

Living Donor Kidney Transplantation

Update

Lisa Burnapp

RTSM, January 2021



Caring Expert Quality

Overview

- Reflections on 2020
- Current activities
- Future Strategy



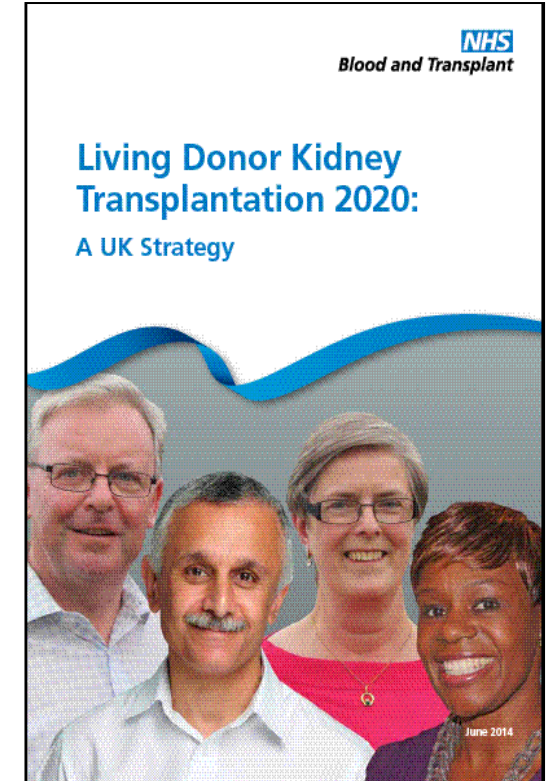
A living donor can donate to someone they know, such as a family member or someone they don't know.

Reflections on 2020

This time last year....

- Increase living donor kidney transplantation (LDKT)
 - Reduce unwarranted variation
 - Increase capacity for LDKT
 - More...
- Improve recipient
 - Increase pre-emptive LDKT
 - Maximise UK living kidney share (UKLKSS)
 - Disincentivise travel outside UK for...
- Look after donors
 - Remove unwarranted barriers to donation
 - Ensure the best outcomes and donor experience

COMPLETED MARCH 2020



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

Living Donor Kidney Transplantation

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

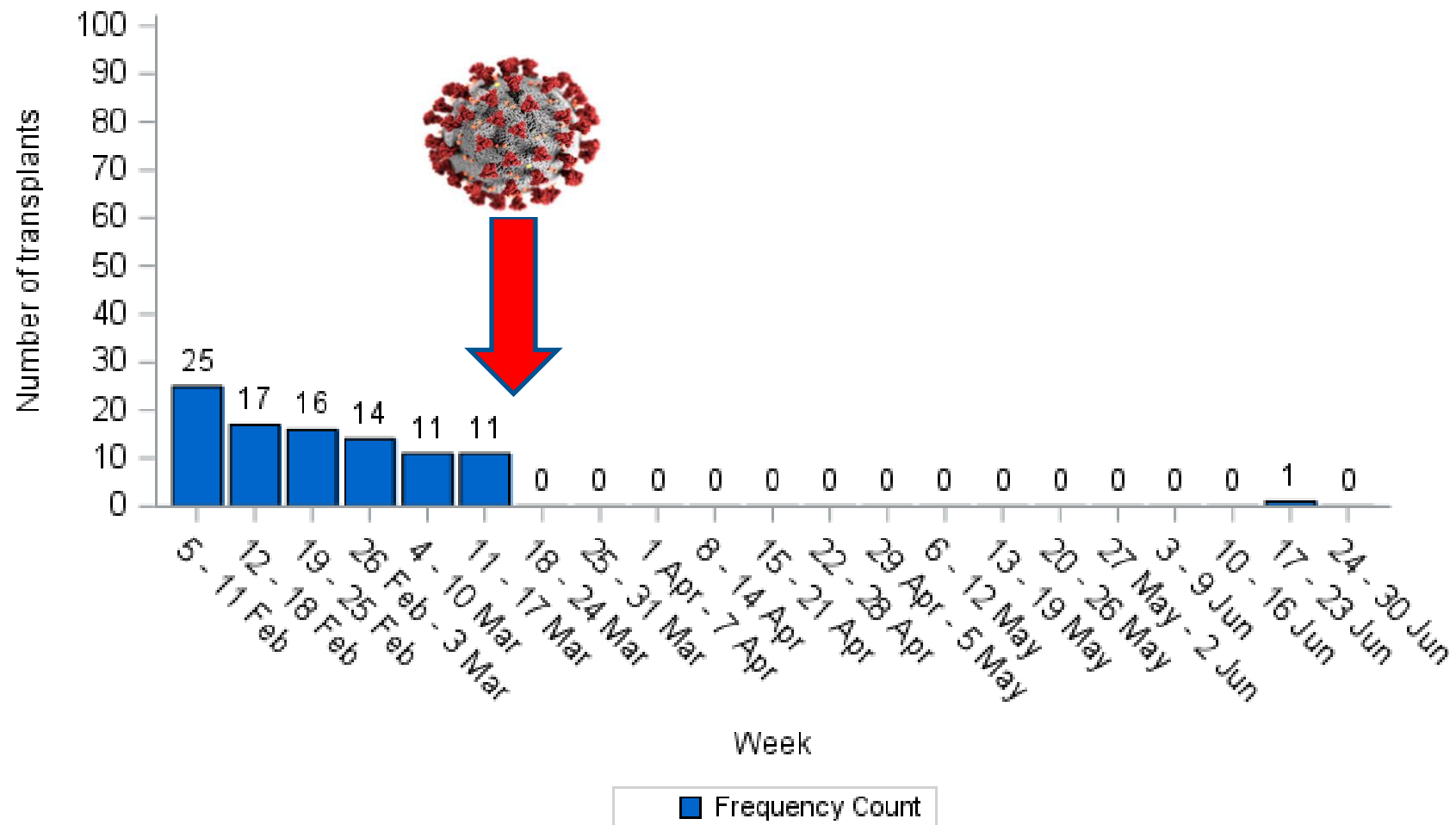
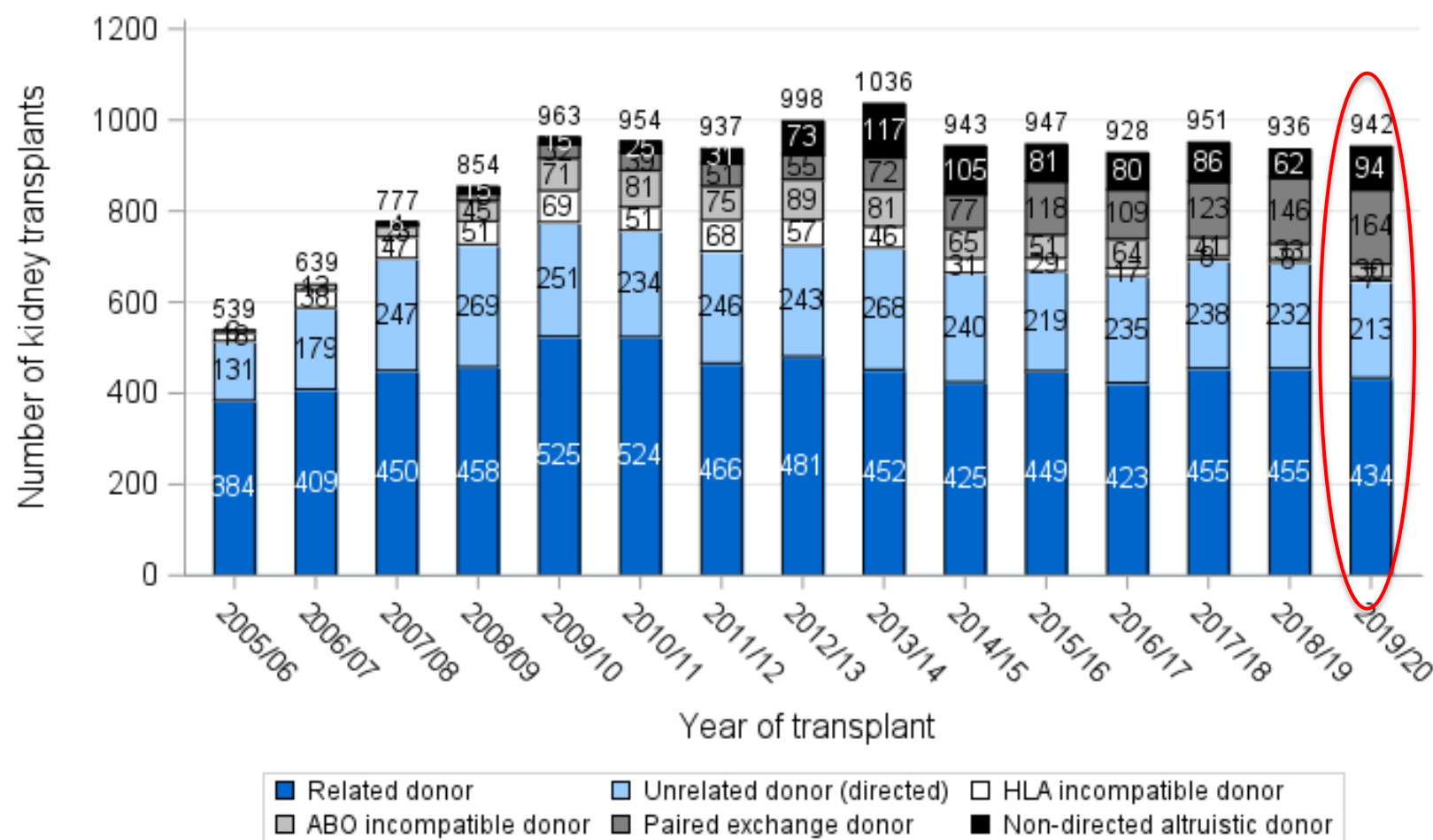


Figure 2.2 Adult living donor kidney transplants in the UK,
1 April 2005 - 31 March 2020



Impact of COVID-19: Round 1

- Urgent living donor liver transplant remained open
- All LDKT activity paused in every centre
 - Pending transplants cancelled/postponed
 - No LDKT from 26th March to 27th May
 - UK Living Kidney Sharing Scheme (UKLKSS) suspended
- Clinical teams redeployed
- All project work paused



Restoration Project

- 1st LDKT 28th May; activity increased in June
- Clinical teams/UK Living Kidney Donation Network re-established
- Projects remain paused
- Every centre asked to produce a restoration plan by 24th July
 - Address backlog of pending transplants
 - Assess feasibility of October UKLKSS matching run
 - Contingency planning for next surge or similar crisis
- All centres reopened by September 2020
- Centre restrictions re-introduced in January 2021 with resurgence in infection rates



What did donors think?*

- NHSBT market research survey of living donors **June/July 2020**
 - Assess appetite for living donation in COVID era
 - Disseminated via twitter and charitable partners
 - Open for 2 weeks
 - UK-wide
 - Aimed at previous, present and potential living donors (including public)



<https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/>

What did donors think?

- 240 responses
- All types of donors responded
 - 72% previously donated
 - 54% family member
 - 33% non-directed (unknown recipient)
- Good geographical spread
- Demographics:
 - All ages represented (18-65+); 32% 45-54
 - 85% White British
 - 80% female



<https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/>

COVID Response?

- Recognised seriousness of the pandemic
- Perception of general 'personal' vulnerability due to COVID evenly distributed
- Concerns about additional recipient risk was the greatest influence to donate or not
- Keen to see programmes re-start
- High level of confidence in clinical teams and in the NHS
- Testing (donors, recipients and staff) and PPE critical
- Willing to
 - Undertake remote/virtual assessments where appropriate
 - Move to another centre for surgery
 - Be looked after by another clinical team



Limitations

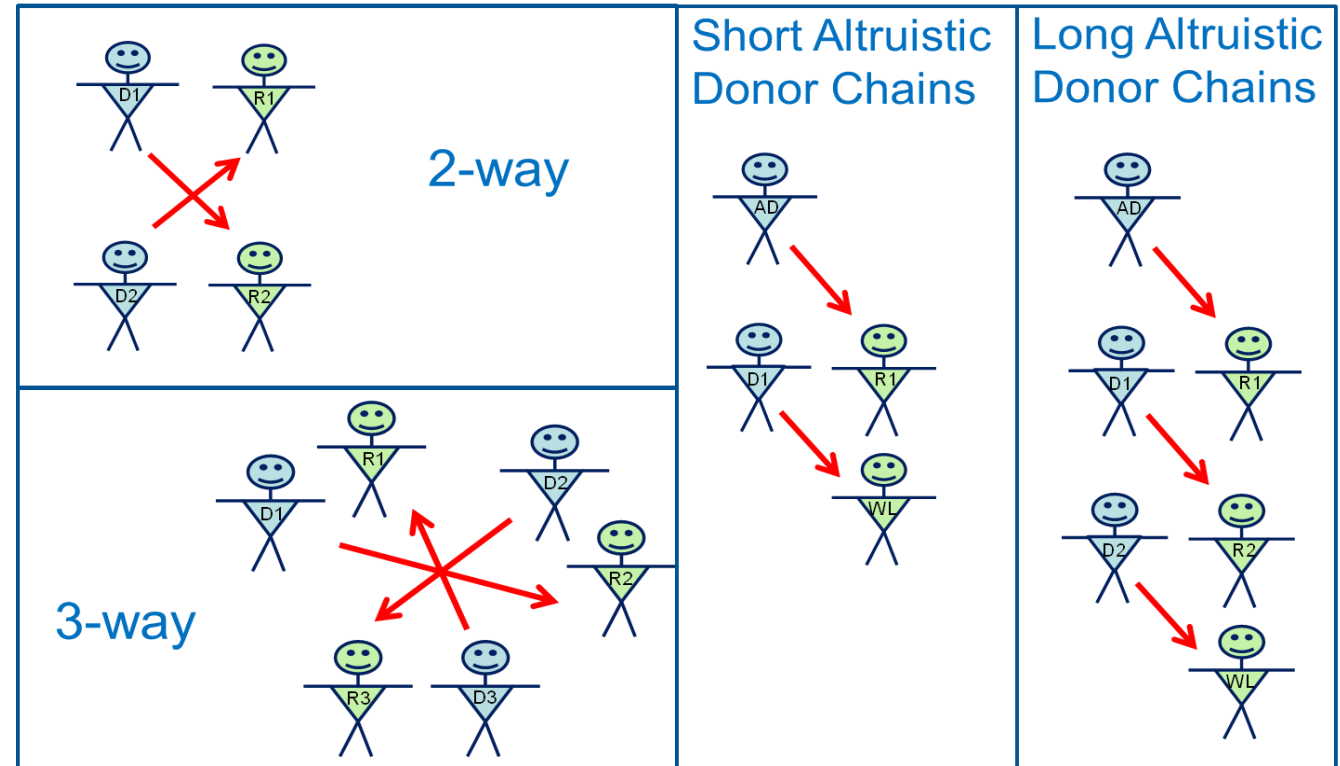
- Limited reach
- Relatively small sample size
- Under representation from
 - BAME people*
 - Men
 - People who have yet to refer/early contemplators



<https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/>

*smaller survey performed by GOLD in May 2020 suggested more fear and anxiety about LDKT in Black people

UK Living Kidney Sharing Scheme



Increasing the Donor Pool

- Inclusion of non-directed donors as a 'default'
- Inclusion of compatible pairs
- Desensitisation and low risk ABOi for highly sensitised recipients

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

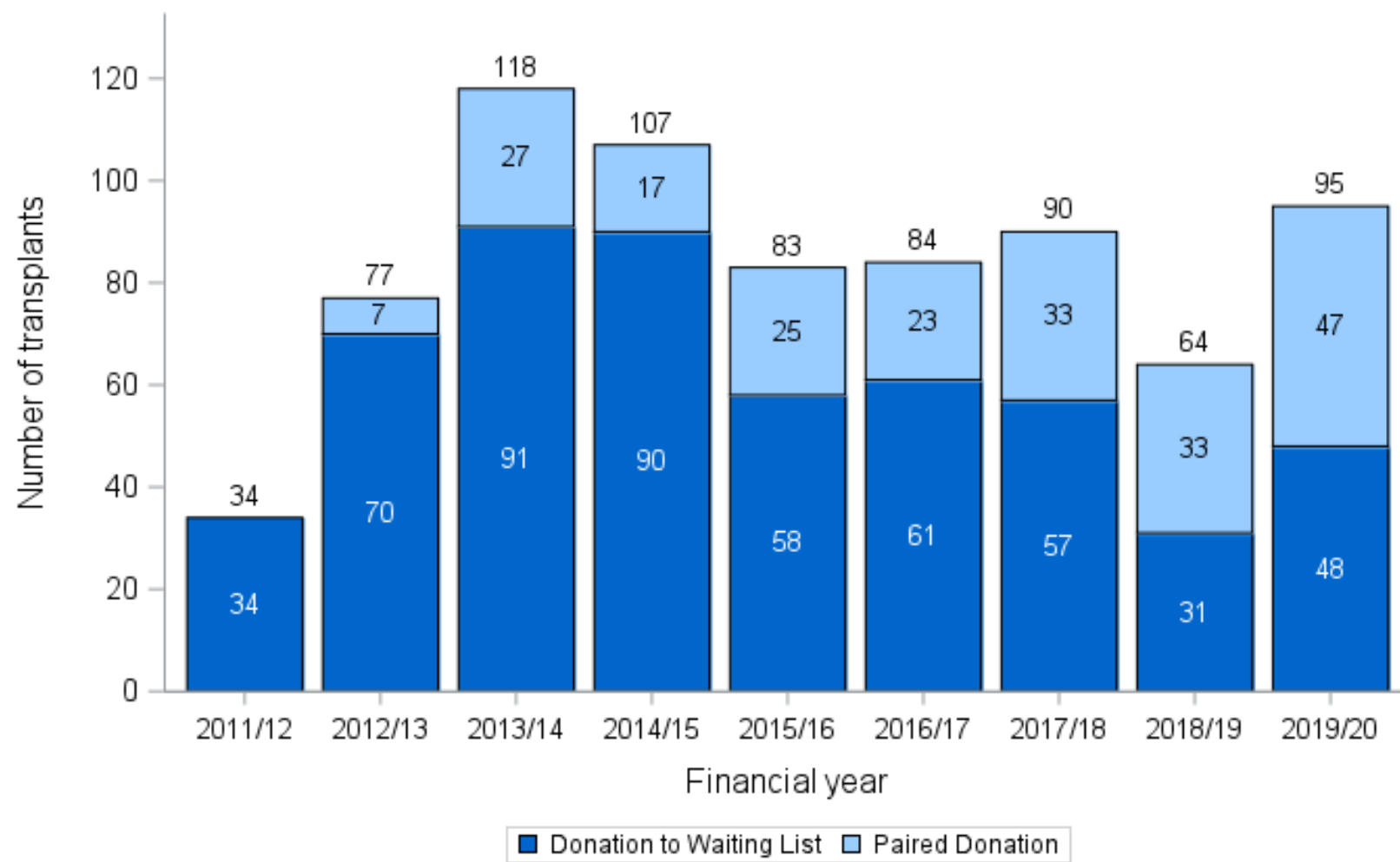
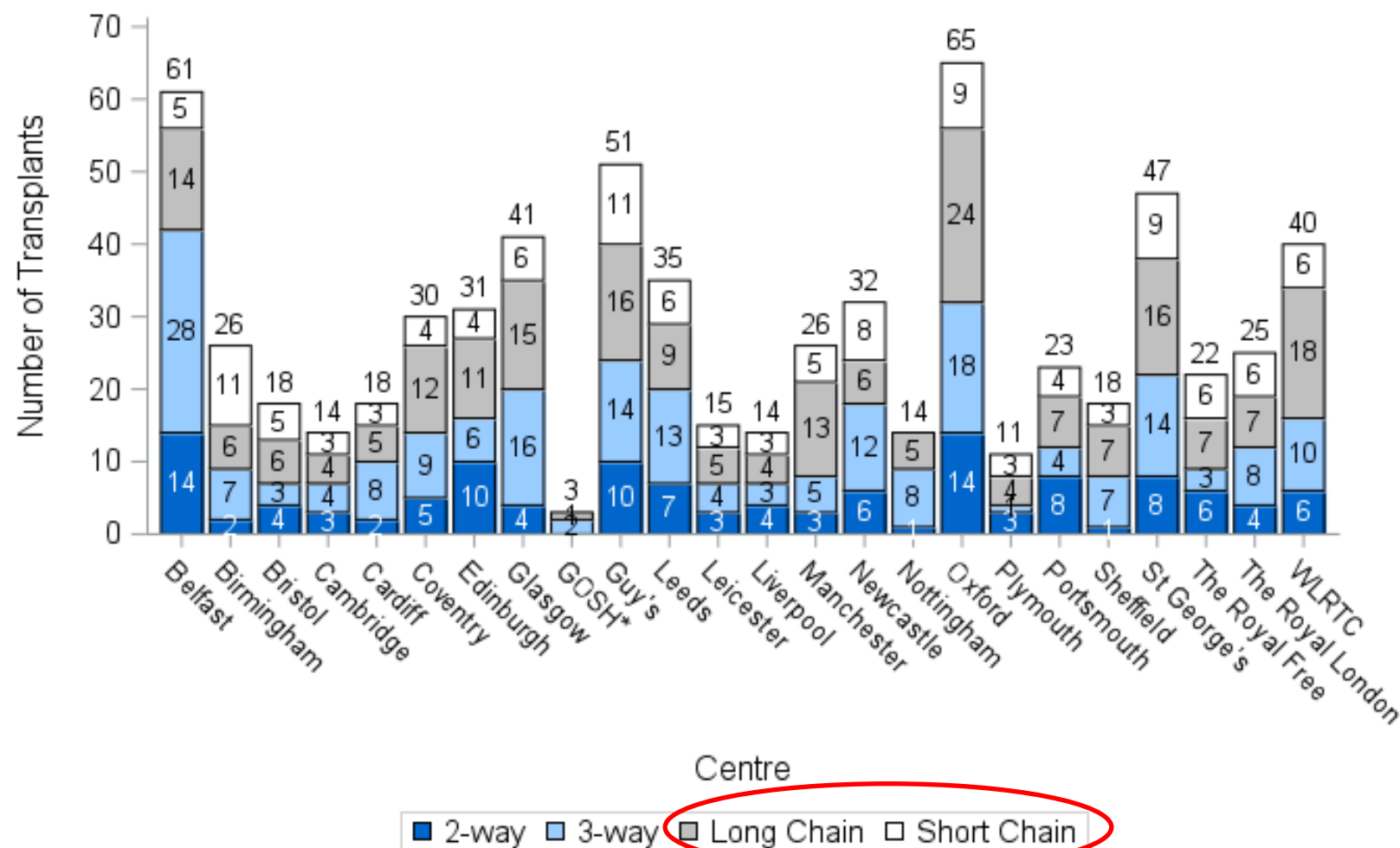
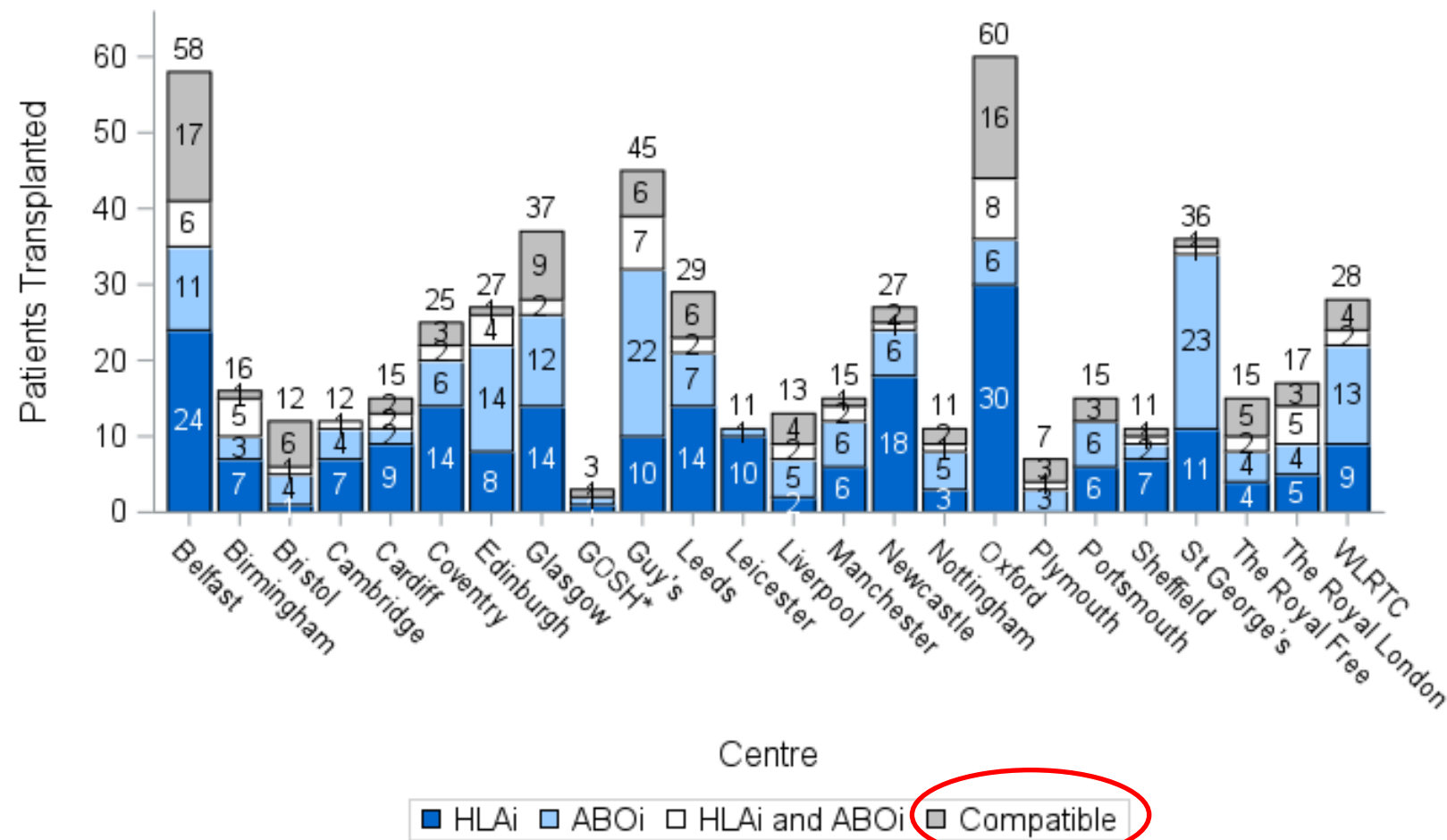


Figure 4.6 Number of transplants by type and centre, 1 April 2016 - 31 March 2020



*Guy's team assess donors and perform transplants for GOSH recipients

Figure 4.7 Patients transplanted by pair incompatibility in matching runs, 1 April 2016 - 31 March 2020



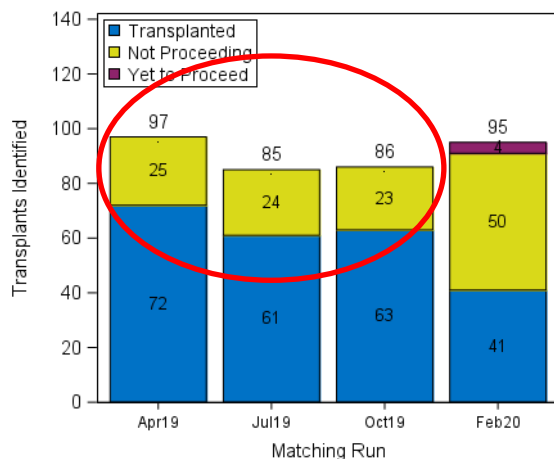
*Guy's team assess donors and perform transplants for GOSH recipients

Impact



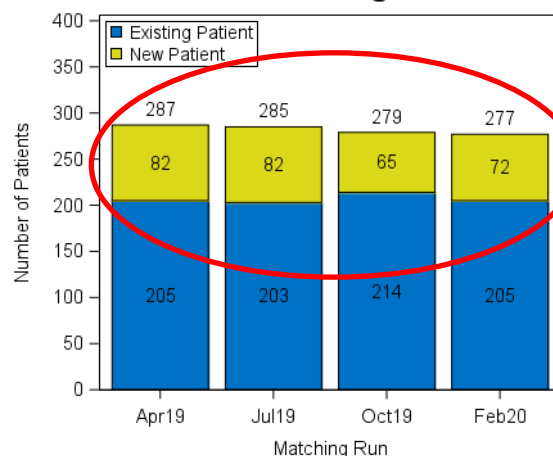
UK Living Kidney Sharing Schemes Performance Figures

Paired Donation Transplants Identified

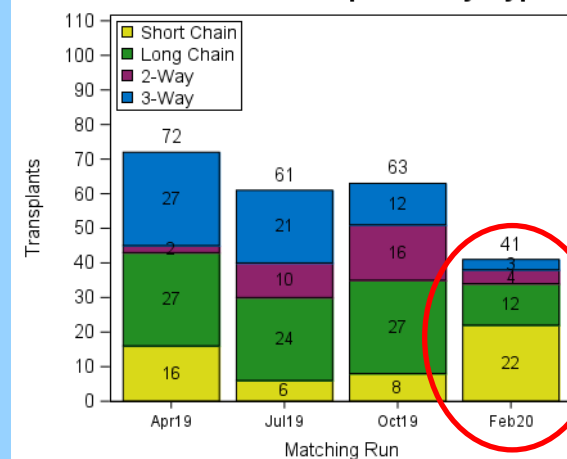


	Total May 2007- Feb 2020
Pairs Registered	2758
Patients Registered	2490
Altruistic Donors in Paired Donation Matching Runs	368
Compatible Pairs Registered	219
Transplants	1284

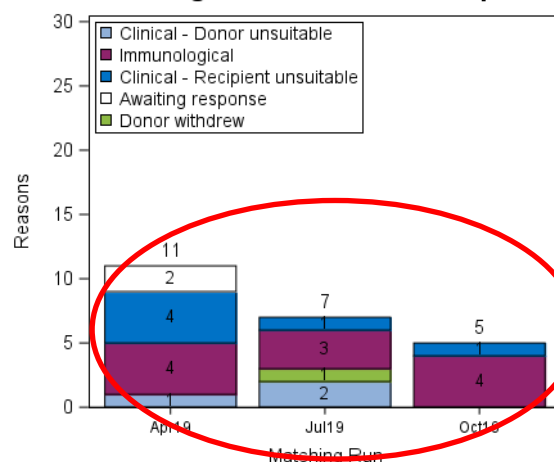
Patients in Each Matching Run



Paired Donation Transplants by Type



Non Proceeding Paired Donation Transplants



Note: each reason may account for multiple transplants

UKLKSS Records	In a Matching Run
Pairs Included	313 (Apr 2019)
Patients Included	287 (Apr 2019)
Altruistic Donors Included	29 (Feb 2020)
Transplants Identified	97 (Apr 2019)
Transplants Proceeded	72 (Apr 2019)

Altruistic Donor Transplants

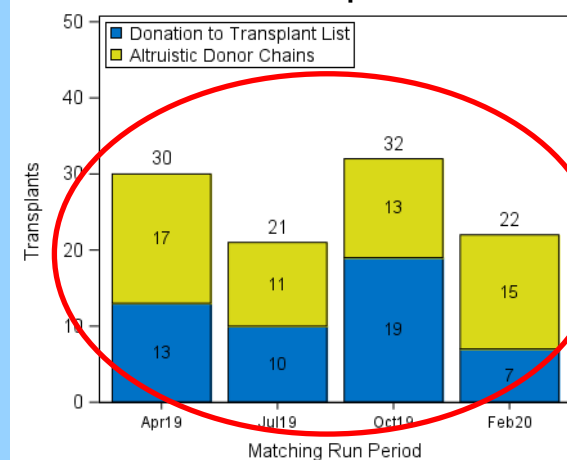


Figure 5.2 Adult living donor antibody incompatible kidney transplants in the UK, 1 April 2010 - 31 March 2020

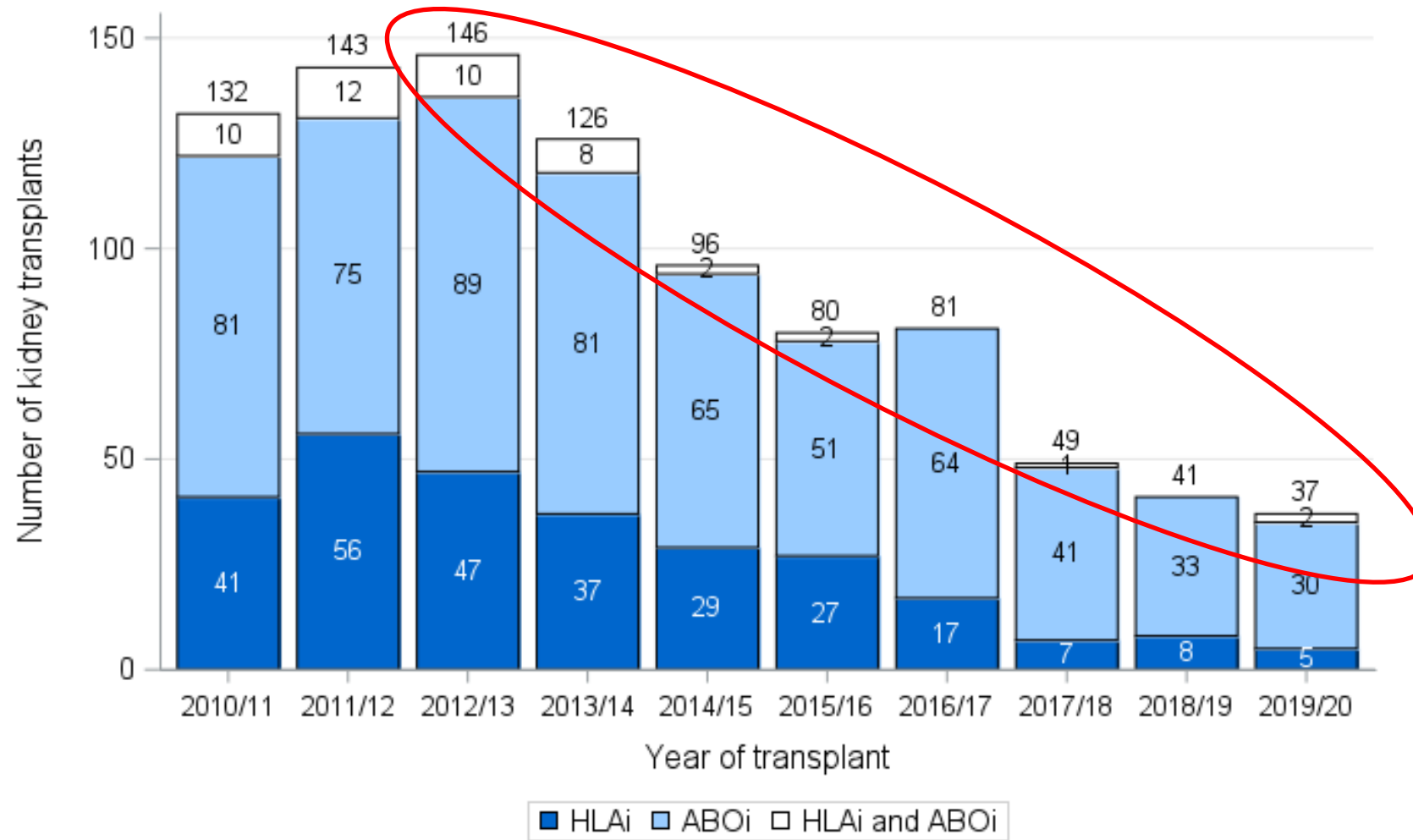
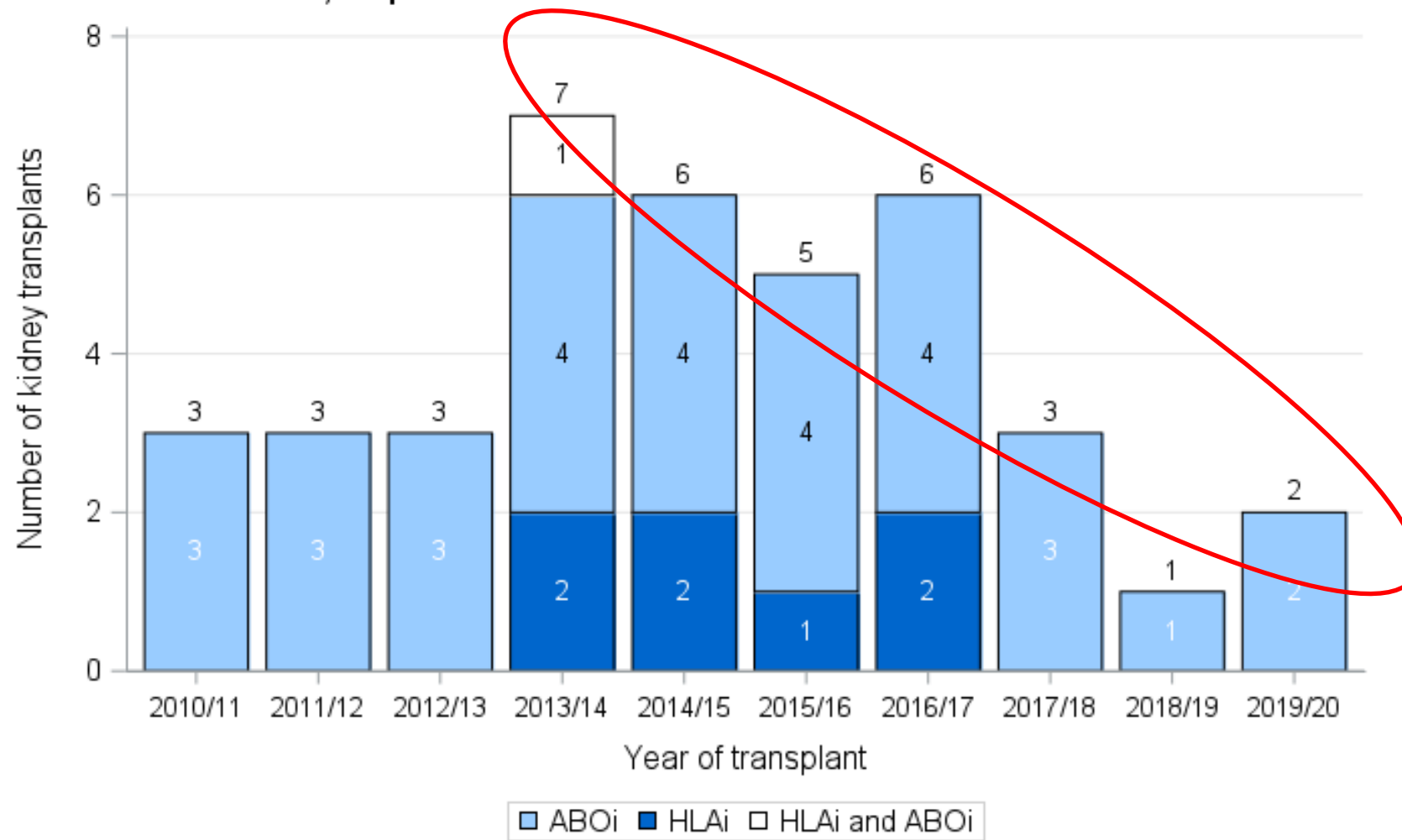
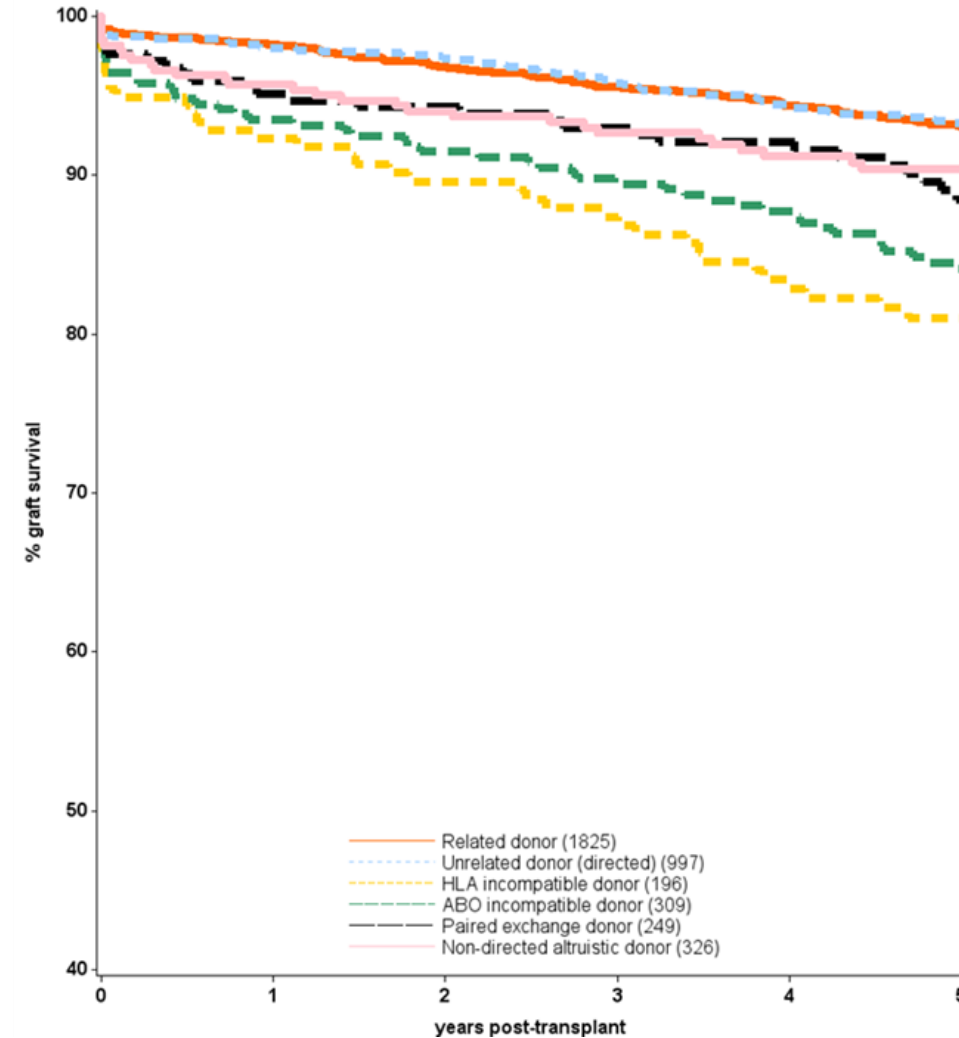


Figure 5.4 Paediatric living donor antibody incompatible kidney transplants in the UK, 1 April 2010 - 31 March 2020



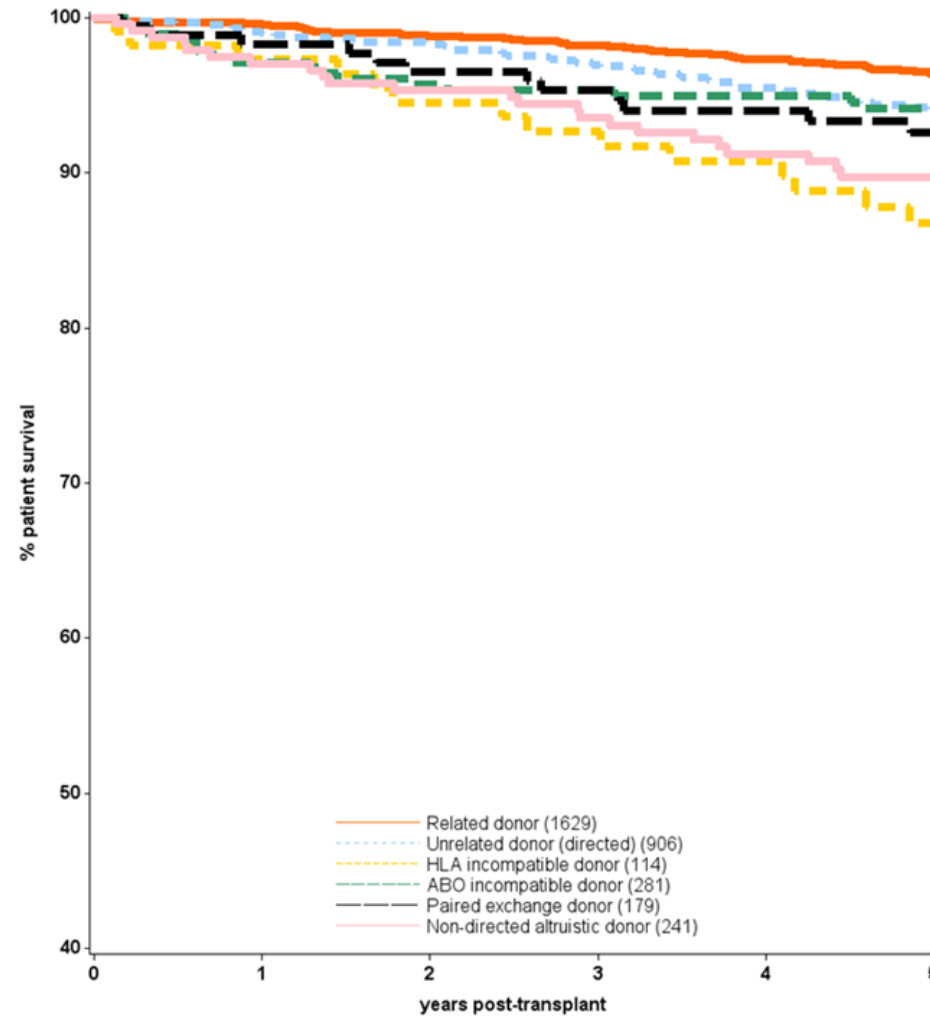
Graft Survival

Figure 7.2 5 year graft survival following adult living kidney transplant between 1 April 2011 and 31 March 2015




Patient Survival

Figure 7.4 5 year patient survival following adult living kidney transplant between 1 April 2011 and 31 March 2015



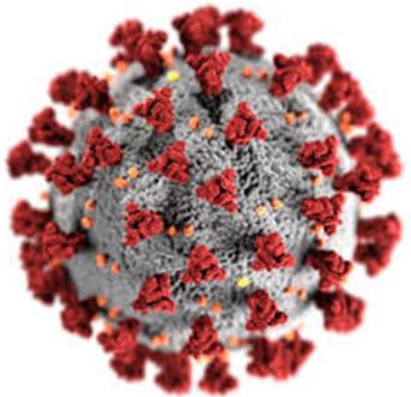
Challenges

- Critical incidents
 - October 2019 and January 2020 matching runs
- Reduced activity due to COVID-19
 - Suspended matching runs April, July, 2020; January 2021
 - Collapsed exchanges due to delay
 - Developments 'on hold'
- Digital platform to
 - Replace manual and paper-based processes
 - Maximise potential of UKLKSS


Blood and Transplant


UK Living Kidney Sharing Scheme

Your questions answered



Paired/Pooled Donation
Non-directed Altruistic Donor Chains

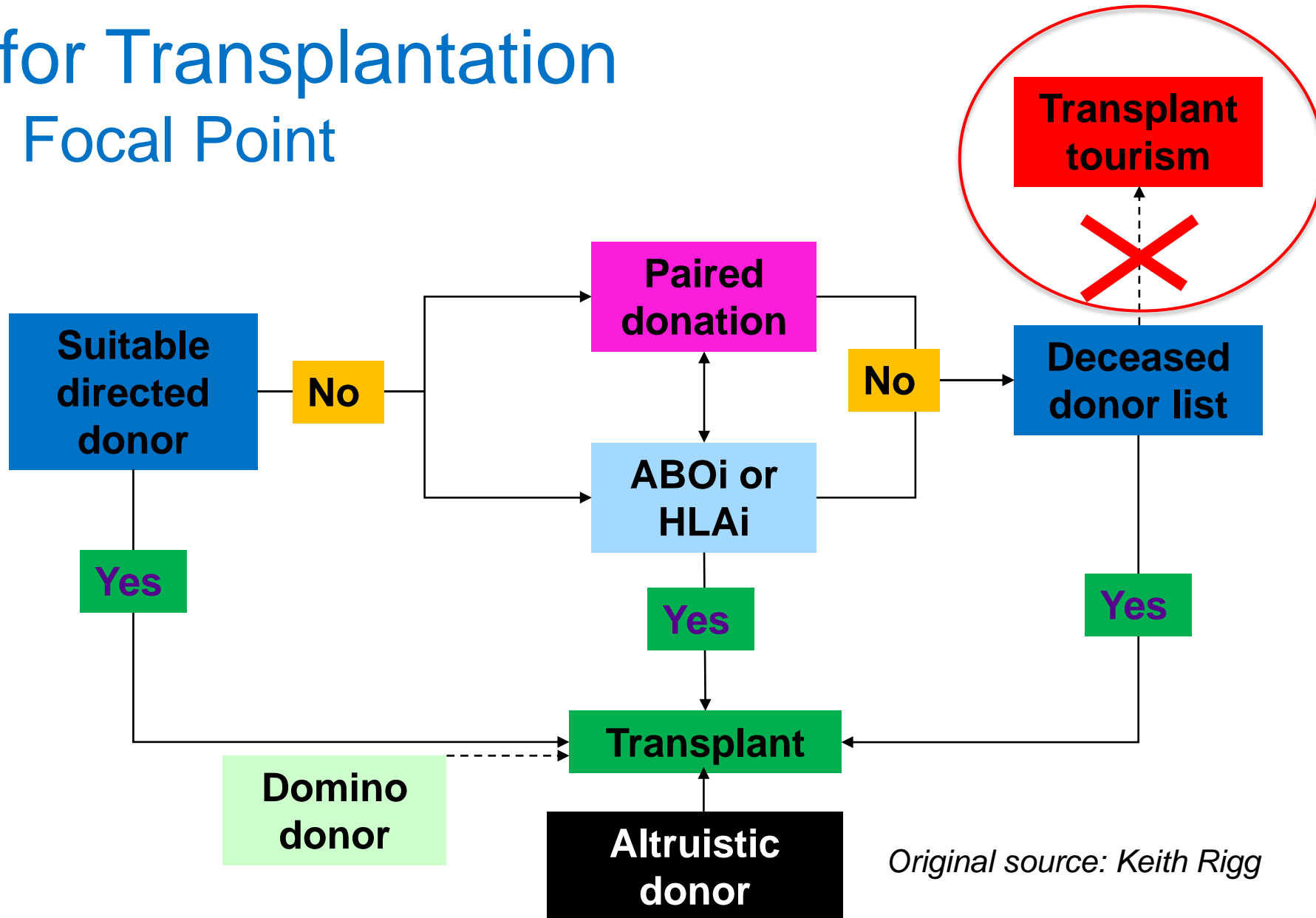
www.organdonation.nhs.uk
enquiries@nhsbt.nhs.uk
0300 123 23 23



Current Activities

Travel for Transplantation

National Focal Point



Original source: Keith Rigg

What can you do?

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
ON ORGAN TRAFFICKING AND TRANSPLANT TOURISM

For more information:
DECLARATION OF ISTANBUL CUSTODIAN GROUP
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

Reporting

- National Focal Points: Council of Europe- annual data collection
 - Collected 2 years in arrears
 - UK residents who return to the UK having received a transplant outside the UK
 - NHS entitled recipients who receive a transplant from a non-resident living donor in the UK
 - Non-NHS entitled living donor recipient and donor pairs who travel to the UK for LDKT
- For cases where patients have received a transplant outside the UK
 - Contact lisa.Burnapp@nhsbt.nhs.uk and report to ODT on-line to follow-up in real time
- Cases of suspected human trafficking for organ donation
 - Report to the HTA to consider referral via National Referral Mechanism for victim protection and support

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



The Next Strategy?

By 2030....

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

A decorative graphic at the bottom of the slide consisting of two overlapping wavy bands in shades of blue.

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

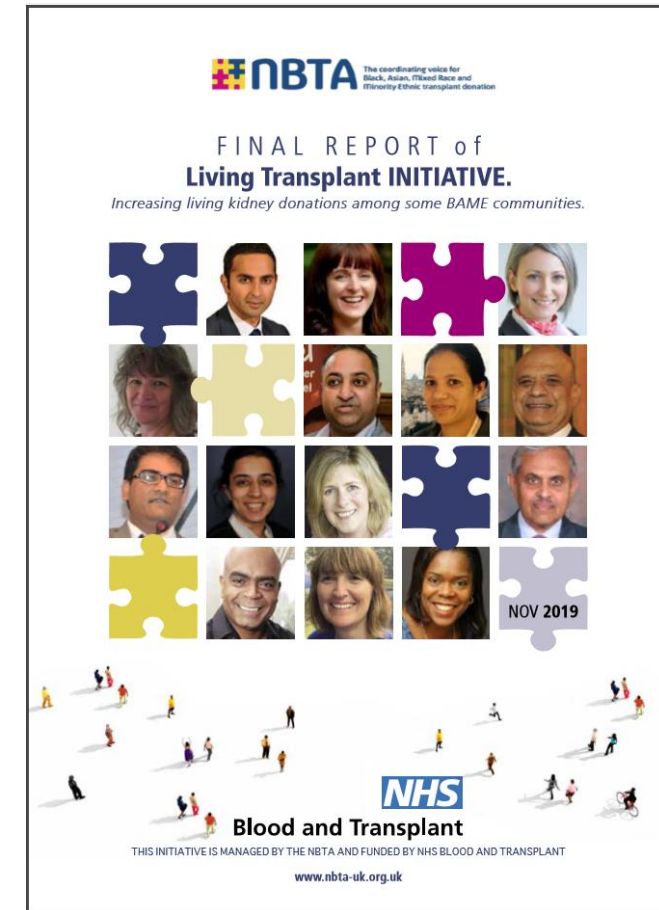
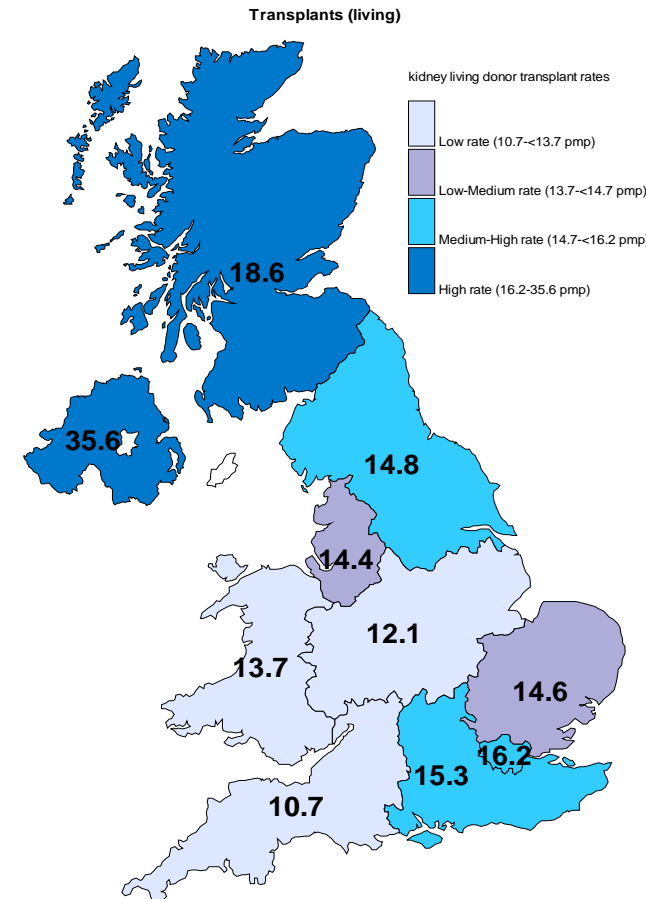


Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/NHS region of residence

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



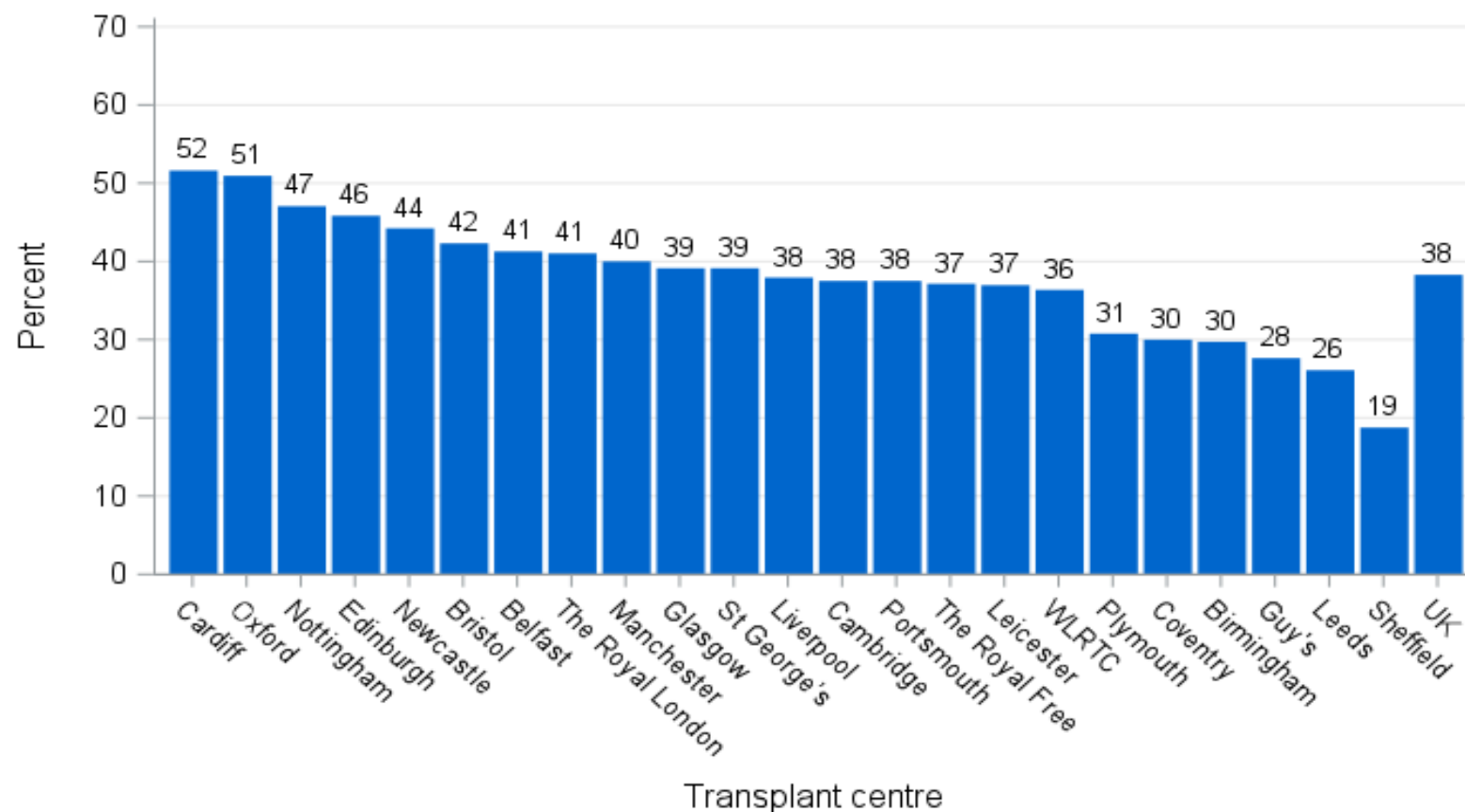
Source: Annual Report on Kidney Transplantation 2019/20, NHS Blood and Transplant

'Transplant First' for Suitable Recipients

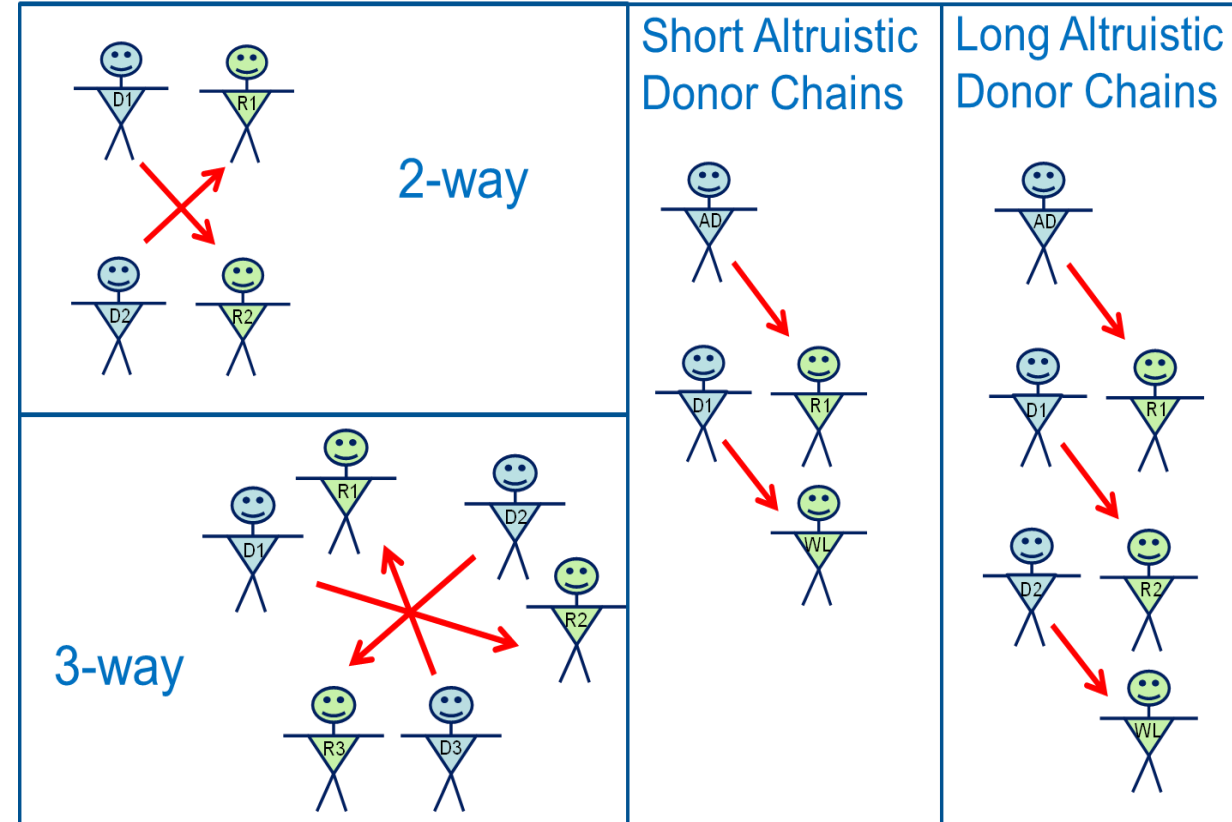


Blood and Transplant

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



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

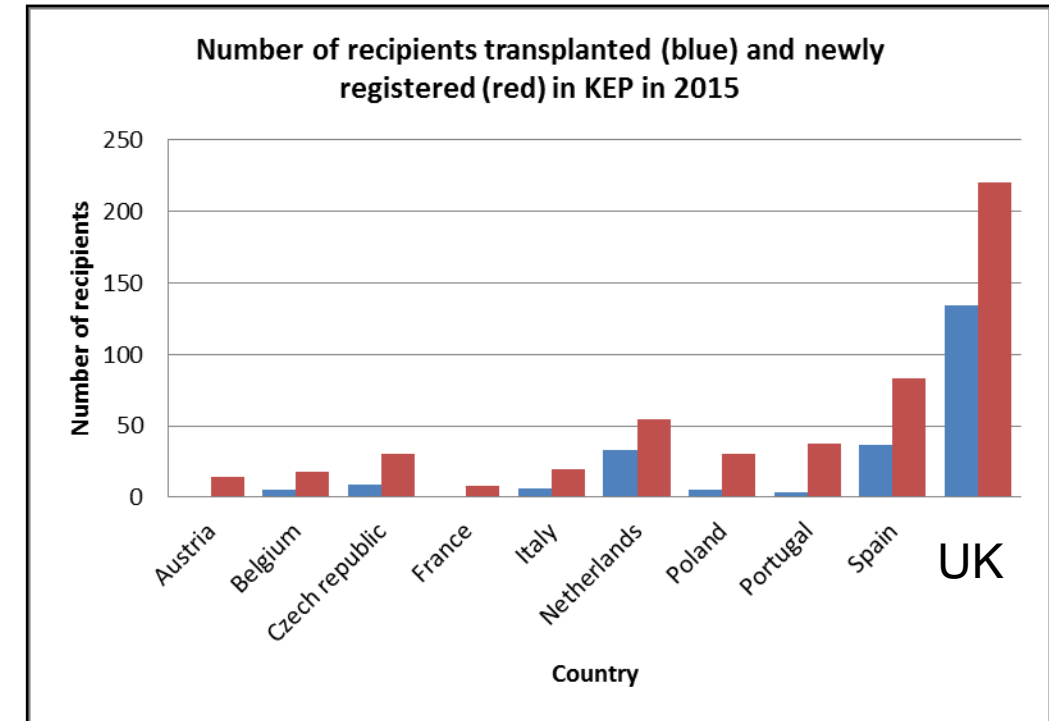
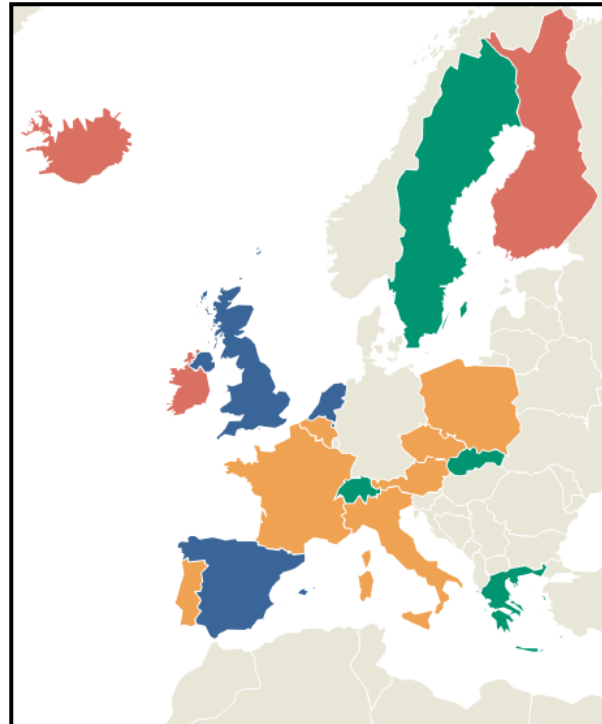


International Collaborations



European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)

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



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](https://doi.org/10.1097/TP.0000000000002432)) (PMID:[30247314](https://pubmed.ncbi.nlm.nih.gov/30247314/)) (Early Online Publication)

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 work up), 1 year and 5 years post donation.

to help you 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 what to expect.

Indicated) Section 2

very poor" and 10 is "excellent?"

here 1 is "almost all the time" and 10 is "as much as I expect?"

scale of 1-10 where 1 is "poor" and 10 is "great?"

ur family or social life on a scale of 1-10 where 1 is "significant effect"

ere 1 is "not at all" and 10 is "very positive?"

ur decision to donate, on a scale of 1-10 where 1 is "they think very"

ere 1 is "poor" and 10 is "excellent?"

image on a scale of 1-10 where 1 is "poor" and 10 is "excellent?"

ere 1 is "poor" and 10 is "excellent?"

activities such as working, housekeeping or travelling on a scale 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

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 (Please answer all questions unless indicated) Section 2

- 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 transplant team?
Please circle: Not at all 1 - 2 - 3 - 4
- How would you rate the speed of response from the transplant team?
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)

Section 3

ordinators?

8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

donation team?

8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

assessment process?

to help you understand the process and the timeframes involved?

6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

not the assessment process?

5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

assessment?

6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

part of your assessment?

6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

8 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

updated through the process?

5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

ing assessment?

5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

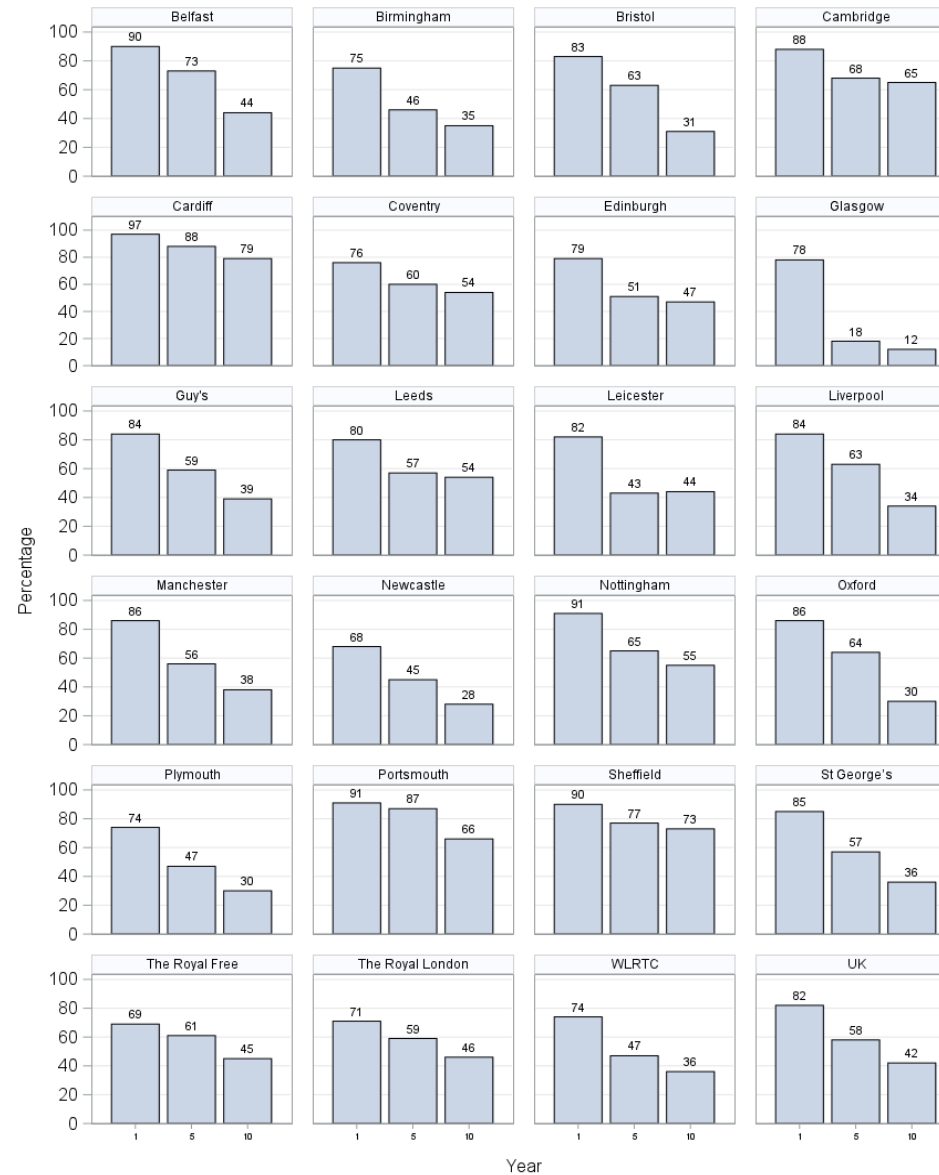
information provided to you?

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

Donor Follow-up by Centre

➤ 1, 5, & 10 years

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





Digital Transformation- LD Pathway

UKLKSS

Donor registration

Donor follow-up

Self-reported measures



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

