NHSBT Board July 27 2017

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Update on UK Living Kidney Sharing Scheme

1. Status – Public

2. Executive Summary

This paper provides an update on activity and plans for the UK Living Kidney Sharing Scheme (UKLKSS), which allows flexible ways to increase the number of living donor kidney transplants. The scheme is the largest in Europe and the UK is seen as one of the leaders in this field in the world. The scheme is under constant review with improvements made regularly to minimise the rate at which transplants do not proceed and to maximise transplant opportunities in innovative ways.

3. Action Requested

The Board is asked to:

- Note the success of the UK scheme and the contribution it makes to kidney transplantation in the UK
- Note ongoing improvements in the scheme to benefit more patients

4. Purpose of the paper

This paper is for the Board's information. It provides an update on recent activity and developments in the UKLKSS.

5. Background

- 5.1. Living donor kidney transplantation (LDKT) offers patients with end-stage kidney disease the opportunity for timely transplantation and excellent transplant outcomes. Around one-third of potential recipients are, however, human leucocyte antigen (HLA) or ABO blood group (ABO) antibody-incompatible with their intended living donor. Historically, this precluded LDKT because of the very high risk of early graft loss but advances now enable many such cases to proceed safely to LDKT.
- 5.2. In some recipients, ABO or HLA antibody levels are sufficiently low that they are amenable to desensitisation (antibody removal) strategies that allow direct transplantation to proceed relatively safely. While for ABO-incompatible LDKT the reported outcomes are similar to those for ABO-compatible transplants, in the case of HLA antibody-incompatible LDKT outcomes remain inferior to those for HLA-compatible transplantation.

5.3. The other major development that has allowed safe transplantation of recipients with willing but antibody incompatible donors is that of kidney paired donation (KPD). Such schemes facilitate exchange of living donor (LD) kidneys between donor/recipient pairs (see examples below, Figure 1), enabling selected recipients to receive antibody-compatible kidney transplants. The UK scheme became operational in 2007 following the Human Tissues Acts 2004 and 2006 (for Scotland) which were enacted in September 2006.



Figure 1 Illustration of exchanges between 2 and 3 donor-recipient pairs

5.4. The possibilities for LDKT are further enhanced by non-directed altruistic living kidney donors. These donors have no intended recipient and volunteer to donate to someone in need of a transplant. They currently have a choice about whether to donate into the KPD pool, to initiate a chain of up to three transplants, or to donate to a single patient on the deceased donor waiting list (see Figure 2 below).

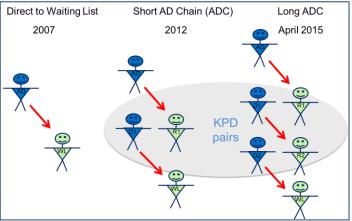


Figure 2 Transplant possibilities for non-directed altruistic living kidney donors

5.5. Further enhancements to the scheme allow compatible pairs to participate (usually to benefit by a better HLA match or a younger donor), to allow non-simultaneous surgery to give more flexibility for patients and transplant centres and to allow low risk desensitisation in an exchange or chain.

6. Activity and Develoment

6.1. The UK scheme has grown to be the largest in Europe, with 707 transplants made possible to date, which is more than double that of the

next most successful European scheme (in the Netherlands), and which represents about half of the total European activity.

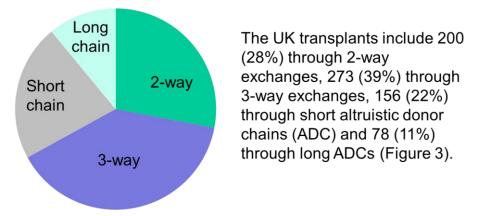


Figure 3 The UK's 707 transplants to date by type of exchange

6.2. The UKLKSS contributes an increasing and important proportion of LDKT in the UK as shown below (Figure 4). While the number of LDKT overall has fallen in the last 4 years, non-directed altruistic donation and paired donation combined have contributed 20% of all LD kidney transplants in the UK (as highlighted). The fall in overall LDKT numbers is linked to the increase in deceased donor transplantation over recent years and the shorter waiting times that patients on the kidney transplant waiting list now face.

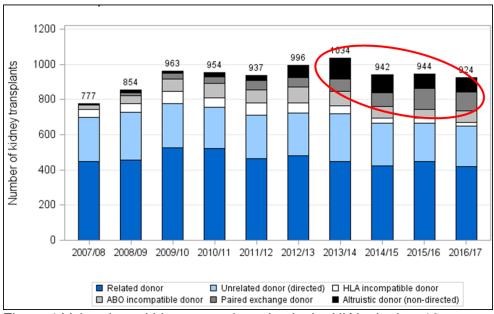


Figure 4 Living donor kidney transplantation in the UK in the last 10 years

6.3. It is clear that to benefit patients, transplants through UKLKSS are increasingly replacing the more risky, complex and expensive antibody incompatible transplants that may otherwise be undertaken.

- 6.4. While successful, the scheme is not without problems and as in other national schemes, a proportion of the transplants identified in the 3-monthly matching runs do not proceed. Among the 1676 patients registered, 1133 transplants have been identified of which 707 proceeded (62%). The proportion of proceeding transplants has, however, increased over time with the introduction of new initiatives. The LDKT 2020 strategy aims for 75% of transplants identified within the UKLKSS to proceed by 2020.
- 6.5. There are many reasons why identified transplants do not proceed, but the most common reason is that one of the potential donors or recipients in an exchange or chain becomes unfit for transplant (because some new issue is identified or they are temporarily unwell at time of planned transplant). Other common reasons are that the match cannot proceed due to unexpected HLA incompatibility (positive cross-match) or a donor or recipient withdraws (some of which is unavoidable).
- 6.6. The reasons why transplants do not proceed are scrutinised and there is a discussion with the transplant centre involved if the issue is considered to be avoidable.

7. Future Improvements

- 7.1. The principle of continuous improvement, to increase transplant opportunities and maximise effectiveness, is embedded within the scheme and is reflected in the developments and activity to date (see sections 5 and 6). All changes to the schemes are approved and monitored by the kidney advisory group at their bi-annual meetings prior to implementation. More recent changes include; introduction of longer altruistic donor chains; non-simultaneous donor surgery; dedicated weeks of surgery for each matching run; and prioritisation for transplantation for recipients who miss out on a transplant during an exchange procedure.
- 7.2. In June the Kidney Advisory Group supported a proposal to offer chain donation as the default for non-directed altruistic donors to increase transplant possibilities for pairs in the pool. They also agreed that pool donors at the end of a chain could donate into the next matching run if they wished to, rather than donate to a patient on the deceased donor waiting list. In this way they act as a 'bridge' donor to generate more transplants in the next matching run. These represent key developments in the evolution of the scheme and will be implemented in January 2018.
- 7.3. A recent internal meeting with relevant individuals highlighted an action plan to further improve efficiency of running the scheme and to discuss operational improvements to optimise transplant numbers. To engage support from the clinical community and embed these changes, NHSBT

will host a UK-wide UKLKSS workshop on 6 October 2017 involving representatives from all 23 kidney transplant centres, their referring nephrology units and histocompatibility and immunogenetics (H&I) laboratories.

7.4. The workshop will provide an opportunity for clinical colleagues to review patient pathways and discuss ways in which they can use the innovations and flexibility within the schemes to maximise patient benefit. As with previous workshops, the aim will be to agree actions to deliver key improvements from January 2018. This will be taken forward by the LDKT 2020 Strategy implementation group in collaboration with local clinical leads for the programme.

8. Promoting Awareness

- 8.1. The success of the UKLKSS relies upon clinical and patient engagement and the confidence that the scheme will deliver benefit. Awareness is essential to ensure that patients and their clinical teams are properly informed.
- 8.2. The contribution of non-directed altruistic kidney donors to the scheme has proven to be a game changer, particularly for long-waiting patients, including those from Black and Asian communities who may not have a living donor of their own, and immunologically complex patients.
- 8.3. There is a lead time before we would expect to see uplift in actual donations from non-directed donors since the Valentine's campaign in February. However, a survey in April of a statistically significant sample in England showed that 53% of the population are now aware of living kidney donation in comparison with 48% prior to the campaign.
- 8.4. After the campaign, there was an increase in the proportion of people (to 50% of participants) who were aware that living donation to an unknown recipient is legal and fewer (27% versus 30%) did not know the answer to the question in comparison with the survey that was performed in January.
- 8.5. Following the campaign, 55% (from 49%) of people would consider donating to a family member and 32% (from 22%) to a friend. The number of people who would consider donating to a stranger remained unchanged at 14% before and after the campaign. This indicates a positive change in the way in which living donation is viewed by the general population.

9. Summary

9.1. The UK Living Kidney Sharing Scheme continues to develop with innovative ways to increase LDKT options for long-waiting patients with complex needs, typically those who are immunologically challenging and patients from Black and Asian communities. The UK scheme is the largest in Europe and we are seen as one of the leaders in this field world-wide. We contribute to developments internationally through working groups and conference presentations (two abstracts will be presented at the European Society of Organ Transplantation in September 2017), and learn new ideas from others in these same forums. With new enhancements agreed and a UK-wide workshop planned, it is hoped that the UKLKSS will continue to flourish and benefit even more patients in the future.

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