

KIDNEY ADVISORY GROUP**November 2019****THE UK LIVING KIDNEY SHARING SCHEME: UPDATE AND IMPACT REPORT****1. BACKGROUND**

This paper provides a regular report to Kidney Advisory Group (KAG) on the UK Living Kidney Sharing Schemes (UKLKSS). KAG has agreed to monitor the scheme and to recommend changes and improvements as required.

This report includes the following updates:

- Inclusion of non-directed altruistic donors (NDADs)
- Non-simultaneous donor surgery
- Requests for recipient prioritisation for transplantation
- Centre-specific reports: non-proceeding and delayed transplants
- On-going and future developments

2. INCLUSION OF NON-DIRECTED ALTRUISTIC DONORS (NDADS)

Following changes introduced in January 2018, all NDADs donate into the UKLKSS unless there is a high priority recipient on the UK Transplant List (UKTL). In 2019, there has been an upward trend in the number of NDADs in comparison with 2018 from 64 to 82 (+28% to date).

Since June 2019, 41 NDADs have donated a kidney, 26 (63%) initiated an altruistic donor chain and 15 donated directly to the UKTL. In comparison with the previous 6 months, the number of NDADs (41 v 42) was equivalent but the proportion initiating a chain increased from 59% to 63%. Of the 15 donors who donated directly to the list:

- 8 (20% of all NDADs) were offered to high priority recipients in the previous kidney offering scheme (long-waiting or Tiers A-C) prior to inclusion in the matching run
- 1 was allocated to a long-waiting recipient who was unwell on the day prior to surgery. The kidney was transplanted in to a Tier B (new offering scheme) recipient because the donor wished to proceed on the planned day of surgery
- 6 donated to Tiers D/E, having been included in the UKLKSS. 4 were matched but the transplant did not proceed and 2 were not matched to a paired recipient. Both donors were blood group A.
- There have been no requests for direct donation to the list in this period.

3. NON-SIMULTANEOUS DONOR SURGERY AND RECIPIENT PRIORITISATION FOR TRANSPLANT

All planned non-simultaneous transplants must be notified in advance to Chair of KAG and approval is required if more than 10 working days (2 weeks) between any two transplants is planned in an altruistic donor chain or for a non-simultaneous paired/pooled exchange. Notifications and requests for approval are made and the decision confirmed to the requester via the Clinical Lead for Living Donation.

4 non-simultaneous exchanges completed from the April and July matching runs at the time of reporting, resulting in 12 transplants. This was fewer than in the previous 6 months, despite increases in the numbers of transplants identified. Exchange types, interval between first and last transplant and the centres involved are shown in Table 1.

Table 1. Completed non-simultaneous exchanges in the UKLKSS for April and July Matching runs*

Matching Run	Exchange Type	No. of Txs.	Days between 1st and last Tx.	Centres involved
Apr-19	Long Chain	3	9	Oxford, Guy's
July-19	Long Chain	3	1	WLRTC, Sheffield, Leicester
July-19	Long Chain	3	1	Cambridge, Leeds, Belfast
July-19	3-way	3	1	St. George's, Belfast
Total	4 exchanges	12		

*Centres involved in any transplants that occurred after the first in the exchange in red.

Two scheduled non-simultaneous chains did not complete from the April and July matching runs:

1 long altruistic donor chain from the April matching run

- Non-simultaneous surgery was scheduled over a one-week period but not notified in advance (as above)
- 28/06/19: the NDAD donated to recipient 1
- Implantation was unsuccessful and early transplant nephrectomy was performed
- The paired donor (wife of the recipient) felt unable to proceed and was supported by the local team to withdraw

- 02/07/2019: the rest of the chain, involving donor-recipient pair 2 and an end-of-chain recipient on the UKTL, was scheduled but did not proceed
- The incident was reported to ODT on-line due to failed implantation and was investigated by the local team
- Cause of graft failure unknown. Recipient investigated for possible contributory factors

1 long-altruistic donor chain from the July matching run

- Exceptional approval given for 'reverse' non-simultaneous chain (end of the chain 1 week before the start of the chain) to accommodate access to theatres in matched centres
- Scheduled in the last 2 weeks of October
- First planned surgery day: unable to proceed due to raised blood pressure in the recipient so postponed until second date of surgery
- 29/10/2019 (second planned date of surgery): start of chain proceeded to plan (involving NDAD, donor-recipient pair 1 and recipient of pair 2).
- Donor 2 to waiting list recipient postponed due to theatre availability- rescheduled within 10 days
- 08/11/2019: Donor 2 experienced ischaemic changes under anaesthetic and surgery did not proceed. Coronary angiogram and cardiology review performed urgently.
- Donor 2 remains willing to proceed but, the clinical team felt that he should not donate.
- The recipient on the UKTL did not proceed to transplant and was reactivated on the UKTL

Key Points

- The option for non-simultaneous surgery is important to facilitate transplants, increase flexibility and reduce the risk of non-proceeding exchanges due to scheduling delays.
- The number and proportion of non-simultaneous exchanges has decreased despite an increase in the number of identified transplants
- Intervals between first and last transplant have reduced overall to within 2 weeks (10 working days)
- Recipients on the UKTL who are identified to complete the chain remain at greater risk of missing out on a transplant and are not eligible for prioritisation.
- The risk of transplants not proceeding is lower in non-simultaneous exchanges than for pairs where there are delays scheduling dates for surgery.

- Delays in scheduling identified transplants have increased with increasing activity in the UKLKSS (see section 5) and increases the risk of non-proceeding or incomplete chains.

4. RECIPIENT PRIORITISATION FOR TRANSPLANT

There have been no requests for recipient prioritisation for transplantation for a paired-pooled recipient and no occasions where a donor has donated leaving his/her paired recipient without a transplant since the last report to KAG.

5. NON-PROCEEDING AND DELAYS TO TRANSPLANTS WITHIN THE UKLKSS

Since 2014, the aim has been for 75% of identified transplants to proceed within 8 weeks of the matching run, which was approved in 2011 as the 'clinical standard'. Improvements to the complex registrations and pre-matching run have reduced the offer decline rate and non-proceeding transplants post matching run by 26% in the past 6 months. 74% of identified transplants from the April matching run proceeded. Transplants from the July matching run are yet to complete so final data is awaited.

207 paired/pooled transplants have been performed this calendar year, in comparison with 174 in 2018. This represents 33 (+19%) additional paired/pooled transplants year to date and is the highest annual activity since the start of the scheme.

As activity has increased, scheduling transplants between the three designated weeks of surgery for each matching run to achieve the 8-week standard has become unachievable and has increased the burden of work on transplant centres. From October matching run, with approval from the Chair of KAG, the designated weeks of surgery have been replaced with an aim to achieve the maximum number of transplants prior to confirmation of pair inclusion in the next matching run (to avoid recipients missing out on the option of re-entering a matching run if an exchange fails to proceed) and a new deadline has been provided for each run in the 2020 timetable.

The impact of delay/rescheduling of dates for surgery, when the time between matching run and date of surgery is extended increases the risk that exchanges will not proceed due to recipient/donor factors that may change interim. Previous survey monkey data, presented in June, confirmed that the main reason for delay is due to logistics, including access to theatre

and surgical capacity with a smaller proportion of cases attributed to donor and/or recipient availability.

For the April and July matching runs the proportion of exchanges that were scheduled outside the previously designated weeks of surgery (> 8 weeks) and after the date of the next run significantly increased. 33 survey monkey requests were sent out to understand reasons for delay. Response rate was low (18%) but, of the 6 responses received, 5 cited logistical reasons and 1 availability of donor/recipient. Due to the low response rate, this data is not included as a figure but, in discussion with centres, access to theatre and surgical lists accounts for most scheduling delays.

Centre specific, self-reported data for non-proceeding transplants from the April and July matching runs, collected by survey monkey and ODT on-line incident reporting is shown in Table 2 and Figures 1-3. The data shows the number, proportion (%) and reasons for non-proceeding transplants by centre and if any of those were considered preventable. 15 (75%) responses were received but data was incomplete in a further 2 responses, which limited analysis. Only 1 case was considered preventable by the centre involved and remedial action has been put in place to avoid it happening again. In a few cases where preventable causes were not identified by the centre, some actions have been discussed to reduce the risk of recurrence.

Key Points

- The proportion of non-proceeding transplants due to improvements in registration in the scheme and complex matching run has reduced by 26% since the last report to KAG
- Approximately one third of exchanges are scheduled beyond 8 weeks with a high proportion related to access to theatre. This proportion has increased in the last 6 months.
- Delay in scheduling transplants increases the risk of a recipient missing out on a transplant because:
 - Any recipient or donor in the exchange may become unwell/unsuitable interim causing it to collapse
 - They may miss out on entering the next run if an exchange is scheduled after the next date of inclusion and does not proceed to plan

Immediate measures to increase flexibility in the scheme by extending the timeframe for scheduling transplants between matching runs have been put in place. It is

recommended that a short time working group is set up to look at further options to manage increasing activity in the scheme, including opportunities for collaboration between centres.

The impact of extending the timeframe for transplants to be performed in the most recent matching run has meant that some NDADs/centres have specified a time for donation up to 10-12 weeks ahead. In some of these cases, where NDAD offers are made direct to a single high priority patient, receiving centres have requested that the recipient remains active on the waiting list. The risk of a NDAD not proceeding in this situation is low and there is additional work and disruption to donors, recipients and centres involved if a kidney is offered out more than once and/or close to the scheduled date of surgery. It is recommended that in these cases, if the recipient wishes to remain active on the list, the centre suspends them 2 weeks prior to the scheduled date of transplant with their matched NDAD.

Table 2: Reasons for non-proceeding transplants, April-July 2019 matching runs*

Preventable	Alt. Tx.	Donor unsuitable	Recipient unsuitable	Donor withdrew	Recipient withdrew	Immunological	Total
No	0	2	4	2	0	4	12
Yes	0	0	0	0	0	1	1
No reason or survey response	-	-	1	-	-	1	7

*self-reported data; 75% response rate

Figure 1: Number of non-proceeding transplants by centre, with classification

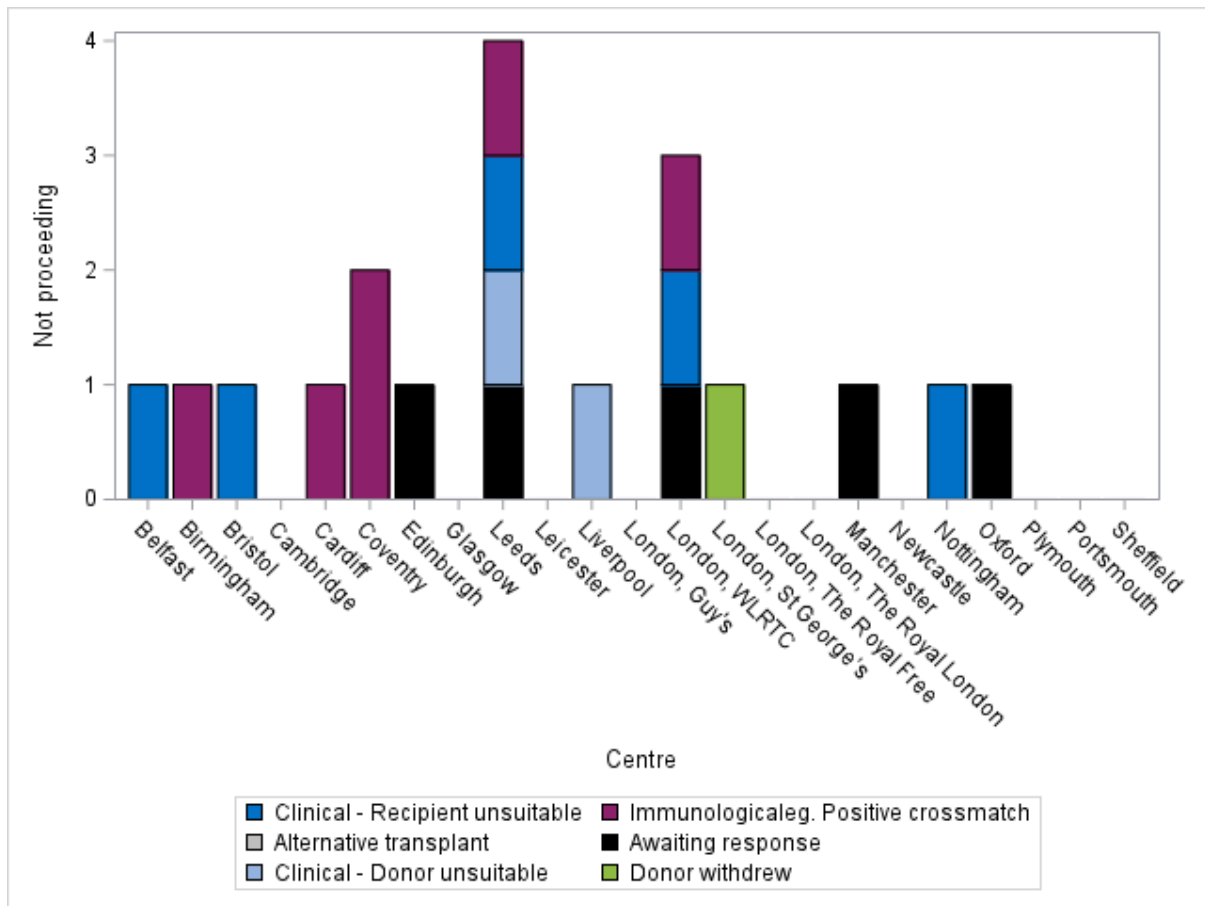


Figure 2: Proportion of non-proceeding transplants by centre, with classification

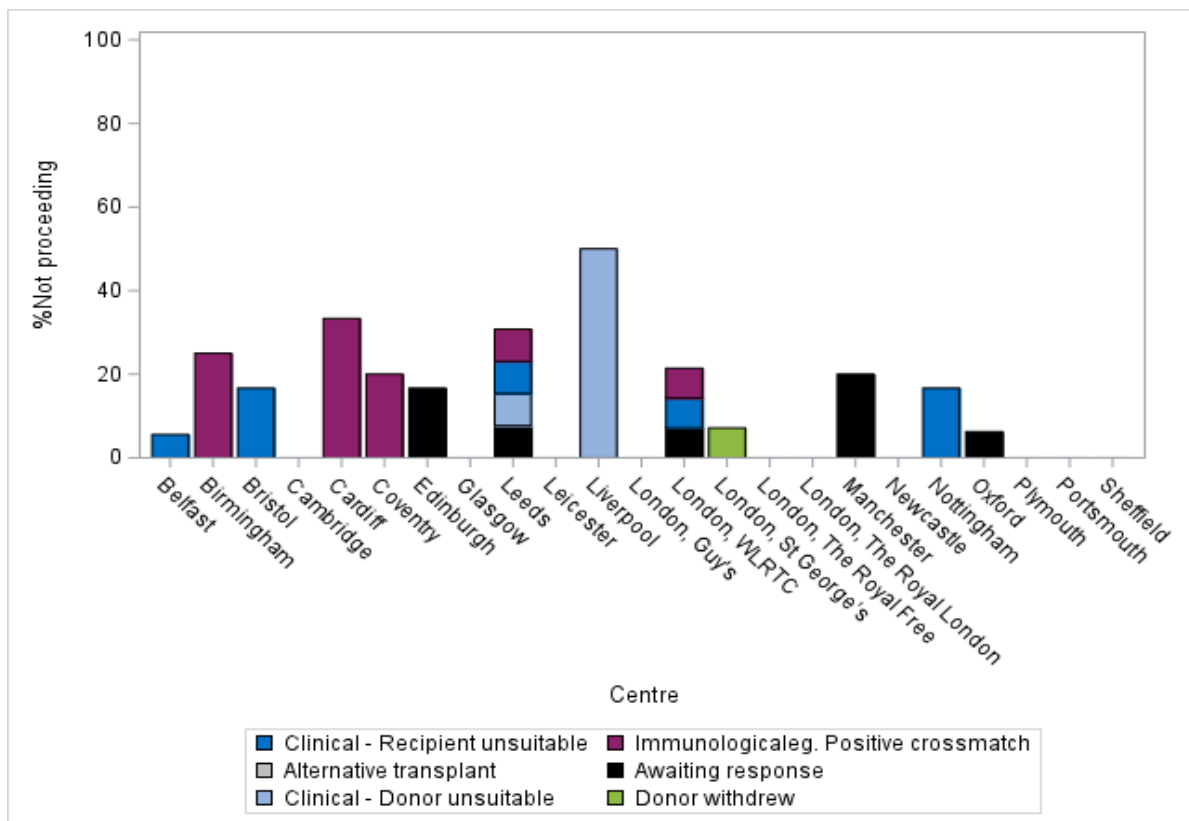
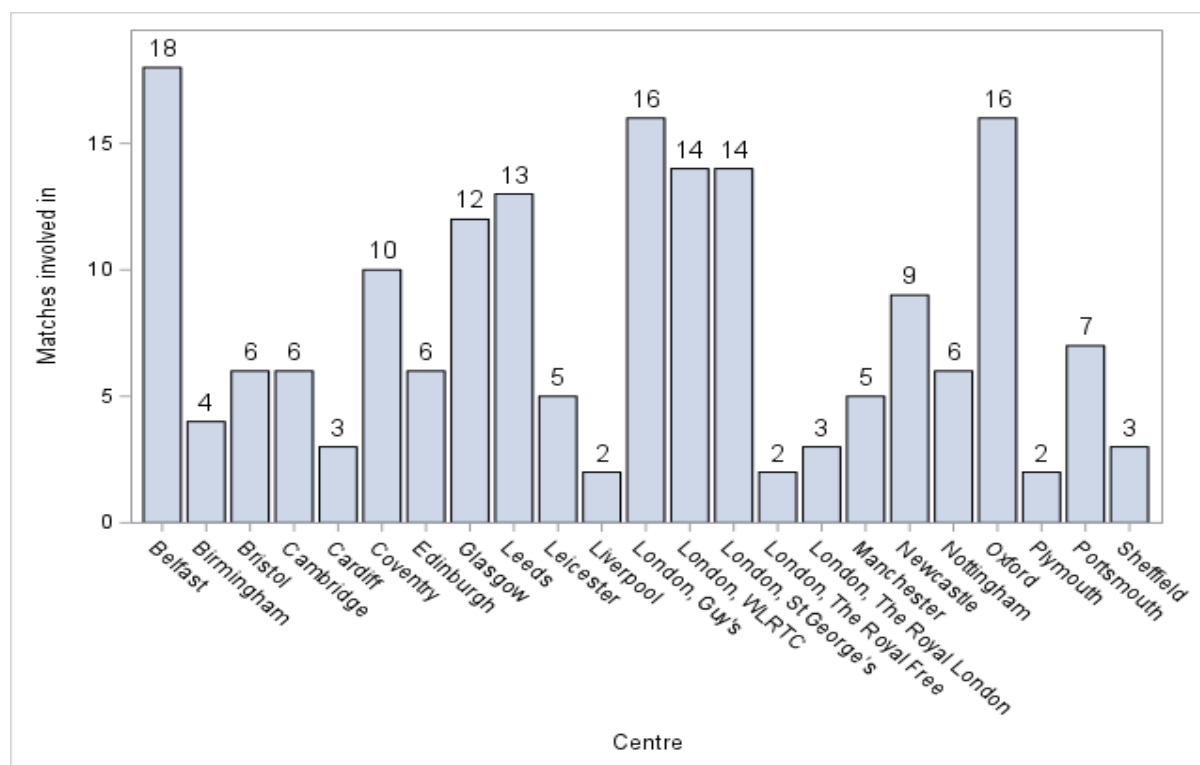


Figure 3: Number of matches in which each centre is involved

6. ON-GOING AND FUTURE DEVELOPMENTS

The UK through NHSBT is a member of the European Network for Collaboration on Kidney Exchange Programmes (ENCKEP) which is looking at opportunities for international collaboration between kidney exchange programmes in European countries. The project has published papers on current practice across the EU and will complete in September 2020 with recommended models for collaboration between countries, optimal matching algorithms and organisational frameworks.

In addition to this, we are currently working with the Netherlands to look at options between the UK and NL that could benefit long-waiting patients in the scheme and statistical modelling, using data from an identified cohort of recipients in both countries is planned. Once complete, this will come to KAG for further discussion.

We have also been approached by one or two other EU countries to consider accepting their selected, long-waiting recipients into the UKLKSS. We put this to the KAG Patient Support Group at their meeting in July, who were supportive. We plan to draw up some criteria that

could form the basis of a Memorandum of Understanding (MoU) between the UK and other EU countries who approach us and bring this back to KAG for further discussion.

7. RECENT CRITICAL INCIDENT IN THE UKLKSS

Under investigation. Verbal update to be given at KAG meeting.

SUMMARY AND RECOMMENDATIONS

KAG members are asked to note the content of this paper, consider actions within local and regional networks to address points 1 and 2 and approve recommendations (point 3).

1. Continue to reduce the risk of non-proceeding transplants within the UKLKSS with careful consideration of complex donor offers and addressing delays to scheduled transplants. Consider the centre-specific data in this report to inform local discussions.
2. Non-simultaneous surgery with short intervals between first and last transplants is relatively low risk and this, together with collaboration with other centres, could be considered more often to manage multiple transplants and reduce delays in scheduling.
3. Approve recommendations (section 5) to:
 - a. Set up a short time working group to look at options to manage increasing activity in the scheme
 - b. To discuss all NDAD offers that are made direct to the UKTL with the recipient concerned to confirm their preference to be suspended or to stay active on the list. If they choose to stay active, agree to suspend recipients with a matched NDAD offer from the deceased donor transplant list 2 weeks prior to scheduled date of transplant.

This paper and the outcomes of the recommendations will be shared with the UK LKD Network in the next quarterly update (December 2019).

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November 2019