

# LIVING DONOR KIDNEY TRANSPLANTATION: POSITION PAPER

AUGUST 2017

## 1. Introduction and purpose

This paper details the status of living donor kidney transplantation (LDKT) activity in the UK, including progress in delivering the LDKT 2020<sup>1</sup> strategic plan and the agreed actions to continue to address the shortfall in activity.

## 2. Background and context

LDKT is well established in the UK and its development has been driven by excellent patient and transplant outcomes, the opportunity for patients and their families to plan a transplant and avoid dialysis and the possibility that LDKT offers for clinically complex patients who may otherwise be denied the option of being transplanted. LDKT is a very good treatment for patients with kidney failure since it offers a better outcome than dialysis and also excellent long-term transplant and patient survival in comparison with deceased donor kidney transplantation (DDKT). Avoidance of dialysis also makes LDKT the most cost effective treatment option for patients with end stage kidney disease (ESKD).

Since 2010, the development of LDKT has been supported by UK strategies, approved by the wider transplant community, Departments of Health (DHs) and Commissioners in all four countries, NHS Blood and Transplant (NHSBT), healthcare professionals and patient and living donor groups and charities. The current LDKT 2020 strategy is aligned with the 'Taking Organ Transplantation to 2020' (TOT 2020)<sup>2</sup> strategy in that it reflects the ambitions of the wider transplant community and relies upon that community working together to deliver the agreed outcomes and increase in transplant activity.

The characteristics and complexity of the LDKT programme have changed significantly in the last decade, driven by a new legal framework under the Human Tissue Act in 2006 and the implementation of the LDKT strategies since 2010. Years ago LDKT was characterised by family and friends with close genetic or emotional relationships donating directly to their loved ones; this has been extended into anonymous 'altruistic' donations from members of society, indirect kidney paired exchange transplants (where living donor kidneys are 'swapped' between donor-recipient pairs to create transplant opportunities for patients) and technologies to remove blood group and tissue type (human leucocyte antigen (HLA) antibodies to facilitate antibody incompatible transplantation for patients with limited options. It is of note that the UK Living Kidney Sharing Scheme (UKLKSS) is acknowledged as one of the leading schemes by international comparison.<sup>3</sup>

Feedback from clinical teams suggests that the success of strategies to increase deceased organ donation, with consequent reductions in waiting times and a consistent fall in the number

of patients waiting for a transplant has impacted on the number of LDKT procedures. Increased availability of deceased donor kidneys and the small but real risk to a donor, combined with the perception of that risk by the potential recipient, may encourage patients to make decisions in favour of DDKT rather than LDKT. This is reflected in other large global programmes such as The Netherlands and USA.

The aim of the LDKT 2020 strategy is to match world class performance in LDKT, by ensuring that the barriers to LDKT are identified and effectively addressed so that all suitable recipients have an informed choice and equal access to LDKT if they so wish.

### **3. Roles and responsibilities in delivering LDKT**

The Departments of Health (DHs) in all four UK countries, commissioners, NHSBT and the clinical community are committed to delivering LDKT 2020<sup>1</sup> to plan. Patient charities and associations also have a key role to play. This is reflected in the membership of the LDKT 2020 Strategy Implementation Group (SIG). The 2020 Oversight Group, chaired by Elizabeth Buggins, is responsible for holding to account all partners for their role in delivering the strategy. The winter meeting of the group will review progress with LDKT 2020.

Service Commissioners from all four UK nations are responsible for commissioning the LDKT programme. Historically, NHSBT provided investment to support the programme through the funding of living donor co-ordinators but this is now entirely the responsibility of commissioners. NHSBT funds a single post working on living donation to help with co-ordination and innovation in living donation e.g. the kidney sharing schemes, to provide professional leadership for living donor co-ordinators, to support development of the Transplant Tariff in England and to work with DHs to embed new arrangements. This post is critical to driving consistency and excellence in LDKT activity and in providing a bridge between NHSBT, health service commissioners and service providers.

NHSBT also supports the programme by: developing and administering the UKLKSS; monitoring donor and recipient outcomes; providing relevant statistics; engaging with professionals, patients and public to raise the profile of LDKT and fostering innovation to support increases in activity.

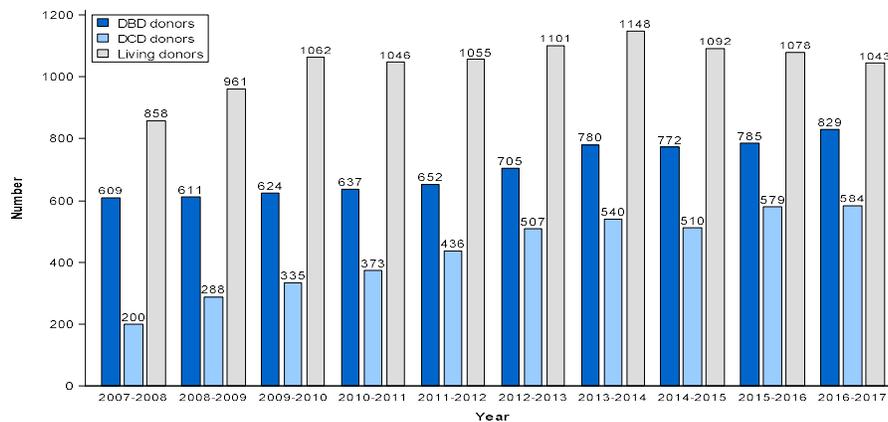
Clinical teams in transplant centres and referring nephrology units, supported by their professional societies, provide clinical leadership to embed best practice in LDKT in every region of the UK and champion local and regional programmes. Transplant surgeons, nephrologists and specialist nurses working with potential recipients and donors have key leadership responsibilities.

Patient charities and associations are asked to support patient and public engagement initiatives to raise the profile and awareness of LDKT and to work in partnership with the clinical community to inform best practice and increase activity. This includes making all their members aware of LDKT and supporting those on the waiting list to explore donor options.

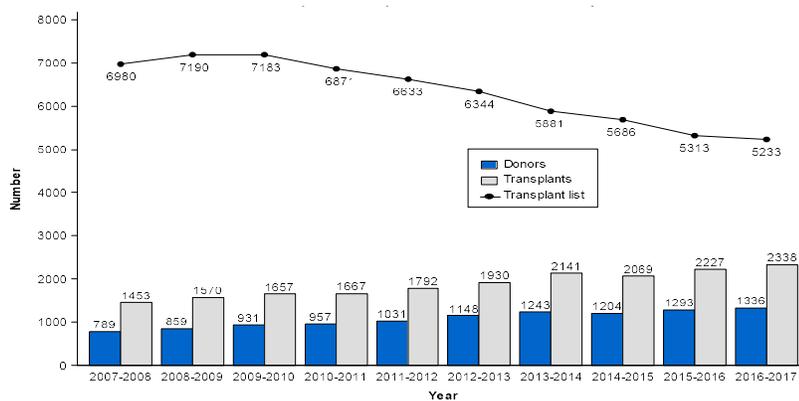
**4. Relevant statistics**

Latest statistics (Figure 1)<sup>4</sup> show that living donors continue to represent 42% (n=1043) of all donors in the UK of which 97% donate a kidney and 3% donate a lobe of liver. The current rate of living donor transplantation (LDKT) represents 16 per million population (pmp), with an ambition to reach 26 pmp (n=1728) by March 2020<sup>1</sup>. NHSBT is collaborating with the Renal Registry to develop accurate pmp data for individual referring nephrology units to include in the Annual Activity Reports. Regional transplant centre pmp data will be published later this year.

**Figure 1: Living and Deceased Donation Activity 2007-2017**



**Figure 2: Deceased Kidney Donation and Transplant Activity and Impact on Waiting List 2007-2017**

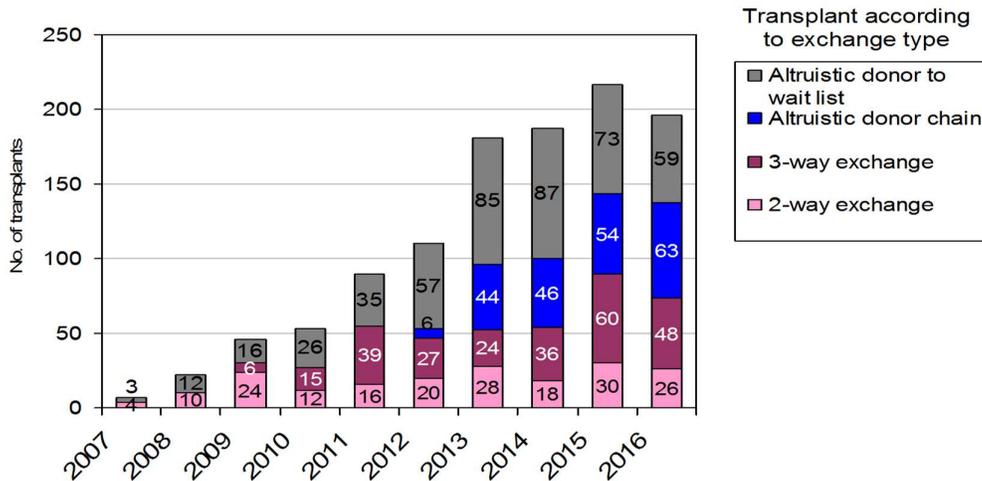


The actual number of living donor transplants performed since 2013/14 has fallen by 9%. In the past three years, there has been an equivalent increase in deceased donation activity, with record levels achieved in 2016/17 (n=1413). An increase in the number of organs available for transplant has seen a consistent fall in the number of patients waiting for a

transplant since 2009/10 with 27% fewer patients waiting for a kidney in the UK at the end of 2016/17 (Figure 2).

The UK has developed the largest living kidney sharing scheme (UKLKSS) in Europe in terms of the number of transplants achieved and the proportion of registered patients receiving a transplant through the scheme. It is recognised as an exemplar in terms of innovation and complexity<sup>3</sup>. The scheme particularly benefits long-waiting patients with immunological complexity and recipients from Black and Asian communities. The effectiveness of the UKLKSS is significantly enhanced by the inclusion of non-directed altruistic kidney donors, who are willing to donate to anyone in need of a transplant and can initiate a chain of up to three transplants by a single donation. The UKLKSS currently contributes up to 20% of total LDKT activity. (Figure 3)

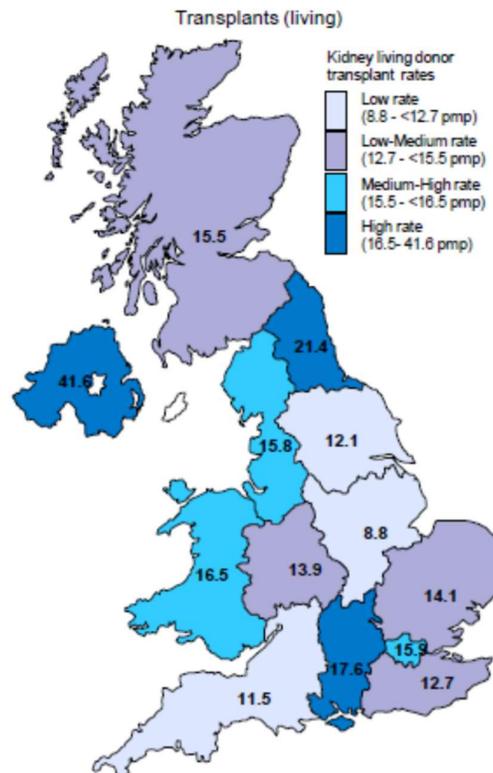
**Figure 3: Non-directed Altruistic and Paired Living Donor Kidney Transplants**



**5. Variation in performance**

Regional and country variations in LDKT activity are well documented but there is limited evidence or hard data available to identify the underlying causes. Throughout 2016/17, the LDKT 2020 Strategy SIG has engaged with the clinical community across the UK in shared learning events to explore these variations, share best practice from regions where sustained increases in LDKT have been achieved and to create local action plans towards delivering the 2020 ambitions. There are examples of excellent practice in LDKT throughout the UK but every region has scope to improve and future action plans across all the LDKT 2020 strategy work streams and in local centres have been tailored accordingly.

**Figure 4: LDKT Rates (pmp) by Recipient Country/Strategic Health Authority of Residence**



Three key recommendations from this initiative have been put into action by the *LDKT 2020* SIG:

1. Establish lead nephrologist for living donor kidney transplantation in each referring unit and transplant centre to work in collaboration with existing surgical and living donor co-ordinator (LDC) leads (network in place by end of July 2017)
2. Incorporate population served and adult living donor kidney transplantation rates per million population (pmp) per regional transplant centre data into NHSBT annual centre specific LDKT report and explore options to incorporate the same data for referring units in future activity reports (see above)
3. Non-directed altruistic donors automatically enter the UK Living Kidney Sharing Schemes (UKLKSS) so that as many altruistic donor chains (up to 3 transplant opportunities per donation) can be achieved with every donation (to commence January 2018)

## 6. Workforce planning

LDKT is delivered by a multi-disciplinary team in which nephrologists, transplant surgeons, specialist nurses and other professionals allied to medicine have key roles. Living donor coordinators (LDCs) are pivotal to streamlining and supporting potential donors through initial

referral, assessment for donation and long-term follow-up. To support workforce planning, NHSBT developed a tool that can be used by transplant centres and referring hospitals to calculate the number of LDCs they need according to the complexity and characteristics of their individual programmes. This has already been successfully used in some centres to support an internal business case to employ additional LDC resource and could be simply adapted for use by other specialist nurses (e.g. recipient coordinators). The calculator was referenced within the 2016 NHS England (NHSE) led UK Peer Review Process of Kidney Transplant Centres and there is commitment from NHSE and the Renal Services Clinical Reference Group (CRG) to include this in the specification for LDKT.

## **7. Engaging with patients, families and public**

Awareness about living donation is low but improving; fewer than 48% of participants in a survey conducted by NHSBT in January 2017 knew that it was possible to donate a kidney as a living person but awareness increased following a focused campaign in February (see below). Engagement is also unequal across different sectors of society<sup>5</sup>. This makes it difficult for patients waiting for a kidney transplant to broach the subject with family and friends and for people to consider donating anonymously to someone in need of a transplant if they are poorly informed.

In February this year, NHSBT ran a public engagement 'Valentine's' campaign dedicated to living donation. This resulted in a 300% overall increase in visits to the NHSBT public facing website to download materials and access information about living donation. A simultaneous campaign was launched in Scotland as part of an on-going commitment from the Scottish Government to focus on LDKT.

Positioning awareness campaigns and improving the availability and consistency of educational resources to support decision-making across all four UK countries is critical. A wide range of updated on-line resources are now available across the UK, including written information and short films to encourage conversations about living kidney donation within families and across society. Further work is in progress in collaboration with donor and patient organisations to provide bespoke information on specific topics of interest to different communities. These resources are designed to help recipients and donors make the decision that is right for them and to support the existing education and information programmes within local and regional centres.

Given the reduction in the average waiting time for a receiving a kidney after death (now 2.5 years; and 3 years for Black and Asian patients), it is important that patients waiting for a kidney transplant and potential living donors fully understand the advantages and disadvantages of a living kidney donation compared to a donation after death. It is also very important that potential living donors fully understand the risks and benefits of donation and transplantation in the short term and long term. NHSBT statisticians have developed on-line calculators that enable patients on the waiting list to understand how long they may have to wait for a deceased donor kidney and their chances of being matched in the UKLKSS. NHSBT has sponsored two initiatives to increase engagement with Black and Asian communities.

During 2015/16, a one year pilot study was commissioned from Kidney Research UK (KRUK) to encourage 'Acceptance, Choice and Empowerment in Living Donor Kidney Transplantation (ACE LDKT)' within Black and Asian communities through a peer volunteer home-education initiative. This project, based on published experience in The Netherlands and USA, was the first to use volunteers as peer educators in the home education setting. Interim data suggests that this has been well received; positively evaluated by patients in Black communities and by professionals, with an increase in potential donation interest from home visit activity. It offers a scalable model for wider dissemination and inclusion in local business plans. A full project report for both the Black and Asian pilot sites will be published in early September.

Currently, NBTA (National BAME Transplant Alliance) is commissioned to undertake an innovative initiative to encourage more living kidney donations from targeted Black and Asian groups. Five projects, aimed at the Hindu, Jain, Sikh, and African and African-Caribbean communities in London and Leicester have been established. The focus is on how more living donors from these communities can be encouraged to come forward through work by and within the targeted communities, development of culturally sensitive resources as well as providing support to the patient through arranging sessions at home with extended family and friends.

## 8. Future priorities

The LDKT 2020 Strategy Implementation Group, chaired by Dr. Aisling Courtney, has identified the immediate implementation priorities to maximise impact on LDKT activity. These include:

- Development of non-mandatory Transplant Tariff in England for introduction April 2018 and mandatory Tariff in April 2019
- Continued engagement by all four DHs to align activities and campaigns
- Establishment of a UK-wide network of nephrology leads for LDKT to enhance clinical leadership (in year)
- Publishing LDKT pmp data for all UK transplant centres and referring units by 2018/19
- Developing further donor and recipient resources to support decision-making (in year)
- Sharing learning from Black and Asian engagement initiatives and embedding successful initiatives as 'business as usual' from 2018/19
- Continuing to maximise transplant opportunities through the UKLKSS (in year)
- Embedding Donor Reported Outcome Measures (DROMs) in collection of follow-up information (in year)
- Making it easy for people to donate by removing identified barriers to LDKT (on-going)

## 9. Conclusion

The LDKT 2020 Strategy sets out ambitious targets for success, which are dependent upon collective effort to deliver. NHS England, commissioners in Scotland, Wales and N Ireland and NHSBT continue to work with representatives of the four UK governments, the clinical transplant and nephrology community and patient and donor associations and charities to embed best practice in LDKT and to deliver the outcomes identified in the LDKT 2020 strategy.

### Sources:

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