KIDNEY ADVISORY GROUP

June 2020

THE UK LIVING KIDNEY SHARING SCHEME: UPDATE AND IMPACT REPORT

1. BACKGROUND

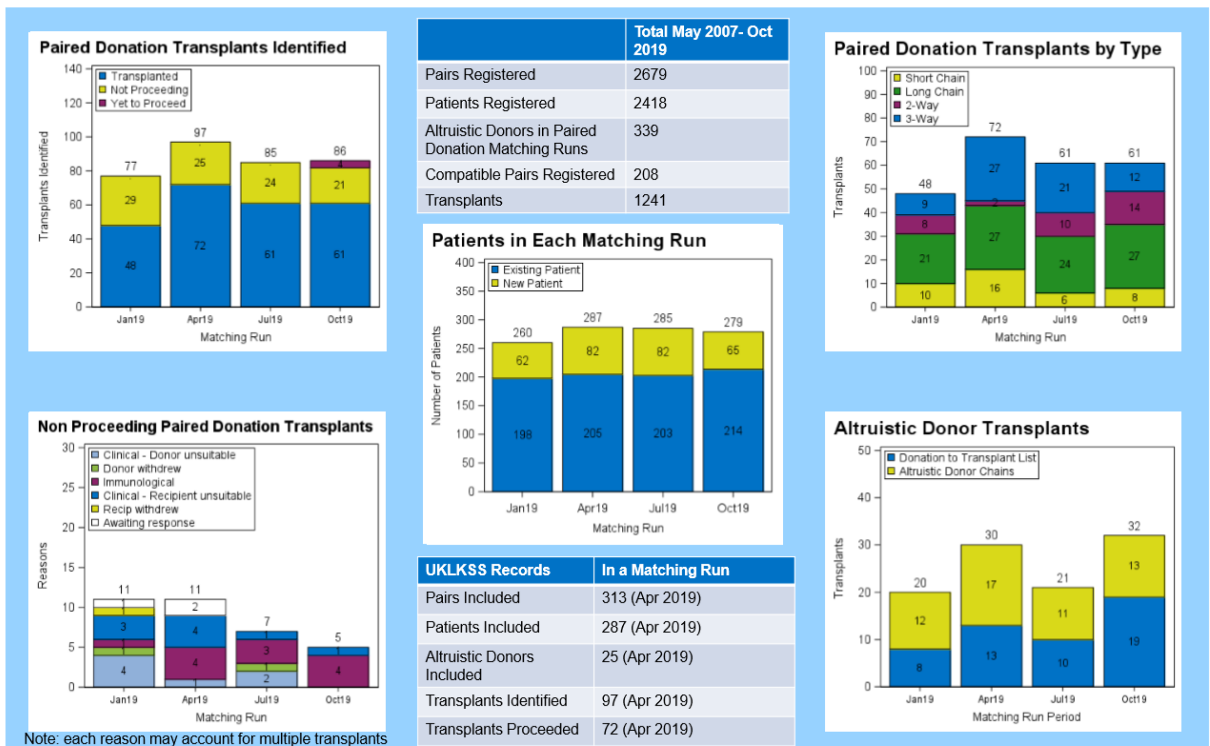
This paper provides a regular report to Kidney Advisory Group (KAG) on the UK Living Kidney Sharing Schemes (UKLKSS). KAG has agreed to monitor the scheme and to recommend changes and improvements as required.

2. ACTIVITY

Figure 1 is the latest UKLKSS quarterly performance report including data from the October 2019 matching run, showing:

- A consistent pool of donors and recipients entering each matching run
- An increase in the proportion of identified transplants proceeding
- An increase in the number of non-directed altruistic donors (NDADs) (> 100 in year for the first time since 2014) and proportion of long altruistic chains identified in each matching run.

Figure 1: UKLKSS Quarterly Performance Report – 2019 Matching Runs



	Total May 2007- Oct 2019
Pairs Registered	2679
Patients Registered	2418
Altruistic Donors in Paired Donation Matching Runs	339
Compatible Pairs Registered	208
Transplants	1241

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)

- The proportion of NDADs donating into a chain has been affected by
    - Introduction of 2019 kidney offering scheme which increased the proportion of NDADs offered to high priority (Tier A) patients. This is expected to resolve overtime
    - Non-proceeding chains – NDADs choose to donate directly to the transplant list rather than wait for the next run
- 4 pending transplants from the October run have yet to proceed due to COVID-19 (see section 3)

3. IMPACT of COVID-19 on UKLKSS

LDKT activity has been paused during the COVID-19 pandemic and no UKLKSS or NDAD transplants have been performed since 14th March 2020. Centre-specific monitoring of non-proceeding transplants and delays has been paused during this period.

The January 2020 matching run was re-run in February due to a registration error (see section 6). Table 1 shows the outcome of the February matching run: 95 transplants were identified, of which 83 were suitable to proceed. 2 transplants proceeded prior to the COVID-19 pandemic, 81 remain outstanding including a recipient who missed out in the October matching run due to a previous registration error (see section 6).

The management of these pending transplants is becoming increasingly critical- delay in scheduling will result in the collapse of many of these exchanges due to recipient suitability, availability of deceased donor transplant offers and/or withdrawal of donors and recipients from the scheme.

Table 1: Outcome of February 2020 Matching Run

Pairs included	299
Recipients included	277
NDADs included	29
Potential transplants identified (including end of chain)	95
2-way exchanges (2 transplants)	4
3-way exchanges (3 transplants)	8
Short altruistic donor chains (2 transplants)	6
Long altruistic donor chain (3 transplants)	17

The April and July 2020 matching runs were postponed due to COVID-19. The October run remains under review. The feasibility of running it is dependent upon:

- The reopening of transplant centres to living donor kidney transplantation (LDKT)
- The scheduling of pending transplants from the previous UKLKSS between now and deadline for inclusion (7th October)
- Capacity of the UK LD programme to accommodate transplants identified within the October matching run within the designated timefame (prior to 7th January 2021).

FOR DISCUSSION

An accompanying paper will discuss options to support the re-starting of LDKT programmes in all centres. KAG is asked to consider the options for proceeding with pending exchanges and whether the October 2020 matching is likely to be feasible, given the above criteria and the rate of recovery of the whole LDKT programme.

4. NON-SIMULTANEOUS DONOR SURGERY

Table 2 shows the number of non-simultaneous exchanges that completed from the October matching run by exchange type, interval between first and last transplant and the centres involved. 15 transplants were facilitated and 4/5 (80%) were completed within 14 days.

Table 2: Completed Non-simultaneous Exchanges- October run

Matching Run	Exchange Type	Days between 1st & last Tx	Centres Involved
Oct-19	Long Chain	3	GOSH, Royal Free, Cardiff Portsmouth
Oct-19	Long Chain	1	Cambridge, Belfast, Portsmouth
Oct-19	Long Chain	4	Guy's, Leicester, Oxford
Oct-19	Long Chain	63	Guy's, Belfast, Manchester, Nottingham
Oct-19	Long Chain	11	Leeds, Guy's, Royal London, Belfast

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

Currently, 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.

FOR DISCUSSION

KAG is asked to consider a recommendation from the fixed-time working group (FTWG) looking at managing capacity in the UKLKSS (see Appendix: outcomes and actions) about the notification and approval of non-simultaneous surgery.

The FTWG recommends that the requirement for centres to **pre-notify** Chair of KAG about non-simultaneous exchanges scheduled to complete within 14 days (2 weeks) is removed and that these transplants and donations are reported to ODT hub information services via the usual post transplant/donation monitoring processes, provided that

- In a 'chain', the NDAD is scheduled to proceed first (i.e. the start of the chain precedes the end)
- The reason for delay is due to logistical/organisational reasons rather than donor or recipient factors

If the scheduled delay is due to donor or recipient factors (clinical or non-clinical) or greater than 2 weeks between any two transplants, approval from Chair of KAG is required. Requests and confirmations for approval to go via NHSBT Clinical Lead for Living Donation.

5. REQUESTS FOR RECIPIENT PRIORITISATION FOR TRANSPLANTATION

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.

In January, KAG approved a request for a recipient to be prioritised who was previously due to receive a direct LDKT. For recipient clinical reasons, the kidney was diverted on the day of surgery to a different recipient. The intended recipient was consequently registered on the transplant list with priority within her Tier (Tier B).

6. CRITICAL INCIDENTS IN THE UKLKSS

Incident 1: October 2019: a registration error within ODT hub information services for the October 2019 matching run resulted in the exclusion of a donor-recipient pair, which was identified two days after the matching run had been notified to all centres. A subsequent run

with the inclusion of the pair identified different combinations of transplants and showed that 5 recipients who would have been matched missed out in the original matching run and 4 patients who were matched, would not have received an offer in the subsequent run. A full internal investigation was performed and actions for improvement identified.

The incident was discussed at November 2019 KAG and it was agreed that:

- The original October run would stand since time had elapsed in the process of resolving the issue and the disruption to patients and colleagues could not be justified.
- The 5 recipients who would have been matched had the error not occurred to be offered prioritisation on the transplant list within their Tier according to the LDKT policy. Additional waiting time points for the next UKLKSS run would be given for recipients who chose to be included.

Prioritisation was discussed with the 5 recipients via their local clinical teams. (see Table 3)

- 3 recipients chose to be prioritised on the transplant list and received deceased donor kidney transplants before inclusion in the next matching run.
- 1 recipient chose to wait for the January matching run and was matched in an exchange that has not proceeded due to COVID-19 (highlighted below).
- 1 centre decided not to discuss prioritisation with their recipient. The recipient's sensitisation status had increased to Crf 100% by the time the matching run had taken place and the donor identified for her would not have been suitable. Other recipient factors were taken into consideration by the local clinical team in making this decision.

Table 3: Outcomes of patients missing out on offers as a result of the incident in the October 2019 matching run

Recip ID	Centre	Outcome
226745	Hammersmith	Prioritised, Tx 17DEC2019 list
226679	St Georges	Prioritised, Tx 22DEC2019 list
220562	Edinburgh	Not prioritised, In Jan run, identified in an exchange. Still outstanding
198897	Leicester	Prioritised, Tx 01JAN2020 list
127358	Birmingham	Not prioritised (Tier A), not transplanted. In Jan run, not identified for Tx

Incident 2: January 2020: a registration error occurred again within the ODT hub information services which was highlighted by the transplant centre concerned on the day that the matching run was notified. As agreed after the previous incident, the run was immediately

declared null and void and the matching run process, including the pre-run for complex donors, was repeated in early February. No recipients affected by this process had been informed of the original offers, so prioritisation did not apply.

A full internal investigation was conducted and actions within ODT hub information services identified to support the manual processes associated with the UKLKSS and communications with centres are in place and will be activated when the UKLKSS resumes post-COVId-19. A business case for a digital platform to support LD activity, including the manual processes associated with the UKLKSS, has been developed and will be discussed internally in the coming months.

7. ON-GOING AND FUTURE DEVELOPMENTS

All development work within the UKLKSS has been paused during COVID-19, including the option for international collaborations with countries through the European Network for Collaboration on Kidney Exchange Programmes (ENCKEP). The ENCKEP project has been extended by 6 months to March 2021 and NHSBT continues to represent the UK within that group.

Following agreement at the last KAG, a FTWG met in March to discuss how capacity in the UKLKSS could be managed given the increasing activity within the scheme. The actions and outcome of the FTWG are attached and are relevant to discussions about COVID recovery plans, including:

- Collaboration between centres
- Increase in low-risk non-simultaneous surgery
- Development of digital platforms to improve scheduling of identified transplants

FOR DISCUSSION

KAG is asked to consider these recommendations and endorse further development work as part of the recovery plans post COVID-19 and as the UKLKSS is reinstated

SUMMARY AND RECOMMENDATIONS

KAG members are asked to note the content of this paper and consider the discussion points in sections 3,4,7 as follows:

1. Consider the options for proceeding with pending exchanges from October 2019 and February 2020 and the feasibility of the October 2020 matching run in the context of restarting the LDKT programme.

2. Remove the requirement to pre-notify non-simultaneous exchanges scheduled to complete within 14 days (2 weeks) provided they meet the criteria set out in section 4.

3. Endorse recommendations from the 'Managing Capacity in the UKLKSS' FTWG.

This paper and the outcomes of the recommendations will be shared with the UK LKD Network.

Lisa Burnapp, Clinical Lead- Living Donation
Matthew Robb, Principal Statistician
June 2020

Fixed Time Working Group (FTWG): Managing Activity in the UK Living Kidney Sharing Scheme (UKLKSS)
10:00-12:30 hrs on Wednesday, 18 March 2020 (by teleconference)
Actions and Outcomes of Meeting

Attended:
Lisa Burnapp (Chair) (LB) Clinical Lead, Living Donation, Organ and Tissue Donation and Transplantation (OTDT), NHSBT
Dr Aisling Courtney Consultant Nephrologist, Belfast City Hospital
Dr Matthew Robb (MR) Principal Statistician, Stats & Clinical Studies, NHSBT
Sam Thomas Higher Information Officer, OTDT Hub Information Services, NHSBT
Mr Frank Dor Consultant Transplant Surgeon, West London Renal Transplant Centre
Mr Keith Graetz Consultant Transplant and General Surgeon and Clinical Director for Transplant, Queen Alexandra Hospital
Lisa Silas Advanced Nurse Practitioner, Guy's & St Thomas' Hospital
Sarah Lundie Living Donor Co-Ordinator, Royal Infirmary of Edinburgh
Mr John Asher Consultant Surgeon and IT Clinical Lead, NHSBT
Jeanette Ayers Transplant Immunology Laboratory, Churchill Hospital, Oxford
Mr David van Dellen Consultant Transplant Surgeon, Manchester Royal Infirmary

Apologies:
Dr Tracey Rees Head of Welsh Histocompatibility and Immunogenetics Service, Chief Scientific Advisor, OTDT, NHSBT
Dr Richard Baker Consultant Nephrologist, Leeds Teaching Hospitals NHS Trust
Dr Gareth Jones Consultant Nephrologist, Royal Free Hospital
Sara Stacey Living Donor Co-Ordinator, University Hospital of Wales

PURPOSE OF FTWG

1. Identify the barriers to proceeding with donation and transplantation for identified exchanges within the scheduled timetable for each matching run.
2. Make recommendations on how to manage increasing activity in the UKLKSS due to the number of transplants that are identified in each matching run.
3. To ensure that recipients do not miss out on a transplant and/or donors do not withdraw due to delay in scheduling dates for surgery.

1. IDENTIFYING THE BARRIERS TO SCHEDULING DONATION AND TRANSPLANTATION

Discussion based on slide presentation from MR (slides previously circulated)
Key points:

Challenge	Discussion Points/Identified causes
1. **Average: c. 90 transplants identified per matching run** but predicted to increase over time (see 5)	• UKLKSS pool size remains c. 275-300 pairs/run. Increase in NDADs and compatible pairs contributing to pool size

	• Post run: 11 week 'window' to transplant (Tx) before inclusion/miss out in next run if exchange does not proceed • Post run window reduced to 9 weeks once xm results confirmed in all centres
2. **72% transplants scheduled within 11 weeks**, average 9 weeks, peak at 8 weeks (range 2-24 weeks), in past 5 years. Minimal change over time.	• All centres participate in UKLKSS, but activity varies between centres • Centre-specific activity (high or low) does not correlate directly with time to transplant (Tx) as high and low volume centres matched in an exchange impact on one another • Access to theatre and synchronised lists across all centres primary cause of delay in scheduling • Often out of hours surgery for recipient centres- requires additional funding, staff and transport requirements (particularly where flights involved)
3. **Non-proceeding transplants-** average 65% proceed (overall); proportion proceeding > 70% in 2019/3 latest runs	• Improved proceeding rate due to improvements in registering donor complexity but work on-going with individual centres to improve further • Immunological complexity main cause of early non-proceeding Txs. • Late non-proceeding Txs. due to recipient unfit/pair withdrew exacerbated by delay to Tx.
4. Future challenges: **Increase in pool size** due to increase in number and proportion of NDADs included in the UKLKSS and uptake for compatible pairs **Increase in complexity** due to developments e.g. longer chains and increased uptake of ABOi Txs.	• Recommendations from FTWG must allow for continuous improvement initiatives within the UKLKSS and maximise benefit for recipients and donors within the scheme

2. POSSIBLE SOLUTIONS

Discussion based on slide presentation from LB (slides previously circulated)

Possible Solution	Impact	Action/Mitigation	By Whom
1. **Increase low risk non-simultaneous surgery** i.e.	• Reduce delay in scheduling Txs.	• Build confidence in non-simultaneous surgery in clinical/donor/recipient community	**All**

transplants within an exchange scheduled within 1-2 weeks for logistical reasons	• Minimise risk of non-proceeding Txs. due to delay • Relieve pressure on Tx. centres to synchronise surgery • Increase resilience in the UKLKSS to accommodate future developments **Potential Risk/s** • Non-proceeding Txs. due to donor withdrawal • Impact on recipients at end of/completing chains if earlier donations do not proceed	• Retain principle of NDAD initiating chain in relevant non-simultaneous exchanges • Discuss with Chair of KAG removing requirement for centres to seek permission for all non-simultaneous surgery within 1-2 weeks as per agreed criteria. Notification to lkdschemes@nhsbt.nhs.uk team to be retained • Ensure donor/recipient consent criteria and template for requests outside the 2 week notification period is widely circulated (see appendix)	**All** **LB** **LB**
2. Collaboration between Tx. centres (new or existing collaborations)	• Share best practice and improve utilisation & effectiveness of UKLKSS e.g. 2nd opinion for complex recipients & donors; use of NDADs, compatible pairs; ABOi within the UKLKSS • Distribute activity between centres if needed to alleviate scheduling delays and non-proceeding Txs. (reasons as above) • Aligned with current initiatives to develop Tx. collaboratives **Potential Risk/s** • Financial implications for centres re performing Tx. activity • Tx. activity reporting not appropriately attributed	• Explore options within existing collaboratives (e.g. London PLC; CoXNet) to agree principles and rules of engagement for UKLKSS cases to alleviate potential risks • Share learning to inform and support practice in emerging collaboratives • As a first step: encourage buddying/self-selected collaborations based on pre-existing relationships that already work informally between centres	**All** **All** **KAG**

	• Cultural shift for colleagues, donors and recipients • Risk management/governance associated with transferring patients between centres		
3. Automated, scheduling of identified Txs. via OTDT (IT solution)	• Effective utilisation of available surgical lists to reduce delay and schedule Txs. identified in each run • Frees up the clinical workforce -reduce time spent by living donor teams coordinating /negotiating lists locally and between centres **Potential Risk/s** • Requires IT solution-cannot be performed by OTDT as a manual process • If it is not uncoupled from matching algorithm, it could influence optimal solution for matching run • Requires clinical 'buy-in' to work across all centres	• Explore IT options/possible algorithms that could be used • Scope appetite within clinical community via KAG • Present possible solutions to KAG for discussion	**OTDT** **LB/KAG** **LB/KAG**

3. NEXT STEPS

1. Present actions and outcomes to next (June) Kidney Advisory Group (KAG) meeting
   LB
2. If approved, progress actions as possible (pending Covid 19)
   LB/All

3. Convene (? on-line) meeting post Covid 19 to agree plan of action
   All

Appendix:

REQUEST FOR NON-SIMULTANEOUS SURGERY IN THE UK LIVING KIDNEY SHARING SCHEME

Please email all requests to lisa.burnapp@nhsbt.nhs.uk and lkdschemes@nhsbt.nhs.uk

Matching run (e.g. January 2020)	
Exchange ID	
Type of exchange/chain (2 or 3 way; short or long chain)	
Centres involved with each donor or donor-recipient pair e.g. NDAD, centre A Donor-recipient pair 1, centre B Donor-recipient pair 2, centre C Recipient on waiting list, centre D (if known)	
Proposed dates of surgery by centre e.g. 1st March: NDAD centre A donating to recipient 1 centre B 2nd March: paired donor 1, centre B donating to recipient 2, centre C 2nd March: paired donor 2, centre B donating to recipient on w/l, centre D (or to be confirmed)	
Reason for non-simultaneous surgery (e.g. access to same day theatres/availability of surgeon/etc.)	
Please confirm that the following points have been included/will be included with all relevant donors and recipients in the exchange in their consent to non-simultaneous surgery: 1. Their commitment to complete the exchange remains the same as for simultaneous surgery 2. All donors and recipients understand that there is a low risk of transplants not proceeding but the consequences for recipients who miss out can be significant, particularly if they are highly sensitised. The recipient at the end of a chain is more vulnerable when chains do not complete because they are not eligible for prioritisation (see below) 3. Recipients who miss out on a transplant when their paired donor has already donated and the kidney has been successfully transplanted within the scheme are eligible for prioritisation on the transplant list within their Tier (A or B on the national deceased donor offering scheme). This does not include recipients from the waiting list who complete the chain. The policy is here: https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/ 4. When discussing prioritisation for transplant with recipients, please explain that 'within their Tier' does not equate to 'top of the list' and their likelihood of receiving a transplant on the list will be influenced by individual factors e.g. sensitisation, age. In particular, patients who are highly sensitised may receive no real benefit from prioritisation in terms of rapid access to a kidney since they are already prioritised within the kidney offering scheme.	