

# Living Donor Kidney Transplantation 2020:

## A UK Strategy



# Acknowledgement


We are grateful to all those who contributed to the development of this strategy and provided advice and support.

## Front Cover captions

*Background: Lynn received a kidney from her husband Billy after living with hereditary polycystic kidney disease for 24 years. Once they heard of the option of live donation they did not hesitate to start the months of rigorous testing, resulting in a successful transplant at the end of 2013.*

*Foreground: Sanjiv was inspired by a TV interview given by Dr Paul van den Bosch who had donated his kidney and wants to inspire others, especially members of the black and Asian communities.*

*Dela offered to donate a kidney to her brother but unfortunately was not compatible; she is currently using her experience to raise awareness of organ donation in the BAME community where there is a need for more people to come forward as donors.*



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# Executive Summary

Living donation plays a vital role in saving and improving lives. Its unique contribution to the organ donor pool offers more patients with end stage kidney disease (ESKD) the possibility of a successful transplant whilst adding to the overall supply of available organs for all those who are waiting. Living donor transplantation (LDT) contributes 35% of overall transplant activity in the UK, of which 97% of living donors donate a kidney.

Significant progress has been made, by implementing the 2010-14 Strategy for Living Donor Kidney Transplantation (LDKT), to develop the safety and sustainability of the UK-wide programme through the collective effort of the wider transplant community – healthcare professionals, health departments, commissioners, other authorities, NHS Blood and Transplant and patient associations.

This paper sets out the key aims and objectives of the new strategy, LDKT 2020, namely **to match world class performance in living donor kidney transplantation.**

This aim is underpinned by three key objectives:

1. Increase LDKT activity for both adult and paediatric recipients, ensuring that donor safety and welfare is consistently sustained through best clinical practice.
2. Maximise patient benefit by ensuring that all suitable recipients have equity of access to LDKT and that the principle of 'transplant first'\* is embedded in best clinical practice across the UK.
3. Maximise the opportunities for suitable donors and recipients to contribute to and benefit from the shared living donor pool by ensuring that the National Living Donor Kidney Sharing Schemes (NLDKSS) are both clinically and cost effective.

Five supporting outcomes have been identified to achieve the objectives.

1. NHSBT, commissioners and all UK health departments will work together to ensure that there are no financial disincentives to support a fully integrated UK-wide LDKT programme.
2. NHSBT, commissioners and clinicians will ensure that appropriate infrastructure, systems and processes are in place to maximise the number of transplants achieved from all suitable living kidney donors.
3. NHSBT, clinicians, commissioners and other authorities will ensure that outcomes of LDKT are monitored and that information is accurately interpreted and utilised to support state of the art donor and recipient care.
4. NHSBT and clinicians will ensure that all suitable recipients have an opportunity to consider the option of LDKT before dialysis or to minimise waiting time if dialysis is unavoidable, regardless of where they live in the UK.
5. NHSBT, society and individuals will ensure that awareness of LDKT is effective across all sectors of society in all four UK countries.

LDKT 2020 builds on the strengths of the previous strategy to continue the safe and sustainable expansion of the living donor pool with the aim of increasing LDKT to 26 transplants per million population, matching world class performance. More patients and their families will benefit from transplantation and it will be possible to offer transplants to patients with complex needs who might not otherwise get a transplant. The NHS will also benefit as more people are transplanted before entering the kidney dialysis programme. Successful implementation of the plan will be dependent upon a call to action from all members of the wider transplant community.

\*Includes pre-emptive transplantation for patients not on dialysis and minimise waiting time for transplantation for patients already on dialysis.

## Consultation and Review

At its meeting on the 22 May 2014 the NHSBT Board approved:

- The strategic aims and objectives for LDKT 2020
- NHSBT's role in delivering the supporting actions to deliver the objectives.

Prior to presentation at the Board, an interim and final draft paper were sent to Chair and Deputy Chair of Kidney Advisory Group, National Clinical Director, NHS England, Specialised Commissioner, NHS England and representatives of all four UK Health Departments for comment. Key stakeholders from all four UK countries were invited to be involved in the development of the strategy through stakeholder consultation and events.

# Background

## Why is living donation important?

Living donation plays a vital role in saving and improving lives. Its unique contribution to the organ donor pool offers more patients the possibility of a successful transplant whilst adding to the overall supply of available organs for all those who are waiting. Current statistics show that every other organ donor is a living donor and living donor transplantation (LDT) contributes 35% of overall transplant activity in the UK. 97% of living donors donate a kidney whilst 3% donate a lobe of their liver.<sup>1</sup>

Living donor kidney transplantation (LDKT) is one of the most innovative and progressive areas of donation and transplantation. From 2000 to 2010, LDT activity in the UK trebled, most of which was in LDKT because:

- State of the art donor care has always been a priority
- Patient and transplant outcomes are better than for deceased donor kidney transplantation (DDKT)<sup>1</sup>
- It is the treatment of choice for planned pre-emptive transplantation (before dialysis) and for clinically complex patients<sup>2</sup>
- It is a cost-effective alternative to dialysis<sup>3</sup>
- The development of new technologies and innovations and changes under the Human Tissue Acts (HT Acts) has made more living donor organs available for transplant.

Supported by the previous strategy<sup>4</sup>, significant progress has been made to develop the safety and sustainability of the UK-wide programme through the collective effort of the wider transplant community – healthcare professionals, health departments, commissioners, other authorities, NHS Blood and Transplant and patient associations.

<sup>1</sup>Includes pre-emptive transplantation for patients not on dialysis and minimise waiting time for transplantation for patients already on dialysis.

## What are we aiming to do?

Building on the achievements of the previous strategy, maximising the opportunities from innovations in the field and, above all, ensuring that living donors are protected from harm; the new strategy aims:

### **‘To match world class performance in living donor kidney transplantation’.**

This aim is supported by three key objectives:

1. To increase LDKT activity for both adult and paediatric recipients, ensuring that donor safety and welfare is consistently sustained through best clinical practice.
2. To maximise patient benefit by ensuring that all suitable recipients have equity of access to LDKT and that the principle of ‘transplant first’\* is embedded in best clinical practice across the UK.
3. To maximise the opportunities for suitable donors and recipients to contribute to and benefit from the shared living donor pool by ensuring that the National Living Donor Kidney Sharing Schemes (NLDKSS) are both clinically and cost-effective.

The strategy reflects:

- UK-wide trends in LDKT practice and global benchmarking
- Emerging research and audit data
- Engagement with key stakeholders throughout the implementation of the 2010-14 strategy
- Gap analysis of partially achieved objectives within each work stream from the 2010-14 strategy
- Root cause analysis of each shortfall.

## Looking to the Future: LDKT 2020

Although LDKT rates have increased in each country, activity remains variable across the four UK countries and within England (see Table 1). The reasons for this are complex and addressing the contributing factors is a key action for LDKT 2020. Of note, Northern Ireland has shown an exceptional increase in the past two years in comparison with other UK countries because the LDKT programme has been historically small. It has expanded rapidly during this period whilst a backlog of suitable patients has been offered LDKT. As the programme matures and the backlog is addressed, activity is likely to settle at a lower rate pmp to reflect only the new patients with end stage kidney disease (ESKD) that enter the LDKT programme.

Latest statistics from the Council of Europe show that The Netherlands has the highest living donation rates (29pmp) of those European countries that operate within similar funding streams. The Netherlands also has one of the most active and effective living donor kidney sharing schemes in Europe<sup>6,7,8</sup>. The proposals and projected activity for LDKT 2020 are based upon a phased expansion of the living donor pool, taking into account current practice and the increased complexity of the UK system, which operates across four countries and 23 regional transplant centres.

The planned implementation of an inclusive transplant tariff in England from 2015-16 has underpinned projected activity and phased implementation. Further delay in implementation would seriously undermine the feasibility of achieving the projected activity and outcomes.

2010-14 Strategy				2020 Strategy**					
FY	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20
LD (n)	1,050	1,081	1,112	1,143	1,174	1,205	1,298	1,422	1,608
pmp	17.0	17.5	18.0	18.5	19.0	19.5	21.0	23.0	26.0
Activity pmp 2012-13 by country									
England	17.3	Regional variation in England is 12.3pmp – 21.6pmp.							
Wales	15.4								
Scotland	14.1								
Northern Ireland	30.4								

\*\*Phased implementation based upon introduction of inclusive transplant tariff in 2015-16 to support additional expansion from 2017-18.

## Expanding the living donor pool

The achievements of the 2010-14 strategy and global evidence show that there is scope to increase the living donor pool and maximise benefit to patients with ESKD. This is dependent upon a number of factors, which are prioritised within the LDKT 2020 strategy:

- Raising public awareness and confidence in LDKT by encouraging engagement from all sectors of society through responsible publicity and safe systems of care.
- Improving the timeliness of LDKT by embedding the principle of 'transplant first' in all discussions with patients and their families at the right time and in the right way to ensure that opportunities are not missed.
- Effective use of the shared living donor pool through the National Living Donor Kidney Sharing Schemes (NLDKSS). This includes maximising the number and combination of transplants achieved in the paired/pooled donation (PPD) scheme through 'kidney exchanges' between incompatible donor and recipient pairs as well as the increasing number of people who choose to donate to someone they do not know or have never met (non-directed altruistic donors – NDADs). Such donors can be used to trigger a chain of transplants through the PPD scheme, thereby maximising the benefit from a single donation.
- Standardising best practice in antibody incompatible transplantation so that patients who have either ABO blood group or human leucocyte antigen (HLA) antibodies against their living donors can be successfully transplanted.

All of these initiatives are underpinned by effective commissioning arrangements that provide the resources needed to enable local Trusts and Hospitals to develop the capability and capacity to increase LDKT. Concluding earlier work by commissioners and the four UK health departments to ensure that transplant and referring nephrology centres are self-sufficient in funding LDKT activity is a key priority to deliver LDKT 2020.

*Dela offered to donate a kidney to her brother but unfortunately was not compatible; she is currently using her experience to raise awareness of organ donation in the BAME community where there is a need for more people to come forward as donors.*

## Living kidney donation in black and Asian minority ethnic groups (BAME)

LDKT in black and Asian minority ethnic groups (BAME) presents unique challenges that impact on the numbers of transplants that can be performed. These include:

- Public awareness and engagement within the BAME population;
- Pre-disposition to kidney disease;
- Culture, beliefs and attitudes to donation and transplantation;
- Logistical and legal complexities for recipients in the UK with potential donors who live overseas.

Knowledge and understanding has improved between the healthcare community and BAME populations and progress has been made in some areas during the previous strategy e.g. work with the Home Office and UK Border Agency to streamline and monitor UK Entry Visa processes for genuine cases of overseas donors. Within LDKT 2020, continued engagement with individual patient representatives and groups has been identified to improve access to LDKT within the BAME population.





## Clinical Governance

Living donor nephrectomy is associated with low but documented risk of mortality and morbidity<sup>10</sup>. This remains central to any expansion in the living donor pool. However, excellent donor and recipient outcomes have consistently underpinned confidence and growth in LDKT. Detailed recommendations were agreed as part of the 2010-14 strategic plan to maximise vigilance in donor safety and welfare and monitor outcomes. These will provide the framework for future governance. The governance structure is also underpinned by:

- Mandatory reporting of Serious Adverse Events and Reactions (SAERs) under the European Organ Donation Directive (EUODD)<sup>9</sup>. NHSBT has delegated responsibility to investigate and report all critical LDT incidents on behalf of the Human Tissue Authority (HTA).
- Opportunity to share learning and inform best practice from critical incidents via NHSBT.
- Evidence-based professional UK best practice guidelines<sup>10</sup>.



Photo: Portsmouth Hospitals NHS Trust

## How will success be achieved?

Five supporting outcomes have been identified to achieve the objectives. Lead responsibility for delivering each of these specific actions is identified in the following plan, together with NHSBT's role:

### Outcome 1

NHSBT, commissioners and all UK health departments will work together to ensure that there are no financial disincentives to support a fully integrated UK-wide LDKT programme by:

Specific Action	Responsibility (lead in bold)	Funding Requirements
Establishing national commissioning arrangements throughout the whole of the UK. (already in place in England, Wales and Northern Ireland).	<b>Scottish Health Department</b> – plans already in place.	Within current baseline.
Ensuring that financial arrangements between all four UK countries support equity of access and quality in both adult and paediatric LDKT.	<b>Four UK Health Departments</b> NHS England NHSBT.	Cost neutral to NHSBT. NHSBT Commissioning team involved in influencing Transplant Tariff development and introduction in 2015-16. NHSBT monitors impact on transplant activity as business as usual.
Ensuring that policies for reimbursement of donor expenses are embedded consistently across all four UK countries.	<b>Four UK Health Departments</b> NHS England.	Funding already identified within current commissioning arrangements.

*Proving that there's no one like your sister, Liam was able to donate a kidney to his sister, Alana.*



## Outcome 2

NHSBT, commissioners and clinicians will ensure that appropriate infrastructure, systems and processes are in place to maximise the number of transplants achieved from all suitable living kidney donors by:

Specific Action	Responsibility (lead in bold)	Funding Requirements
Establishing UK-wide workforce capacity and capability to organise the assessment of and donation from all suitable living donors (i.e. paired/pooled, non-directed altruistic, family and friend donors) within agreed standards.	<b>NHS England Specialised Services and other UK Commissioners</b> Four UK Health Departments NHSBT KAG LDKT sub-group Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres.	Covered by implementation of Transplant Tariff in 2015-16 (England) and Commissioning to Transplant 2020 (Scotland).
Ensuring effective use of all donated kidneys within the National Living Donor Kidney Sharing Schemes (NLDKSS) by identifying and implementing innovative allocation options and clinical pathways (e.g. longer altruistic donor chains, inclusion of all compatible pairs within the schemes, antibody removal).	<b>NHSBT</b> Four UK Health Departments KAG LDKT sub-group NHS England Specialised Services and other UK Commissioners Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres	Human resources within NHSBT already identified i.e. Clinical Lead, Statistics and Clinical Studies, Information Services. IT systems already in place to support extended altruistic donor chains. Additional costs to NHSBT: NHSBT national stakeholder event in 2014 to agree actions and define clinical pathways – venue and meeting costs.
Reducing the number of non-proceeding transplants after donors and recipients have been 'matched' in the NLDKSS.	<b>KAG LDKT sub-group</b> NHSBT NHS England Specialised Services and other UK Commissioners Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres.	Cost neutral to NHSBT. Resources already identified i.e. Clinical Lead, Statistics and Clinical Studies, Information Services.

## Outcome 2 (continued)

Specific Action	Responsibility (lead in bold)	Funding Requirements
Developing a register of interest for potential non-directed altruistic donors to manage multiple donor referrals.	<b>NHSBT</b> Transplant centres.	Detail to be determined. Unlikely to be resource intensive for NHSBT.  Clinical Lead to work with transplant centres.
Developing best practice guidelines to support clinical practice in all areas of LDKT.	<b>KAG LDKT sub-group</b> NHSBT Renal Transplant CRG Area commissioners Transplant and DGH nephrology centres Professional Societies Other Authorities Patient/donor representatives and charities.	Cost neutral to NHSBT. Resources already in place i.e. Clinical Lead, Statistics and Clinical Studies.
Monitoring and addressing regional and/or country variations in LDKT across the UK.	<b>NHS England Specialised Services and other UK Commissioners</b> <b>Renal Transplant CRG and Local Area Teams</b> Four UK Health Departments NHSBT KAG LDKT sub-group Transplant and DGH nephrology centres.	Cost neutral to NHSBT. NHSBT monitors impact on transplant activity as business as usual.

### Outcome 3

NHSBT, clinicians, commissioners and other authorities will ensure that outcomes of LDKT are monitored and that information is accurately interpreted and utilised to support state of the art donor and recipient care by:

Specific Action	Responsibility (lead in bold)	Funding Requirements
Establishing consistent reporting systems and governance structures to monitor donor and recipient health outcomes and experiences.	<b>KAG LDKT sub-group</b> NHSBT Four UK Health Departments NHS England Specialised Services and other UK Commissioners Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres Human Tissue Authority.	Cost neutral to NHSBT. Resources already identified i.e. Clinical Lead, Statistics and Clinical Studies, Information Services, Quality Assurance.
Establishing effective mechanisms for healthcare professional peer support and review.	<b>KAG LDKT sub-group</b> Four UK Health Departments NHS England Specialised Services and other UK Commissioners Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres.	Currently under development through commissioning pathways e.g. Renal Transplant CRG. Likely to be cost neutral to NHSBT.
Participating in and accurately interpreting emerging research to inform the UK-wide programme.	<b>KAG LDKT sub-group</b> NHSBT Patient/donor representatives and charities Transplant and DGH nephrology centres Professional Societies Healthcare professionals.	Cost neutral to NHSBT. Resources already identified i.e. Clinical Lead, Statistics and Clinical Studies.

### Outcome 3 (continued)

Specific Action	Responsibility (lead in bold)	Funding Requirements
Developing best practice, evidence based guidelines to encourage consistency and UK standardisation of practice across all areas of adult and paediatric LDKT.	<b>KAG LDKT sub-group</b> NHSBT UK Commissioners, Renal Transplant CRG Area commissioners Transplant and DGH nephrology centres Professional Societies Other Authorities Patient/donor representatives and charities.	Cost neutral to NHSBT. Resources already in place i.e. Clinical Lead, Statistics and Clinical Studies.
Establishing effective systems and processes to support LDKT from suitable overseas donors.	<b>NHSBT</b> Four UK Health Departments NHS England Specialised Services and other UK Commissioners Renal Transplant CRG and Local Area Teams Transplant and DGH nephrology centres Patient/donor representatives and charities Human Tissue Authority Home Office.	Cost neutral to NHSBT. Resources already in place through Clinical Lead.
Develop responsive and timely electronic reporting to maximise patient benefit through accurate collection and interpretation of data to and from NHSBT.	<b>NHSBT</b>	Full implementation is dependent upon competing priorities within the NHSBT Information and Technology (IT) business case. Some low cost improvements can be delivered without IT development.

## Outcome 4

NHSBT and clinicians will ensure that all suitable recipients have an opportunity to consider the option of LDKT before dialysis or to minimise waiting time if dialysis is unavoidable, regardless of where they live in the UK by:

Specific Action	Responsibility (lead in bold)	Funding Requirements
Establishing a UK-wide healthcare professional education programme – Multi-Disciplinary Educational Team (UK MET) on a regional basis.	<b>KAG LDKT sub-group</b> NHSBT Transplant and DGH nephrology centres Healthcare professionals.	Costs to NHSBT. Travel +/- venue for colleagues running regional meetings.
Developing web-based, NHSBT hosted (i.e. via the ODT clinical website) educational resources for healthcare professionals to use at local level, supported by UK MET.	<b>KAG LDKT sub-group</b> NHSBT Transplant and DGH nephrology centres Healthcare professionals.	Cost neutral to NHSBT. Resources already identified/in place i.e. Clinical Lead, Statistics and Clinical Studies ODT clinical website, UK MET colleagues.
Monitoring and accurately interpreting variations in pre-emptive transplantation (before dialysis) rates between different transplant centres.	<b>KAG LDKT sub-group</b> NHSBT.	Cost neutral to NHSBT. NHSBT monitors impact on transplant activity as business as usual.



*In sickness and in health,  
Todd donated a kidney to his wife Chantelle.*

## Outcome 5

NHSBT, society and individuals will ensure that awareness of LDKT is effective across all sectors of society in all four UK countries by:

Specific Action	Responsibility (lead in bold)	Funding Requirements
Collaborating with individual donor/recipient representatives and patient associations.	<b>NHSBT</b> Patient/donor representatives and charities.	Cost neutral to NHSBT. Resources already in place through Clinical Lead.
Updating existing patient information schemes to ensure that informative, accessible donor and recipient educational materials are available in a variety of formats and readily available to the general public e.g. existing leaflets and web-based materials.	<b>NHSBT</b> Patient/donor representatives and charities Transplant and DGH nephrology referring centres Healthcare professionals.	Costs to NHSBT associated with updating and/or production of existing and some new materials to add to portfolio; leaflet/web-based. Clinical Lead to work with Strategic Marketing to identify options to minimise costs and maximise access to information.
Supporting publicity to raise the profile of LDKT, particularly in sectors of society and/or areas of the UK where awareness is low.	<b>NHSBT</b> Patient/donor representatives and charities Transplant and DGH nephrology centres Healthcare professionals.	Cost neutral to NHSBT. Resources already identified to support these activities within Communications Team Strategic Plan. The plan includes working with the Clinical Lead to publicise key achievements twice per year and on-going collaboration with charities to provide media support.
Considering innovative approaches e.g. social networking and/or organised public awareness events/campaigns to raise the profile of LDKT.	<b>NHSBT</b> Patient/donor representatives and charities Transplant and DGH nephrology centres Healthcare professionals.	Cost neutral to NHSBT. Clinical Lead to work with Strategic Marketing and Communications to identify opportunities within existing resources.
Contributing to relevant research to improve understanding and decision-making.	<b>KAG LDKT sub-group</b> <b>NHSBT</b> Patient/donor representatives and charities Transplant and DGH nephrology referring Healthcare professionals Professional Societies.	Cost neutral to NHSBT. Resources already identified within research budget and/or in place.



## How will success be measured?

A number of measures will be used to assess the impact of the strategic plan and to track improvements against the detailed action plan. Key Performance Indicators are highlighted in bold: the remaining measures will be reported annually in the Transplant Activity Report. The Kidney Advisory Group is responsible for implementation of the strategy, whilst oversight will be provided by the TOT 2020 oversight group.

## Measurable outcomes:

### 1. Global benchmarking:

- a. LDKT rates of 26 per million population (pmp) across the UK with less variance and equivalent rates in each UK country.
- b. Adherence to evidence based clinical practice guidelines<sup>10</sup> by monitoring donor death and serious complication rates as defined within the guidelines.
- c. 100% data capture for donation episode and 80% for life-long follow in the UK and pan EU (in development) living donor registry.

### 2. Commissioning:

- a. National commissioning in all four UK countries by 2015-16.

### 3. Timely assessment and surgery:

- a. 50% of eligible recipients are consistently transplanted pre-emptively (avoiding dialysis) in 100% of transplant centres. (Currently variable across centres).
- b. All potential donors consistently offered the opportunity to complete donor assessment within 18 weeks of referral (where appropriate). (Currently variable).

### 4. National Living Donor Kidney Sharing Schemes:

- a. 75% of suitable donors entering the NLDKSS proceed to donation and achieve the maximum number of possible transplants from their donation. (Currently 62%).
- b. All suitable donors and recipient in the NLDKSS proceed to surgery within the agreed standard of eight weeks of a suitable 'match' being identified. (Currently 33%).

### 5. Antibody incompatible transplantation:

- a. Standardised testing and consistent clinical pathways in place for all potential recipients of antibody incompatible LDKT. To be measured by national audit.

## Risks to delivering the strategy

Successful implementation of the LDKT 2020 Strategy is based upon the following assumptions:

- Effective leadership within the wider transplant community – healthcare professionals, health departments, commissioners, other authorities, NHS Blood and Transplant and patient associations.
- Engagement from society and the wider transplant community.
- National commissioning for LDKT in all four UK countries by 2015-16 to support integrated, UK-wide practice. This includes full implementation of a national tariff in England.
- Streamlining of organisational processes and clinical pathways to support best clinical practice.

Failure to deliver on any of these aspects will jeopardise the success of LDKT 2020.

# Conclusion

LDKT 2020 builds on the strengths of the previous strategy to continue the safe and sustainable expansion of the living donor pool with the aim of increasing LDKT to 26 transplants per million population, matching world class performance. More patients and their families will benefit from transplantation and it will be possible to offer transplants to patients with complex needs who might not otherwise get a transplant. The NHS will also benefit as more people are transplanted before entering the kidney dialysis programme, thus reducing costs overall. Successful implementation of the plan will be dependent upon the active engagement of all members of the wider transplant community.



*The silver donor pin originated in Nottingham City Hospital and was adopted by NHSBT. It is sent to every living organ donor in recognition of the gift of donation.*

# Appendix 1 – Background to living kidney donor transplantation in the UK and the Development of the Strategy

## Living donation in other organs

NHSBT is committed to maximising the availability of deceased donor organs for all patients waiting for a transplant through the Taking Organ Transplantation to 2020 strategy for deceased donation<sup>5</sup>.

LDKT 2020 focuses specifically on increasing and promoting living kidney donation. LDKT represents 97% of LDT activity in the UK and is low risk for both donor and recipient, compared to other forms of living donor transplantation. In 2013-14 there were 28 living donor liver transplants (LDLT) in the UK. The majority of these transplants are performed between adult donors and paediatric recipients, where the risks to the donor are lower than in adult to adult LDLT.

NHSBT will advise and support best clinical practice in all forms of living donor transplantation where patient benefit from successful transplantation is maximised and donor risk is minimised.

## Developing the Strategy

NHSBT has co-ordinated the development of this Living Kidney Donor Transplantation strategy in its role as the UK Organ Donor Organisation. However NHSBT's role is limited\* and consequently all members of the UK wider transplant community – healthcare professionals, UK Health Departments, commissioners, NHSBT, other authorities (e.g. Human Tissue Authority (HTA), UK Border Agency (UKBA)) and patient associations have been engaged throughout the development of the strategy, both on an individual basis and through consultation meetings to confirm their support. All participants will need to work together if the strategy is to be delivered successfully.

Although the precise funding implications are not known in detail, stakeholders have demonstrated their support for LDKT by including it in their own strategic plans e.g. Renal Transplantation Clinical Reference Group (CRG) five year plan for NHS England, Commissioning Transplant to 2020 for Scotland. The expected implementation of an inclusive transplant tariff in England from 2015-16 has underpinned projected activity and phased implementation. Effective commissioning is key to removing financial disincentives so that the option of LDKT is offered to all eligible recipients and donors.

\*NHSBT supports developments in LDT and is responsible for monitoring activity and outcomes. NHSBT also collaborates with the clinical, scientific and academic communities to deliver the National Living Donor Kidney Sharing Schemes (NLDKSS). The NLDKSS now offers the greatest scope to expand the living donor pool and to maximise the benefits of successful LDKT for patients.

## What have we achieved so far?

When LDT activity fell in 2010, it prompted a UK-wide review of the LDKT programme and the development of the first NHSBT UK Strategy for LDKT, 2010-14<sup>4</sup>. The aim was to *'Promote increases in living donation to match the best international benchmarks within comparable funding streams'* and 17 recommendations across four work streams were agreed to establish a safe and sustainable UK-wide programme.

With credit to all four UK countries and the wider transplant community, the main aim of the 2010-14 strategy, to increase overall UK living donation rates to 18pmp, was achieved. Significant progress was made in all work streams. Latest statistics show that during the period 2010-14<sup>1</sup>:

- 4,199 living donor kidney transplants were performed, with an increasing trend year-on-year.
  - An average of 37% of LDKT is performed before dialysis (pre-emptively) and 64% of pre-emptive transplants in both adults and children are achieved through LDKT.
  - 253 patients have been matched with a compatible donor and transplanted from the paired/pooled (PPD) scheme in which incompatible donor-recipient pairs are matched in combinations of two or three-way swaps to achieve compatible transplants.
  - 256 non-directed altruistic donors (NDADs) donated a kidney anonymously to an unknown recipient. Donations from NDADs is a growing trend and increased by 55% between 2012 and 2013.
- Since the introduction of altruistic donor chains (ADC) in January 2012, 34 NDADs achieved 68 transplants by donating a kidney to a recipient in the PPD scheme whose incompatible donor in turn donated to a recipient on the national transplant list.
  - In 2013-14, the National Living Donor Kidney Sharing Schemes (NLDKSS), which includes the NDAD, ADC and PPD schemes, contributed 17% of LDKT activity. Patient and transplant outcomes were equivalent to direct LDKT.
  - In 2012, 12% of LDKT recipients received a kidney following removal of either blood group antibodies (ABO) or tissue type (HLA) from the blood.

The recommendations that were agreed to deliver the 2010-14 strategy were intentionally ambitious and not all were achieved within the time available. Root cause analysis shows that there is scope to increase LDKT activity in all areas, using these previously agreed recommendations to inform future priorities and action planning.

# Appendix 2 – Sources

1. NHSBT Activity Data 2012-2013 [http://www.organdonation.nhs.uk/statistics/transplant\\_activity\\_report/current\\_activity\\_reports/ukt/activity\\_report\\_2012\\_13.pdf](http://www.organdonation.nhs.uk/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2012_13.pdf)
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## **NHS Blood and Transplant**

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England and North Wales. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs.

We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells. Their generosity means each year we're able to supply around 1.9 million units of blood to hospitals in England and North Wales and around 4,200 organ and 5,800 tissue donations, which save or improve thousands of lives.

### **For more information**

**Visit** [nhsbt.nhs.uk](https://nhsbt.nhs.uk)

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**Call** **0300 123 23 23**