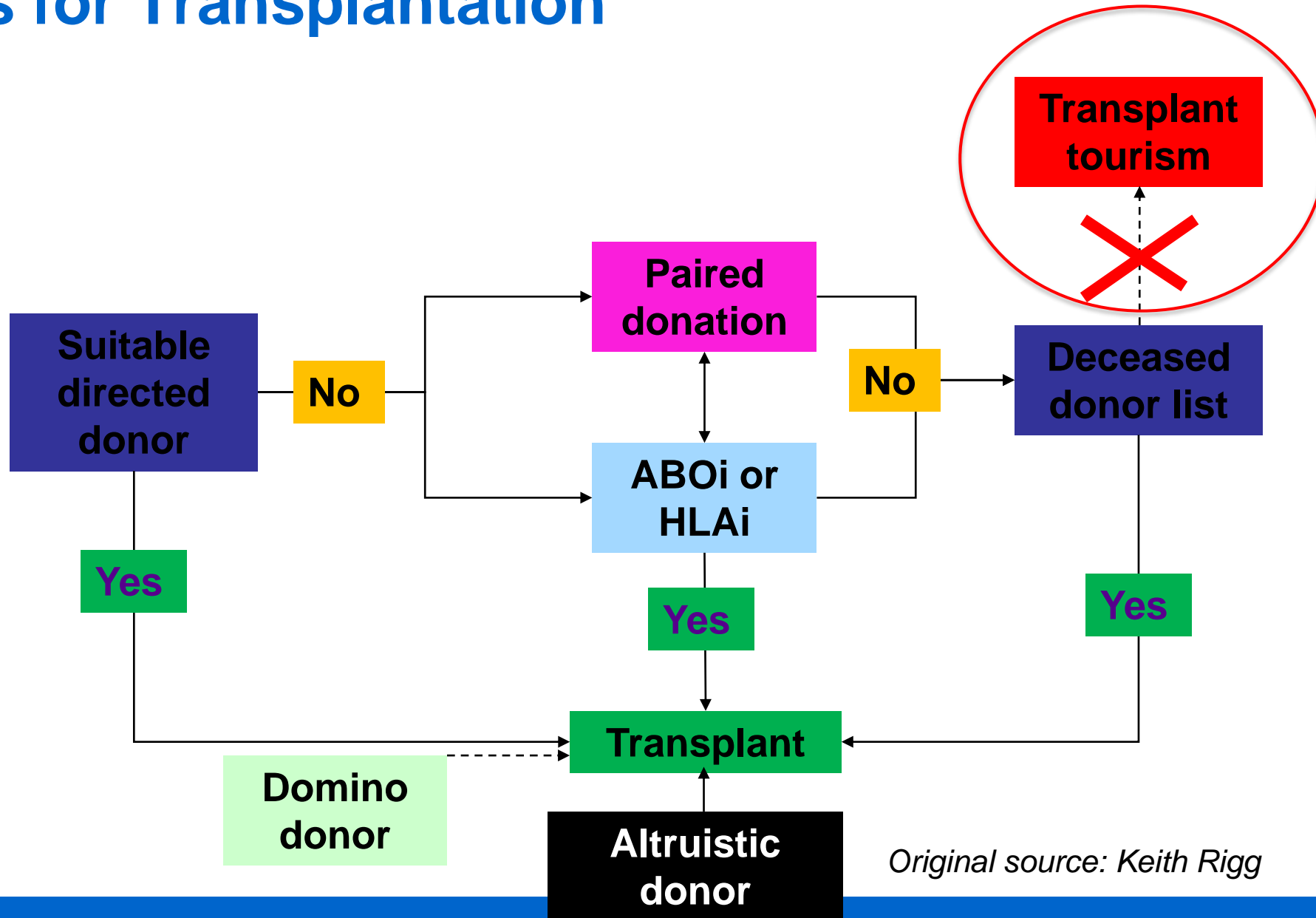
Source: Transplant activity in the UK, 2019-2020, NHS Blood and Transplant

For the person sitting in front of you....

Receiving the right kidney at the right time.

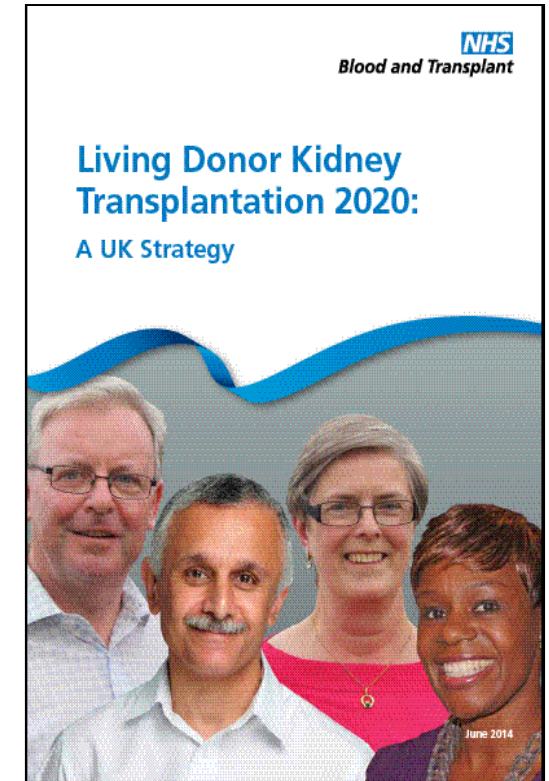


Choices for Transplantation



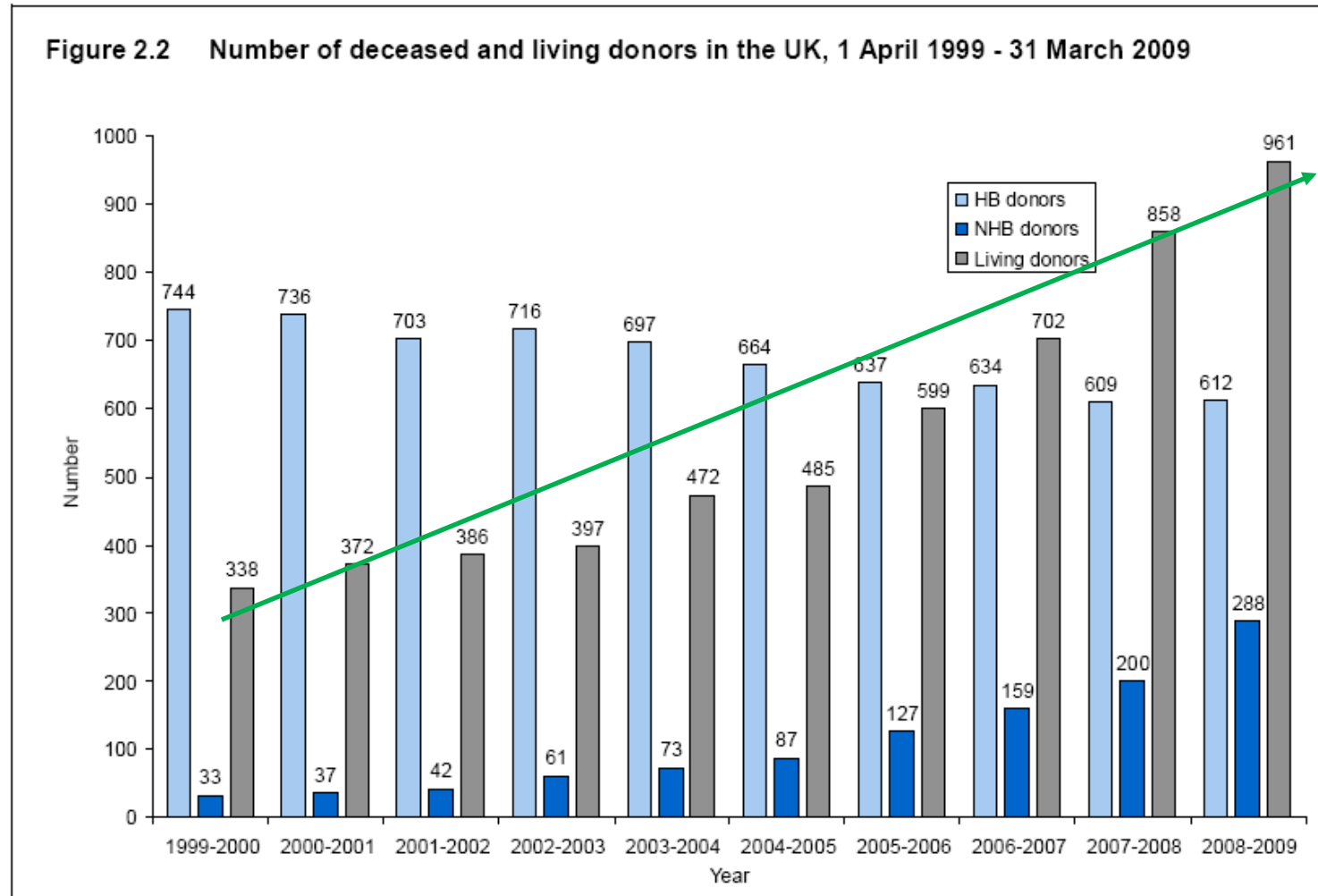
Original source: Keith Rigg

- 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

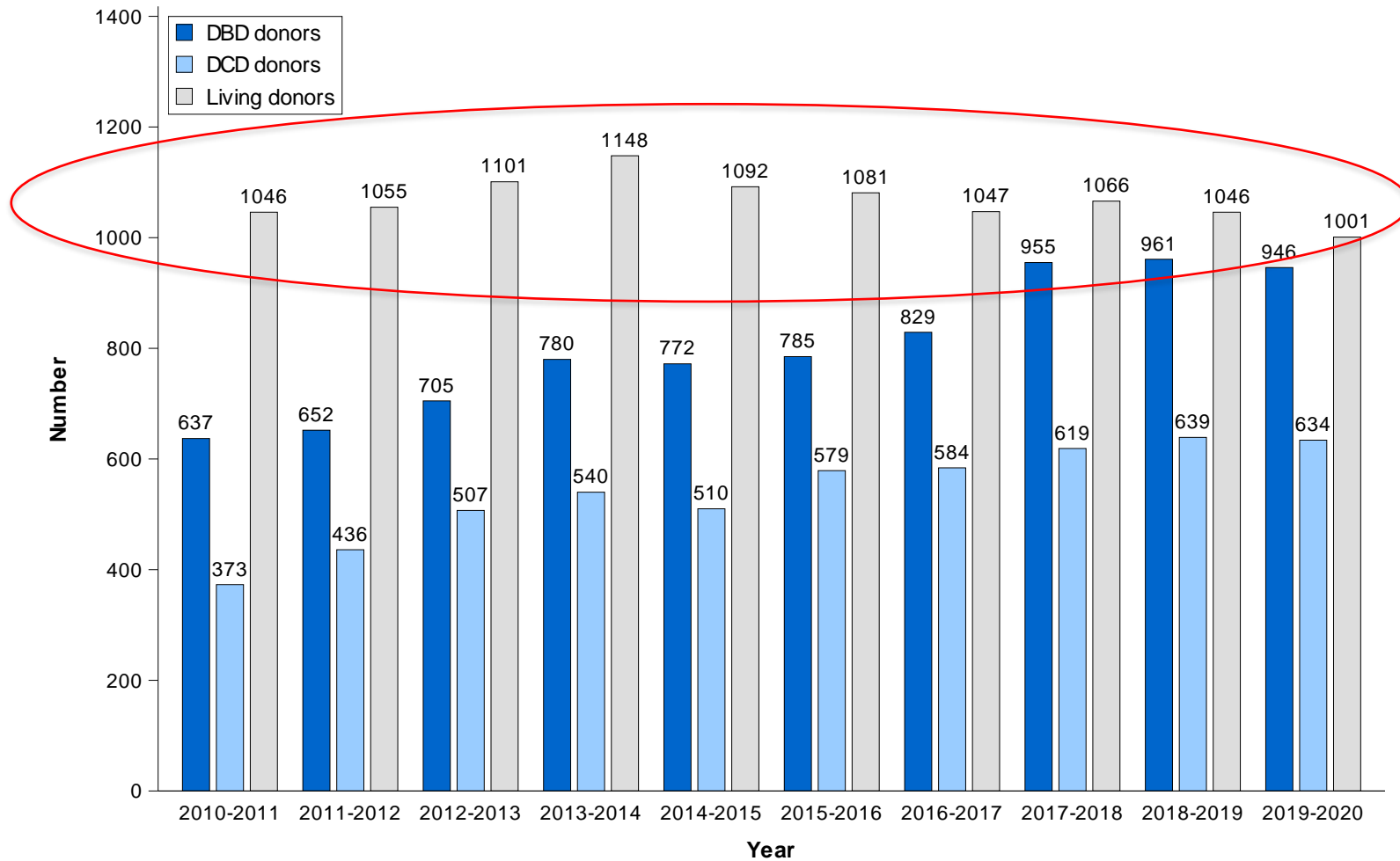


“To match world class performance in living donor kidney transplantation”

Deceased v Living Donor Activity 1999-2009

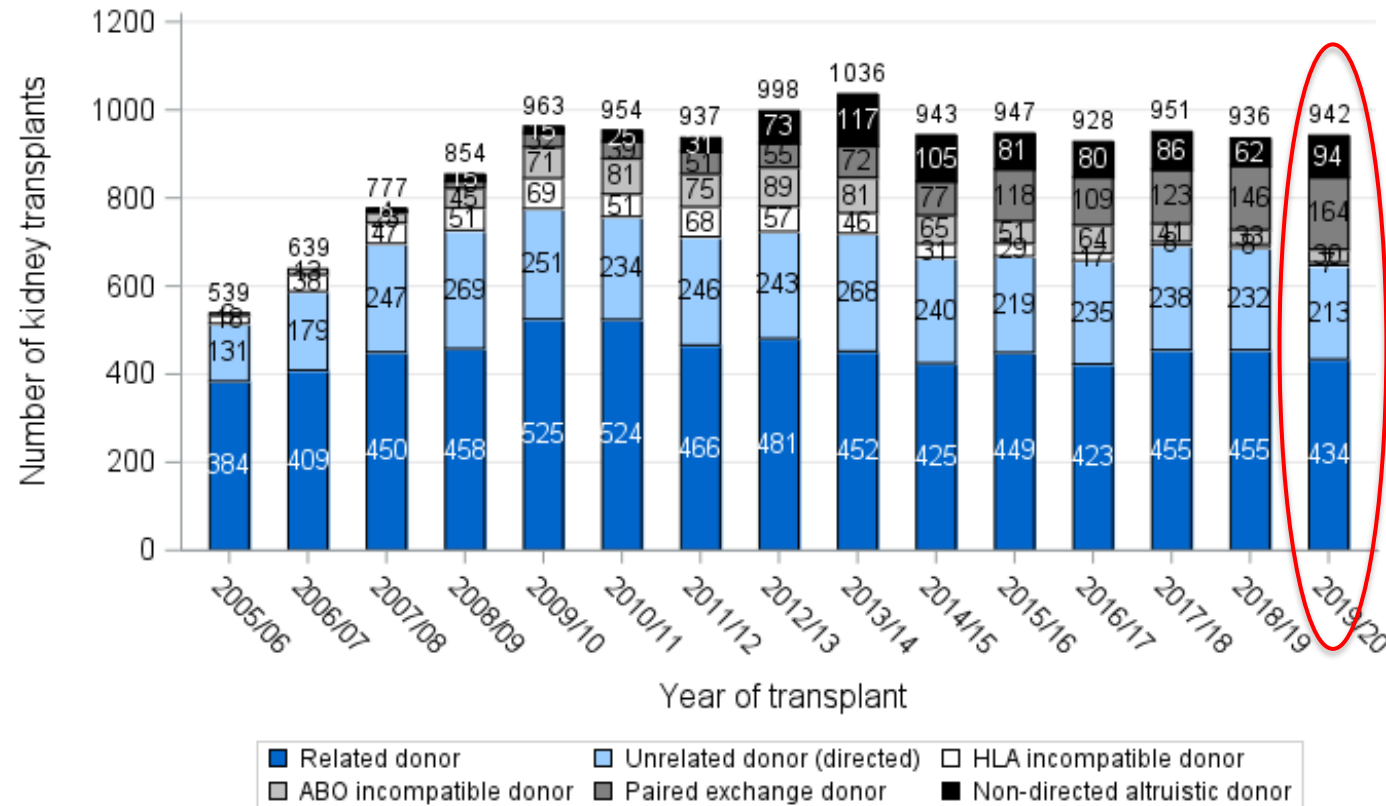


Number of deceased and living donors in the UK, 1 April 2010 - 31 March 2020

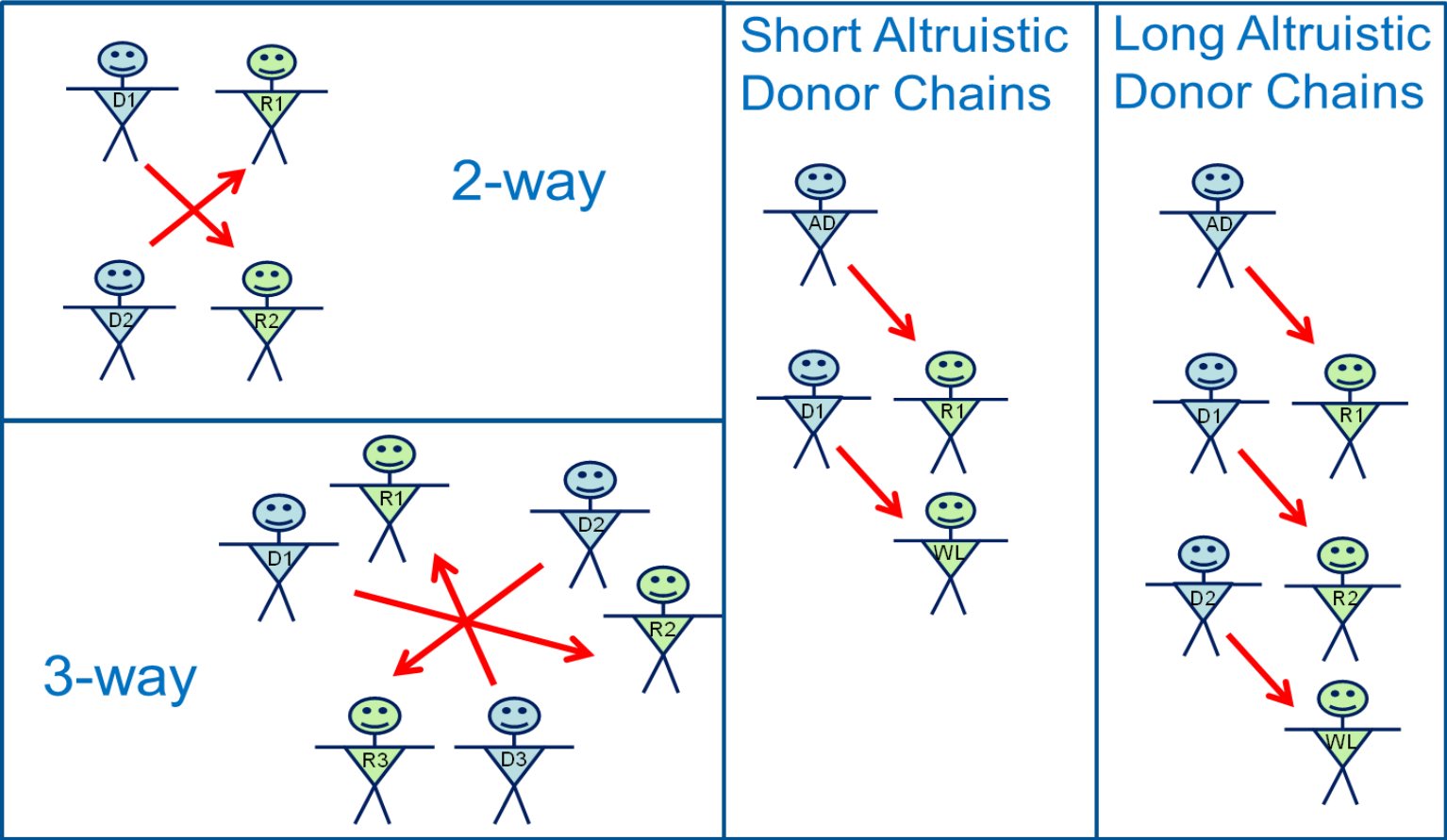


Source: Transplant activity in the UK, 2019-2020, NHS Blood and Transplant

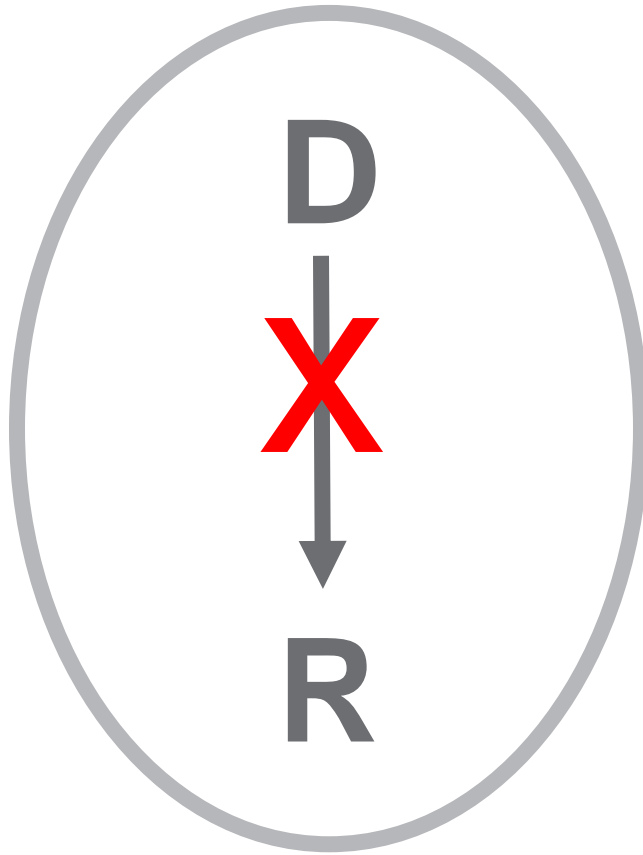
Figure 2.2 Adult living donor kidney transplants in the UK,
1 April 2005 - 31 March 2020



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



Potential Donor-Recipient pair



- Blood group incompatibility
- Positive crossmatch

Approx 20-30% of possible living donor transplants

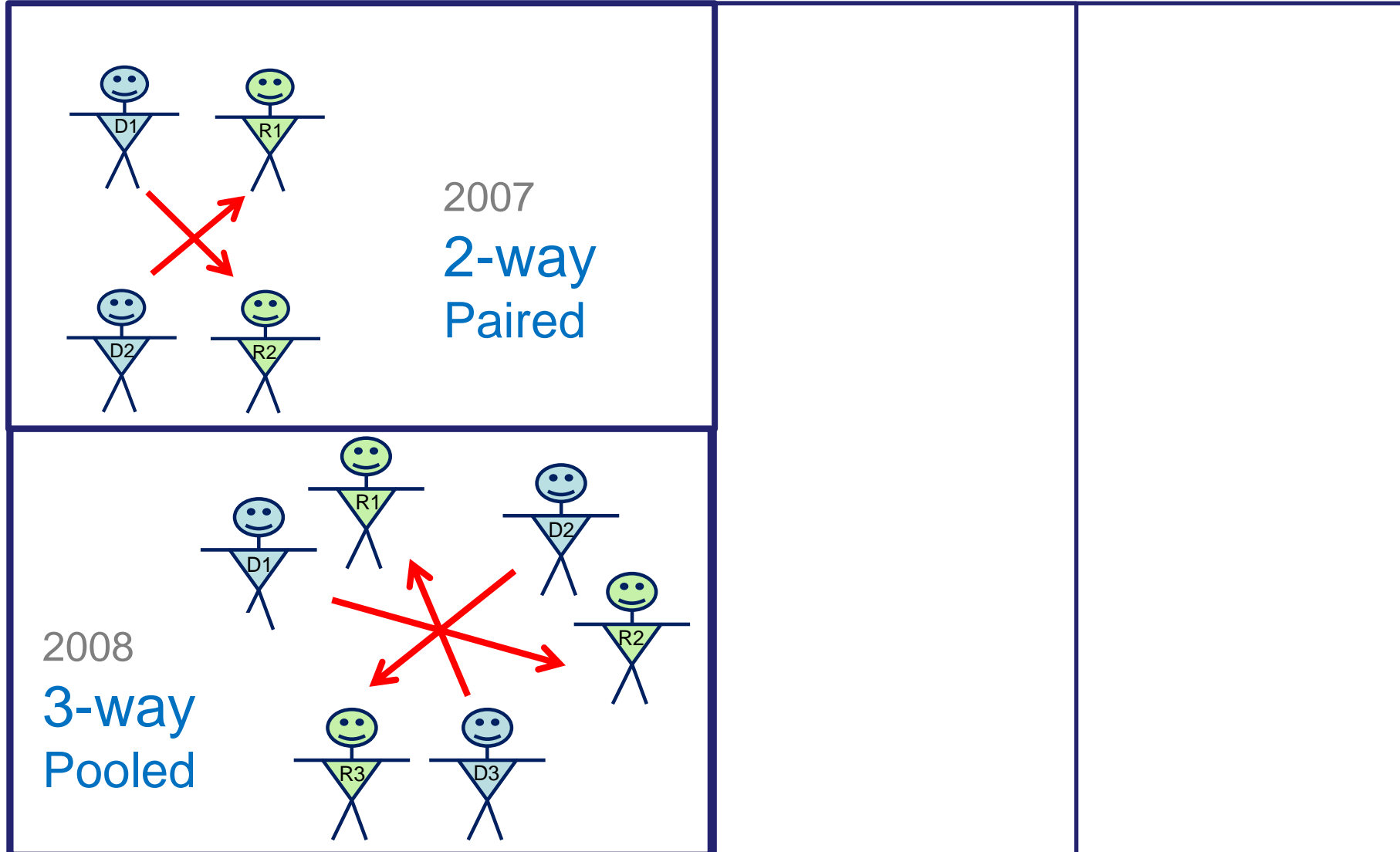
Background



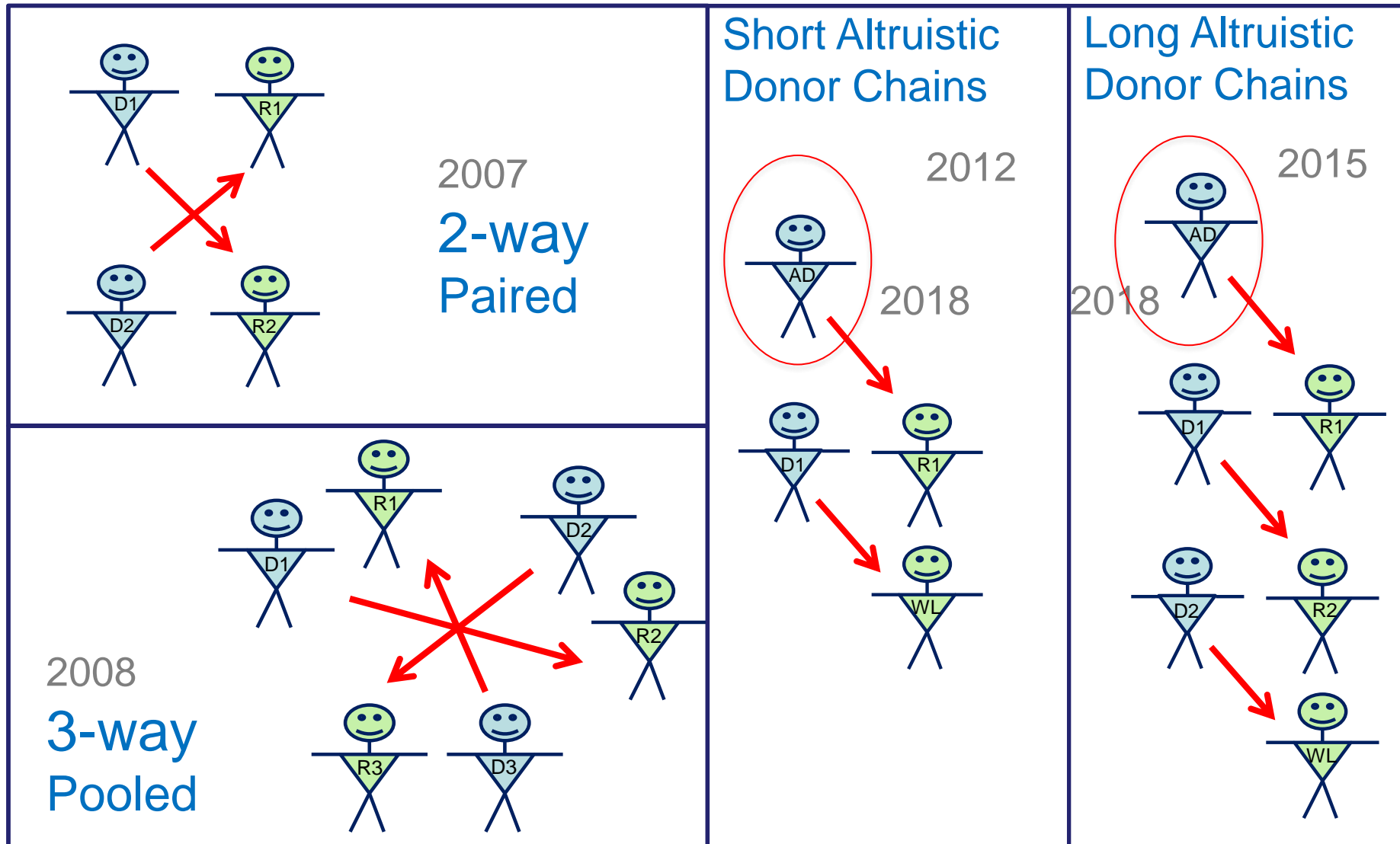
- September 2006 Change in legal framework
Development of national scheme including matching algorithm*
- April 2007 First paired exchange matching run
First non-directed altruistic donation
- Ongoing Review and refinement of the sharing schemes

**Matching algorithm developed with University of Glasgow, Manlove et al*

The scheme today - matching runs identify....



The scheme today - matching runs identify....

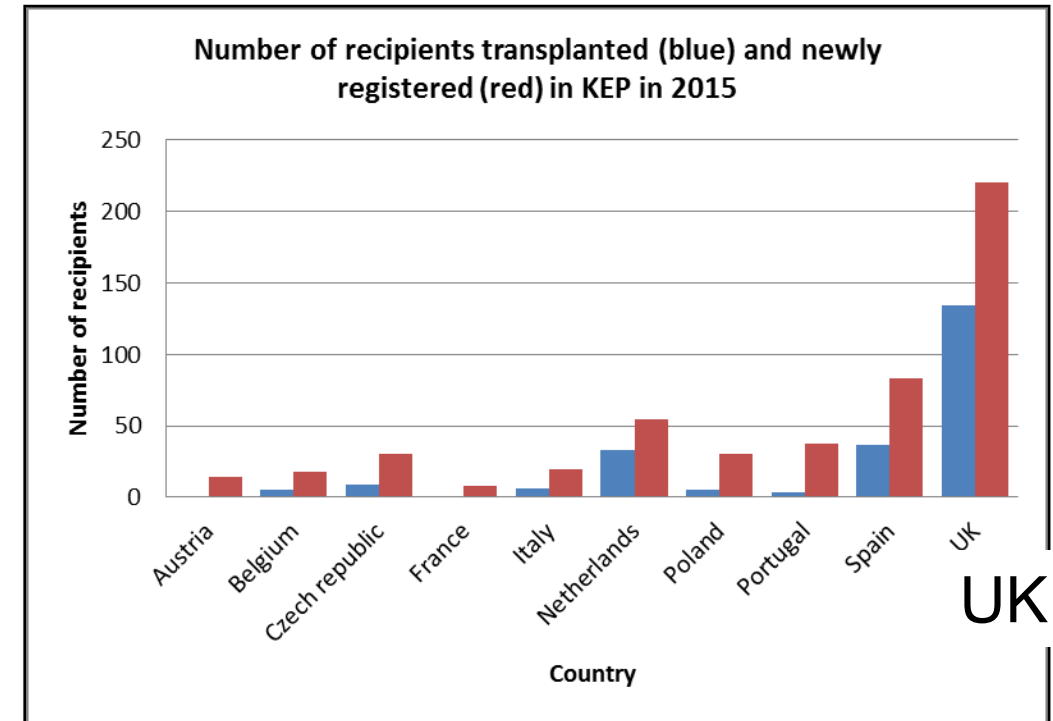
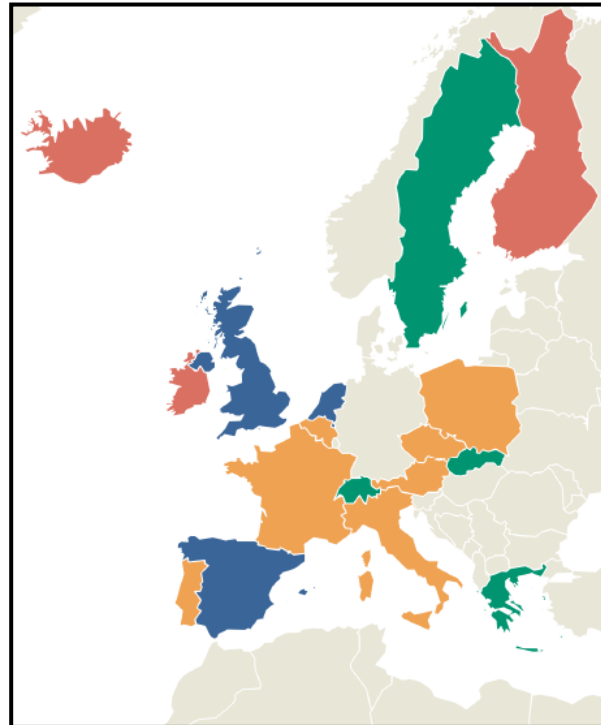


UK scheme - largest in Europe



European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)

- Large, advanced programmes
- New, smaller programmes
- Programmes in development
- Countries with no programme

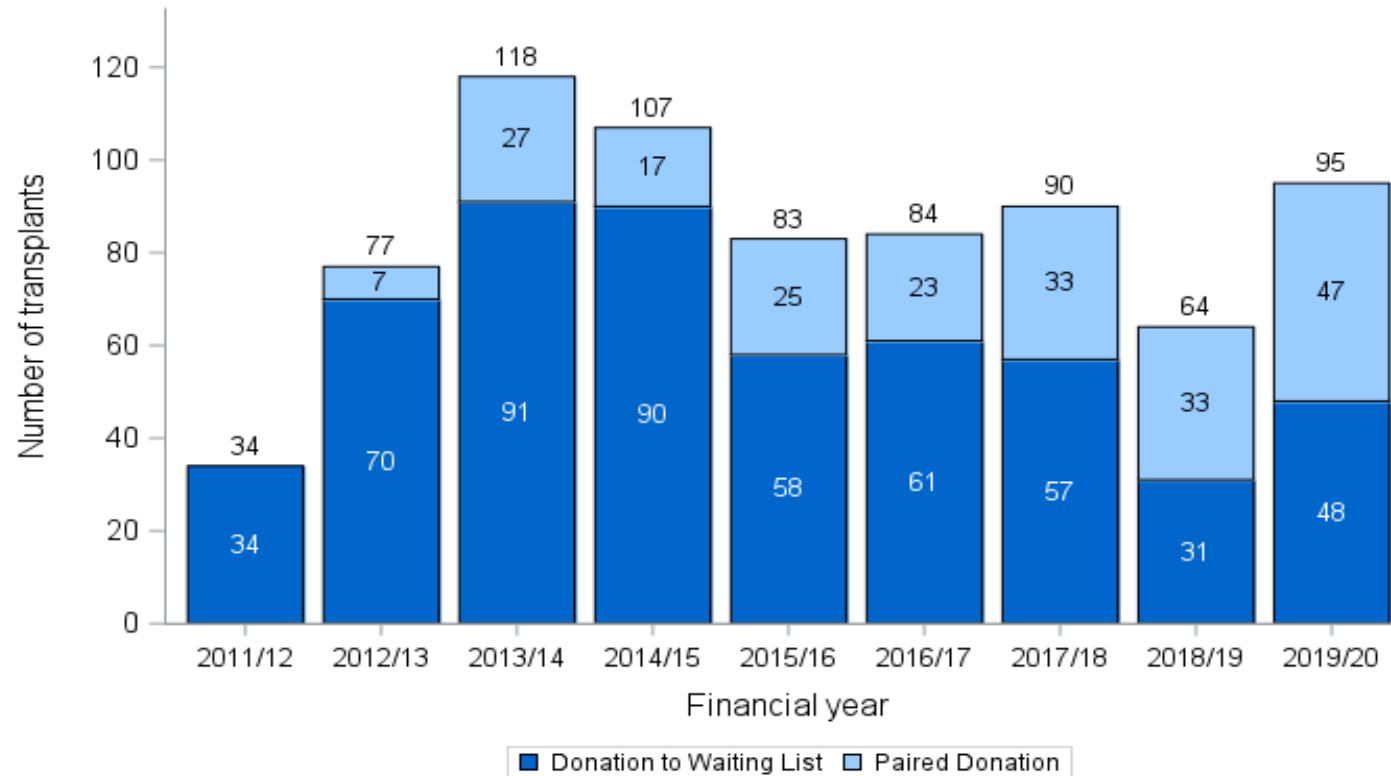


Building kidney exchange programmes in Europe - An overview of exchange practice and activities

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

Transplantation

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



31st March 2021

847 donors

1177 transplants

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

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

Impact



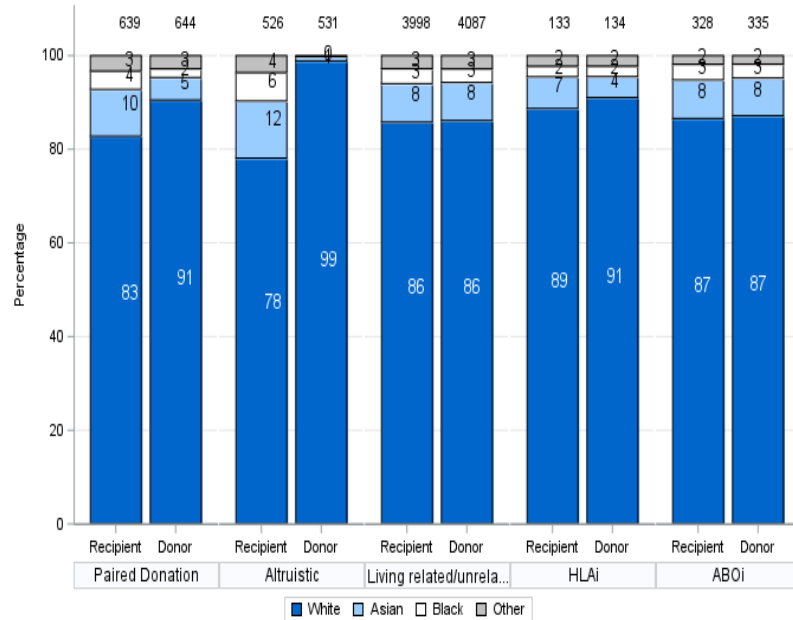
Recipient Ethnicity

Adults



Blood and Transplant

Figure 3.2 Ethnicity of recipient and donor by adult transplant type, 1 April 2013 - 31 March 2019



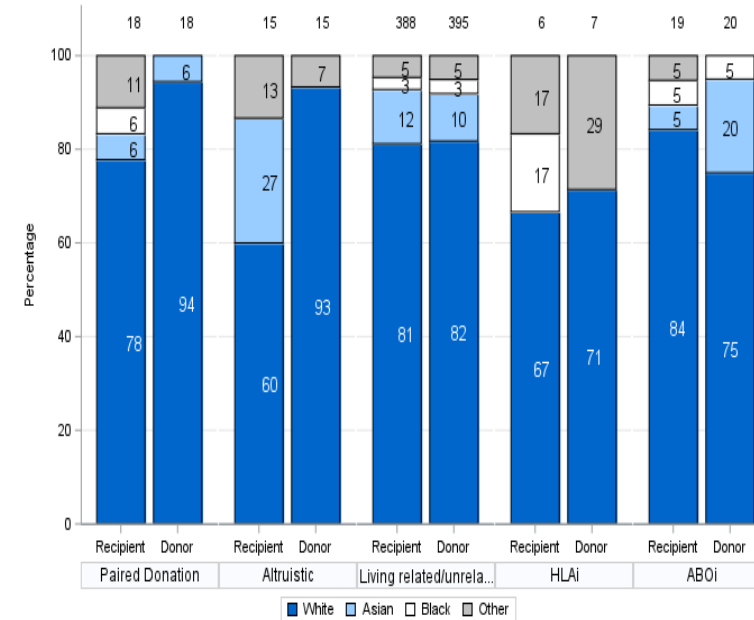
Source: Annual Report on Living Donor Kidney Transplantation 2018/19, NHS Blood and Transplant

Children



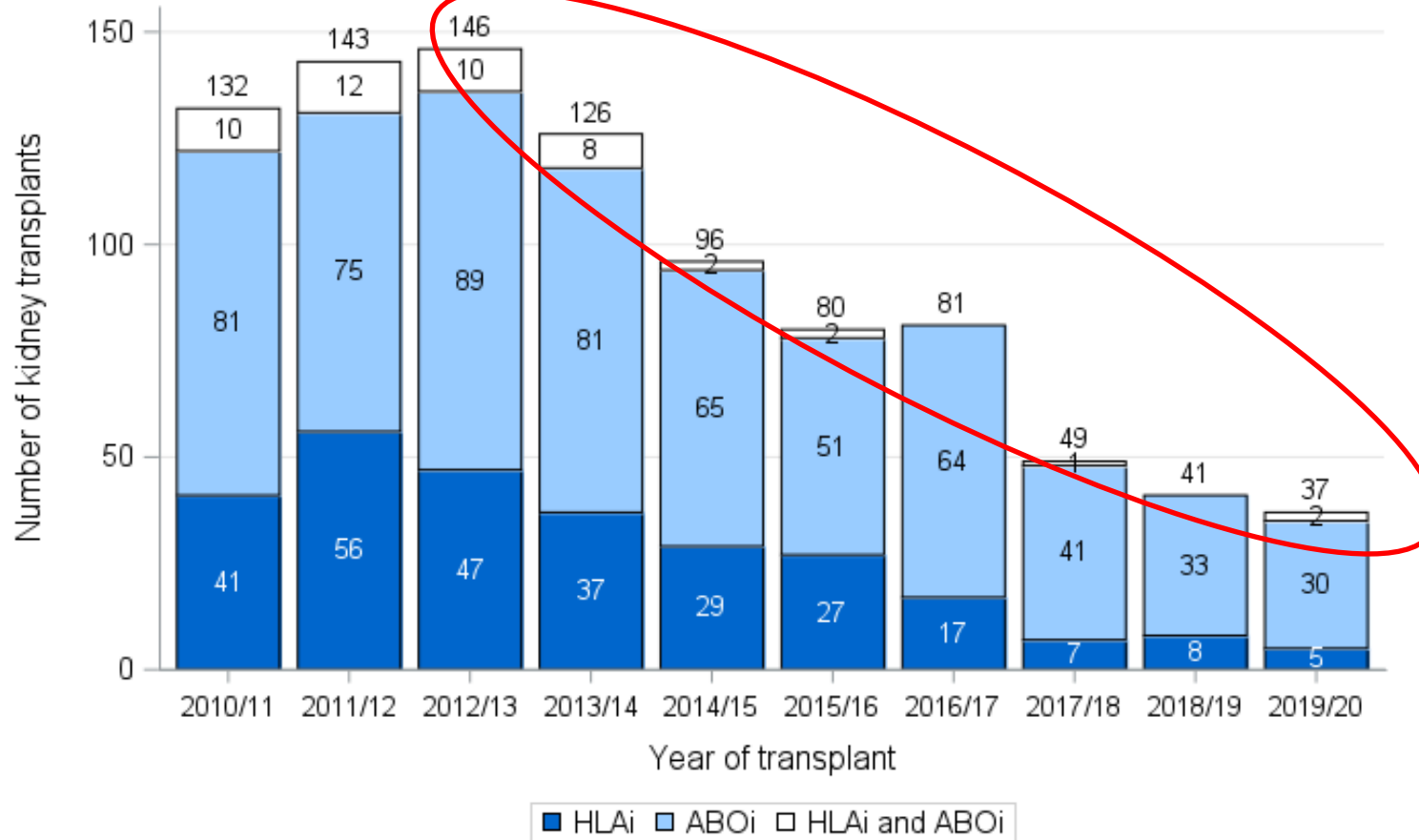
Blood and Transplant

Figure 3.10 Ethnicity of recipient and donor by paediatric transplant type, 1 April 2013 - 31 March 2019



Source: Annual Report on Living Donor Kidney Transplantation 2018/19, NHS Blood and Transplant

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



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

Living Transplant Initiative (LTI)



- September 2016 - March 2019
 - NHSBT commissioned the National Black, Asian, Mixed Race and Minority Ethnic (BAME) Transplant Alliance (NBTA) to deliver a pilot LTI scheme to increase living donor kidney transplantation (LDKT) from BAME people
 - Initially funded for 18 months. until March 2018 but extended to 2019 after interim analysis
 - Steering Group established
 - Evaluated and awarded individual bids
 - Supported individual project leads
 - Monitored progress to plan
 - BAME community groups worked with local transplant and non-transplanting centres

LTI Projects & Deliverables

Large Projects (n=4)	For Whom?	Where?	What?
BAPS Swaminayan Sanstha	Hindu faith	Neasden, London (yr. 1) Multiple mandirs, England (yr. 2)	Community awareness events Faith-based information resources
Vanik Council UK	Jain faith	North West London Manchester, Leicester, Crawley	Community awareness events Faith-based information resources
Afro-Caribbean Leukaemia Trust (ACLT)	Black people	London, South East, Birmingham Manchester	Research into attitudes to LDKT Community awareness events Donor registration initiatives
South Asian Health Action (SAHA)	Hindu, Sikh faiths	Leicester, Leeds	Focus groups Faith-based information video Community ambassadors Community awareness events

LTI Projects & Deliverables

Small Projects (n=3)	For Whom?	Where?	What?
Guy's & St. Thomas' Trust/Gift of Living Donation (GOLD)	Black people	London	Peer volunteer home education initiative
St. James' Hospital, Leeds	South- Asian, Muslim faith	Leeds	Community awareness Focus groups Engagement with local religious and community leaders
Queen Elizabeth Hospital, Birmingham	BAME people	Birmingham	Discontinued – unable to deliver project to initial plan

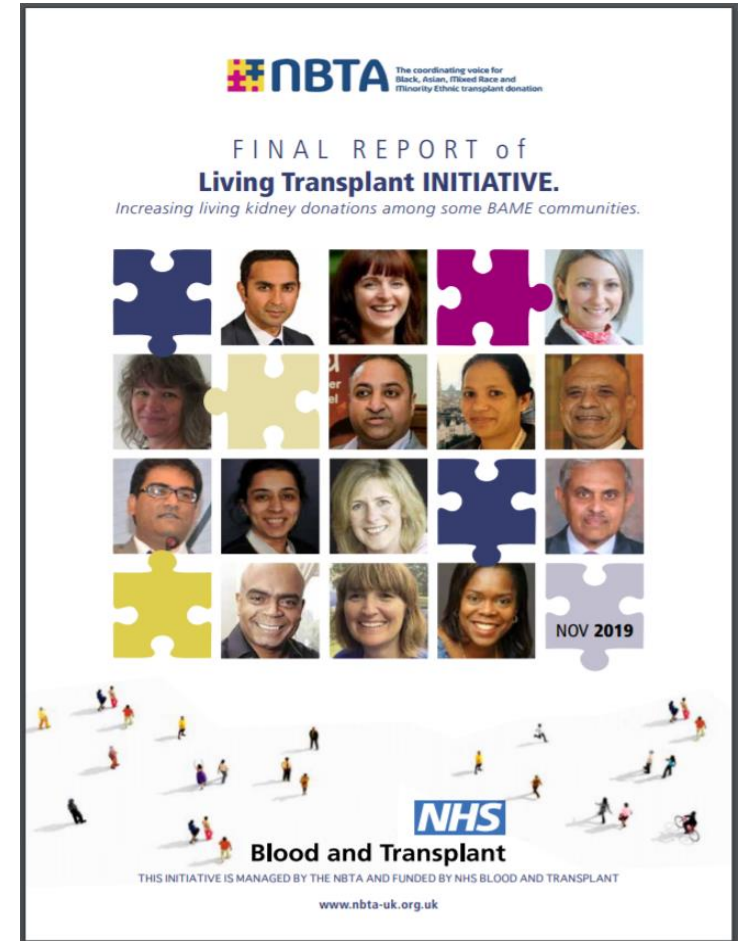
LTI: Measurable Outcomes

1. Number of people who expressed an interest in LDKT
2. Number of people who started the donor assessment process
3. Number of people who donated a kidney

What did we learn?

- 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

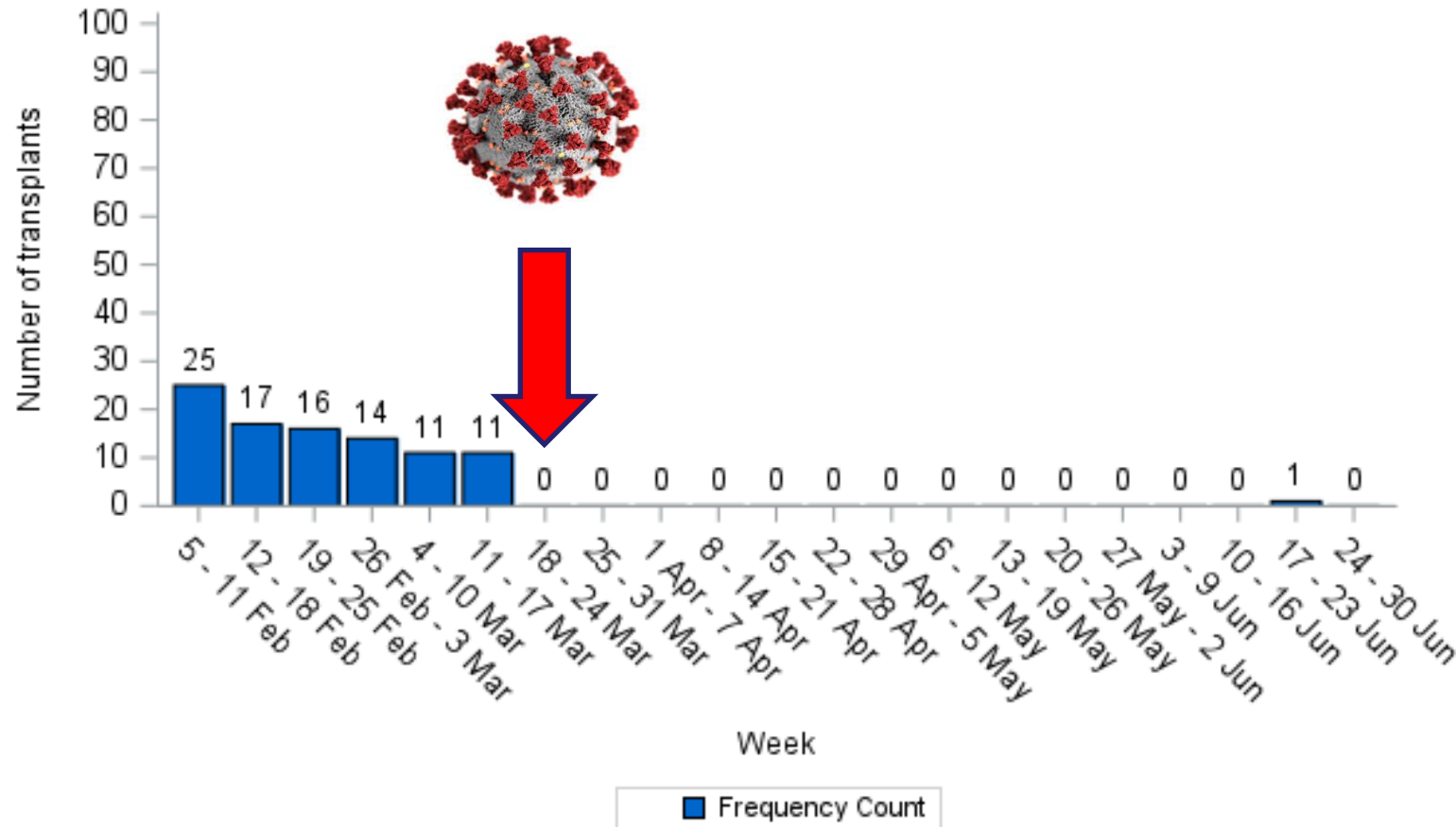
<https://www.nbta-uk.org.uk/wp-content/uploads/2019/11/LTI-FINAL-REPORT-Nov-2019.pdf>



- April 2019 - March 2021
 - Aim to increase living kidney donation from BAME people and those in lower socio-economic circumstances
 - Built on outcomes and learning from NBTA/NSHBT initiative
 - Run 'in house' by NHSBT to reduce administration
 - Project Board established to award bids, support project leads and monitor outcomes
 - Targeted interventions with culturally sensitive/appropriate educational resources
 - Collaborative ventures between community representatives and transplant professionals
 - Initially funded for 1 year until March 2020 but extended to 2021 due to COVID-19
 - 5 large projects (Max. 20k)
 - 9 small bids- 'one-off' events/initiatives (remaining funds)
 - Final report to be published May 2021

Living Donor Kidney Transplantation

Figure 3 Number of living donor kidney transplants performed in the UK, 5 February 2020 to 30 June 2020



LTI: Large Projects 2019-20

Large Projects (n=5)	Who?	Where?	What?
Edinburgh- REACH Completed	All potential donors	East of Scotland	Healthcare professional home education
Cornwall living donors, Truro Completes March 2021	All potential donors	Cornwall	Healthcare professional led educational interventions Community engagement
Royal Free Hospital- LINK Discontinued post COVID-19: unable to complete	Asian and Black people	North London and regional referrals	Local community stakeholder engagement in Collaboration with local KPA Tailored education
Imperial – ILDA Discontinued post COVID-19: unable to complete	Asian people	North-West London and regional referrals	Early identification and intervention Tailored, culturally sensitive information
Guy's & St. Thomas' Trust/Gift of Living Donation (GOLD) Completed	Black people	South- East London- regional referrals	Peer volunteer home education

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

LTI: Phase 3- Learning

- **Community representative outreach, peer volunteer support and advocacy** were effective strategies to support transplant professional-led educational programmes to engage with 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
- **It is likely that different strategies will be required to engage with people in lower socio-economic circumstances** in comparison with people from a BAME background

LTI: Next Steps

- Publish outcome report for NHSBT 2019-2021 LTI
- Use learning to inform development of next organ donation strategy
- Invest in
 - Targeted initiatives that increase LDKT over a longer time period (avoid annual funding cycles)
 - Further research to inform future policy and improve our ability to engage with communities to improve health inequalities in living donor transplantation

‘Meeting the Need’

By 2030....

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

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

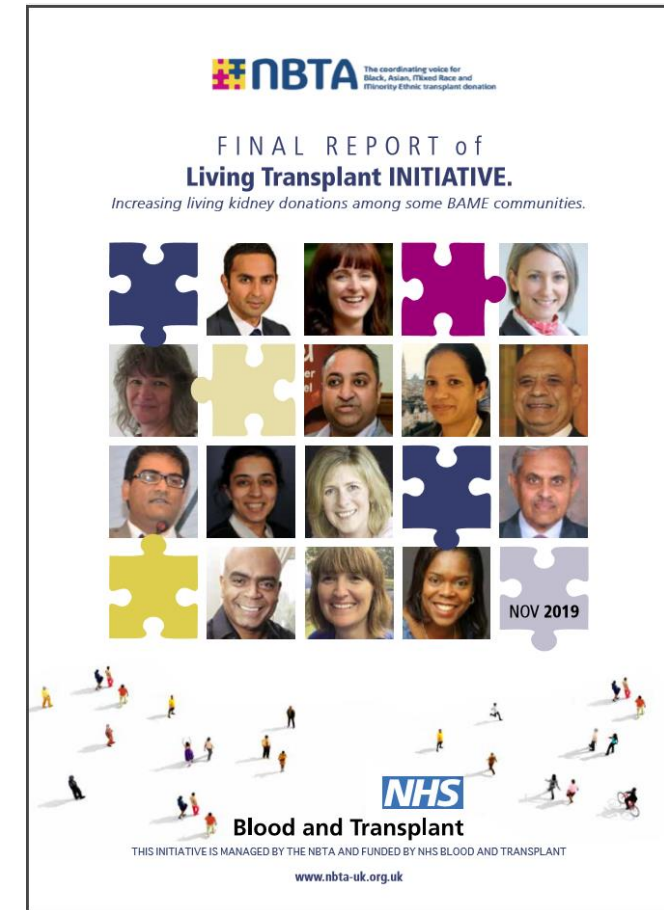
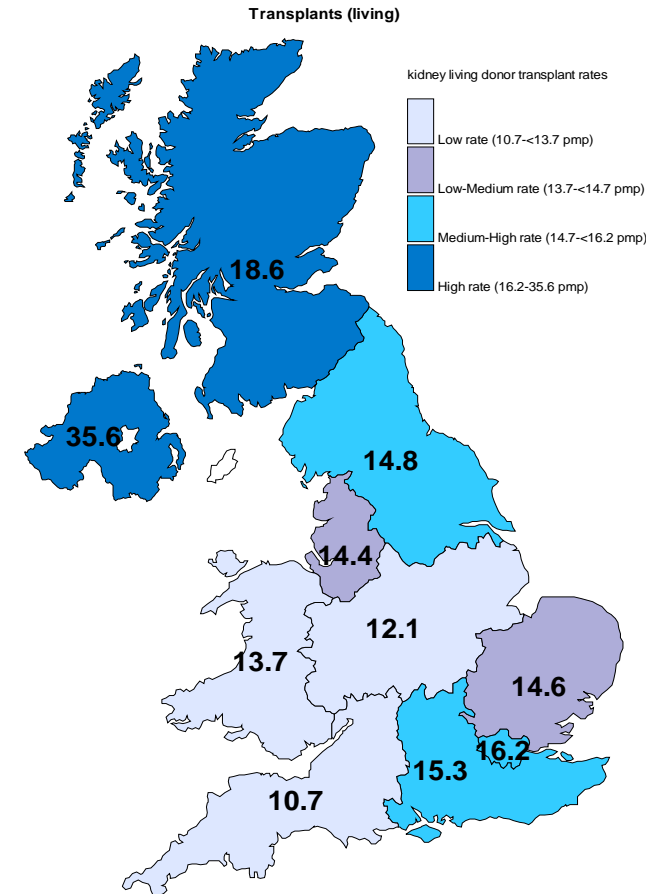


Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/NHS region of residence

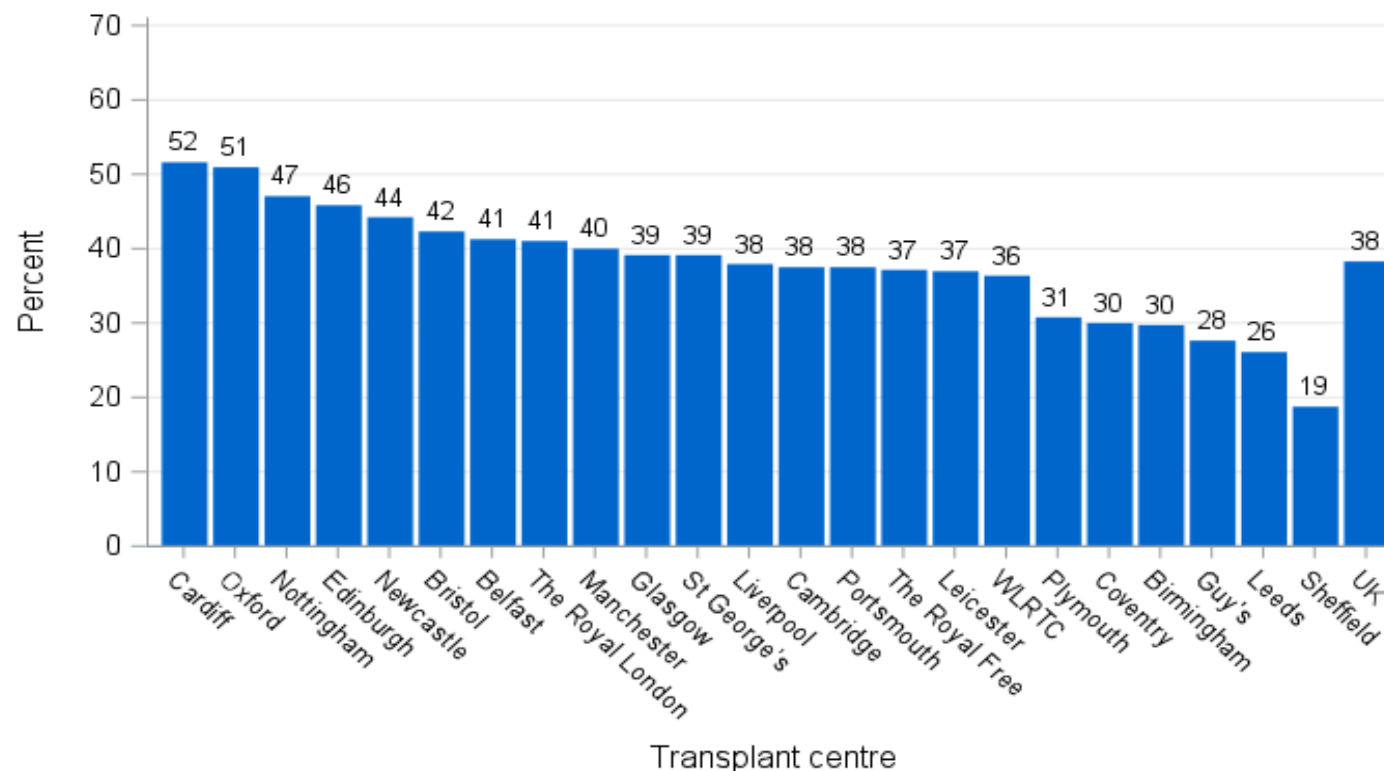


- Addressing unexplained variation
- Removing unwarranted barriers to living donation
- Making it easy for people to donate and receive

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

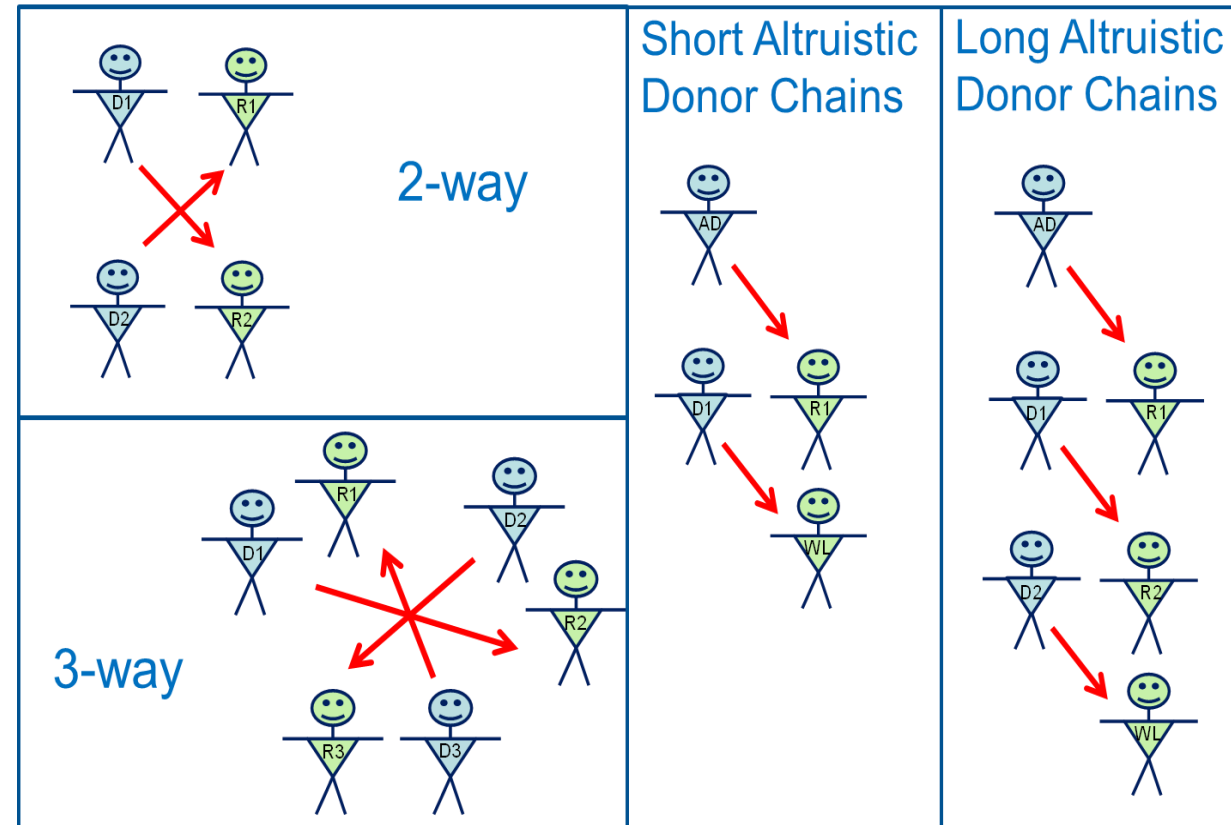
'Transplant First' for Suitable Recipients

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

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



LDKT Safety, Outcomes, Experience

UK TRANSPLANT REGISTRY Blood and Transplant

DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY

Please return data to ODT Hub: Information Services along with Kidney Living Donor Assessment Pre- and Post-Operative (FRM4190) form or Kidney Living Donor Assessment Follow-Up (FRM4191) form as appropriate.

ODT Hub: Information Services
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
BRISTOL
BS34 8RR

Data will be collected at the following time points:
Pre-donation (on completion of

- 20 point questionnaire
- Self-reported **outcomes**
- Collected in UK Living Donor Registry
 - **Pre-donation:** once assessment complete
 - **Post donation:** 1 & 5 years

UK TRANSPLANT REGISTRY Blood and Transplant

DONOR REPORTED EXPERIENCE MEASURES (DREMS) SURVEY

Please return data to ODT Hub: Information Services along with Kidney Living Donor Assessment Follow-Up (FRM4191) form as appropriate. Data will be collected at 1 year post donation.

ODT Hub: Information Services
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
BRISTOL
BS34 8RR

DONOR DETAILS Section 1

Surname _____ Date of birth (DD/MM/YYYY)

Forename(s) _____

ODT donor number _____

Dear Donor,

We would be grateful if you could complete this short survey to help us understand more about your donation experience. Your information will be held by NHS Blood and Transplant in the UK Living Donor Registry to help monitor the wellbeing of kidney donors over time and also inform people who are considering donating a kidney about what to expect.

Thank you for your support.

ACCESSING THE LIVING DONOR PROGRAMME

- How easy was it to find out about living donation?
Please circle: Not at all 1 - 2 - 3 - 4
- How easy was it for you to make contact with the ODT Hub?
Please circle: Not at all 1 - 2 - 3 - 4
- How would you rate the speed of response from the ODT Hub?
Please circle: Very poor 1 - 2 - 3 - 4
- How welcoming was the response to you?
Please circle: Not at all 1 - 2 - 3 - 4

FRM5385/1 (Donor Reported Experience Measures)

- Self-reported **experience**
 - **Assessment**
 - **Hospital stay**
 - **After donation**
- Collected in UK Living Donor Registry
 - **Post donation:** 1 year anniversary

Saying 'Thank You' to Living Donors

- Fixed Time Working Group
 - Representation from living donors, recipients, coordinators, NHSBT
- 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'
- Deliver by Spring 2021



Looking Ahead

- 2020/21 LDKT activity is likely to be reduced by 50-60% due to COVID-19
- 2030 Strategy:
 - Combines living (kidney and liver) and deceased donation for first time
 - Builds on previous success for living donor kidney transplantation
 - Identifies improvements and future development opportunities



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>

First-hand account of Living Transplant Initiatives

Guest speaker, Dela Idowu, Founder, Gift of Living Donation

Community Investment Scheme Cohort Three

Guest Speaker – Dela Idowu



Dela Idowu is the founder of [Gift of Living Donation \(GOLD\)](#) an organisation that works to raise awareness of living kidney donation in the Black Community. She is the author of *More Than a Match*, a book she wrote after coming forward as a living kidney donor for a family member. She is the co-writer and producer of *We Are Family*, an educational film on a living kidney donation from a black family's perspective. She has been involved in previous Living Transplantation Initiatives.

Dela was a member of the Living Donation and Kidney Transplantation 2020 Strategy Implementation Group for the UK and is a member of The National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance (NBTA).



Changing Perceptions

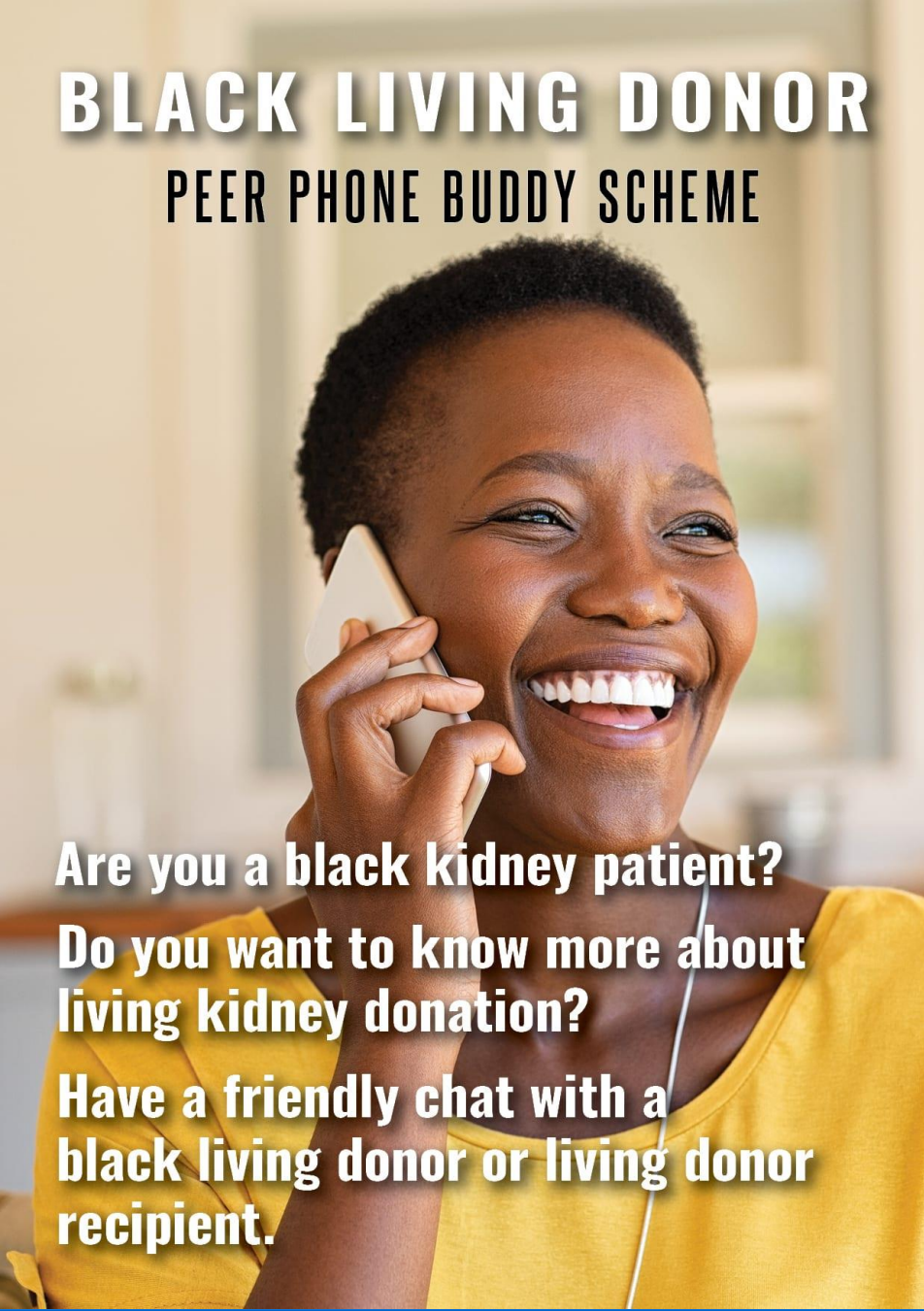
Photographic portraits of black living donors



You can download the booklet here -

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/17296/changing-perceptions.pdf>

BLACK LIVING DONOR PEER PHONE BUDDY SCHEME



**Are you a black kidney patient?
Do you want to know more about
living kidney donation?
Have a friendly chat with a
black living donor or living donor
recipient.**

You can find out more information about the Peer Phone Buddy Scheme here -

<http://giftoflivingdonation.co.uk/gold-telephone-buddy-scheme/>

To support this initiative we have also created a black living donor peer phone buddy video aimed at healthcare professionals -

<https://youtu.be/8jrPNmIHxZw>



'THANK YOU FOR THE GIFT OF LIFE'

People who have selflessly donated organs to loved ones honoured at milestone event



INSPIRATIONAL: The men and women celebrated at the first-ever *Because of You* event held in Bloomsbury, London (photo: Adedayo Olaseinde)

By Vic Motune

IN THE FIRST event of its kind, black living donors, people who have donated their organs to family members and others, were celebrated with a public thank you last week. Hundreds gathered at the Holiday

Inn in Bloomsbury, London for a special appreciation lunch called *Because of You*.

The donors, and the family members they had given their organs to, shared emotional moments, stories about their journey and how the process had changed their lives.

Dela Idowu, founder and director of the charity Gift of Living Donation (GOLD), which organised the event, said she believed visible and relatable black living donors would help dispel the fear that often surrounds organ donation in the community. She told *The Voice*: "The majority of

black people don't know of anyone who is a living donor so they often focus on the negative aspects of organ donation.

SHOWCASE

"They fear something could go wrong with the transplant operation

or something terrible could happen. It was therefore important for us to showcase some of the hundreds of black men and women who have overcome fear to successfully donate a kidney to a loved one."

Continued on page 2

Living Donation Q&A



Living Donation Resources

- On our [Become a living donor](#) webpage you will find information on donating your kidney which you can direct people to. On here there is also information about the [UK Living Kidney Sharing Scheme](#).
- On our [Get Involved hub](#) you will find:
 1. Downloadable digital materials to enable you to promote Living Donation within your community.
 2. Social media graphics for you to use on your own channels to promote Living Donation
 3. A number of Living Organ Donation videos which you can view and share
 4. You can order leaflets about Living Donation
 5. A guide on how to share your story to promote Living Donation in the media and on social media
- We have a [dedicated webpage](#) with information about the need for more black, Asian and minority ethnic living organ donors. On this page you will find a wealth of fantastic materials aimed at the Hindu, Jain and Black communities. All of these materials have been created by projects during previous rounds of the Community Investment Scheme and by charities such as Dela's - Gift Of Living Donation.

Next steps

1. Attend our next workshop on Thursday 13th May, 12pm – 1pm. This will look at How to have a Taboo Conversation and will include advice from one of our specialist nurses. Zoom joining details are in the [Sway calendar](#). Do let us know if there is a topic you feel requires a lunchtime workshop.
2. Please contact your Advisor if you haven't yet done so and set up your introductory meeting. They would love to hear from you and learn about your project and how best to support and work with you over the year.
3. Be sure to add your campaign code and tracked link to all marketing activity you prepare. More information on this is available in the [Measuring Success from the Start presentation slides](#) from the 1st April and we will be sending out more guidance on this. If you have already started to use your campaign code and tracked link next week you will receive your personal dashboard showing how many people have clicked on your tracked link and visited our webpage and / or registered to become a blood or organ donor. We recognise that it is only the very start so not all projects will be using their tracked links yet.
4. Familiarise yourself with existing resources including the [Sway document](#) and digital tools. Also visit our new [CIS Resources webpage](#).
5. Consider booking a lunchtime drop-in sessions 12 -1 on a Tuesday or Thursday if you have any questions. You can join via your phone or using Microsoft Teams on a laptop, tablet or computer.

Thank You For Attending

Any questions please contact us:
community.funding@nhsbt.nhs.uk