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Living Donor Kidney Transplantation

Maximising Opportunities

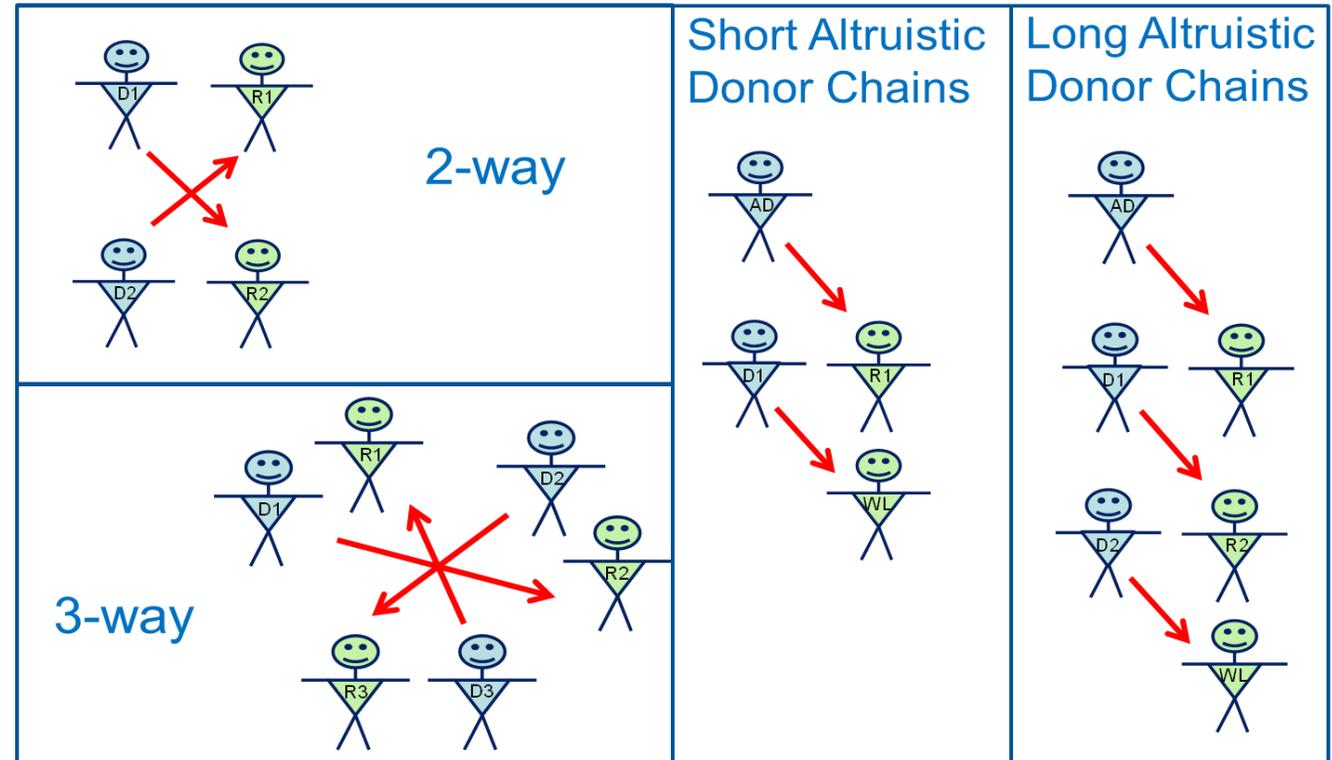
Lisa Burnapp

RTSM, January 2019

Overview

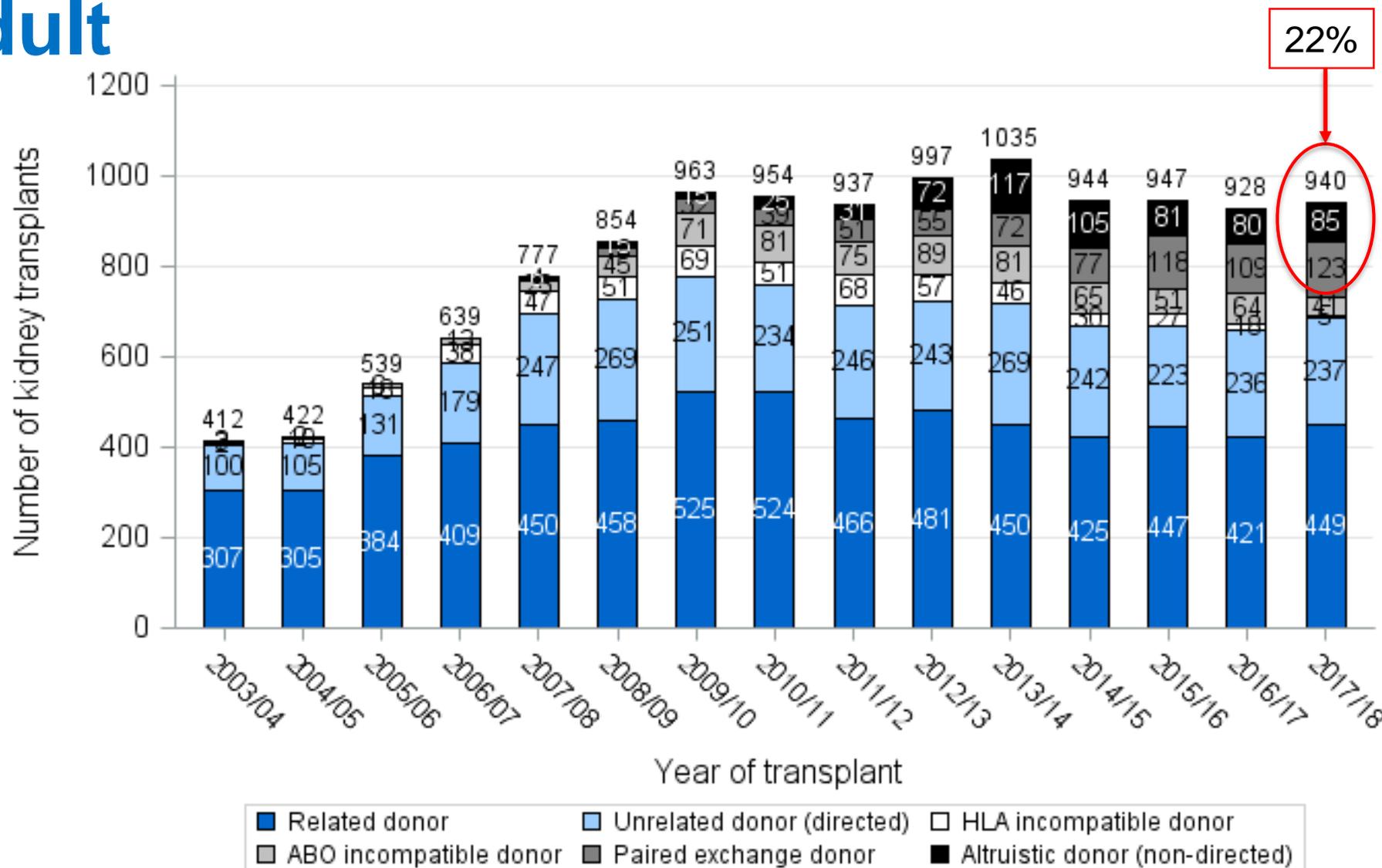
- UK Living Kidney Sharing Schemes
 - Activity
 - Demographics
 - Outcomes
 - Impact of changes implemented in 2018
- Donor Reported Outcome Measures (DROMs)
 - Development
 - Implementation
 - Next steps

UK Living Kidney Sharing Scheme



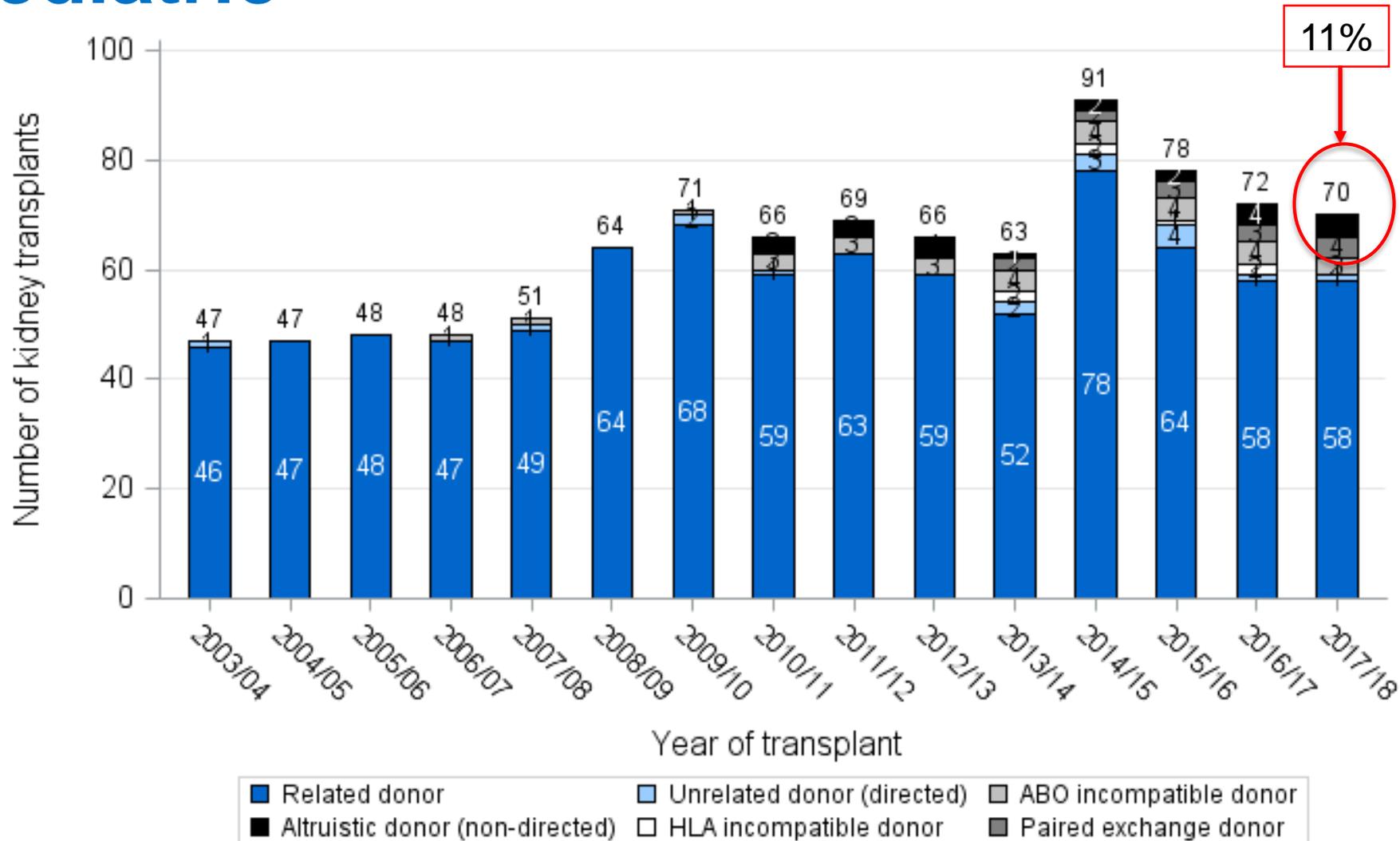
Living donor kidney transplants by type

- Adult

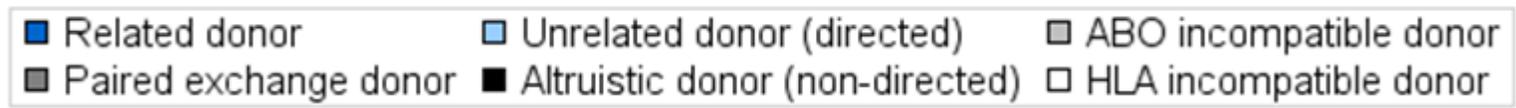
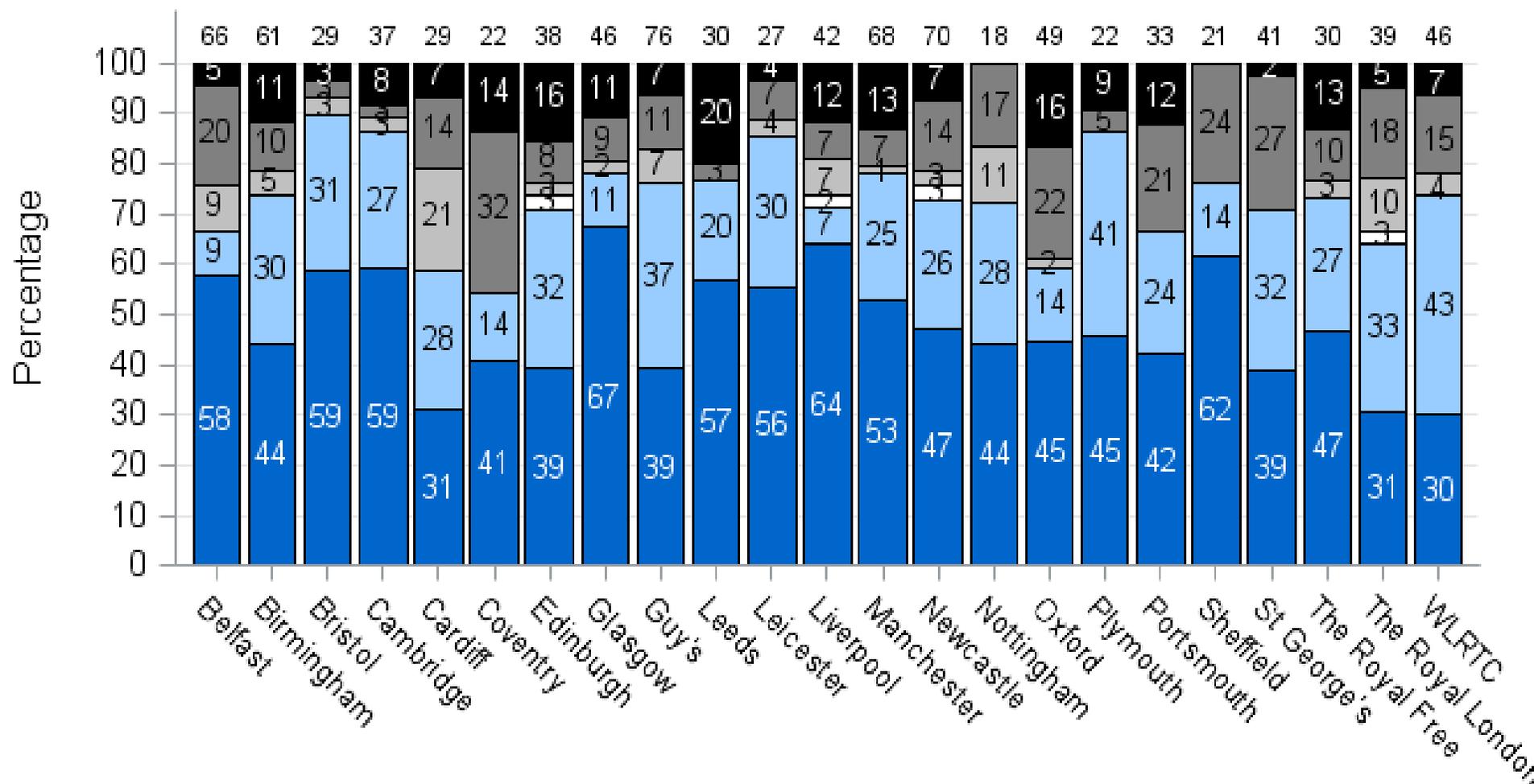


Living donor kidney transplants by type

- Paediatric

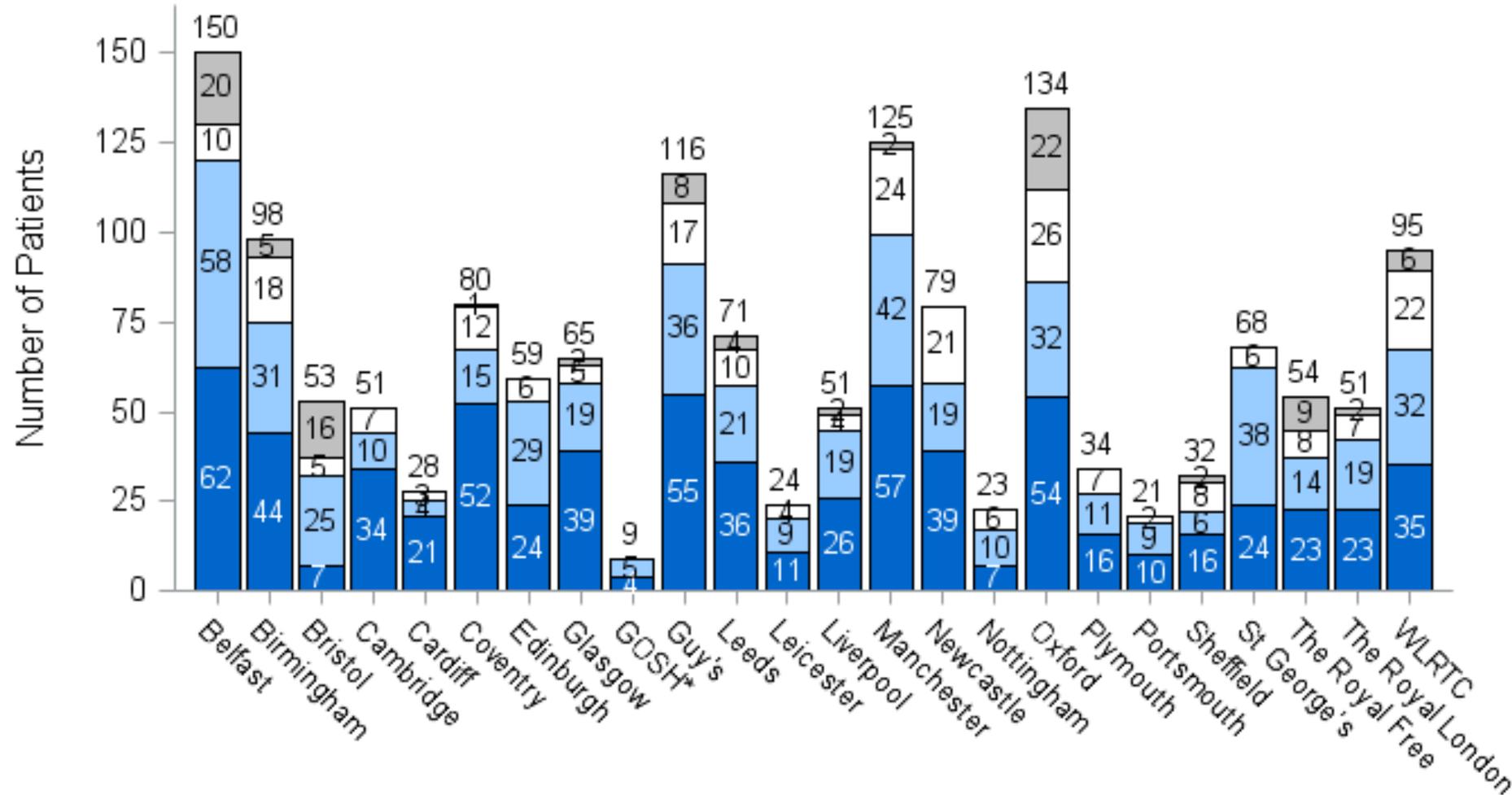


Living donor kidney transplants by type



1 April 2017 - 31 March 2018

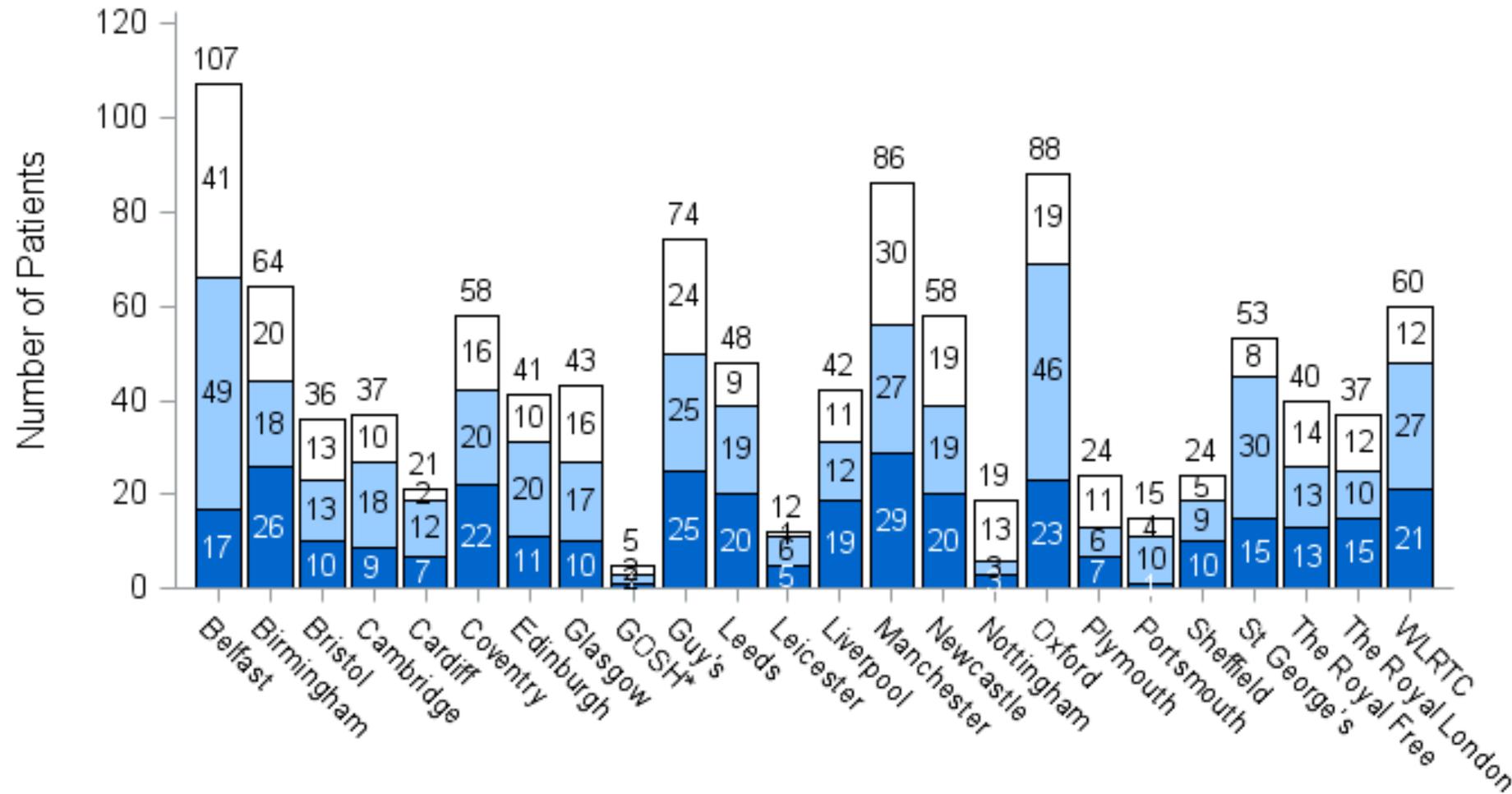
UKLKSS pairs registered by centre



■ HLAi
 ■ ABOi
 HLAi and ABOi
 ■ Compatible

1 April 2012 - 31 March 2018

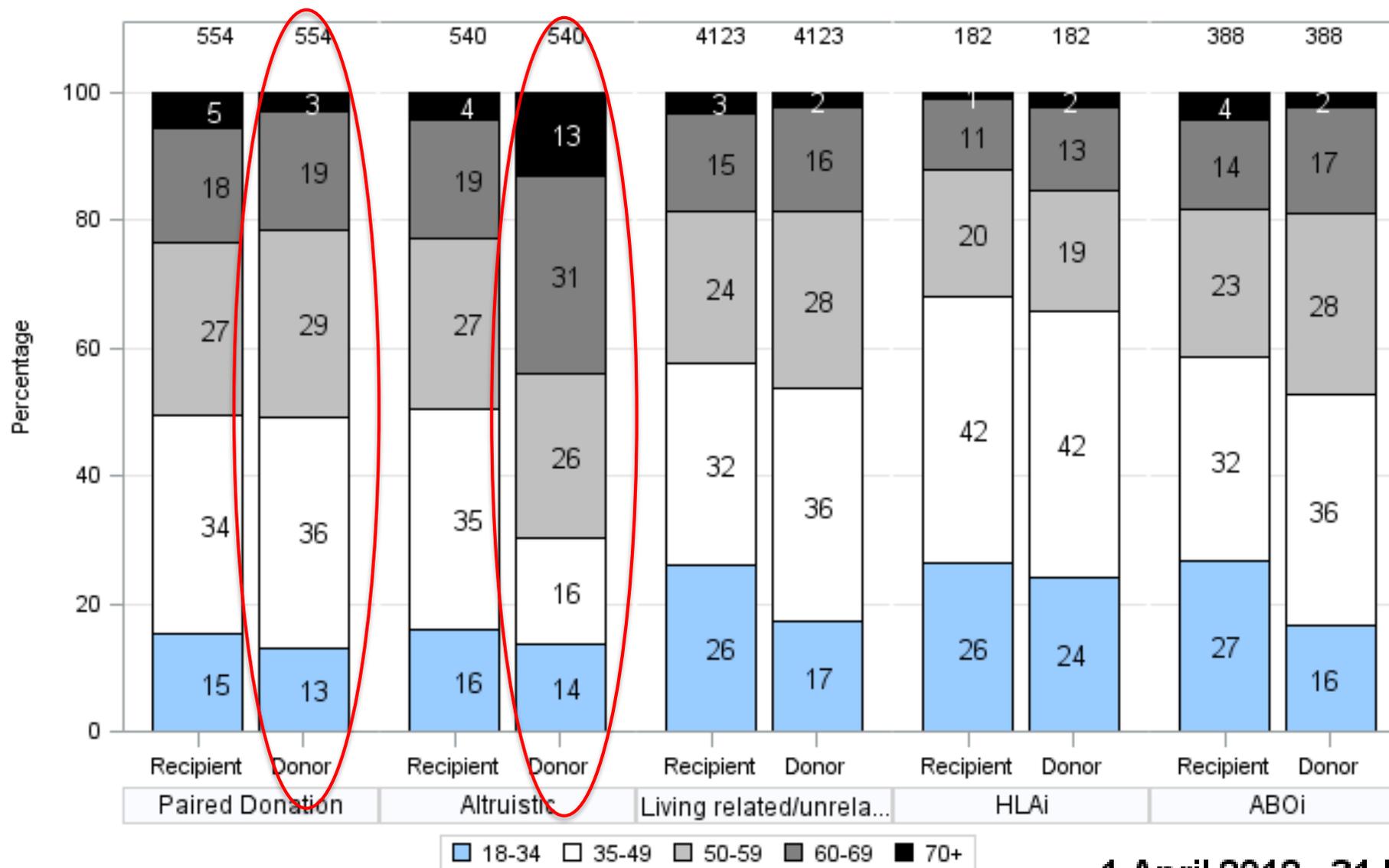
UKLKSS Outcomes by centre



■ Active/Delisted ■ Transplant through Scheme □ Transplant outside Scheme

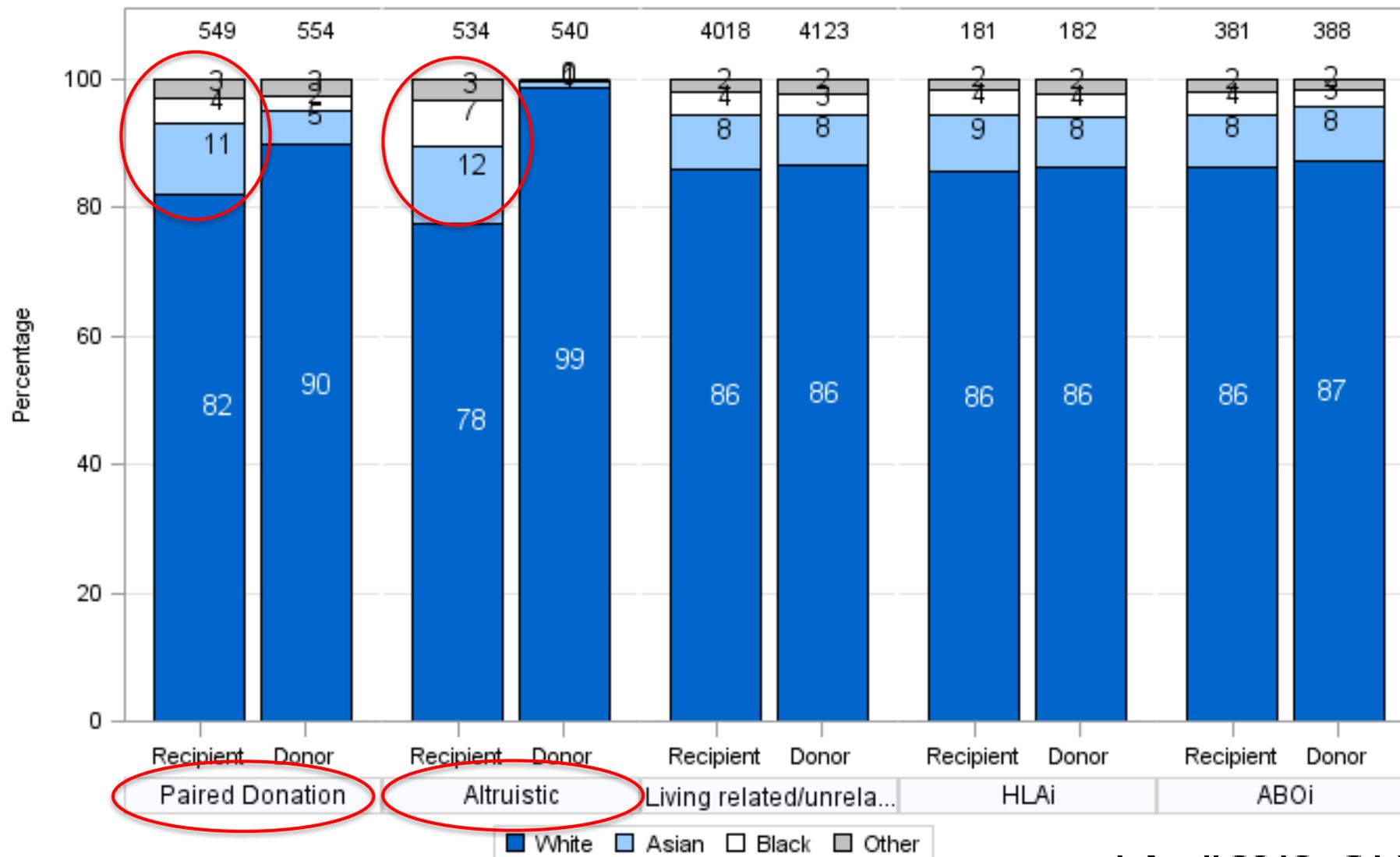
1 April 2014 - 31 March 2018

Demographics LDKT – Age



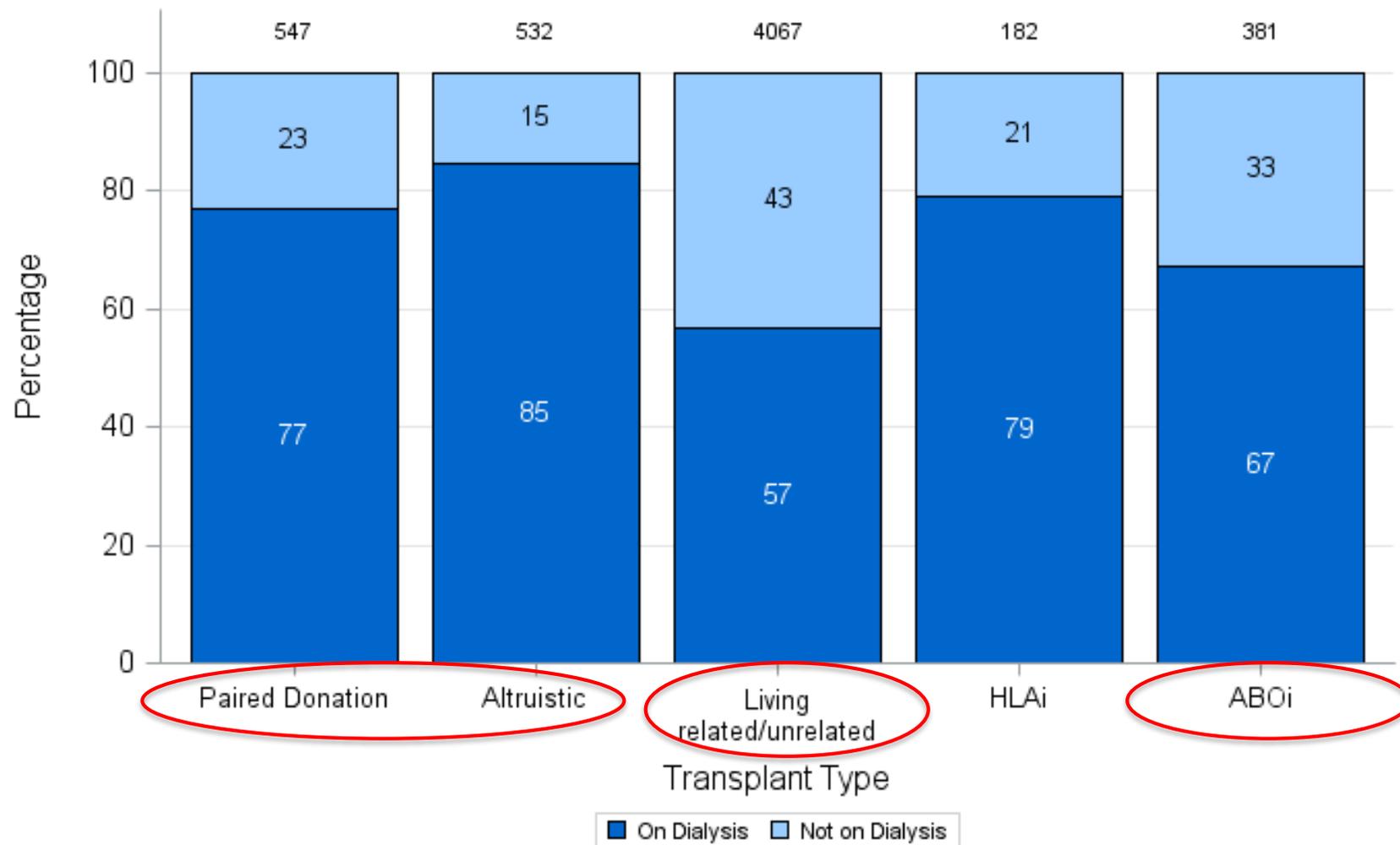
1 April 2012 - 31 March 2018

Demographics LDKT – Ethnicity

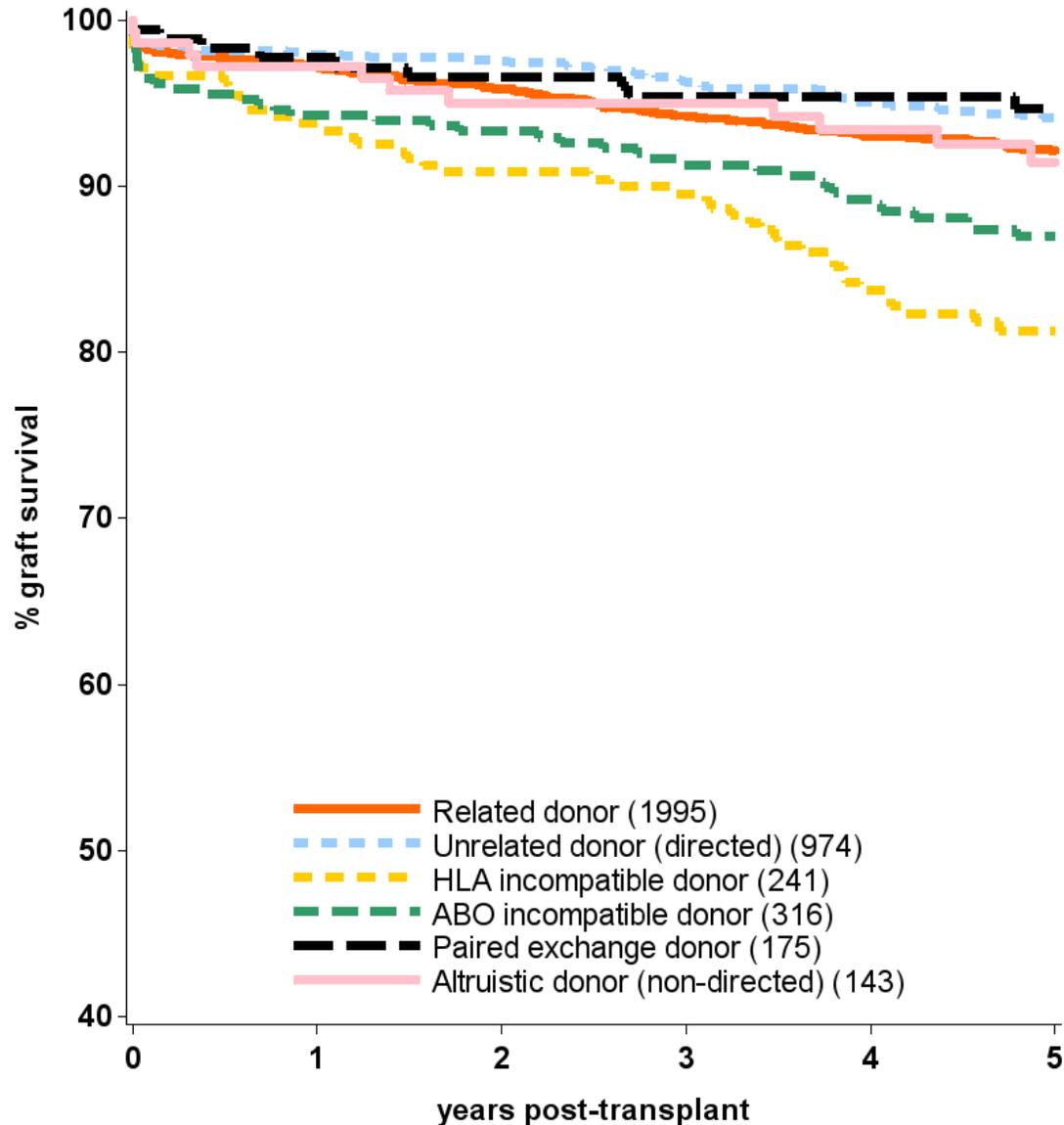


1 April 2012 - 31 March 2018

Demographics LDKT – Dialysis status



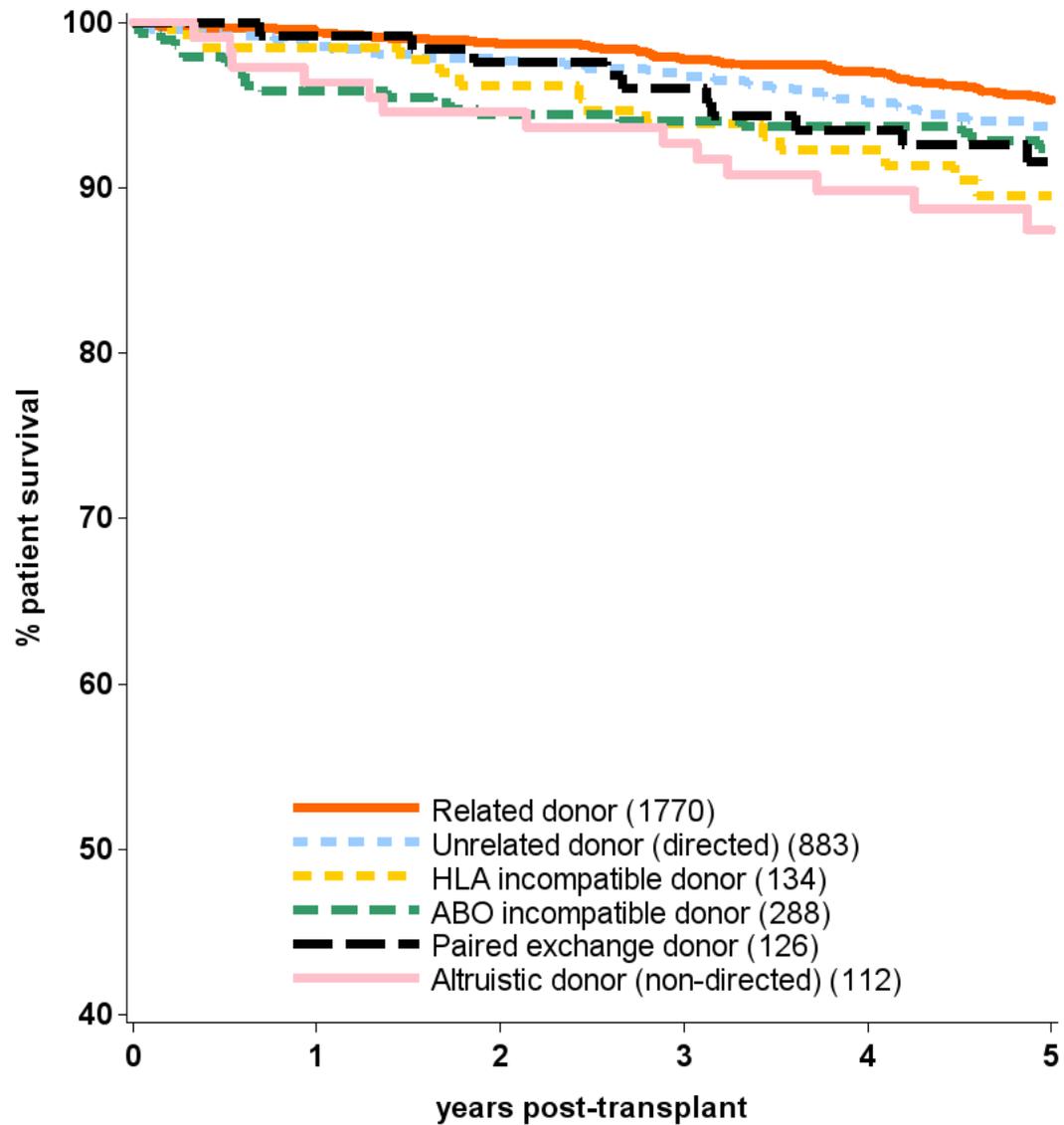
Survival Outcomes – Graft Survival



	Survival %	(95% CI)	N
Paired exchange donor	94.7	(90, 97)	175
Direct (unrelated)	94.1	(92, 95)	974
Direct (related)	92.2	(91, 93)	1995
Altruistic donor	91.4	(85, 95)	143
ABO incompatible	87.0	(83, 90)	316
HLA incompatible	81.3	(76, 86)	241

p<0.0001, log-rank test 5df

Survival Outcomes – Patient Survival



	Survival %	(95% CI)	N
Direct (related)	95.3	(94, 96)	1770
Direct (unrelated)	93.7	(92, 95)	883
ABO incompatible	92.4	(89, 95)	288
Paired exchange donor	91.6	(85, 95)	126
HLA incompatible	89.5	(83, 94)	134
Altruistic donor	87.4	(79, 93)	112

P=0.0006, log-rank test 5df

Based on transplants April 2009 - March 2013

Priorities for 2018

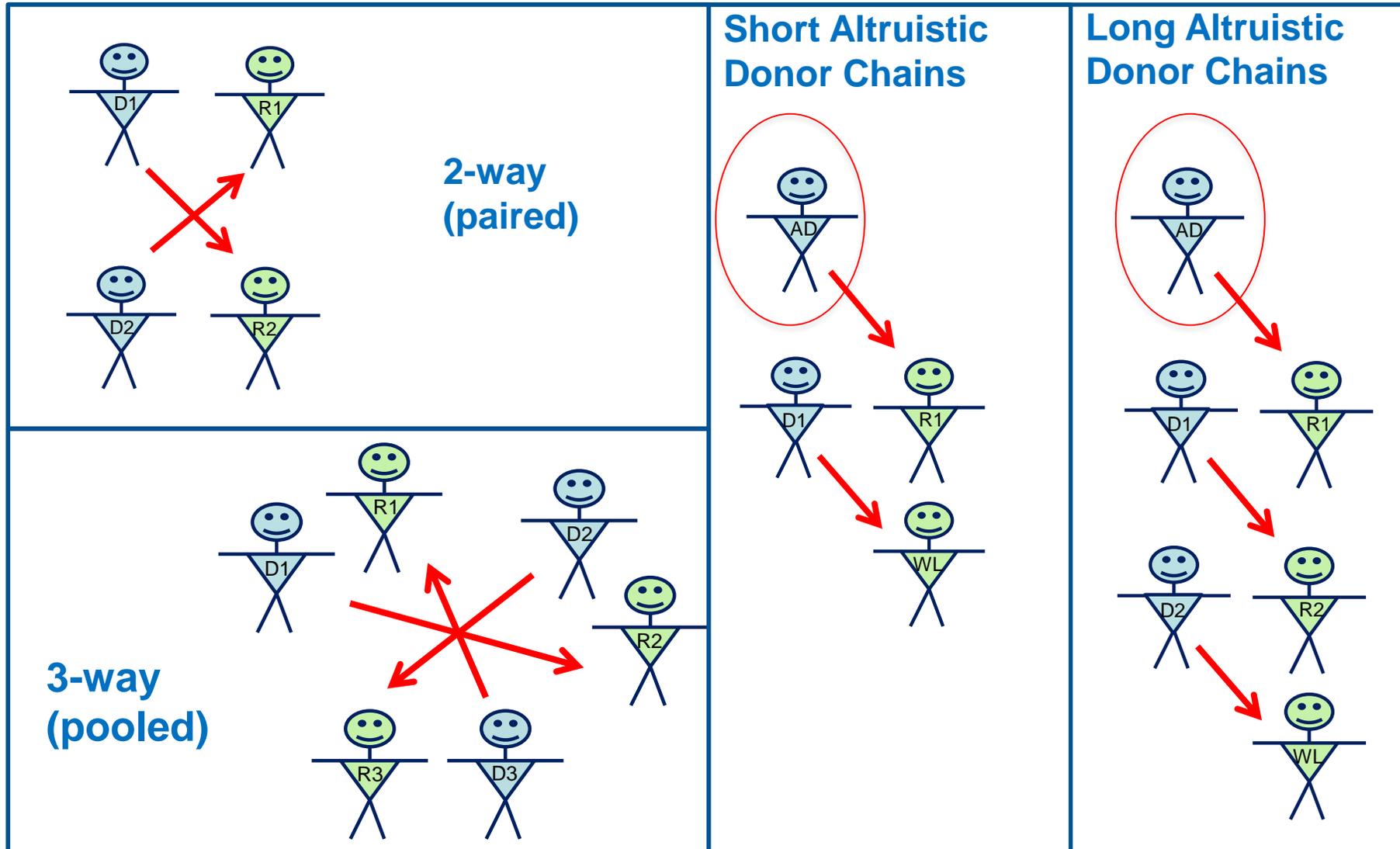
- Maximise transplants
- Increase flexibility in the scheme
- Tackle non-proceeding transplants
- Improve access and awareness

Maximise Transplants

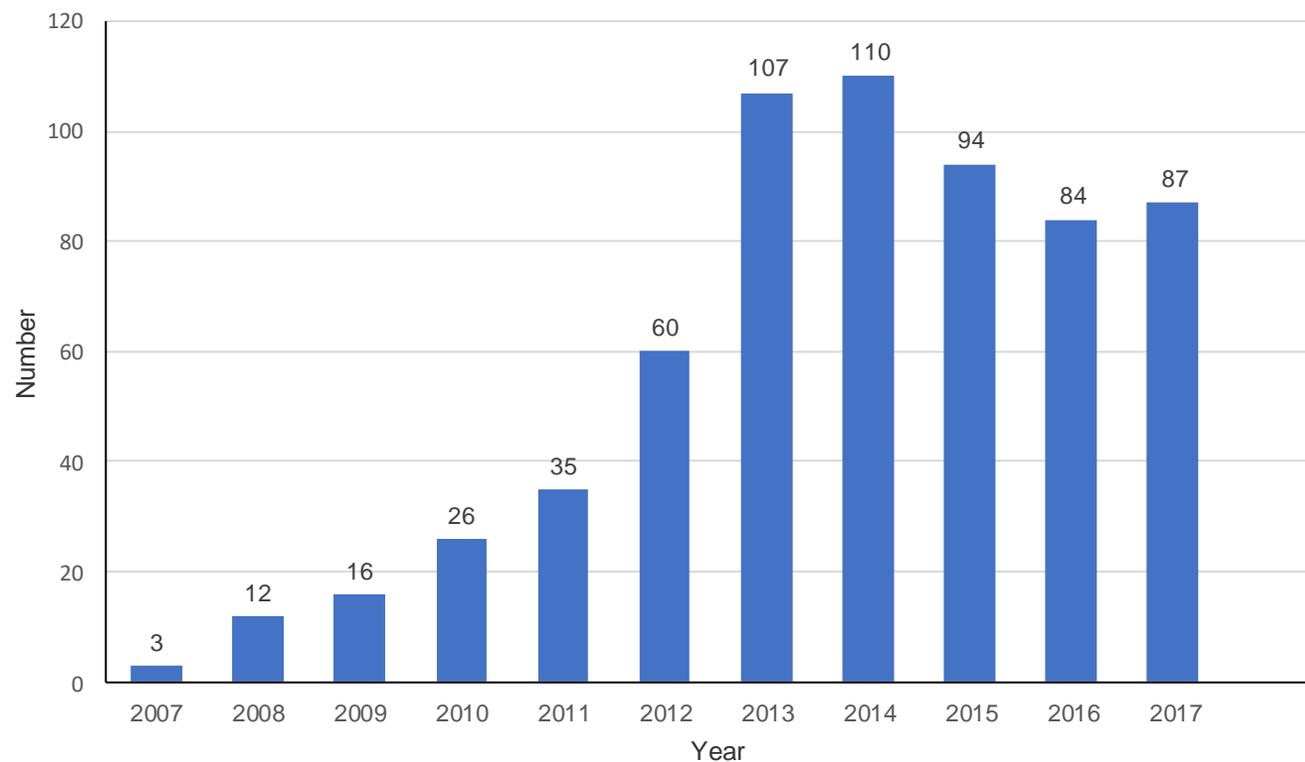
Increasing the Donor Pool

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

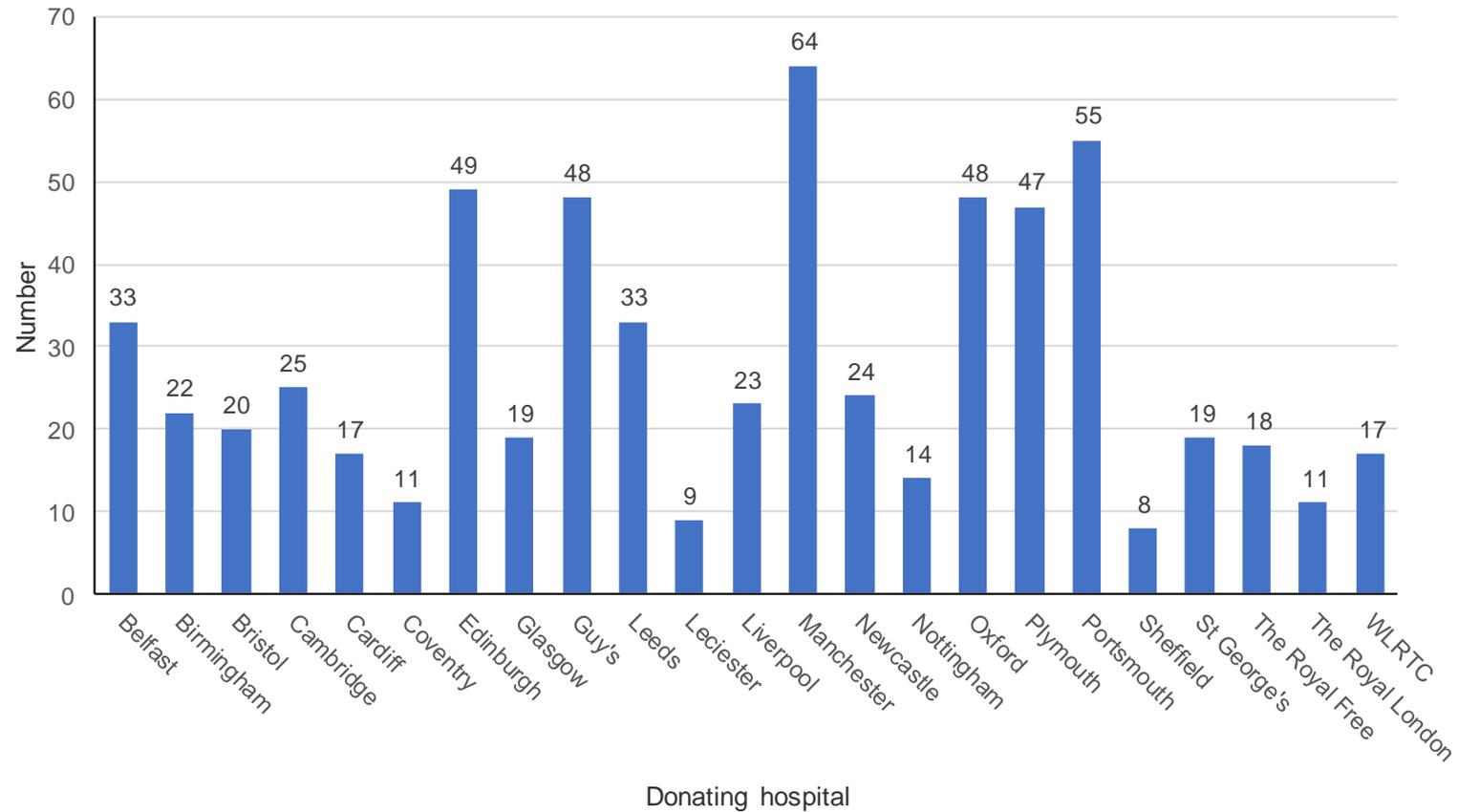
Non-Directed Altruistic Donors



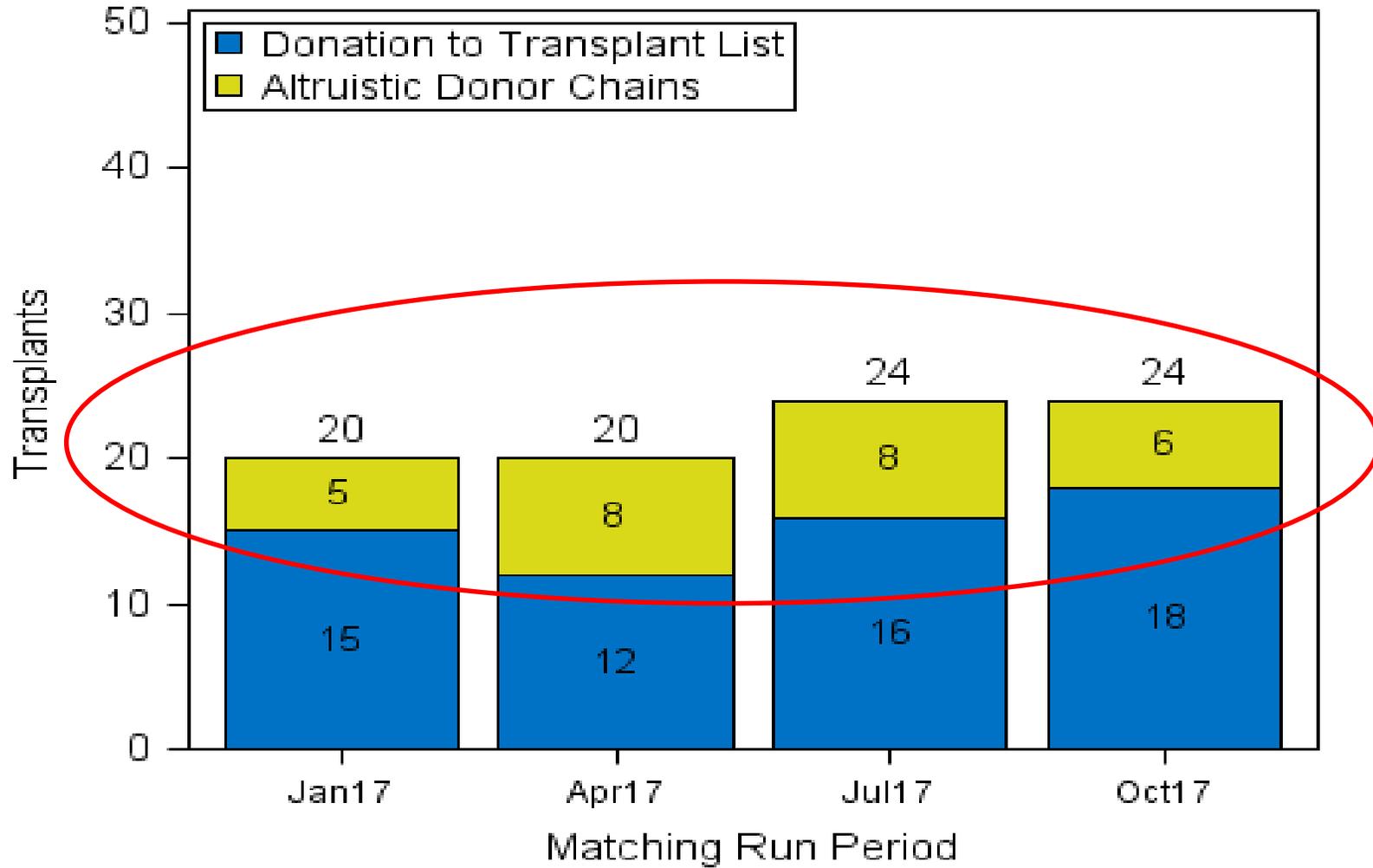
Non-Directed Altruistic Kidney Donors (NDADs)



NDADs By Donating Hospital 2007-2017



Altruistic Donor Transplants



Altruistic donors in the UKLKSS

- Since January 2018, altruistic donors have been registered into the scheme by default
- Limited by:
 - Transition period for donors in assessment prior to January 2018
 - Donors unmatched in the scheme
 - Increased proportion of high priority recipients due to backdated waiting time points to start of dialysis
- In 2018 there were
 - 64 altruistic donors (87 in 2017); 112 transplants (125 in 2017)*
 - 48% of transplants from altruistic donors were as part of a UKLKSS chain (30% in 2017)

	2017	2018
Direct to list	61	33
Chain donation	26	31
Total chain transplants	64	79

*October run yet to complete

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

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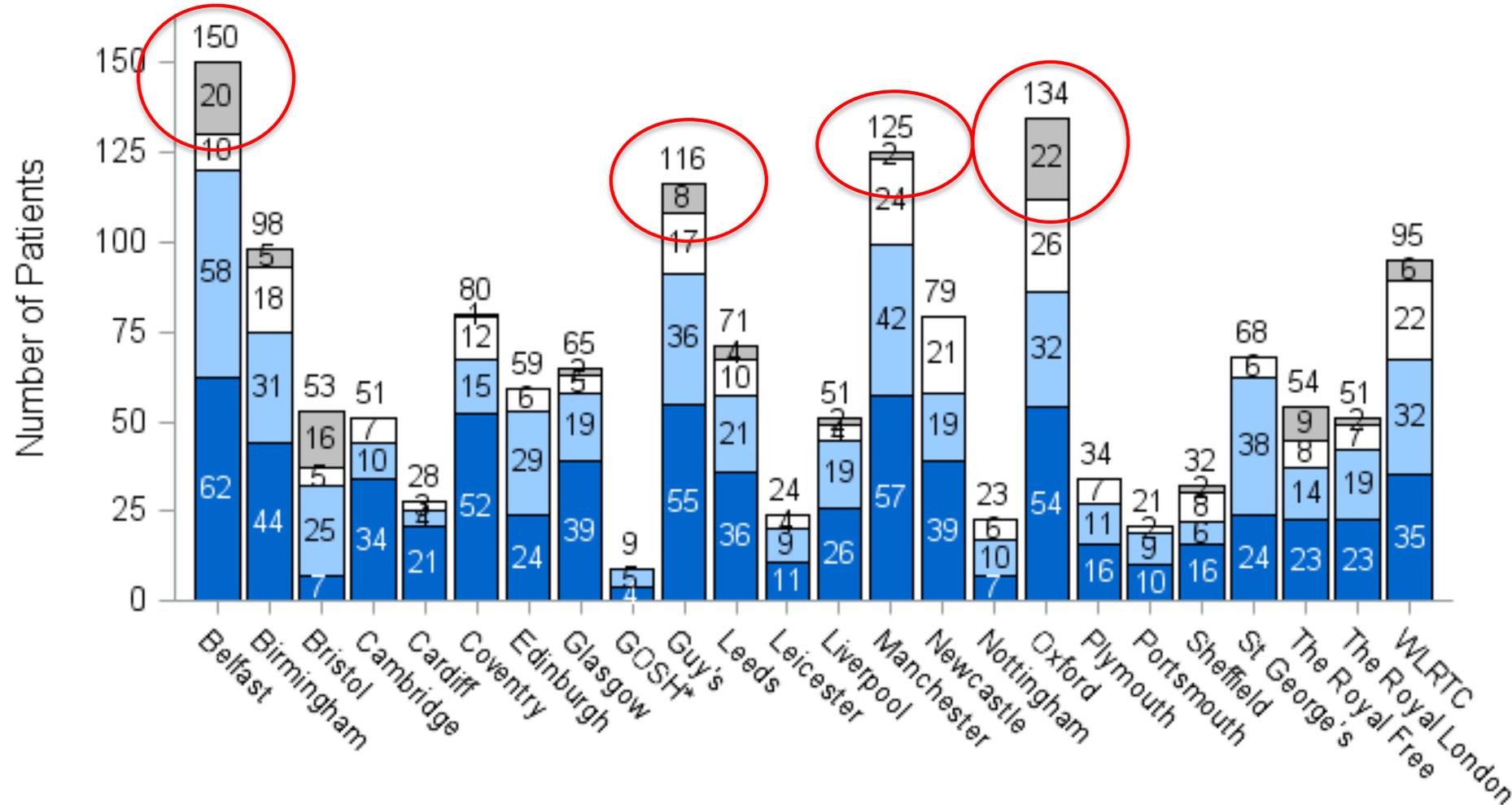
Compatible Pairs

- First compatible pair registered in June 2011
- 148 compatible pairs have been registered in the scheme
- 100 (68%) appeared in only 1 matching run of whom 55 (55%) recipients were transplanted
- 14 (61%) centres registered compatible pairs in the scheme in 2017/18

In summary

- Increasing trend of recipients in compatible pairs transplanted in UKLKSS (25 in 2018)
- 71 patients from a compatible pair have been transplanted through the scheme
- 97 transplants for other patients have been facilitated by compatible pairs
- Proportion of compatible pairs registered varies between centres

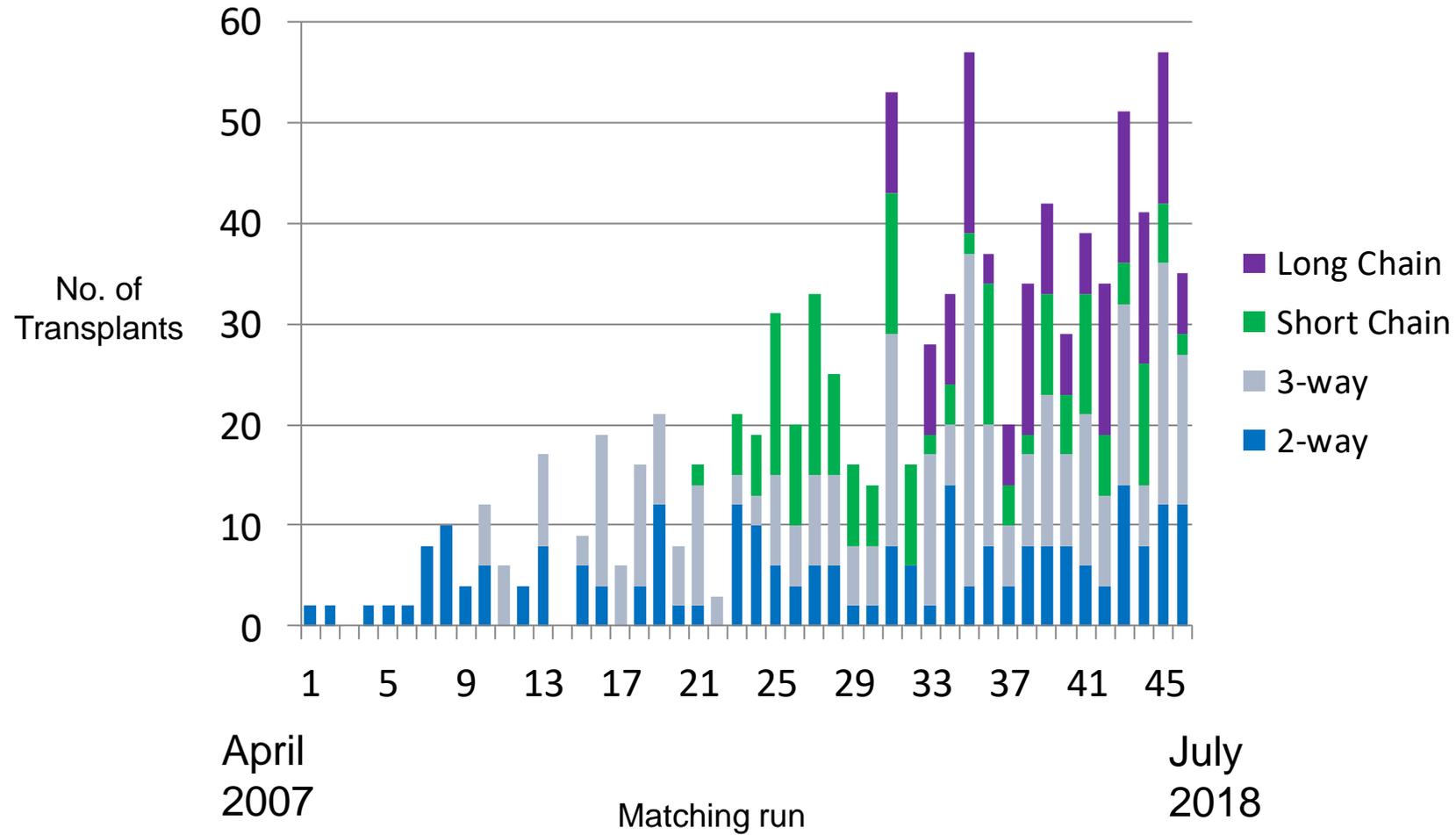
UKLKSS pairs registered by centre



■ HLAi
 ■ ABOi
 ■ HLAi and ABOi
 ■ Compatible

1 April 2012 - 31 March 2018

Transplant by Exchange Type



Increasing Flexibility

- Recipient age and HLA preferences required at inclusion
- Simplified timetable of key dates for matching runs
- Agreed framework for non-simultaneous surgery
- Prioritisation for transplant for 'paired' recipients if they miss out on a transplant
- Extended designated weeks of surgery across all centres (weeks 5,6,& 8 post matching run)*

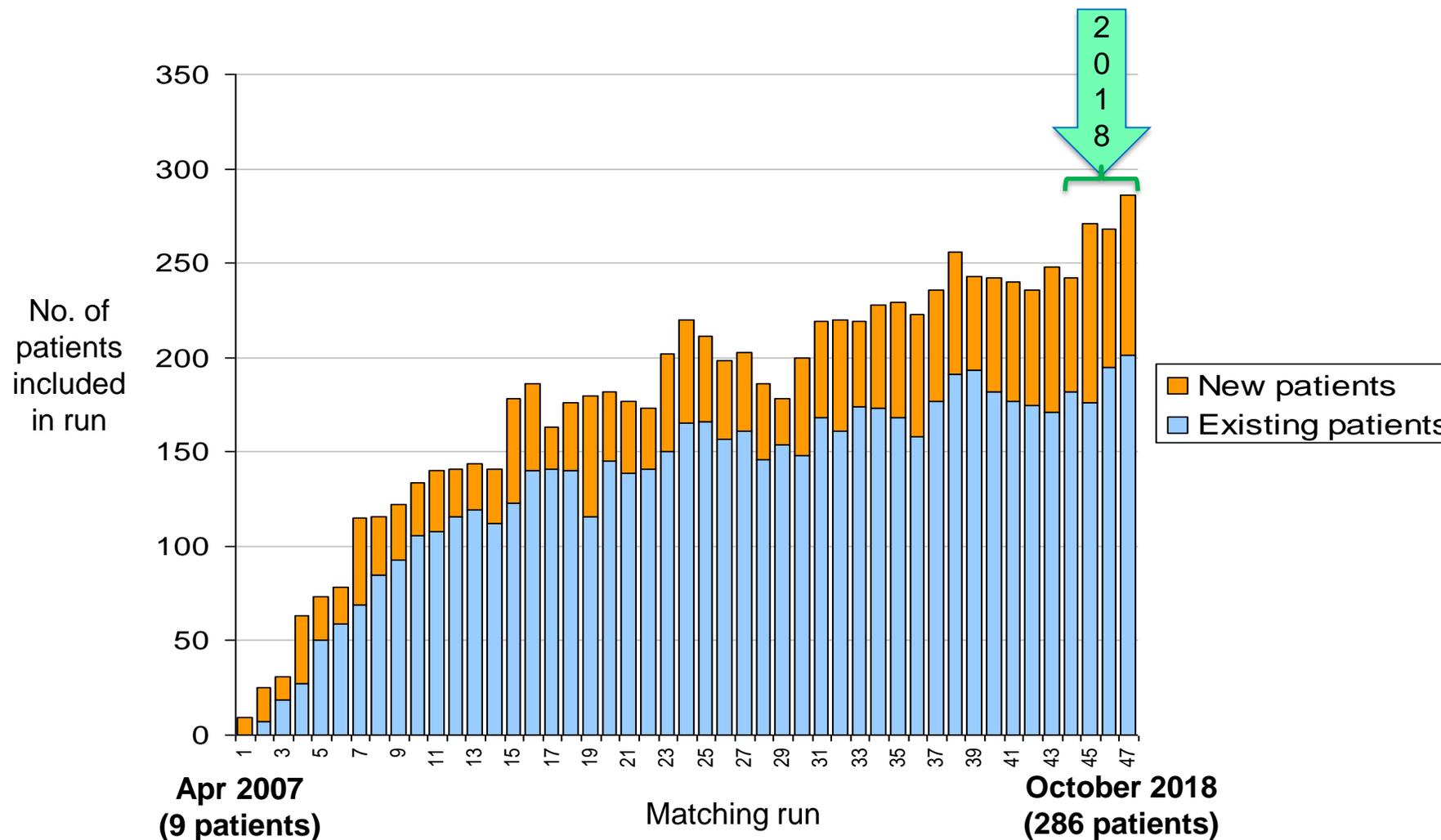
*Extended to 10 weeks for October run to accommodate Christmas and New Year

Non-simultaneous Surgery

- Introduced in 2015 to facilitate ‘long chains’ and logistically complex exchanges
 - Within 2 weeks (10 working days)- discussion with Lead Nurse and notification to Chair of KAG
 - Outside 2 weeks- discussion with Lead Nurse and approval from Chair of KAG
- Low risk of non-proceeding but increased risk associated with
 - Clinical reasons for staggering
 - Extended intervals between transplants
- Requests for recipients requiring priority listing are low; occurs in both simultaneous and non-simultaneous surgery
- 50 non-simultaneous exchanges (133 transplants) to date

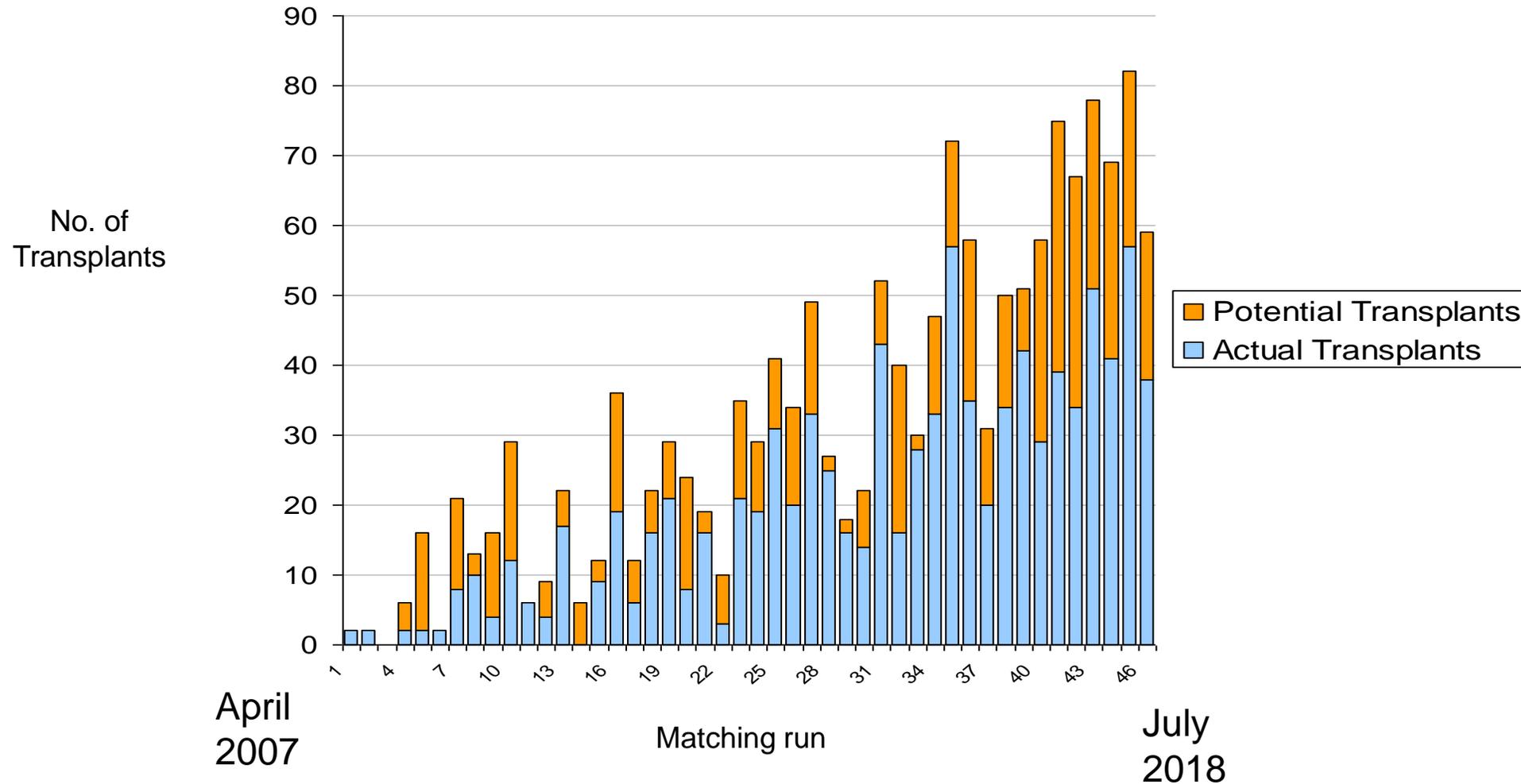
	2015	2016	2017	2018
Non- simultaneous exchanges (%)	13 (23%)	12 (22%)	13 (24%)	12 (17%)

Number of Patients in Quarterly Matching Runs



Non-proceeding Transplants

Potential and Actual Transplants



Non-proceeding Transplants*

- 54% of identified transplants proceeded 2007-2011
- 66% proceeded 2012-present
- 60% proceeded since January 2017

*Aim: 75% proceed within 8 weeks of being identified

Non-proceeding Transplants

Date represents run date of living donor kidney matching run							
	Apr 2017/18	Jul 2017/18	Oct* 2017/18	Jan 2017/18	Apr 2018/19	Jul 2018/19	Oct* 2018/19
Number of paired donation transplants identified	75	67	78	69	82	59	85
Number of paired donation transplants proceeding	39	34	51	41	57	38	
Proportion of paired donation transplants proceeding (%)	52	50.7	65.4	59.4	69.5	64.4	
Number of paired donation transplants proceeding within 8 weeks	19	15	28	26	39	23	
Proportion of paired donation transplants proceeding within 8 weeks (%)	48.7	44.1	54.9*	63.4	68.4	60.5	

*Designated weeks of surgery extend to 10 weeks for October run

Tackling Non-Proceeding Transplants

- Donor-recipient registration
- Agreed criteria for donor complexity in the 'pre-run'
- Minimum data set for exchange of donor-recipient information
- Governance and reporting

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.

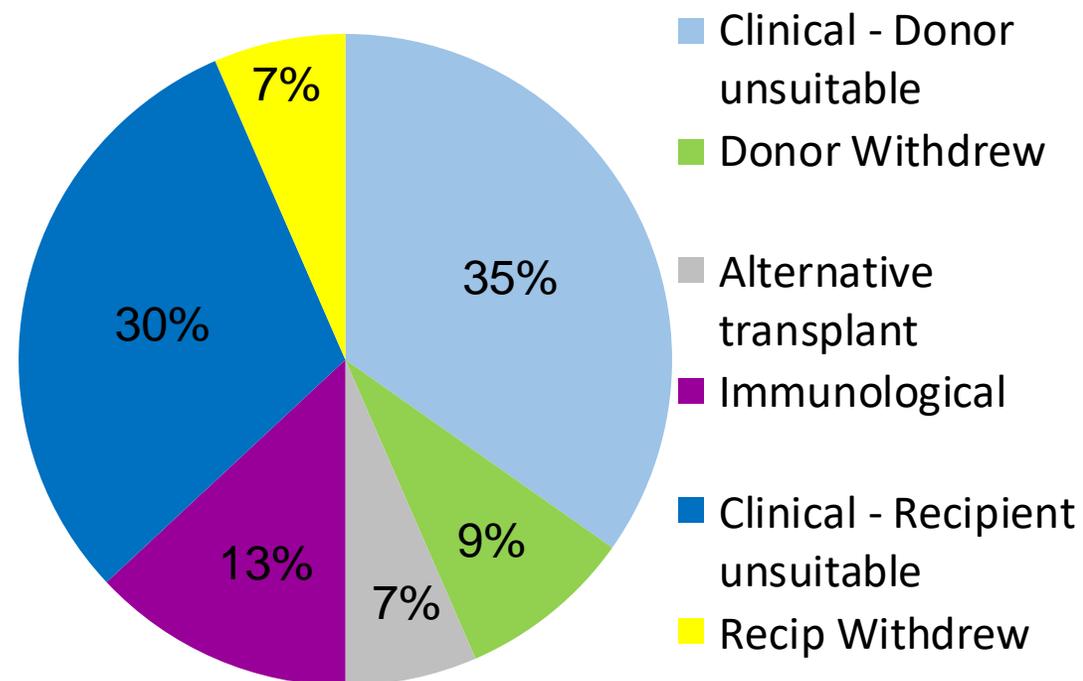
* Feedback ID (from the covering email)

Next

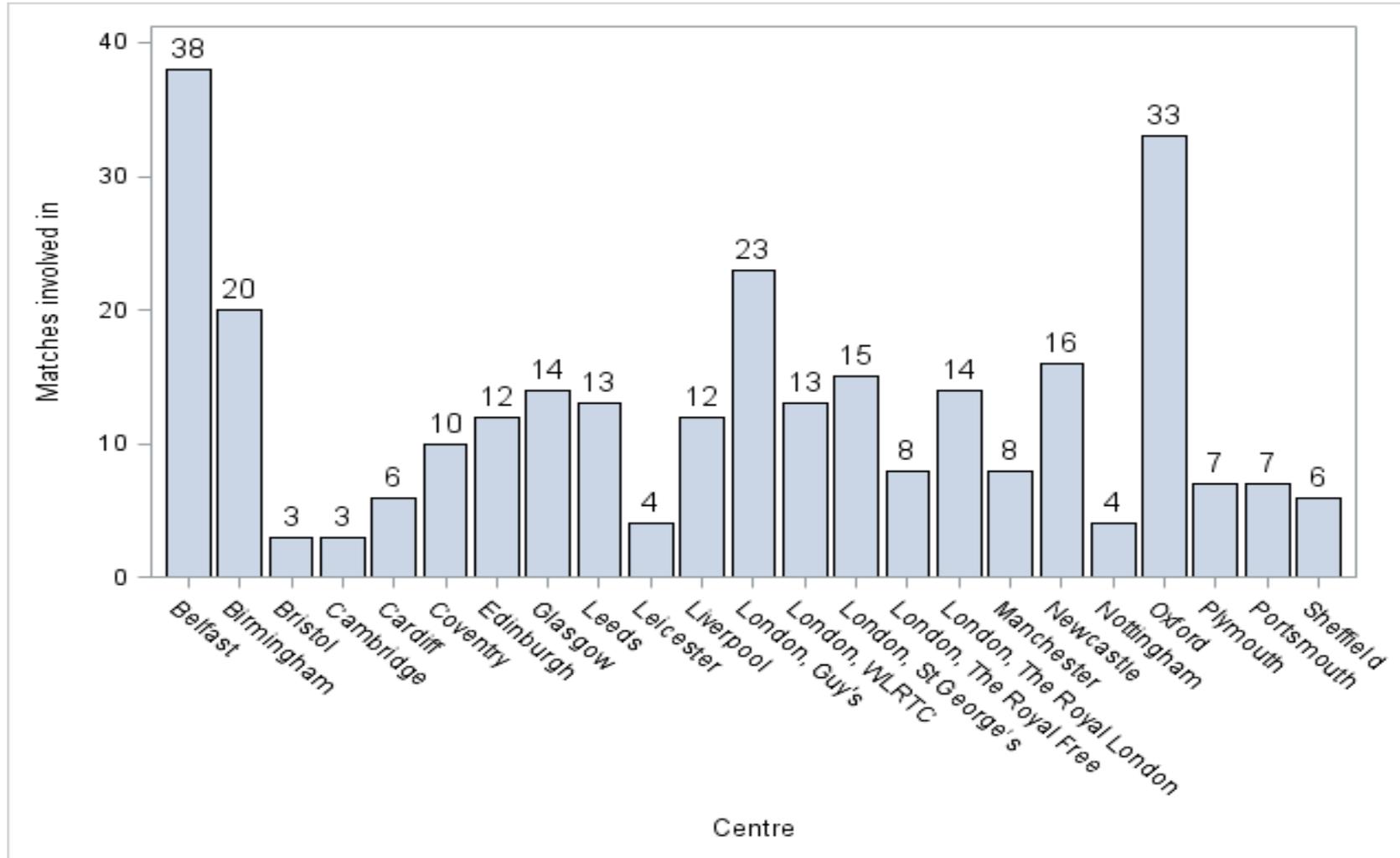
Powered by
 SurveyMonkey
See how easy it is to [create a survey](#).

Privacy & Cookie Policy

October 2017- July 2018 (46 reasons)

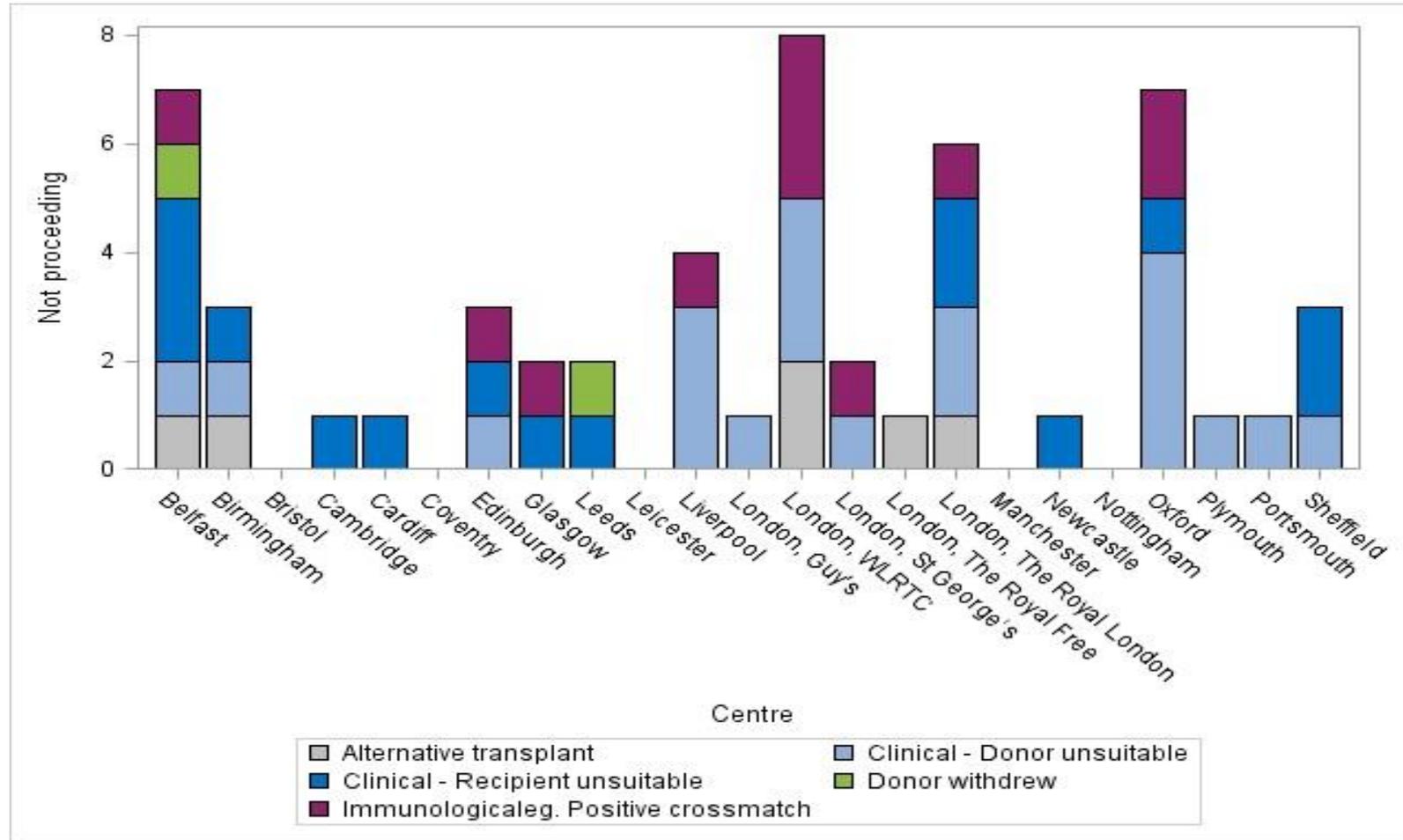


Number of Matches by Centre



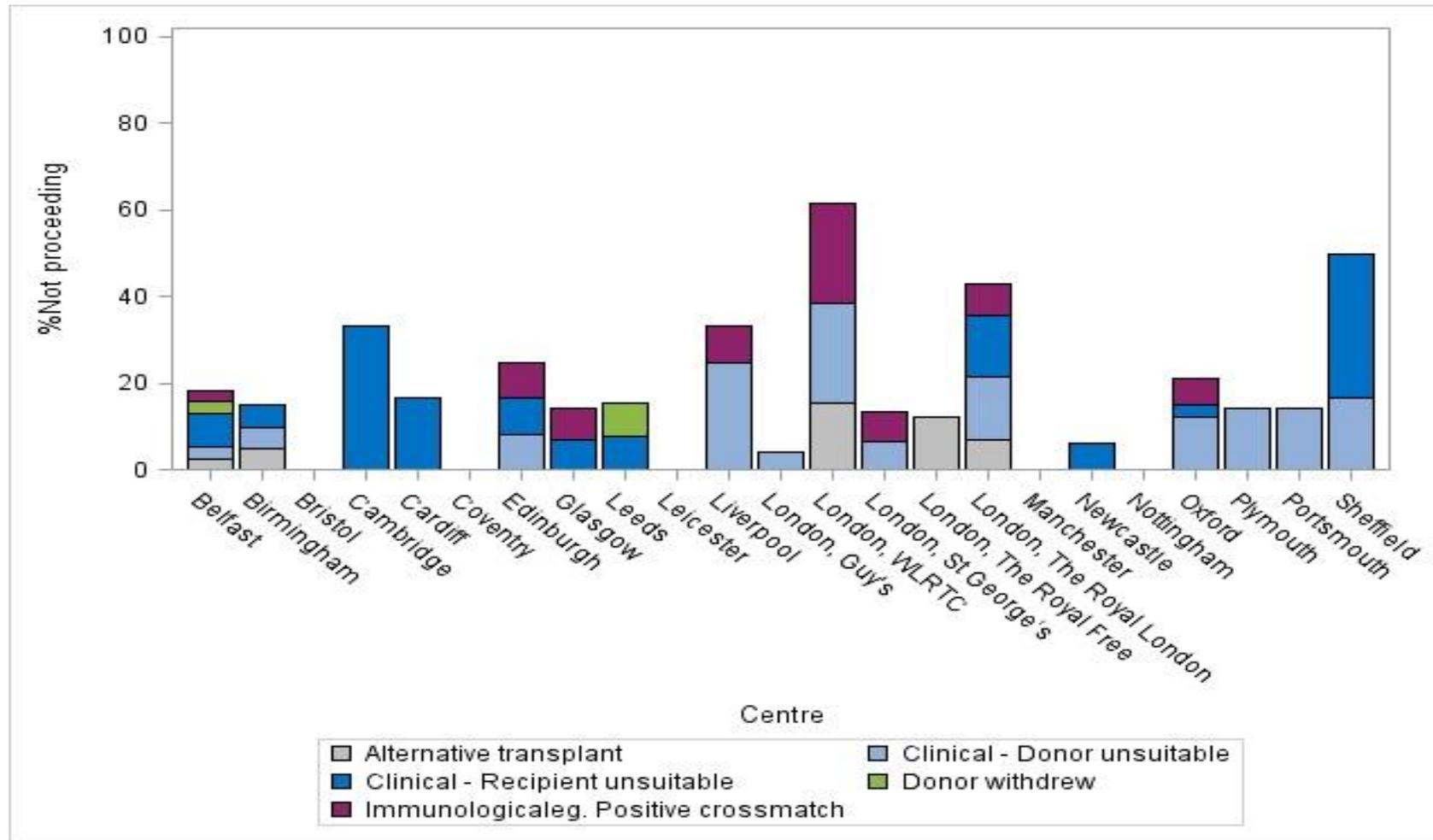
**Data derived from on-line survey monkey*

Number of Non- proceeding Transplants by Centre



**Data derived from on-line survey monkey*

Proportion of Non- proceeding Transplants by Centre



**Data derived from on-line survey monkey*

Improving Access and Awareness

Improving Access and Awareness

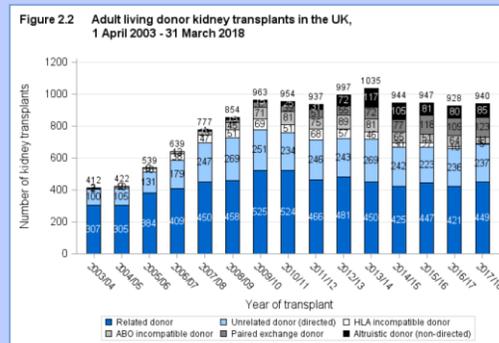
- Public and patient engagement
- Shared learning
 - Annual activity and centre specific reports
 - UK Living Donor Kidney Network meeting
 - Quarterly newsletter and update
 - Key contacts within ODT
- On-line decision-making resources¹
- Extended portfolio of donor-recipient information²

¹<https://www.odt.nhs.uk/living-donation/living-donor-kidney-transplantation/> ²<https://www.organdonation.nhs.uk/about-donation/living-donation/>

What information is available to support decision making?

ANNUAL REPORT ON LIVING DONOR KIDNEY TRANSPLANTATION
REPORT FOR 2017/2018
(1 APRIL 2003 – 31 MARCH 2018)
PUBLISHED SEPTEMBER 2018

Figure 2.2 shows the number of adult living donor kidney transplants performed in the UK between 1 April 2003 and 31 March 2018. The number of transplants increased from 412 in 2003/04 to 940 in 2017/18.



UK Living Kidney Sharing Schemes Performance Figures

Total May 2007 - July 2018	
Pairs Registered	2256
Patients Registered	2042
Altruistic Donors in Paired Donation Matching Runs	234
Compatible Pairs Registered	135
Transplants	947

Patients in Each Matching Run		
Matching Run	Existing Patient	New Patient
Oct17	171	248
Jan18	182	242
Apr18	178	271
Jul18	195	268

UKLSS Records		In a Matching Run	
Pairs Included	305 (Apr 2018)	Pairs Included	305 (Apr 2018)
Patients Included	271 (Apr 2018)	Patients Included	271 (Apr 2018)
Altruistic Donors Included	17 (Jan 2018)	Altruistic Donors Included	17 (Jan 2018)
Transplants Identified	82 (Apr 2018)	Transplants Identified	82 (Apr 2018)
Transplants Proceeded	57 (Apr 2018)	Transplants Proceeded	57 (Apr 2018)

Incompatible Pairs Living Donor Information Application

Variable	Select
Recipient Blood Group	Select
Calculated Reaction Frequency	Select
Donor Blood Group	Select
ABOi TX with willing Donor	Select
HLAi TX with willing Donor	Select
Recipient Age	Select

	Estimated Chance of Transplant			
	Deceased Donor	NLDKSS	ABOi	HLAi
6 Months	-	-	-	-
1 Year	-	-	-	-
3 Years	-	-	-	-

	Transplant Survival Rates			
	Deceased Donor	NLDKSS	ABOi	HLAi
6 Months	-	-	-	-
1 Year	-	-	-	-
3 Years	-	-	-	-

Disclaimer: The information is provided for guidance only
 Note: Chances of transplant through the NLDKSS could be increased by considering and antibody incompatible transplant within the scheme
 For a more accurate estimation of waiting time for a deceased donor transplant based on more variables, please visit
http://www.odt.nhs.uk/doc/chance_of_transplant.xls

Work in Progress

- Dedicated workstream in LDKT 2020 Strategy Implementation Group
- Continue to embed innovation and maximise transplant opportunities
 - Compatible pairs
 - Longer 'chains'
 - Increase threshold for acceptable ABOi titres in higher immune risk recipients
- IT infrastructure to support on line registration and offering
- Options for collaboration with other European countries
 - Fixed Time Working Group
 - Partner in COST European Network for Collaboration on Kidney Exchange Programmes (ENNCKEP)

Summary

- The scheme delivers effective kidney sharing across the UK with scope to improve
- Largest national scheme in Europe; international reputation
- Continuous innovation and improvement is vital to make the most of every transplant opportunity
- An increase in the number of transplants through the UKLKSS has led to a decrease in antibody incompatible transplants
- There is variation in the utilisation of the UKLKSS, contribution of non-directed donors and use of compatible pairs in the scheme

Donor Reported Outcome Measures

DROMS

UK TRANSPLANT REGISTRY	
<h3>DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY</h3>	
<p>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.</p> <p>ODT Hub: Information Services NHS Blood and Transplant Fox Den Road Stoke Gifford BRISTOL BS34 8RR</p> <p>Data will be collected at the following time points: Pre-donation (on completion of work up), 1 year and 5 years post donation.</p>	
DONOR DETAILS Section 1	
Surname _____	Date of birth <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Forename(s) _____	
ODT donor number (if applicable) _____	
<small>FRM62041 (Donor Reported Outcome Measures (DROMS) Survey) Effective: 11/12/18 Page 1</small>	

DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY	
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.	
ABOUT YOUR DONATION (Please answer all questions unless indicated) Section 2	
1. How would you rate your health on a scale of 1-10 where 1 is "very poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
2. How would you rate your need to sleep on a scale of 1-10 where 1 is "almost all the time" and 10 is "as much as I expect"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
3. How would you rate the way you feel about your eating on a scale of 1-10 where 1 is "poor" and 10 is "great"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
4. Do you feel that your health has had a negative impact on your family or social life on a scale of 1-10 where 1 is "significant effect" and 10 is "not at all"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
5. How positive are you about your future on a scale of 1-10 where 1 is "not at all" and 10 is "very positive"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
6. Overall, what do people in your life think of you related to your decision to donate, on a scale of 1-10 where 1 is "they think very poorly of me" and 10 is "they think very highly of me"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
7. What is your view of your body image on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
8. What is your partner's perception (if applicable) of your body image on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
9. How would you rate your overall mobility on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
10. How would you rate your overall ability to cope with everyday activities such as working, housekeeping or travelling on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
11. How would you rate your overall ability to exercise on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
12. How would you rate your overall ability to engage in leisure activities on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	

What is DROMs?

Aim:

- First phase of developing self-reported measures for living donors
- 20 point questionnaire survey to capture self-reported **outcomes** from living donors to add to clinical information collected in UK Living Donor Registry
 - Pre-nephrectomy (after completion of assessment)
 - Post nephrectomy at 1 and 5 years

Developed by:

- Members of the donor safety and welfare workstream on behalf of the LDKT 2020 Strategy Implementation Group (SIG)

Development

- Work stream chaired by Vassilios Papalois with representation from
 - Living donors
 - Clinical colleagues
 - NHSBT representatives
- Questionnaire survey developed and refined with support from Vassilios' PhD student, work stream and SIG members
- Pilot- 2 phases
 1. Donor focus group: questionnaire further refined
 2. Donor follow-up clinics: 3 transplant centres; 1 non-transplanting centre

Implementation

- UK-wide from January 2019; supported by ODT colleagues
- Communication via the UK Living Donation Network
- Pre-op data collection on all donors who have completed assessment and undergo nephrectomy from 1st January 2019
- 1 & 5 year follow-up to be collected on all donors with pre-nephrectomy data submitted
 - Forms will be automatically generated with annual follow-up request and sent to centres for named donors

Limitations

- Manual data collection- form based system; IT solution required to support on-line submission, data entry and analysis
- Requires living donor coordinators to initiate and return pre-nephrectomy data collection to ensure that donors are eligible for post-nephrectomy follow-up
- Follow-up data will be limited to those donors who attend a transplant or non-transplanting centre for 1 and 5 year follow-up until on-line solution is available

Next steps

- Agree timeframe for initial data analysis of DROMs
- Develop self-reported **experience** measures for living donors (DREM) to add to survey
- Develop on-line solutions to support self-reporting activities and facilitate more comprehensive data capture in future

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

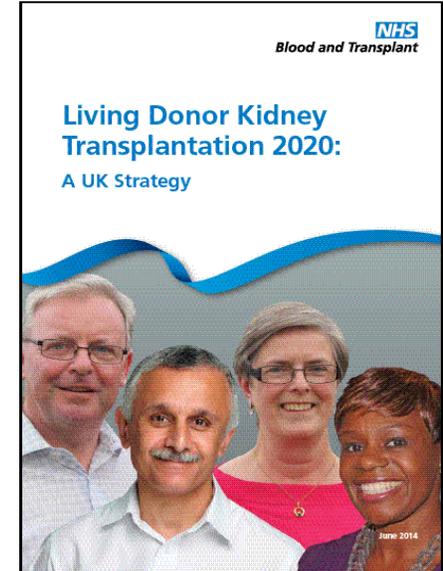
Kidney Advisory Group

LDKT 2020 Strategy Implementation Group

Aisling Courtney (Chair) and members

DROMs

Vassilios Papalois, Maria Thedosopoulou, Jan Shorrocks, Dela Idowu, Caroline Wroe, Aisling Courtney, Matthew Robb, Mike Gumn



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

Thank You



www.nhsbt.nhs.uk

www.odt.nhs.uk