

A thick blue wavy line that spans the width of the slide, starting from the left edge and ending at the right edge, with a slight dip in the middle.

Living Donor Kidney Transplantation

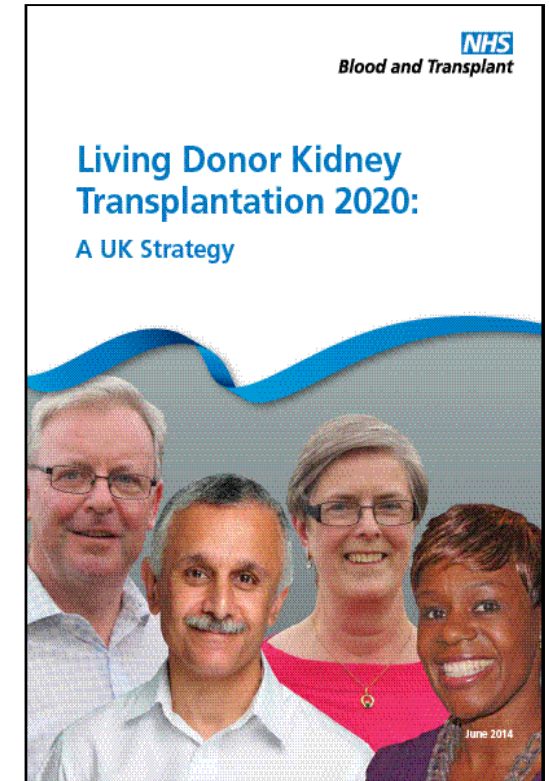
In 2020

Lisa Burnapp

RTSM, January 2020

We committed to

- Increase living donor kidney transplantation (LDKT)
 - Address unwarranted variation
 - More options for LDKT
 - More living donors
- Improve recipient outcomes
 - Increase pre-emptive 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



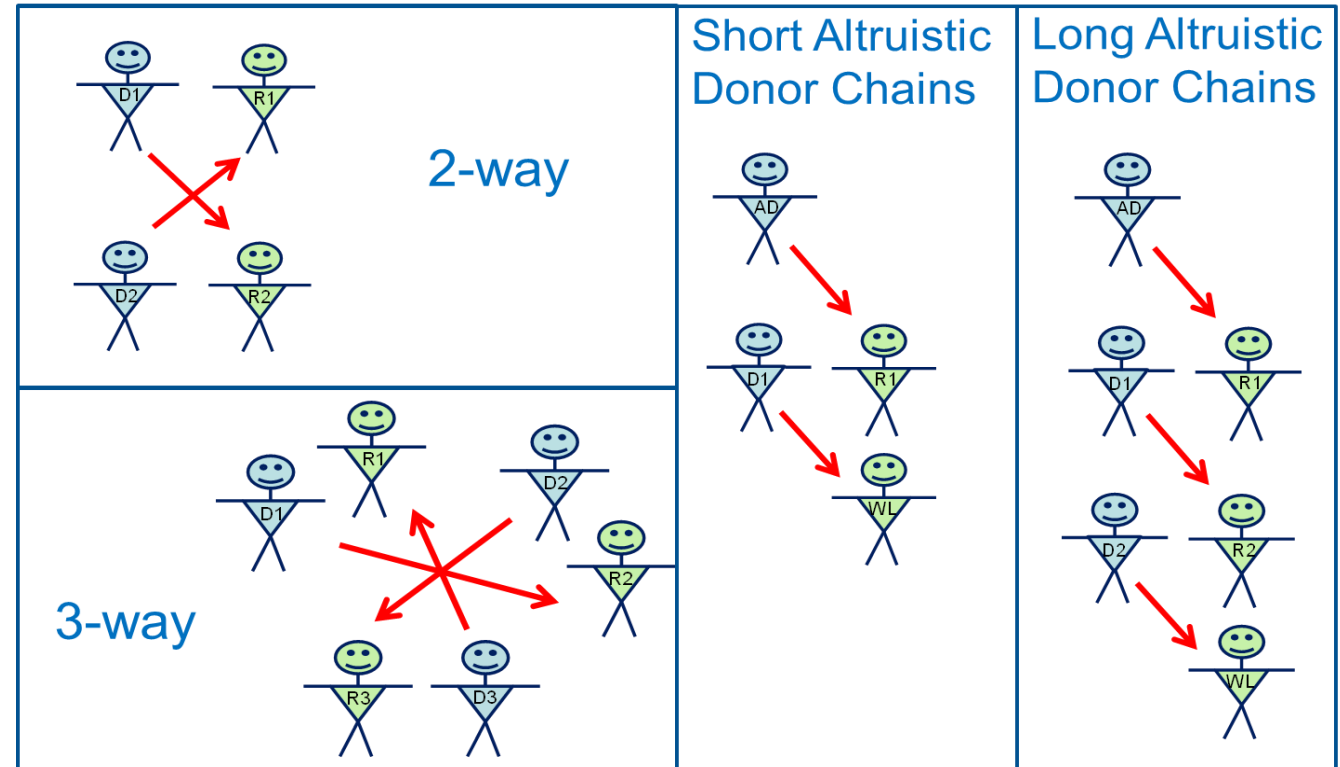
“To match world class performance in living donor kidney transplantation”

Overview

- Some achievements
- Some recent developments
- Some areas for improvement

Achievements

UK Living Kidney Sharing Scheme

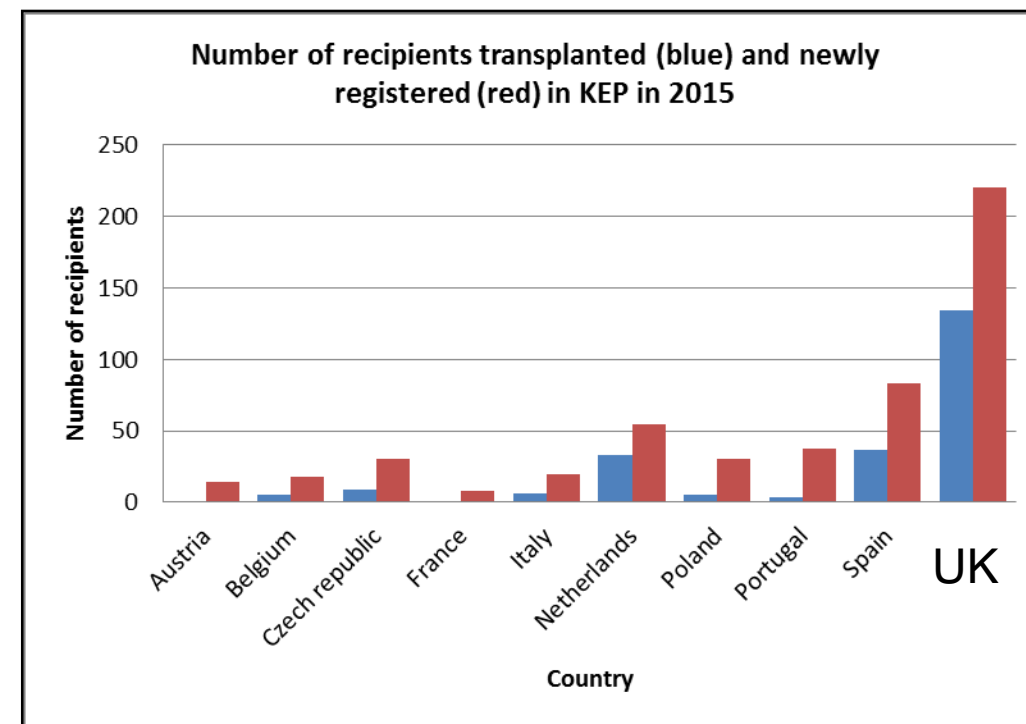
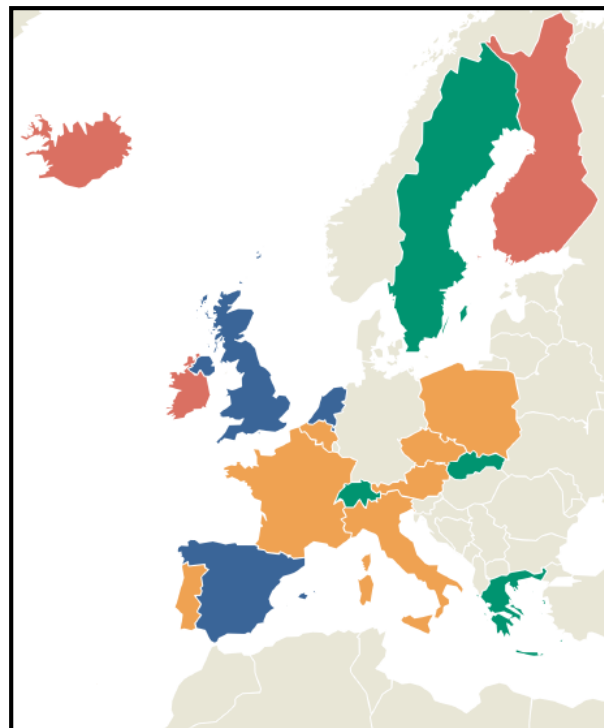


UK scheme - largest in Europe



European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)

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



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)

World Kidney Day- 14th March 2019

UK's living kidney sharing scheme to hit 1000th transplants milestone this week

Non-directed donors are 'game changers' in fight to cut kidney transplant waiting list

11 March 2019



NHS Blood and Transplant is marking the week of World Kidney Day (14 March) by announcing the 1000th kidney transplant under the UK Living Kidney Sharing Scheme (UKLKSS) is due to be carried out this week.

The scheme started in April 2007 because many 'difficult to match' patients had friends and family who wanted to donate a kidney but weren't a compatible match by blood group or tissue (HLA) type.

If the patient enters the sharing scheme with their friend or family member, the pair may be matched with another couple in the scheme so that each recipient receives a kidney from the other's friend or family member. This kidney exchange programme increases the number of people who can receive transplants from living kidney donors and the opportunities for patients who wait a long time for a transplant.

The latest 'matching run' to pair up donors and recipients has taken place and the resulting operations will lead to the 1000th transplant scheduled this week (the week commencing March 11). All donors and recipients in the scheme are anonymous and the transplant recipient who becomes the 1000th will come down to how operations are scheduled by hospitals this week.



Priorities

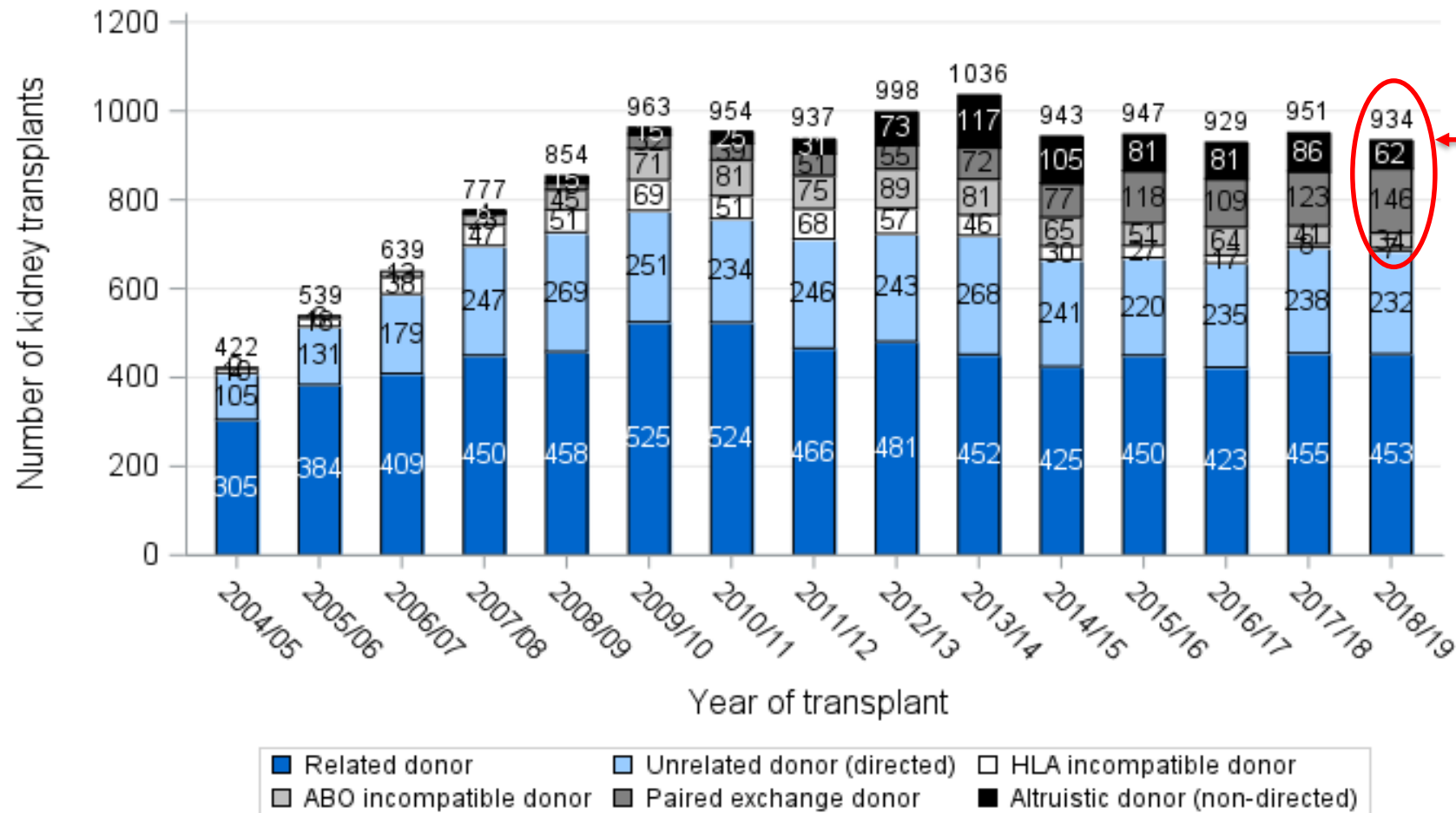


- Maximise transplants
- Increase flexibility in the scheme
- Tackle non-proceeding transplants
- Improve access and awareness



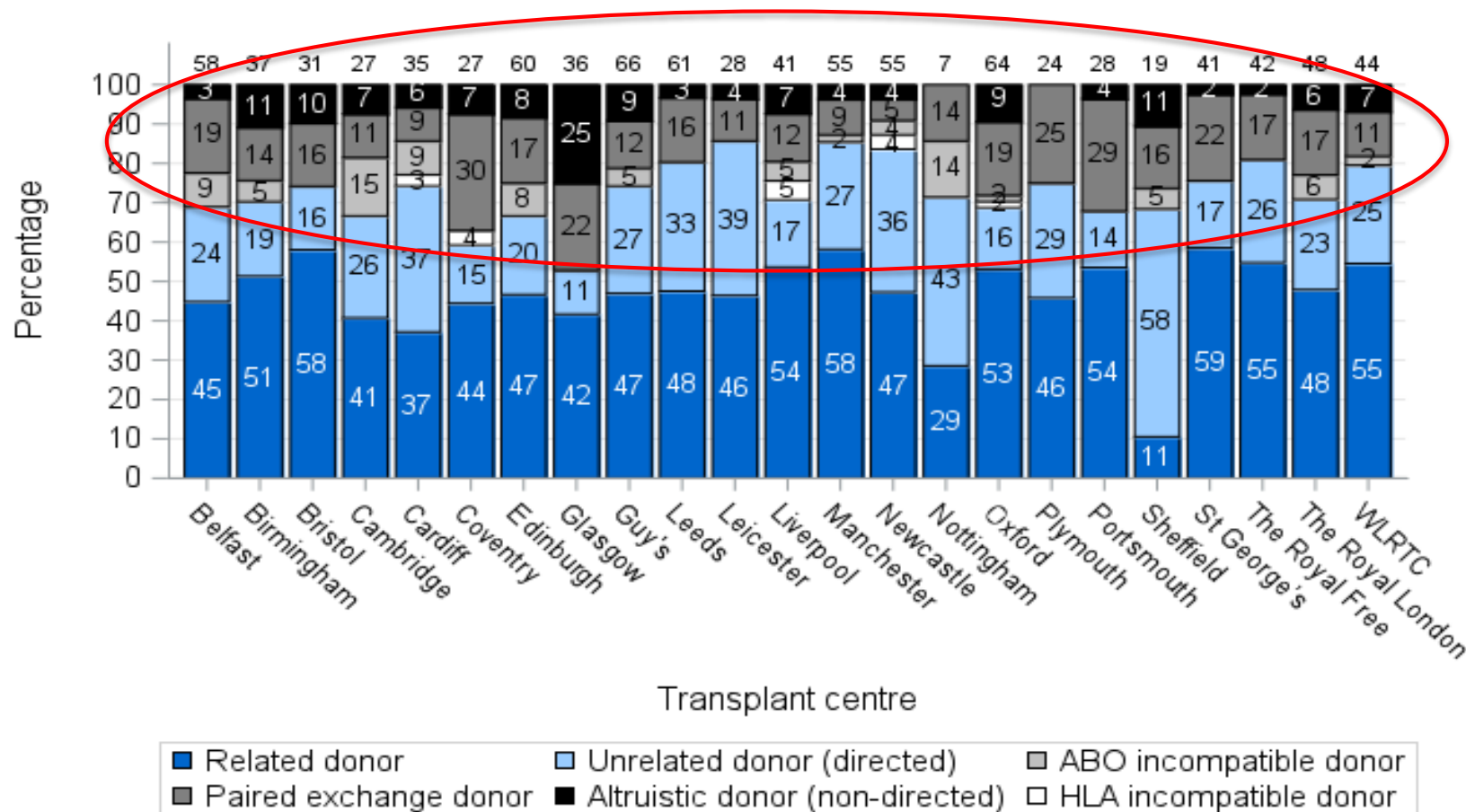
Adult living donor transplants

Figure 2.2 Adult living donor kidney transplants in the UK, 1 April 2004 - 31 March 2019



21% of adult LDKT
8% of paediatric LDKT

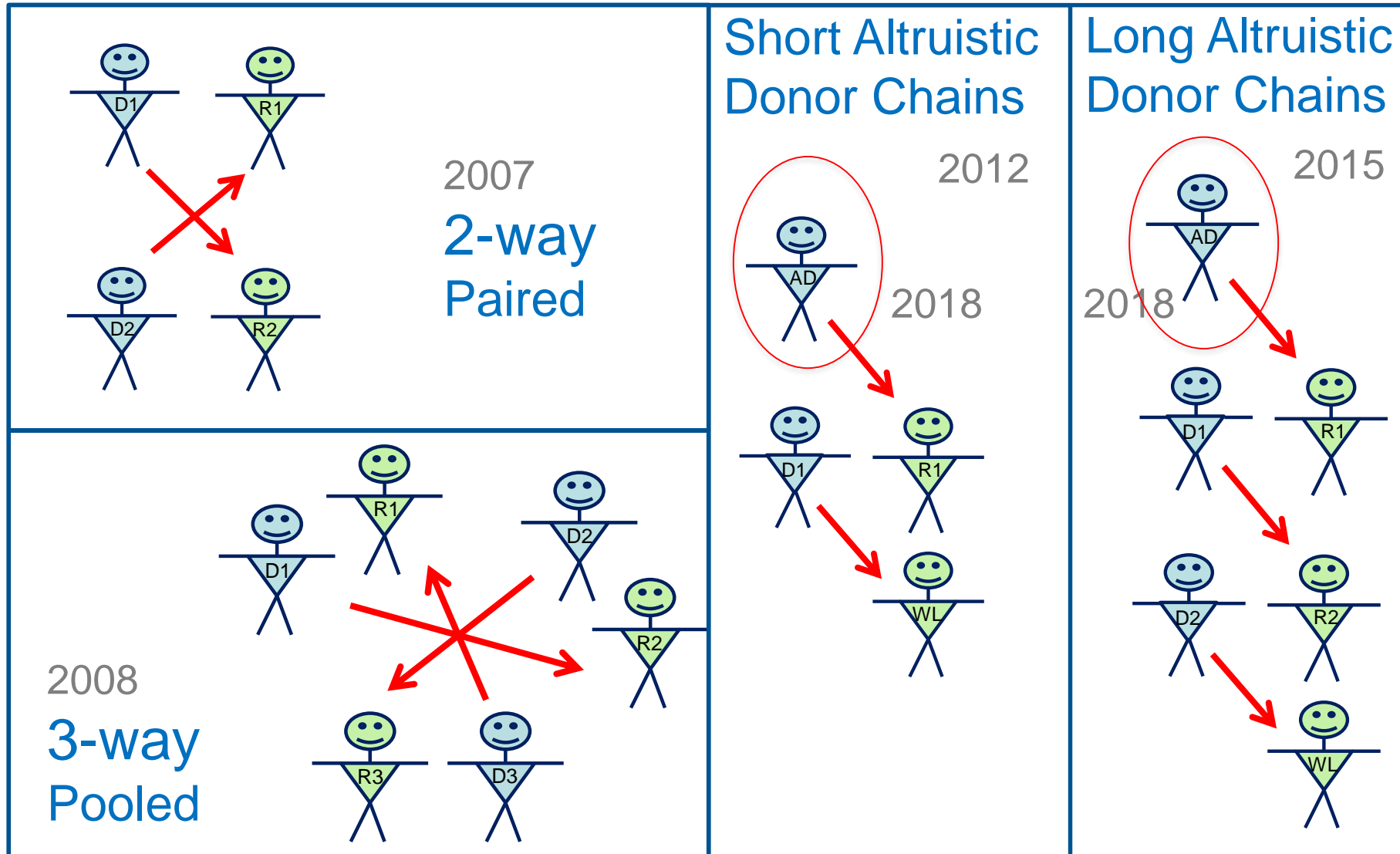
Figure 2.4 Adult living donor kidney transplants in the UK,
1 April 2018 - 31 March 2019



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

Quarterly matching runs



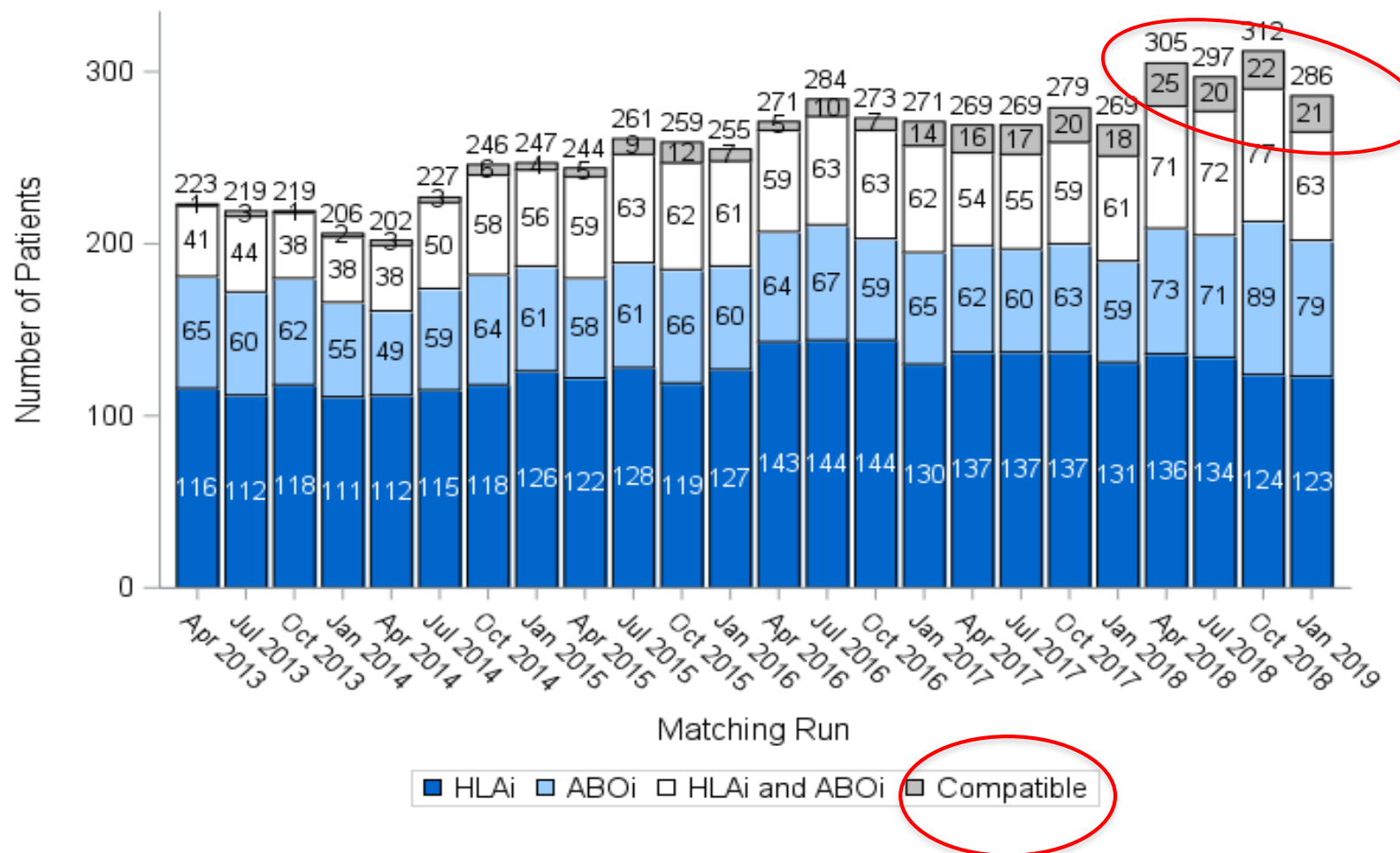
NDADs: Latest Statistics*

	Total NDADs	NDADs direct to transplant list	NDADs donating to UKLKSS	Total transplants from 'Chains'	Total transplants from NDADs
2012	60	57	3	6	63
2013	107	85	22	44	129
2014	110	87	23	46	133
2015	94	73	21	54	127
2016	85	59	26	63	122
2017	87	61	26	64	125
2018	64	33	31	79	112
2019	102	50	52	133	183

*31st December 2019

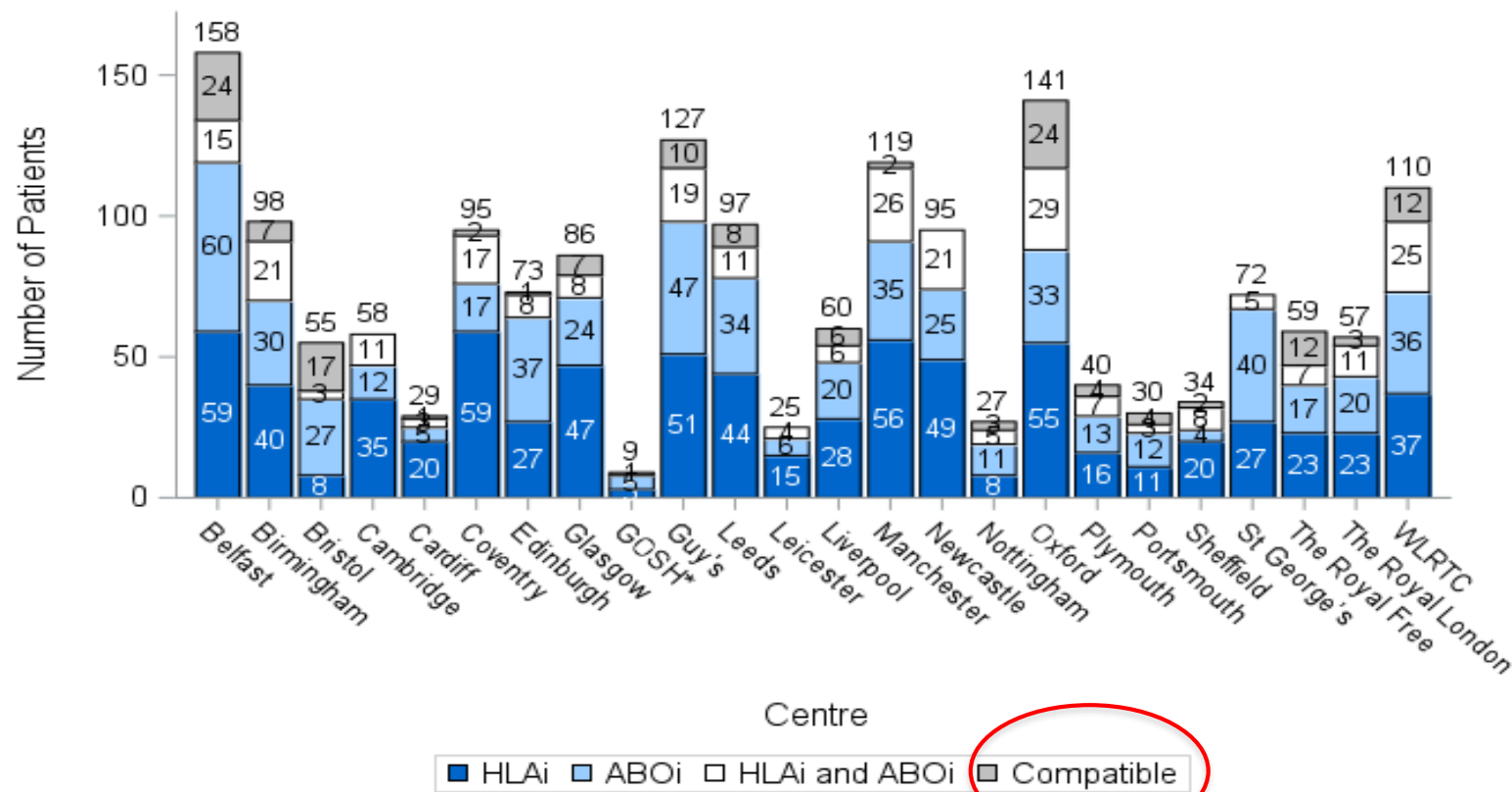
Pair Inclusion by Matching Run

Figure 4.2 Pairs included in matching runs, 1 April 2013 - 31 March 2019



Pair Inclusion by Centre

Figure 4.3 Number of pairs included in matching runs, 1 April 2013 - 31 March 2019



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

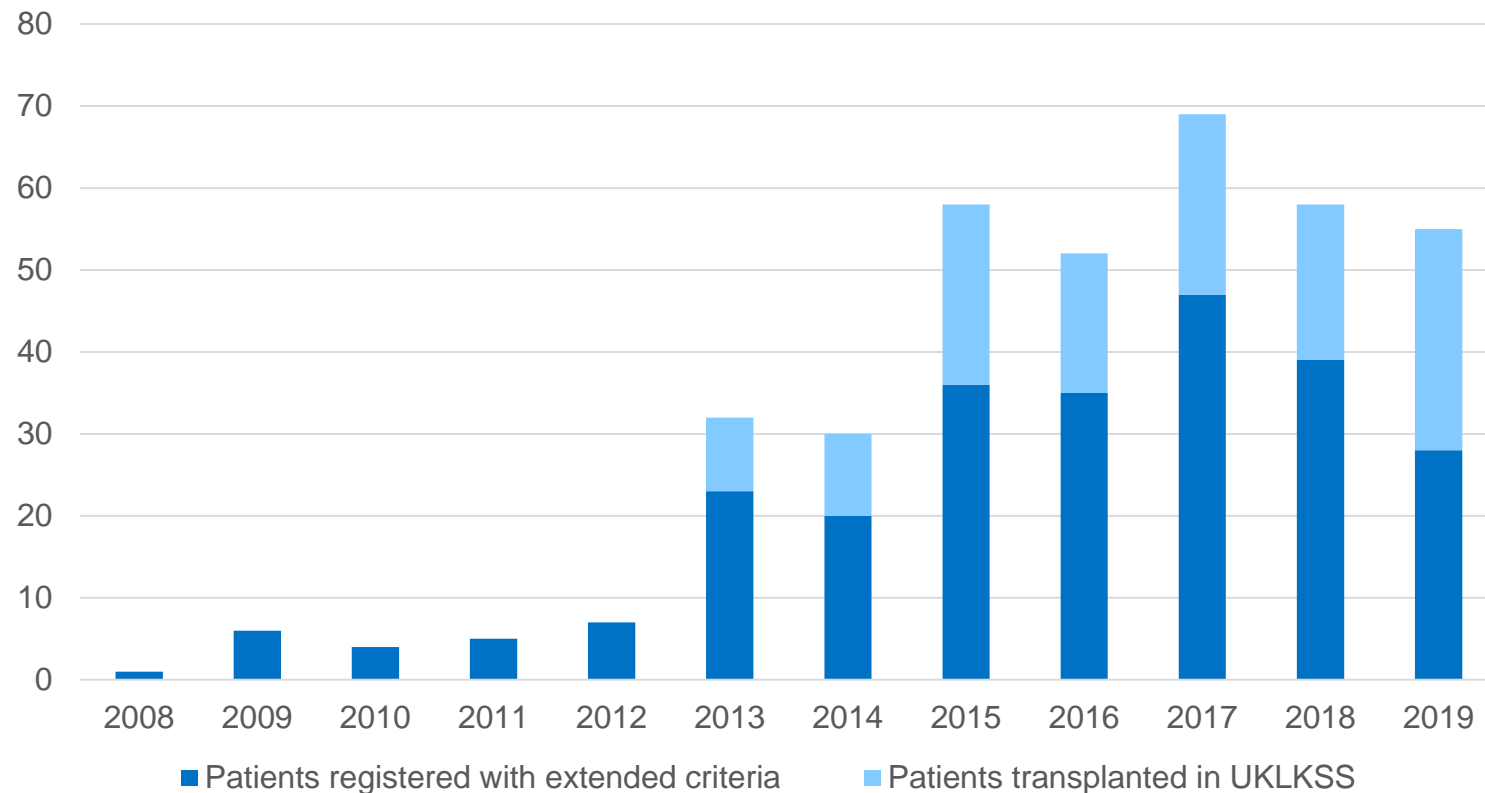
Compatible Pairs*

Calendar year of transplant	Number of compatible pair transplants	Number of additional Tx. due to inclusion of compatible pairs	Total number of Tx. due to inclusion of compatible pairs
2012	3	2	5
2013	2	2	4
2014	4	6	10
2015	10	19	29
2016	10	17	27
2017	17	24	41
2018	25	27	52
2019	36	46	82
Total	107	143	250

*31st December 2019

Extended Criteria in UKLKSS*

Number of Patients Registered with Extended Antigen Criteria and Transplanted in the UKLKSS



Total:

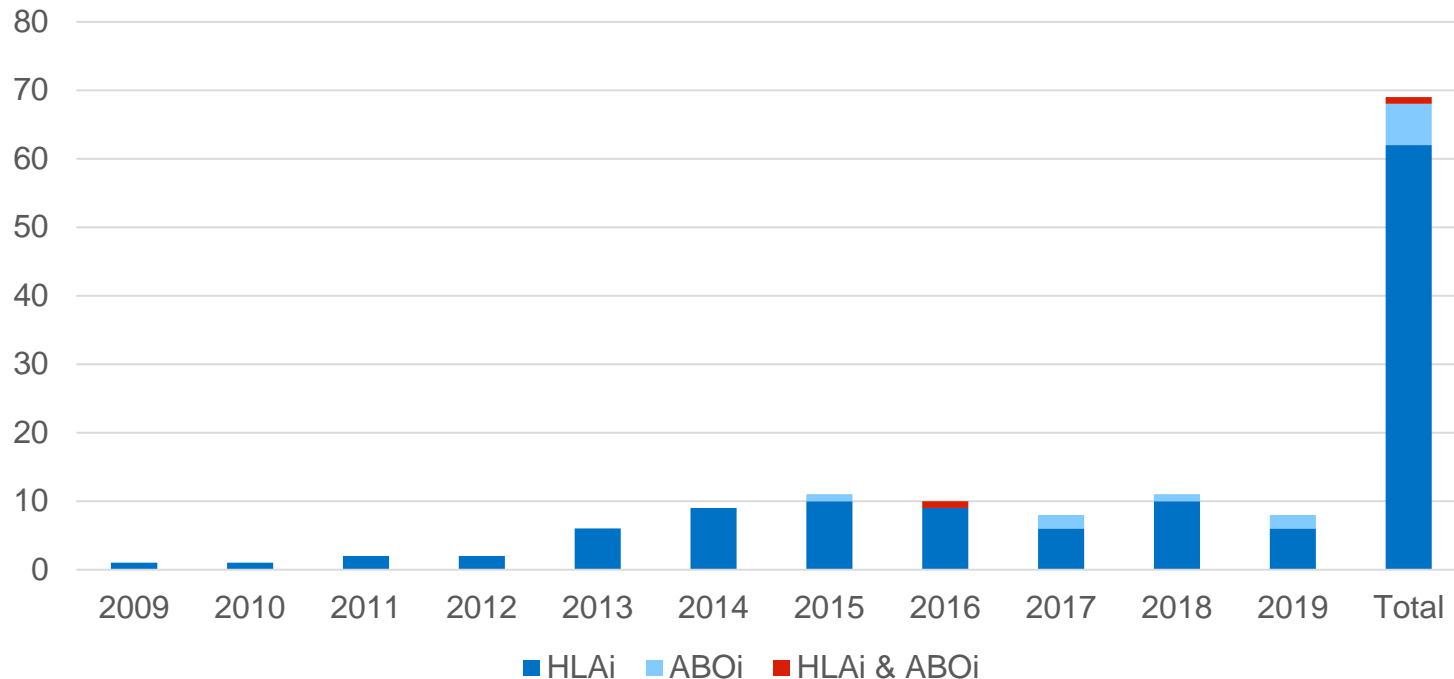
251 patients registered

126 patients transplanted

*31st December 2019

Antibody Incompatible Transplants in the UKLKSS*

Number of Antibody Incompatible Transplants in UKLKSS 2009-2019



HLAi	62
ABOi	6
HLAi & ABOi	1
Total transplanted 69	

* AiT Registry, 31st December 2019

Non-proceeding Transplants

Non-proceeding Transplants


NHS
Blood and Transplant

Non-proceeding or delayed transplants through the UK Living Kidney Sharing Schemes

This information is being requested to analyse the reasons for non-proceeding transplants identified through the UK Living Kidney Sharing Scheme. The data will then be used as part of the ongoing process of improving the rates of proceeding transplants through the scheme. Before submitting your response please ensure you have discussed the cause and any remedial action with the wider multi-disciplinary team.

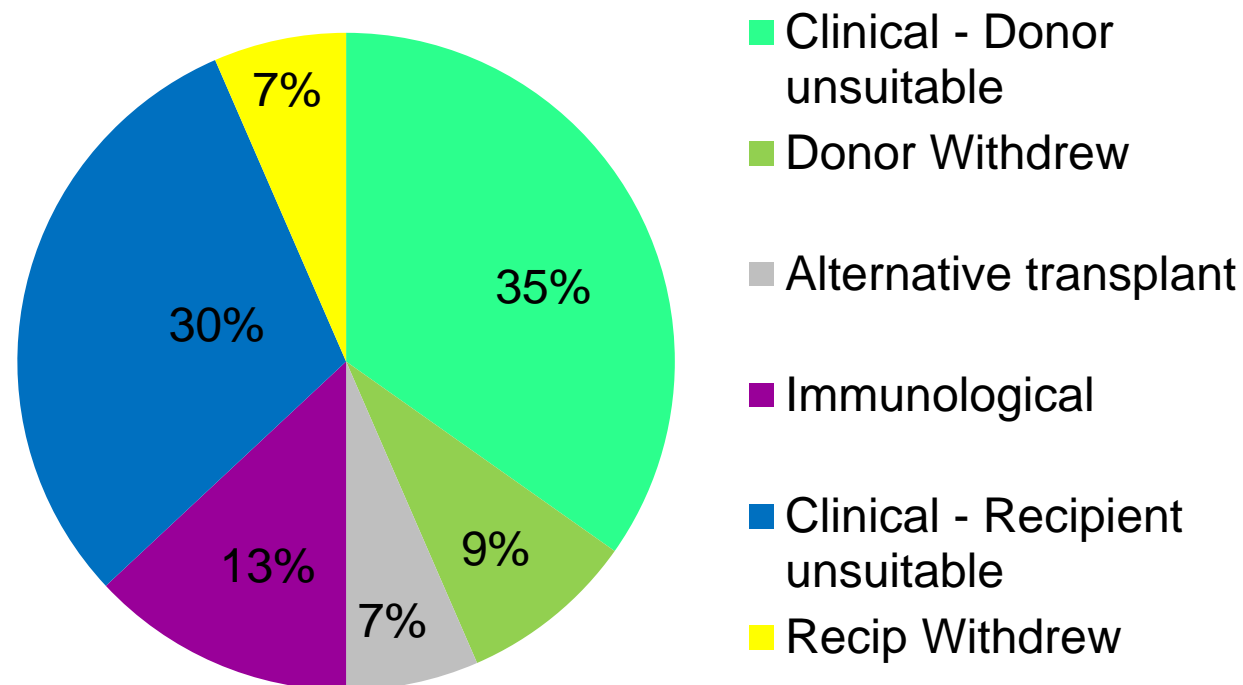
* Feedback ID (from the covering email)

Next

Powered by
 SurveyMonkey
See how easy it is to [create a survey](#).

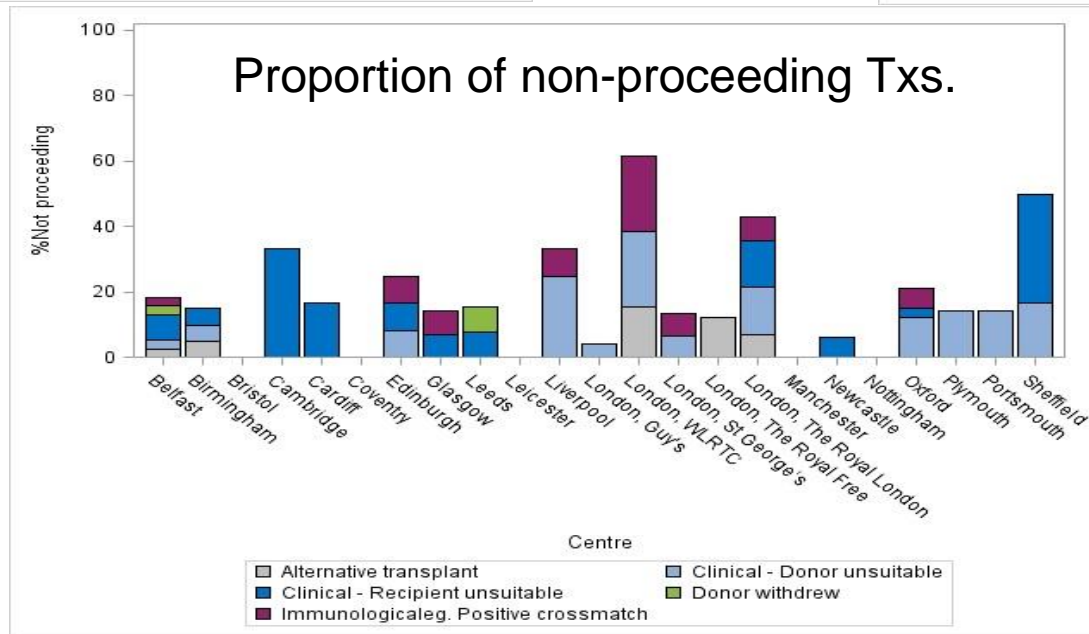
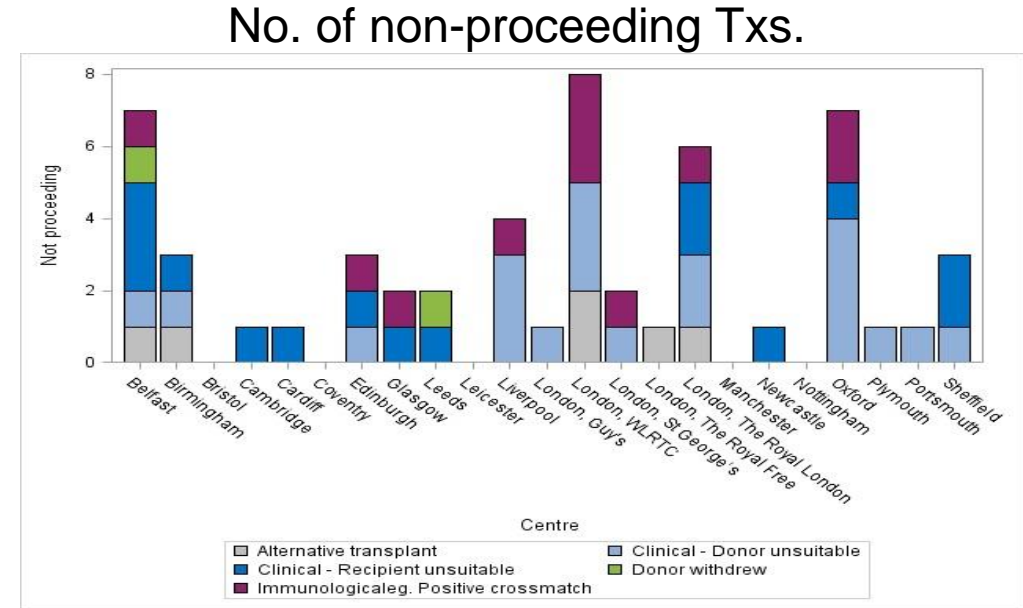
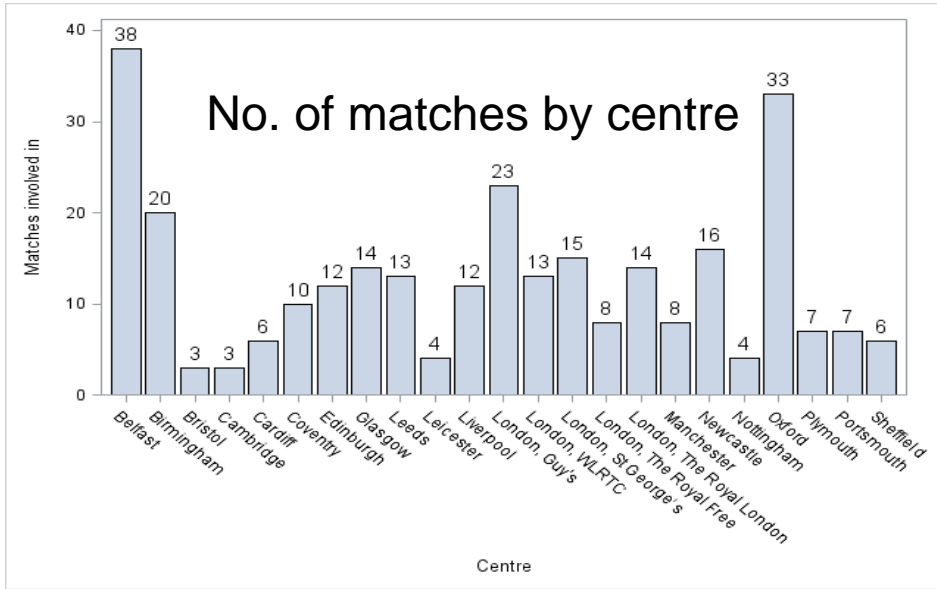
Privacy & Cookie Policy

October 2017- July 2018 (46 reasons)



**Data derived from on-line survey monkey*

Centre-Specific Data



*Data derived from on-line survey monkey

Thank you.

‘If in doubt, leave them out’



Non-simultaneous Surgery

- Introduced in 2015 to facilitate ‘long chains’ and logistically complex exchanges
 - **Within 2 weeks (10 working days)-** discussion with Clinical Lead and notification to Chair of KAG
 - **Outside 2 weeks-** discussion with Clinical Lead and approval from Chair of KAG
- Most due to theatre availability/capacity in individual centres
- **Low risk of non-proceeding but increased risk associated with**
 - Clinical reasons for staggering
 - Extended intervals between transplants
 - End of chain recipients are the most vulnerable if a chain does not complete
- 64 non-simultaneous exchanges have facilitated 172 transplants (133 transplants) to date

	2015	2016	2017	2018	2019
Non-simultaneous exchanges (%)	13 (23%)	12 (22%)	13 (24%)	12 (17%)	14 (15%)

Impact

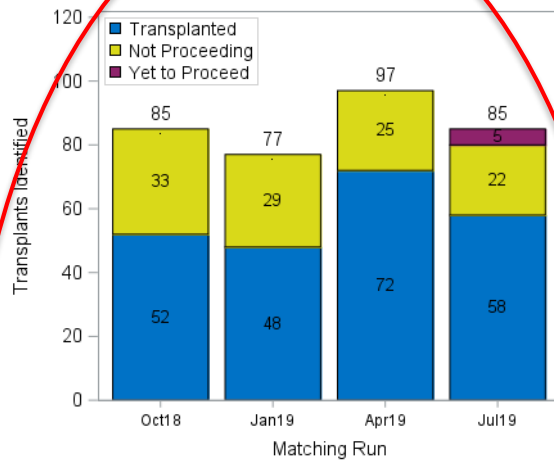


UK Living Kidney Sharing Schemes Performance Figures

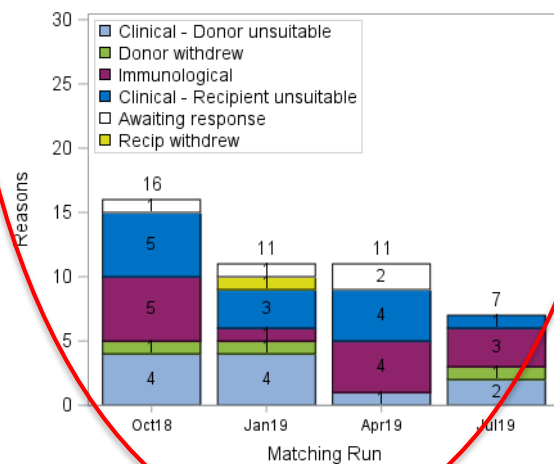
Non-
proceeding
Tx.

Tx. Activity

Paired Donation Transplants Identified



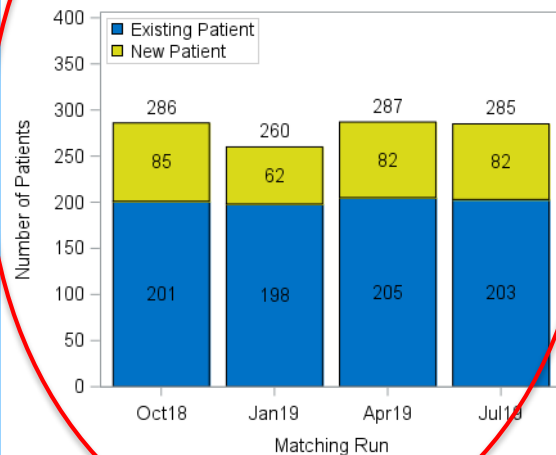
Non Proceeding Paired Donation Transplants



Note: each reason may account for multiple transplants

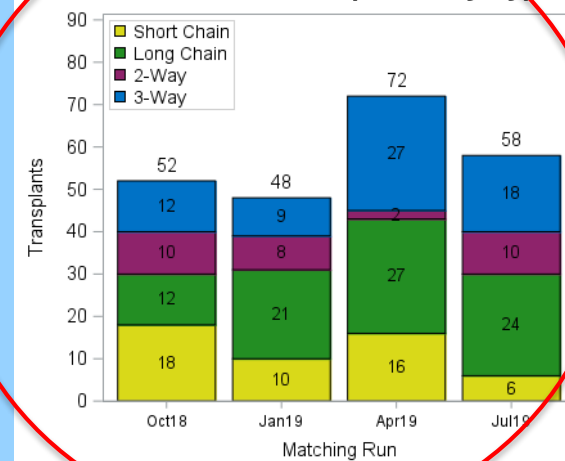
	Total May 2007- Jul 2019
Pairs Registered	2605
Patients Registered	2353
Altruistic Donors in Paired Donation Matching Runs	318
Compatible Pairs Registered	190
Transplants	1177

Patients in Each Matching Run

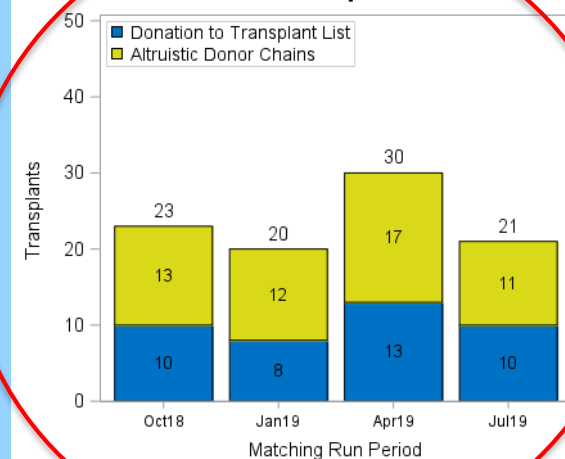


UKLKSS Records	In a Matching Run
Pairs Included	313 (Apr 2019)
Patients Included	287 (Apr 2019)
Altruistic Donors Included	25 (Apr 2019)
Transplants Identified	97 (Apr 2019)
Transplants Proceeded	72 (Apr 2019)

Paired Donation Transplants by Type



Altruistic Donor Transplants



NDADs &
'Chains'

3-way
Long
chains

Tx. Activity

Impact of Altruistic Donor Chains

– Chance of transplant by blood group

Pre 2012

Recipient ABO

**Donor
ABO**

	O	A	B	AB
O	26/133 (20%)	30/60 (50%)	7/24 (29%)	1/2 (50%)
A	30/179 (17%)	16/68 (24%)	12/39 (31%)	0/5 (0%)
B	7/53 (13%)	11/29 (38%)	1/20 (5%)	1/3 (33%)
AB	0/8 (0%)	0/3 (0%)	0/8 (0%)	0/1 (0%)

Impact of Altruistic Donor Chains

– Chance of transplant by blood group

2012 onwards

Recipient ABO

Donor
ABO

	O	A	B	AB
O	125/323 (39%)	107/166 (64%)	28/47 (60%)	6/13 (46%)
A	137/492 (28%)	78/214 (36%)	38/68 (56%)	3/13 (23%)
B	39/118 (33%)	30/59 (51%)	14/39 (36%)	1/8 (13%)
AB	4/19 (21%)	11/20 (55%)	4/14 (29%)	1/8 (13%)

Impact of Altruistic Donor Chains

– Chance of transplant by blood group

2012 onwards

Recipient ABO

Donor
ABO

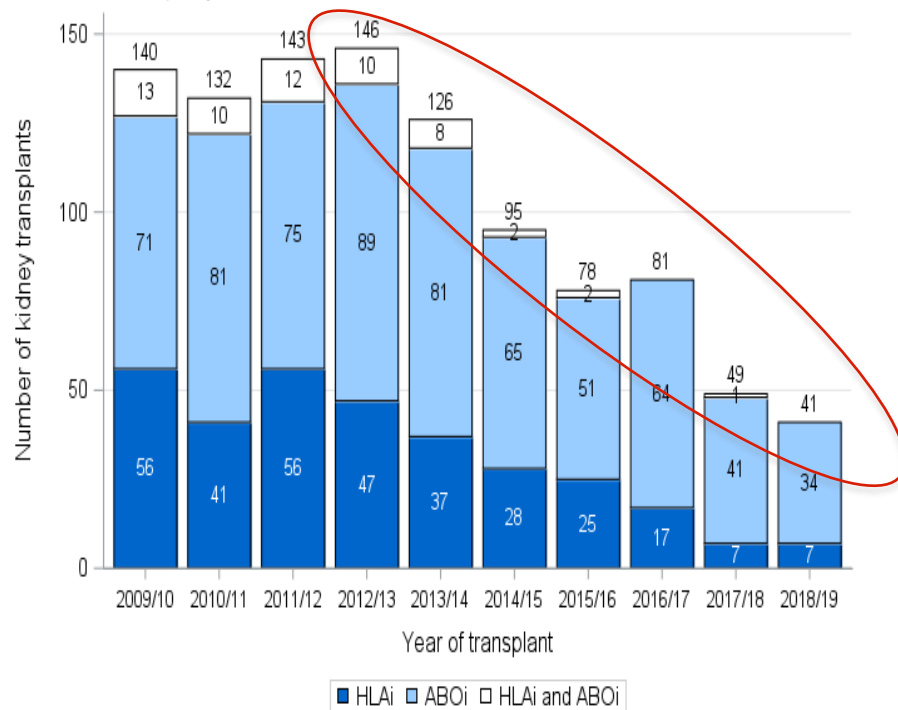
	O	A	B	AB
O	125/323 (39%)	107/166 (64%)	28/47 (60%)	6/13 (46%)
A	137/492 (28%)	78/214 (36%)	38/68 (56%)	3/13 (23%)
B	39/118 (33%)	30/59 (51%)	14/39 (36%)	1/8 (13%)
AB	4/19 (21%)	11/20 (55%)	4/14 (29%)	1/8 (13%)

Antibody Incompatible Transplantation

Adult

NHS
Blood and Transplant

Figure 5.2 Adult living donor antibody incompatible kidney transplants in the UK, 1 April 2009 - 31 March 2019

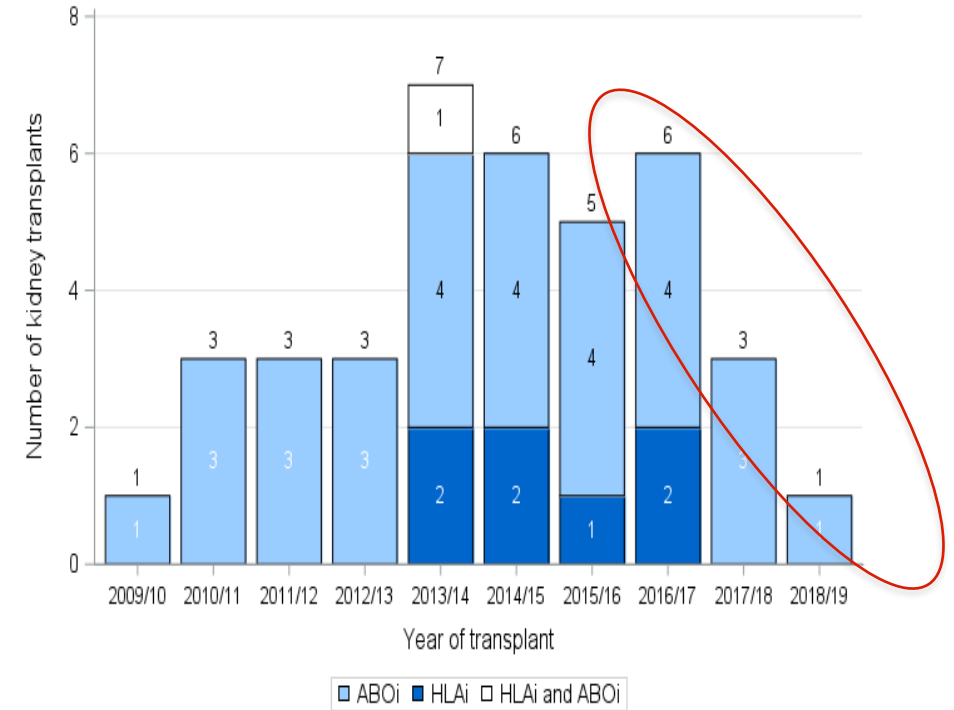


Source: Annual Report on Living Donor Kidney Transplantation 2018/19, NHS Blood and Transplant

Paediatric

NHS
Blood and Transplant

Figure 5.4 Paediatric living donor antibody incompatible kidney transplants in the UK, 1 April 2009 - 31 March 2019

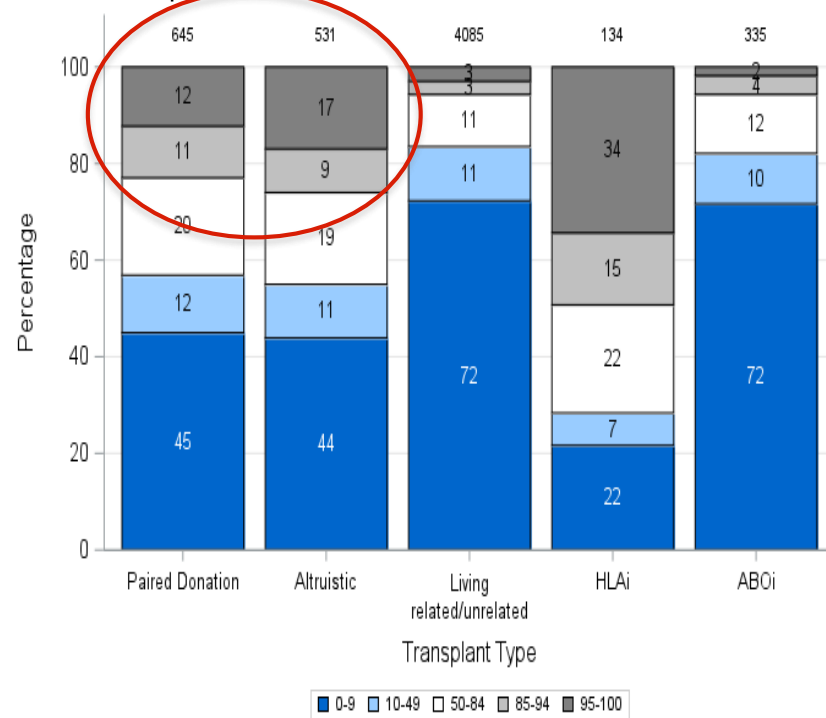


Source: Annual Report on Living Donor Kidney Transplantation 2018/19, NHS Blood and Transplant

Recipient CRF by Transplant Type

Adult

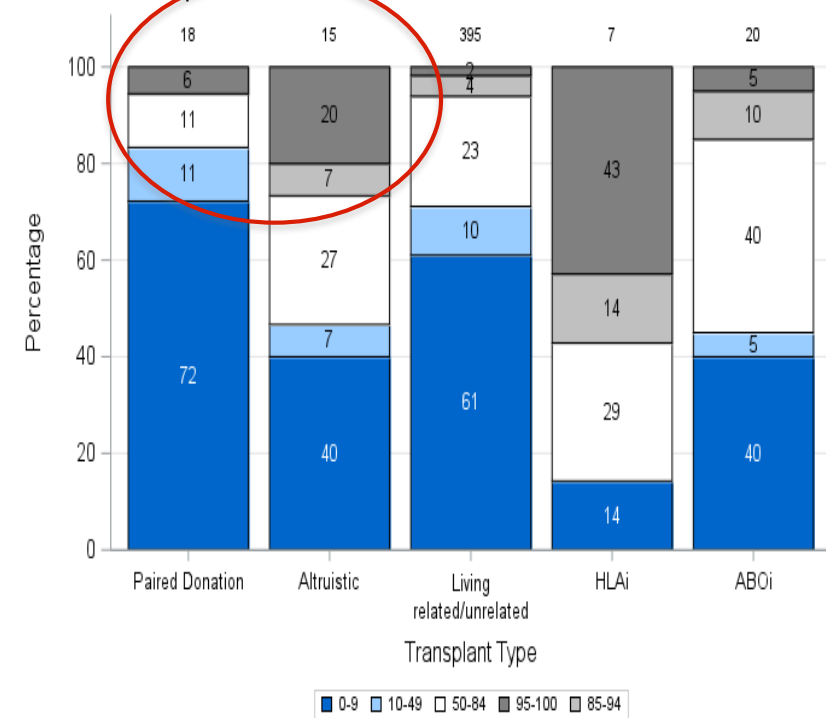
Figure 3.4 Recipient Calculated Reaction Frequency by adult transplant type
1 April 2013 - 31 March 2019



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

Paediatric

Figure 3.12 Recipient Calculated Reaction Frequency by paediatric transplant type
1 April 2013 - 31 March 2019

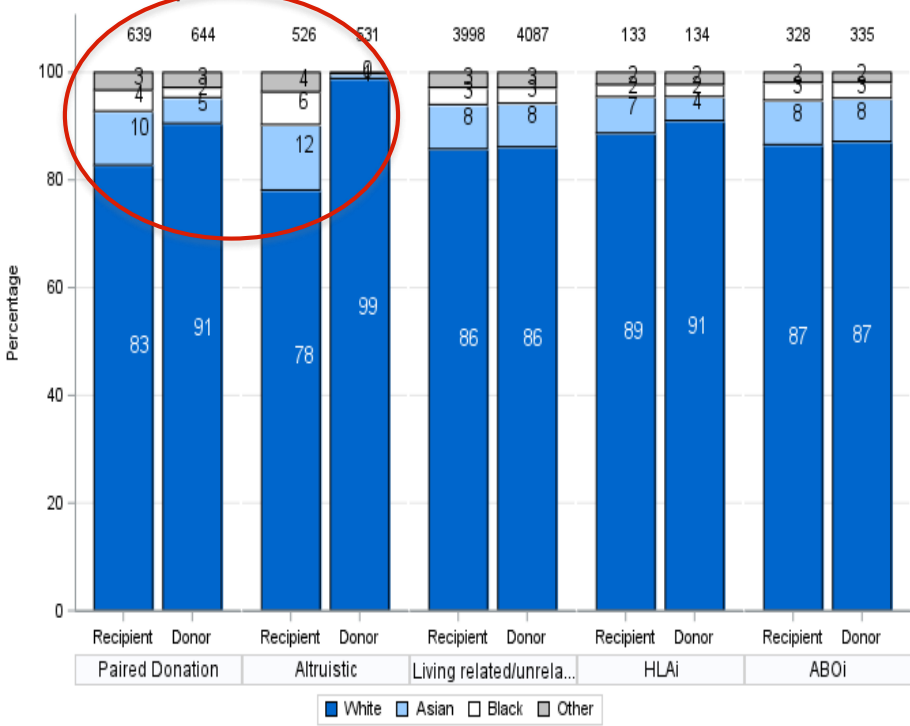


Source: Annual Report on Living Donor Kidney Transplantation 2018/19, NHS Blood and Transplant

Recipient Ethnicity

Adult

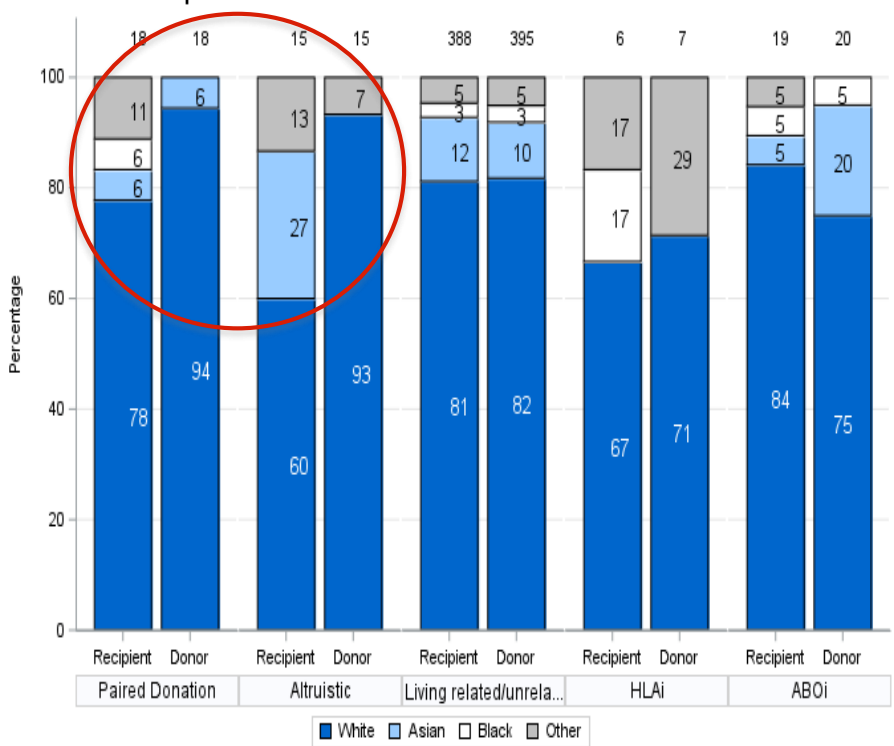
Figure 3.2 Ethnicity of recipient and donor by adult transplant type, 1 April 2013 - 31 March 2019



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

Paediatric


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


Challenges

- Critical incident in October 2019 matching run
- Delays scheduling transplants with increased activity
 - Resulting in collapsed exchanges
 - Extension of 8 week standard to 'prior to next matching run'
 - FTWG set up in March 2020
- IT infrastructure to support expansion
- Establishing possible European collaborations due to logistics/governance issues


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



Summary

- Large, effective living kidney sharing scheme with significant (34%) increase in activity in 2019 (234 transplants v 178 in 2018)
- Non-directed donors increased to >100 for the first time in 5 years and facilitated the highest number of transplants to date via the UKLKSS
- Largest national scheme in Europe; international reputation
- Utilisation of the UKLKSS remains variable between centres but there is increased uptake of compatible pairs
- Continuous innovation and improvement necessary to make the most of every transplant opportunity and to avoid serious adverse events
- Non-simultaneous surgery is low risk and may help to reduce the risk of non-proceeding transplants due to delay

New Developments

Unique Identity

NHS
Blood and Transplant

What do these four people have in common?




They have all been willing to donate their kidneys during their lifetime to transform someone else's life.

Find out more about living kidney donation, visit organdonation.nhs.uk/livingdonation, call 0300 123 23 23 or email enquiries@nhsbt.nhs.uk

NHS
Blood and Transplant

What do these four people have in common?



They have all been willing to donate one of their kidneys during their lifetime to transform someone else's life.


Living kidney donation

Yes I donate
ORGAN DONATION

Why is living kidney donation important?
Around 5,000 people in the UK are in need of a kidney transplant to transform their lives. The average waiting time for a kidney transplant from someone who has died is more than two and a half years. For some ethnic groups and people for whom it is difficult to find a compatible donor, the wait is even longer. Sadly, some people die waiting.

While most transplant recipients receive an organ from a deceased donor, living kidney donors make 4 in every 10 kidney transplants possible across the UK.

Over 500 people have donated a kidney anonymously during their life to someone on the National Transplant list, alongside the many thousands who have donated to a family relative or friend.



Celia: "It seemed to me that as a fit and healthy person, I could give my spare kidney to someone who could then have a more normal life, away from the tyranny of dialysis. It didn't matter to me that the recipient was unknown. It was a very satisfying experience and I'm thrilled to have been able to donate."

Celia donated a kidney to someone in need in 2015.

Can I volunteer to be a living kidney donor?

Any adult over the age of 18 (over 16 in Scotland) can volunteer to be considered as a living kidney donor. You will undergo a series of medical tests to check that you are fit and healthy enough to donate.

What do I need to do to transform a life?

You could donate a kidney during your lifetime to someone you love, a friend, relative or even someone you don't know. To find out more information about living kidney donation, visit: organdonation.nhs.uk/livingdonation

If you cannot find the information you are looking for on our website, please contact us:

By Email: enquiries@nhsbt.nhs.uk
By Phone: 0300 123 23 23

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Yes I donate
ORGAN DONATION

Yes I donate
ORGAN DONATION

NHS
Blood and Transplant

Could I be a living kidney donor?




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

NHS
Blood and Transplant

UK Living Kidney Sharing Scheme

Your questions answered

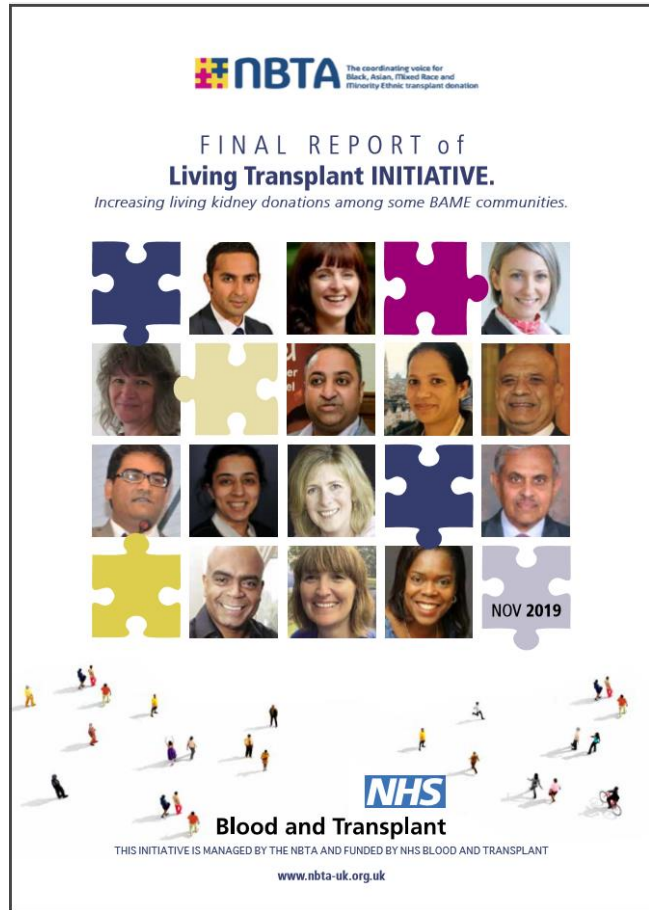


- Paired/Pooled Donation
- Non-directed Altruistic Donor Chains

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

Yes I donate
ORGAN DONATION

Living Transplant Initiative



- Commissioned by NHSBT from NBTA for 2 years - completed March 2019
 - Community based awareness events
 - Faith based educational living donation resources
- 2019/20 NHSBT LTI
 - Based on learning from NBTA LTI
 - Focused interventions to engage with Black and Asian people and those living in lower socio-economic circumstances
 - Due to complete 2020

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

January 2019

January 2020

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

Development

- 2-phase development through LDKT 2020 Strategy Implementation Group
- Phase 1: DROMS led by Vassilios Papalois
- Phase 2: DREMS in collaboration with University of Hertfordshire
 - Steering group
 - Living donor and recipient of living donor kidney
 - Clinical colleagues
 - NHSBT representatives
- Questionnaire survey developed by steering group and refined following pilot in transplant and non-transplanting centres

Implementation

- UK-wide; via the UK Living Donation Network
- Paper-based data collection- forms provided by information services and sent to all centres and non-transplanting centres as required
- **DROMS Pre-op data collection** on **all donors who have completed assessment and scheduled for nephrectomy** from 1st January 2019
- **DROMS 1 & 5 year follow-up** on all donors **with pre-nephrectomy data submitted**
- **DREMS 1 year follow-up** on **all donors at 1st nephrectomy anniversary** (with 1 year registry data) from 1st January 2020

DROM: 1st year (Pre-donation)*

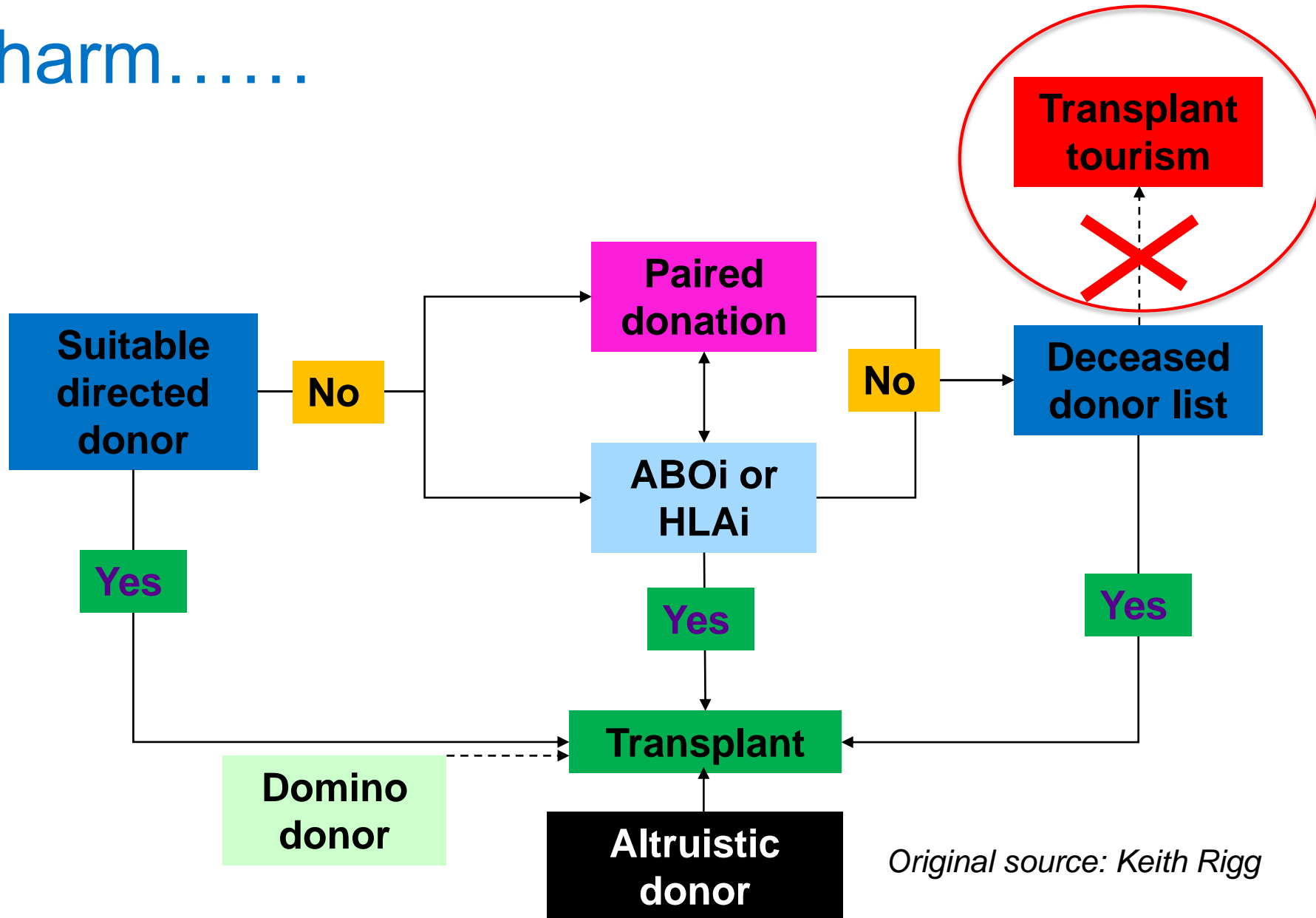
Total number of questionnaires completed:	494	
Total number of living donors in 2019:	1009	
Proportion of living donors in 2019 that completed a DROM questionnaire:	458	45%
Questionnaires completed after donation (answered Q19 or Q20):	144	30%

*Data to be presented at UK LKD Network Meeting, February 2020

Limitations

- Manual data collection
 - Paper form based system; IT solution required to support on-line submission, data entry and analysis
- Incomplete data
 - DROMS requires living donor coordinators to initiate and return pre-nephrectomy data so that donors are eligible for post-nephrectomy follow-up
 - DROM and DREM follow-up data currently limited to donors who attend a transplant or non-transplanting centre at 1 and 5 years post donation

Do no harm.....



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

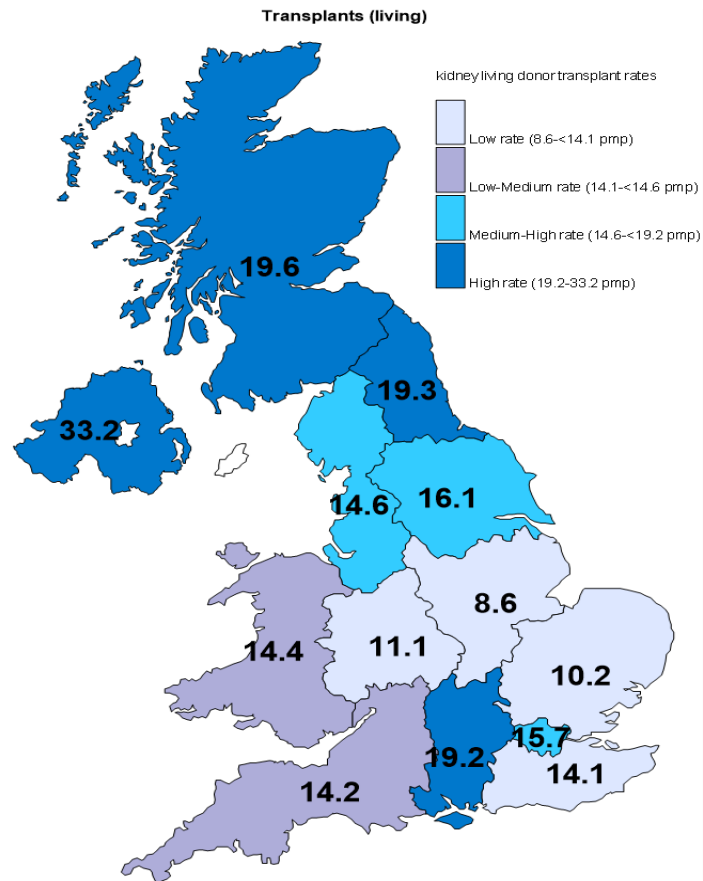
Reporting

- National Focal Points: Council of Europe- annual data collection
 - Collected 1 year in arrears
 - UK residents who receive a transplant outside the UK
 - Residents who travel to the UK to receive a transplant
- For cases where patients have received a transplant outside the UK
 - Contact Clinical Lead and report to ODT on-line
- Cases of suspected human trafficking for organ donation
 - Report to the HTA to consider referral via National Referral Mechanism for victim protection and support

What could we improve for the future?

Unexplained Variation

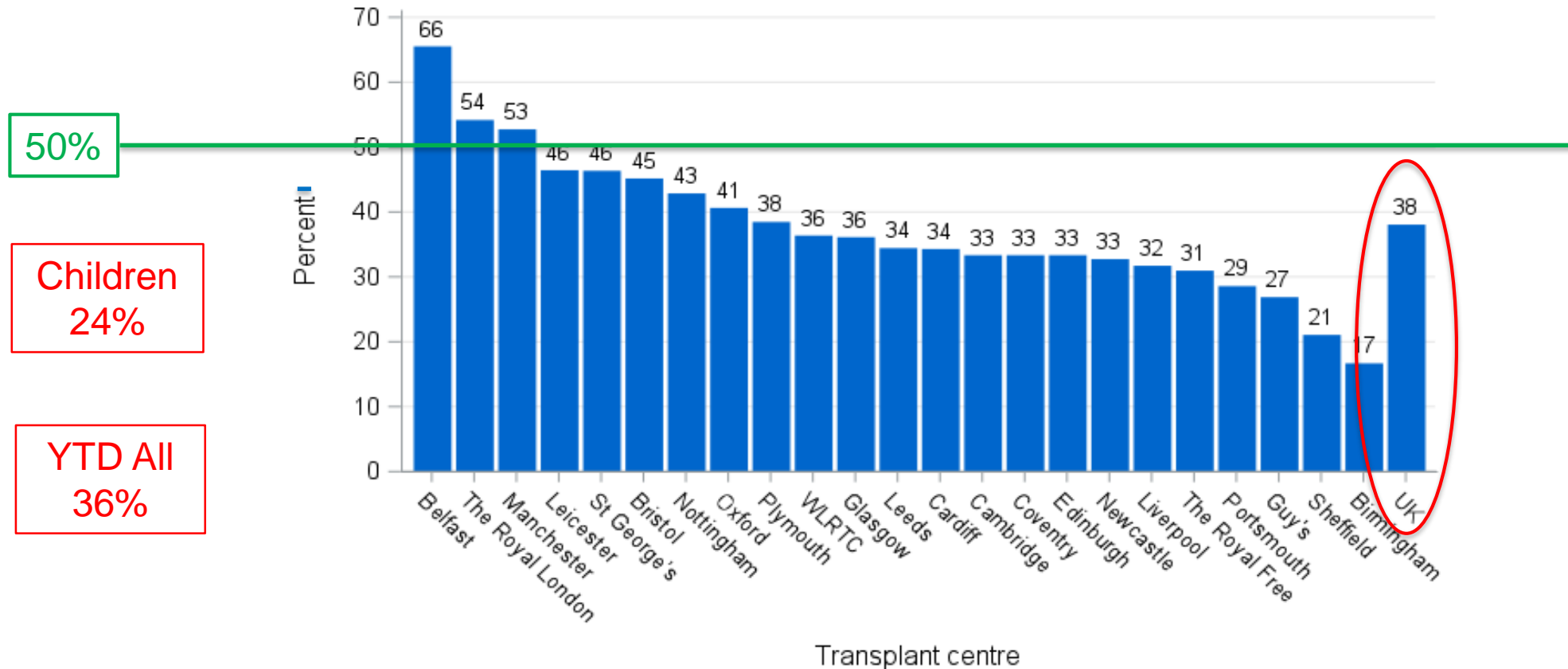
Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/Strategic Health Authority of residence



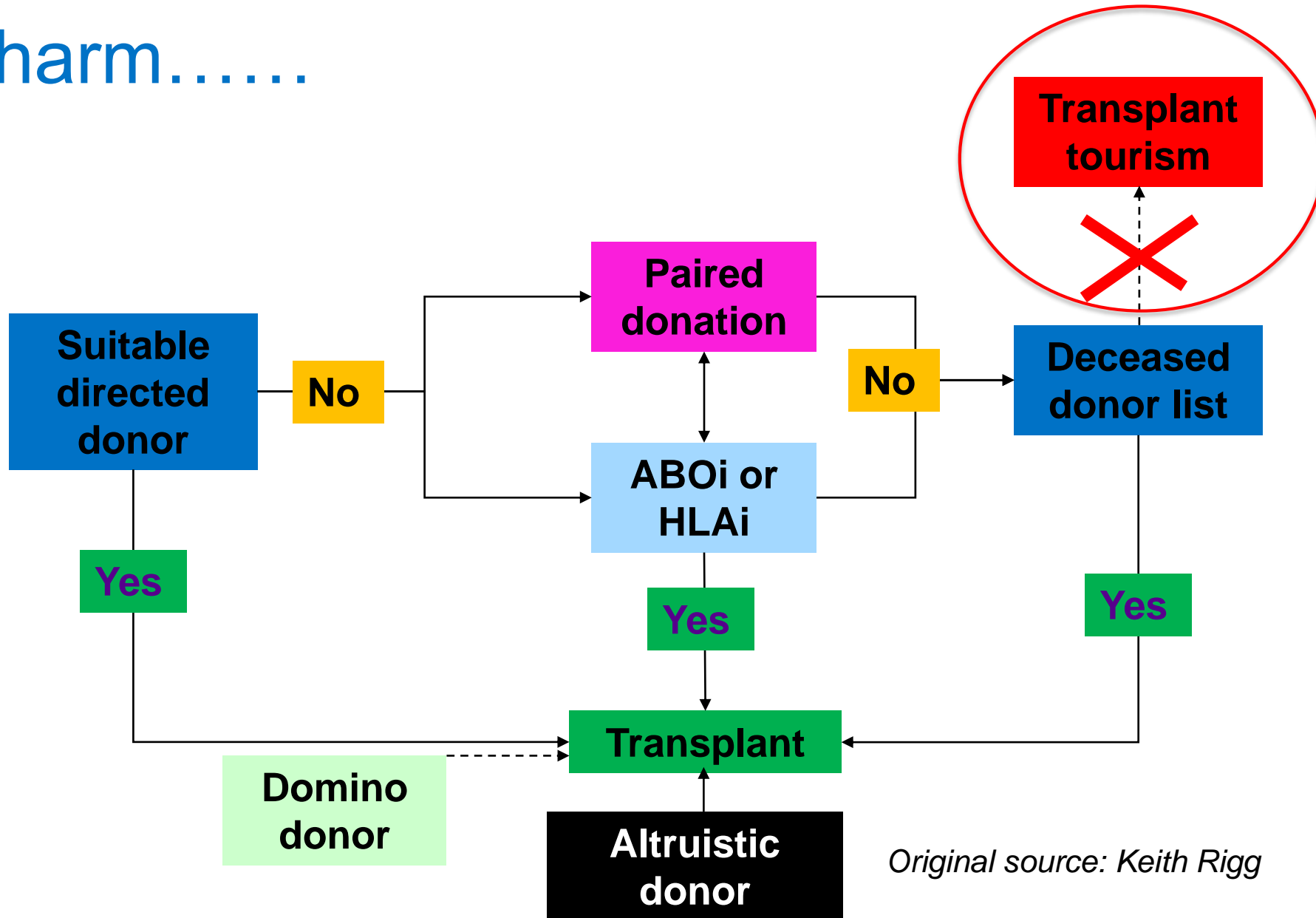
Source: Annual Report on Kidney Transplantation 2018/19, NHS Blood and Transplant

Pre-emptive LDKT

Figure 3.8 Adult living donor pre-emptive transplant rates by centre,
1 April 2018 - 31 March 2019



Do no harm.....



Original source: Keith Rigg

Summary

- Work in progress
- Post 2020: living and deceased donation combined in the same strategy
- Best opportunity yet to shape the future of living donation



Acknowledgements

NHS Blood and Transplant colleagues

Matthew Robb, Lisa Mumford, Rachel Johnson, Chloe Brown, Iain Harrison, Lin Shelper, David Clegg, Sam Thomas

University of Glasgow (matching algorithms)

David Manlove, Peter Biro, Gregg O'Malley, James Trimble

Transplant centres and referring renal units

Kidney Advisory Group

LDKT 2020 Strategy Implementation Group

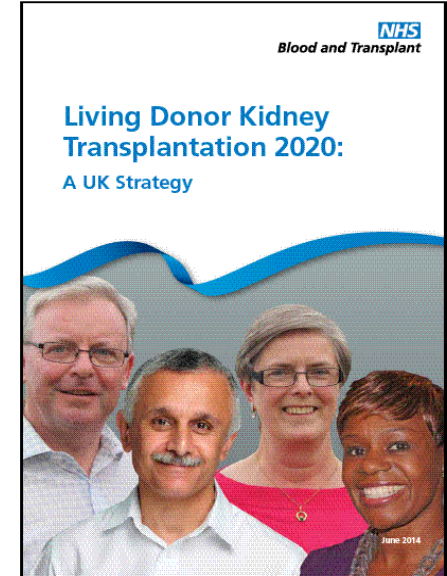
Aisling Courtney (Chair) and workstream members

DROM/DREM

Vassilios Papalois, Maria Thedosopoulou, SIG Members

University of Hertfordshire – Janine Hawkins, David Wellsted

Jan Shorrocks, Fiona Loud, Lisa Silas, Matthew Robb, Mike Gurn



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

Thank You



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www.odt.nhs.uk

www.organdonation.nhs.uk