

**KIDNEY ADVISORY GROUP
NOVEMBER 2020
LIVING DONOR KIDNEY TRANSPLANTATION: UPDATE**

1. BACKGROUND

This paper provides an update on activities related to living donor kidney transplantation (LDKT). It will cover:

- Activity and impact of COVID-19
- UK Living Kidney Sharing Schemes (UKLKSS)
- Requests for prioritisation for transplantation
- National Focal Point (NFP): travel for transplantation

2. ACTIVITY AND IMPACT OF COVID-19

Figure 1 shows overall LDKT activity between February and October 2020. All adult and paediatric LDKT paused for 2 months from 27th March until 28th May during the first wave of the COVID-19 pandemic. Between 28th May and end of September, all centres resumed LDKT activity. This indicates that LDKT activity post-COVID is reduced by approximately 50% and is likely to continue on a similar trajectory until the end of the financial year.

Figure 1

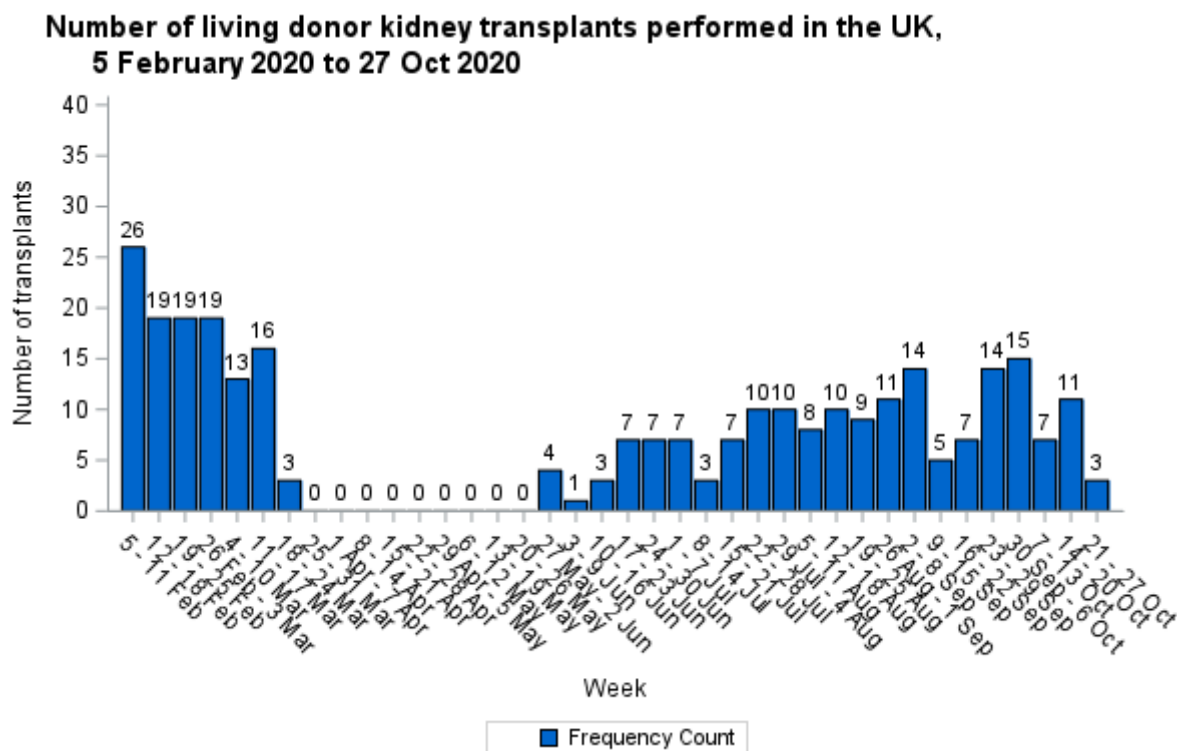
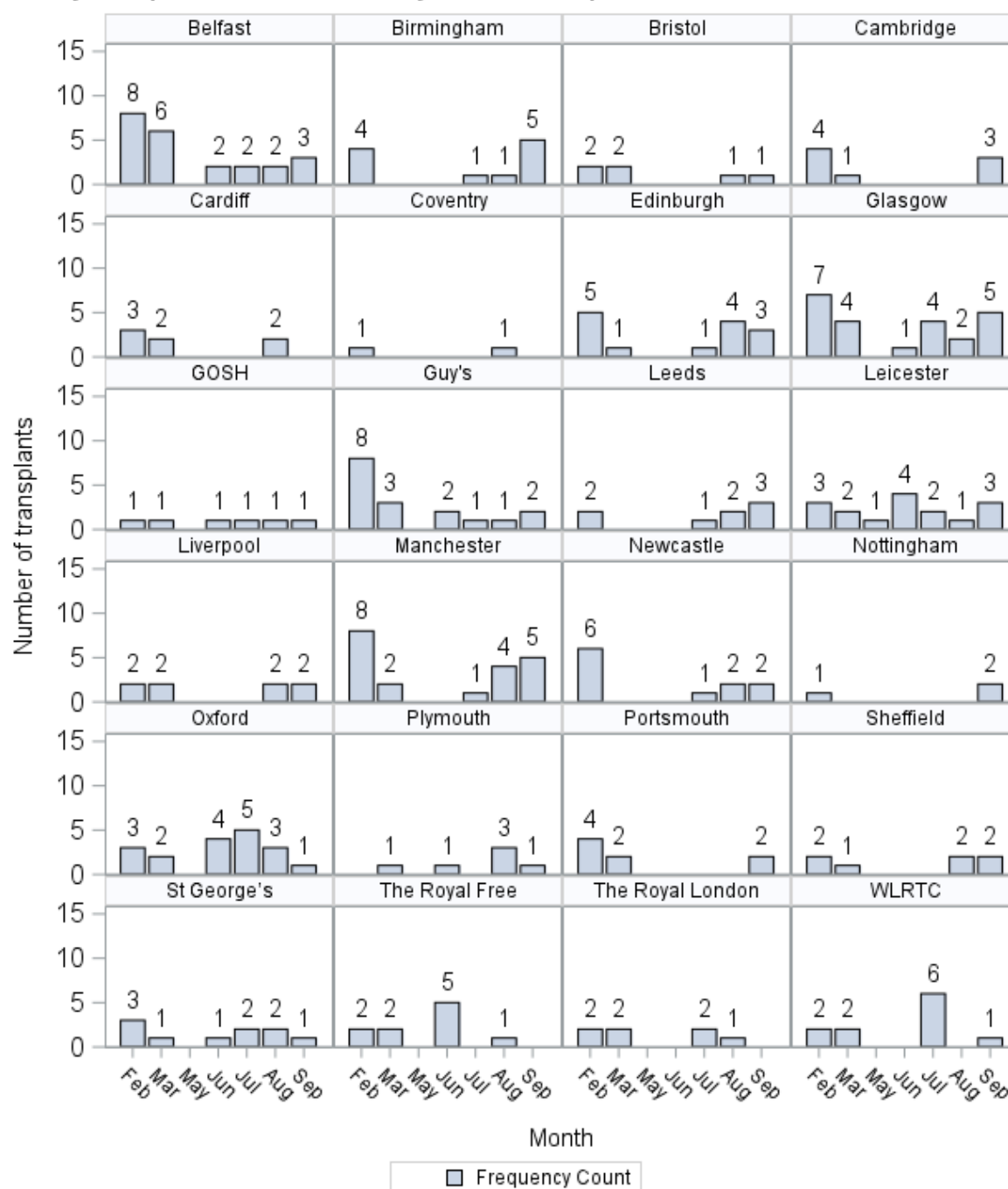


Figure 2 shows activity by centre from February to September. Following discussion at Kidney

Advisory Group (KAG) in June 2020, 22/23 adult LDKT transplant centres (including their linked paediatric centres) submitted 'Restoration Plans' to recover and protect their programmes in the event of a second wave of the pandemic. LDKT 'business as usual' is still impacted by local restrictions and community prevalence of COVID but all centres have remained open during the second wave of the pandemic.

Figure 2:

Number of living donor kidney transplants performed in the UK, by transplant centre, 1 February 2020 to 30 September 2020



LDKT is reported by NHSBT 1 month in arrears to accommodate late reporting of transplant activity. This has made it difficult to track the progress of recovery in real time through the COVID-19 era and accurately assess progress and recovery.

The 2019/20 centre-specific LDKT report is due to be published at <https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/> within the next few weeks

Centres are asked to note the importance of timely reporting of LDKT activity to NHSBT and to consider ways in which they could improve this to increase the accuracy and completeness of data.

3. UK LIVING KIDNEY SHARING SCHEME (UKLKSS)

Matching Runs and Activity

The April and July 2020 matching runs were suspended due to the COVID-19 pandemic and the UKLKSS was reinstated in October 2020 with the support of KAG and all transplant centres. Table 1 shows the outcome of the October run, which was comparable in size to those in the immediate pre-COVID era. Selection of donors and recipients for inclusion was performed by individual centres, taking into account donor and recipient factors, local constraints and capacity to safely proceed with identified transplants in the COVID environment.

Table 1: Summary of October 2020 Matching Run

Pairs included	247
Recipients included	231
Non-directed altruistic donors included	21
Transplants identified	92
2-way exchanges	9
3-way exchanges	8
Short altruistic donor chains	10
Long altruistic donor chains	10

Of the outstanding transplants identified in matching runs pre-COVID, it is anticipated that 50% will proceed, which is a significant achievement and testament to the hard work in every centre. An updated breakdown of this data will be available for the meeting next week

The main reasons for identified transplants not proceeding after the first wave of the pandemic was due to recipients becoming clinically unsuitable and donors withdrawing.

In view of this, the management of transplants identified in the October run is critical to reduce the risk of non-proceeding and missed transplant opportunities. Centres are asked to consider the following options to overcome local constraints to facilitate timely surgery:

- Low risk non-simultaneous surgery (all transplants performed within a maximum of 14 days; non-directed altruistic donor proceeds first in any staggered chain) to overcome logistical challenges
- Collaboration with other centres (within/out with the identified exchange group) to facilitate donor and/or recipient surgery

Please contact lisa.burnapp@nhsbt.nhs.uk directly if further discussion about these options for individual cases would be helpful or if there are particular limitations in your centre that are likely to cause delays in scheduling transplants. Progress to plan will remain under review.

Incidents in the UKLKSS

We previously reported two critical incidents related to the October 2019 and January 2020 matching runs. One recipient who missed out on a transplant in October 2019 entered the January 2020 matching run and remained matched in an exchange in the repeat February run, which was unable to proceed following the first COVID wave. He then asked to be prioritised on the waiting list and has now received a deceased donor kidney. All recipients from the October 2019 matching run who missed out on the offer of a transplant and requested prioritisation have now been transplanted from the waiting list.

As a result of these incidents, Root Cause Analyses were performed and the following actions have been put in place to mitigate risks:

- All manual processes related to the registration and inclusion of donors and recipients in the UKLKSS matching runs have been reviewed and additional safeguards put in place to minimise risks
- Development of a digital platform to underpin the critical processes within the UKLKSS has been prioritised within NHSBT and work is in progress to develop a full business

case. Members of a previously convened KAG fixed time working group (FTWG) have been invited to attend an users' workshop in the next 2 weeks

Of note, the additional scrutiny and safeguards were successful in identifying and averting two near misses prior to the October 2020 matching run. However, a further near miss, which may have had a significant impact on the matching run, was subsequently noted and fully investigated. Additional safeguards will be implemented before the next matching run to prevent a similar recurrence.

The Scientific Support Team and Registration Team within OTDT Hub Information Services have worked tirelessly with relevant colleagues to implement the necessary changes, including additional safety checks and cross-checks with key contacts (living donor coordinators) in transplant centres; often working remotely due to COVID restrictions.

The dependence on manual, paper-based processes, has been recognised as a risk in the prioritisation of developing a digital platform to support critical functions related to the UKLKSS. In the meantime, we ask all centres to help us to safeguard the scheme by:

- Using the required linked donor-recipient registration forms for all registrations in the UKLKSS
- Ensuring that registration details are complete and accurate and include appropriate HLA and age mismatch requirements (recipient) and relevant donor complexity
- Submitting all amendment requests for donors and/or recipients on the correct forms and within the specified deadlines for inclusion, to the correct NHSBT inbox
- Checking all confirmation reports are correct or amended and returning them to the correct NHSBT inbox by the required deadline
- Understanding that exception requests are associated with a high risk of error and cannot be safely accepted outside agreed processes
- In the 'COVID era', selecting donors and recipients that you include in each matching run carefully to minimise risk of non-proceeding transplants in the event of scheduling delays

Thank you for your continued support in helping us to deliver this important scheme.

4. REQUESTS FOR PRIORITISATION FOR TRANSPLANTATION

Apart from the scenario described above, there have been no additional 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 accordance with Living Donor Kidney Transplantation Strategy at

<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19841/pol274-living-donor-kidney-transplantation.pdf>, a previous donor from 2010 has recently been prioritised for transplantation, having commenced renal replacement therapy in May. The cause of kidney failure is unknown.

5. LIVING DONATION IN THE NEXT ORGAN DONATION AND TRANSPLANTATION STRATEGY

The next 10-year strategy for organ donation and transplantation includes both living and deceased donation, incorporating the learning and recommendations from the 'LDKT 2020' strategy implementation group in the ambitions for living donation. This is a significant achievement. The strategy will be presented to the NHSBT Board on 26th November 2020 and, subject to approval by all 4 Health Departments, it is anticipated that it will be launched early next year.

6. NATIONAL FOCAL POINT (NFP) FOR TRANSPLANT RELATED CRIMES

NHSBT has provided the National Focal Point (NFP) representation for the UK on the Council of Europe NFP Network since its inception in 2016. The purpose of the network is to identify illegal travel for donation and/or transplantation to help prevent transplant-related crimes.

In 2018, a letter from NHSBT was sent to all centres related to this activity, explaining its purpose and the requirements for data collection. (Appendix 1) Since then, anonymised data has been submitted annually to the European Registry, 2 years in arrears (to allow 1-year follow-up) on:

- Recipients 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

A minimum data set is held in the UK Transplant and Living Donor Registry on these cases, which indicates that the incidence of patients returning from abroad with a transplant is low and all related to LDKT. Recipients of LDKT in the UK from a non-resident donor must comply with the Human Tissue Act requirements so these present a low risk in our current practice in comparison with other countries.

To improve the effectiveness of the NFP work and the completeness and accuracy of data we collect on travel for transplantation, we would be grateful for your support in:

- Reporting all cases of recipients returning from outside the UK with a transplant on arrival in the UK on-line at <https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-quality/tell-us-about-an-incident/>
- Completing the relevant questionnaire survey on these cases, as requested
- Contacting lisa.burnapp@nhsbt.nhs.uk with any queries or concerns about patients who may wish to seek a transplant outside the UK without a proper referral

SUMMARY AND RECOMMENDATIONS

KAG members are asked to note the content of this paper and consider the following requests:

1. Centres are asked to note the importance of timely reporting of LDKT activity to NHSBT and to consider ways in which they could improve this to increase the accuracy and completeness of data.
2. To reduce the risk of non-proceeding and missed transplant opportunities in the October run. Centres are asked to consider the following options to overcome local constraints to facilitate timely surgery:
 - Low risk non-simultaneous surgery (all transplants performed within a maximum of 14 days; non-directed altruistic donor proceeds first in any staggered chain) to overcome logistical challenges
 - Collaboration with other centres (within/out with the identified exchange group) to facilitate donor and/or recipient surgery

- Contact lisa.burnapp@nhsbt.nhs.uk directly if further discussion about these options for individual cases would be helpful or if there are particular limitations in your centre that are likely to cause delays in scheduling transplants.
3. To support critical functions related to the UKLKSS, that are currently dependent on manual processes, we ask all centres to help us to safeguard the scheme by:
 - Using the required linked donor-recipient registration forms for all registrations in the UKLKSS
 - Ensuring that registration details are complete and accurate and include appropriate HLA and age mismatch requirements (recipient) and relevant donor complexity
 - Submitting all amendment requests for donors and/or recipients on the correct forms and within the specified deadlines for inclusion, to the correct NHSBT inbox
 - Checking all confirmation reports are correct or amended and returning them to the correct NHSBT inbox by the required deadline
 - Understanding that exception requests are associated with a high risk of error and cannot be safely accepted outside agreed processes
 - In the 'COVID era', selecting donors and recipients that you include in each matching run carefully to minimise risk of non-proceeding transplants in the event of scheduling delays
 4. To improve the effectiveness of the NFP work and the completeness and accuracy of data we collect on travel for transplantation, we would be grateful for your support in:
 - Reporting all cases of recipients returning from outside the UK with a transplant on arrival in the UK on-line at <https://www.odt.nhs.uk/odt-structures-and-standards/governance-and-quality/tell-us-about-an-incident/>
 - Completing the relevant questionnaire survey on these cases, as requested
 - Contacting lisa.burnapp@nhsbt.nhs.uk with any queries or concerns about patients who may wish to seek a transplant outside the UK without a proper referral

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

Lisa Burnapp, Clinical Lead- Living Donation

With thanks for data provided by

Matthew Robb, Principal Statistician

Iain Harrison, Product Owner, OTDT

Scientific Support Team, Hub Information Services, OTDT

November 2020

Appendix 1: Letter re Transplant Related Crimes



Blood and Transplant

006-2018: SJJFLB/CR

For the attention of
All Clinical Directors of Transplant Centres
Nephrology Centres
UK LKD Network

Head Office
Oak House
Reeds Crescent
Watford
Hertfordshire
WD24 4QN

Tel: 01923 388800
www.blood.co.uk

24 January 2018

Dear Colleagues

Help us eradicate illegal transplantation

The UK is working with colleagues across Europe and further afield to eradicate illegal transplantation, a form of modern slavery where organ donors are procured using reward or coercion for living donor transplantation. The Modern Slavery Act 2015 makes it illegal for anyone from the UK to arrange a transplant abroad that does not meet the ethical requirements of the Human Tissue Act.

UK data for 2015 shows that 8 UK residents presented at transplant centres for follow-up care following kidney transplantation abroad. The detail of the data means that we do not know if this captures all patients who have travelled for a transplant or if any of these transplants have been associated with criminal activity. Some patients had been suspended from the transplant list and many travelled to the Indian sub-continent and Sri Lanka for their transplant.

We want to support you in caring for your patients whilst also collecting information that will help the proper authorities end UK involvement in transplant related crime. To do this, we need more detail in the data that you already provide to the UK Transplant Registry.

We need your help to:

- Collect comprehensive data about anyone who has a transplant abroad. We will request this from you annually by questionnaire on a retrospective basis, one year in arrears.
- Where someone returns following transplantation abroad and you suspect that there may be something untoward, contact Sally Johnson at sally.johnson@nhsbt.nhs.uk or Lisa Burnapp at lisa.burnapp@nhsbt.nhs.uk who act as the National Focal Point for transplant related crime. We can provide advice where there is potential trafficking.
- Provide your usual standard of care to the returning transplant recipient. We are interested in finding out information about brokers and transplant centres that engage in transplant related crime, NOT in prosecuting vulnerable transplant recipients.
- If you have patients who ask about travel for transplantation, advise them that this may be both illegal and dangerous. You can use the leaflet on the following website to support you in this discussion. <http://www.declarationofistanbul.org/resources/patient-brochure-thinking-about-a-kidney> It is available in a range of languages.



If a patient has a potential family donor living outside the UK, they may plan to travel abroad to avoid delay -for example, awaiting UK Entry Visa clearance for their relative. We already work with other agencies to discourage this activity. Please contact us to provide advice and support.

With your help we can achieve a better understanding of this activity and work with other agencies to support patients and their families and stop illegal activity.

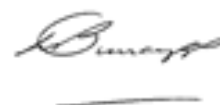
Yours sincerely



E Sally Johnson
Director of Organ Donation
& Transplantation (ODT)



John Forsythe
Associate Medical Director – ODT



Lisa Burnapp
Lead Nurse for Living
Donation

cc Alan Marriott Smith, Human Tissue Authority - Allan.Marriott-Smith@hta.gov.uk
Kevin Hyland, Modern Slavery Commissioner - IASC@antislaverycommissioner.gsi.gov.uk
Lorna Marson, British Transplantation Society - Lorna.Marson@ed.ac.uk