

**NHS Blood and Transplant  
Organ Donation and Transplantation Directorate**

**Kidney Advisory Group**

**Draft presented 25<sup>th</sup> May 2011  
Amended and updated June 2011**

**REVIEW OF NATIONAL LIVING DONOR KIDNEY  
TRANSPLANT PROGRAMMES**

**Executive Summary**

Since 2002, NHSBT has funded Living Donor Kidney Transplant (LDKT) Programmes throughout the UK. There are now over 1000 Living Donor Kidney transplants performed every year, accounting for one in three kidney transplants.

A Lead Nurse, Living Donation was appointed in August 2010 to provide clinical leadership nationally, raise the profile of living donation and support service expansion.

To benchmark current services, a review of all Living Donor Kidney Transplant Programmes has been undertaken.

The findings of this review, which will inform the NHSBT UK Strategy for Living Donor Kidney Transplantation, were presented to the ODT Senior Management Team (SMT) in April 2011 and the following recommendations were approved. The Strategy will be presented to the NHSBT Board in July.

**Recommendations**

**KAG is asked to note the recommendations and approve:**

The development of a NHSBT UK Strategy for Living Donor Kidney Transplantation based upon the following strategic aims:

1. Increase transplant activity from living kidney donors for both adult and paediatric recipients, ensuring that donor safety is consistently promoted through best clinical practice.
2. Achieve optimum pre-emptive living donor kidney transplantation rates and equity of access for patients within each transplant centre across the UK.

3. Maximise the opportunities for donors and recipients who wish to participate in the National Living Donor Kidney Sharing Schemes, which include paired/pooled donation, non-directed altruistic donation and altruistic donor chains.
  - Holding an event involving key stakeholders within the wider transplant community to launch the Living Donation Strategy. It has been suggested that this could be incorporated into the Renal Transplant Services Meeting (RTSM).
  - The establishment of a Steering Group with representation from key stakeholders across the transplant community to develop an implementation plan for the Strategy. Clinical representation will be recommended through the appropriate NHSBT Advisory Groups.

## **Appendix**

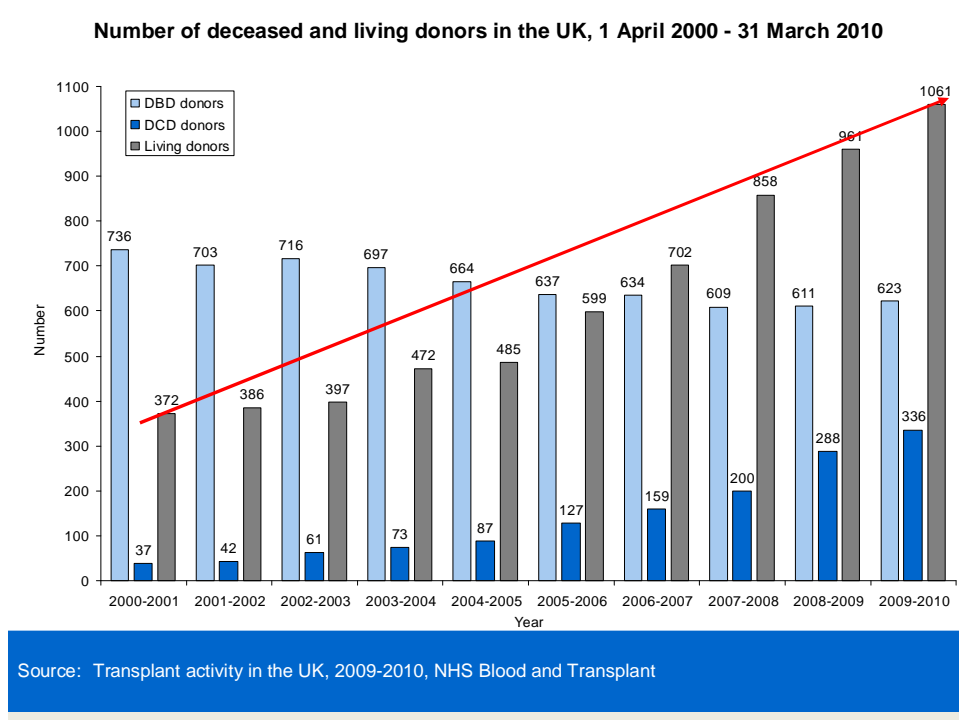
- Transplant centres participating in living donor kidney transplantation activity.

# 1. Introduction

## 1.1 Context

Latest statistics show that living donor transplants account for 1 in 3 kidney transplants performed across the UK and 1 in 2 donors are living donors. There has been a 65% increase in living donor activity in ten years (**Figure 1**) and this currently represents a rate of 16 per million population (pmp), which compares favourably with countries with whom we have traditionally benchmarked our practice, e.g. Norway (17 pmp). Ninety-eight percent of this activity is in kidney programmes but transplants from living liver donors in both children and adults are also performed in a small number of centres (n=4). The Directorate of Organ Donation and Transplantation (ODT) has made the development of a Strategy for Living Donor Kidney Transplantation one of its priorities and the overall objective is to *'Promote increases in living donation to match the best international benchmarks within comparable funding streams'*.

**Figure 1**



## 1.2 Commissioning

LDKT is subject to local commissioning arrangements between Trusts and Specialist Commissioning Groups. Whilst NHS Blood and Transplant (NHSBT) does not have direct responsibility for commissioning the service, since 2002 there has been investment in LDKT programmes through Grant in Aid schemes from the Department of Health (DH) via NHSBT. The current investment is approximately £3 million per annum and extends to all transplanting centres across the UK (n=24) and 11 referring DGH nephrology units. This funding stream, originally disseminated through UK Transplant

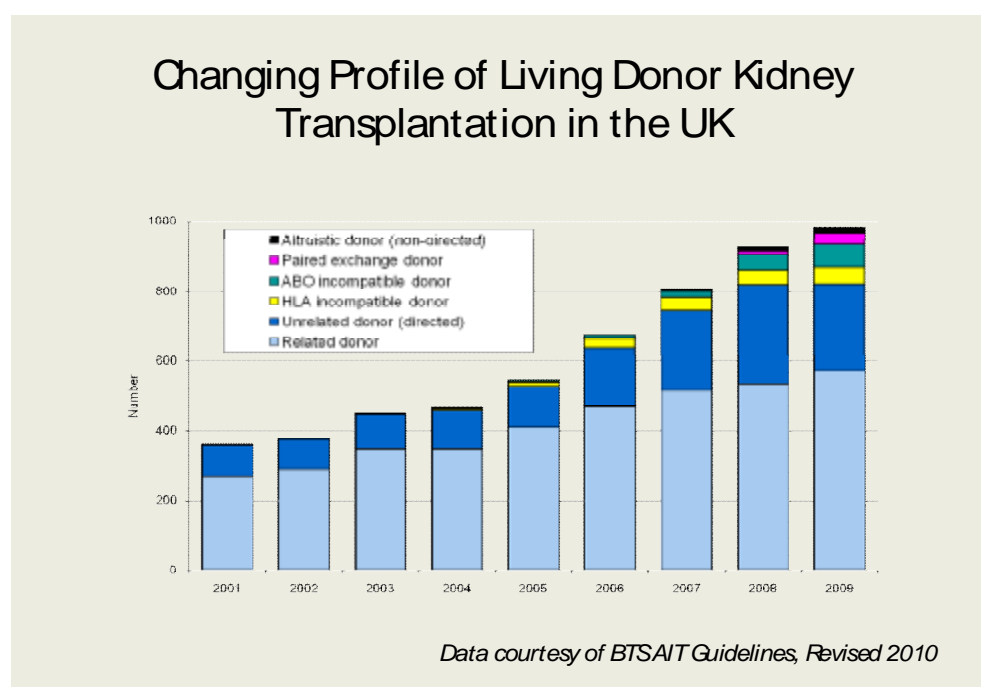
(UKT), has been awarded in three separate phases through a series of bidding processes. It was initially designed to ‘pump prime’ programmes in transplant centres to establish basic infrastructure. Subsequent investment has supported the expansion of activity in referring centres and further innovation and practice in some transplant centres. To date, funding has been available on a recurring basis, ranging from one to three years.

Due to NHS spending reviews and reduction in Grant in Aid to NHSBT, ODT will review its financial commitment to LDKT programmes and consider re-focusing support at the end of this financial year (2011/2012). It is acknowledged that this presents challenges to the transplant community in the current financial climate and ODT is keen to work with colleagues and key stakeholders to ensure that the national LDKT programme has a sustainable future and is appropriately resourced.

### 1.3 Clinical Profile

The profile of LDKT programmes has changed dramatically in the last ten years with an increasingly complex recipient case-mix and extended donor pool (**Figure 2**). This has been influenced by changes in the legal framework <sup>1,2</sup> new technologies and professional guidelines that reflect growing expertise in the field <sup>3,4</sup>.

**Figure 2.**



1. Human Tissue Act 2004 [www.opsi.gov.uk/acts/acts2004/ukpga\\_20040030\\_en\\_1](http://www.opsi.gov.uk/acts/acts2004/ukpga_20040030_en_1)
2. The Human Tissue (Scotland) Act 2006 [www.opsi.gov.uk/legislation/scotland/acts2006/asp\\_20060004\\_en\\_1](http://www.opsi.gov.uk/legislation/scotland/acts2006/asp_20060004_en_1)
3. United Kingdom Guidelines for Living Donor Kidney Transplantation, British Transplantation Society/Renal Association, 3<sup>rd</sup> version, June 2011. [www.bts.org.uk/](http://www.bts.org.uk/)
4. Guidelines for Antibody Incompatible Transplantation, January 2011, [www.bts.org.uk/](http://www.bts.org.uk/)

The relationship between ODT and the wider clinical transplant community is key to the development of the service and future strategy planning and is strengthened through the Advisory Groups. NHSBT also provides support in a number of other ways, including outcome monitoring, National Registries and the facilitation of the National Kidney Sharing Schemes.

Investment in living donation from NHSBT has mostly been used by Trusts to fund living donor co-ordinator (LDC) roles which have been considered pivotal to the development of local and regional LDKT programmes. Such posts are embedded within clinical teams and managed within local Trusts through established nursing structures. The appointment of a Lead Nurse for Living Donation will enhance professional leadership for these roles within ODT and offers an opportunity to establish peer support networks and training and development opportunities to nurses actively involved in LDKT.

Transplantation services are organised across different models of care but primarily there is a central transplant 'hub' into which donor-recipient pairs are referred into the service for LDKT. For kidney transplantation, there are 23 adult transplant centres, nine of which have embedded paediatric centres and there is one stand-alone paediatric centre which refers to another adult centre for the purposes of LDKT (**Appendix**)

## **2. Review**

### **2.1 Purpose and Scope**

The review was designed to provide an in-depth assessment of LDKT programmes across the UK in order to:

- Understand how the service is currently delivered across all four countries (England, Scotland, Wales and Northern Ireland)
- Understand the potential for expansion in activity and inform future activity targets
- Identify challenges to future development and sustainability
- Identify examples of clinical excellence
- Share learning and best practice across the wider transplant community
- Inform the development of a NHSBT UK Strategy for Living Donor Kidney Transplantation
- Identify the role of NHSBT in supporting the wider transplant community to deliver a clinically excellent service that meets the needs of patients and their families

The scope was limited to living donor kidney programmes as they contribute 98% of total UK living donor activity. It included both adult and paediatric programmes.

## **2.2 The Review Process**

Teleconferences were set up with transplant centres from late October to early November 2010. LDCs and Transplant Managers (TMs) were invited to participate as a minimum. The purpose of the teleconferences was to:

- Check LDKT activity against current and projected activity targets within financial year
- Identify any potential problems that may impact on activity
- Identify key contacts for LDCs, TMs and Clinical Leads (CLs) to arrange future clinical face-to-face meetings
- Explain purpose and timeframe (December 2010 to February 2011) for face-to-face meetings
- Agree preferred timeframe for clinical meeting within review period

## **2.3 Limitations**

Twenty three adult transplant centres (n=24) are represented in this review. A visit to the remaining centre will have been achieved by end of July. Representation from paediatric transplant centres was lower than anticipated; 4 centres (n=10) were represented. Following discussion with the paediatric representative on NHSBT KAG, it was accepted that the specific views expressed by this small cohort may not be sufficiently representative of the wider paediatric community to include in the findings. Further engagement with the wider paediatric nephrology community will be included as part of the future strategy.

Representation at review meetings from DGH nephrology referring units and support services e.g. Histocompatibility and Immunology (H&I) laboratories was variable. Where DGH nephrology units were not represented, separate visits/further contact was arranged on request.

### 3. Outcomes and Findings

#### 3.1 Clinical

All centres are actively engaged in LDKT and there appears to be unanimous support for the key themes outlined in the Draft National Strategy that relate to LDKT i.e.; Increase in activity, donor safety and optimisation of pre-emptive LDKT and the National Sharing Schemes. Activity per million population (pmp) varies between centres and is influenced by demographics, ethnicity and type, complexity of case-mix, deceased donor listing practices, capacity and capability (see below).

There is no shortage of potential recipient-donor referrals in adult programmes but all centres report an increasing trend in the complexity of recipient case-mix in terms of immunology, blood group incompatibility and co-morbidity. The expansion of the donor pool has increased the complexity of donor evaluation and there are some specific challenges in the assessment of non-directed altruistic donors (NDAD), related to the structure of clinical pathways to identify unsuitable donors at an early stage and managing the logistics of the paired/pooled scheme. This has implications for the service in terms of both human resource and money. There is likely to be some inadvertent activity capping where workload exceeds the capacity of the team to manage new referrals or progress those already accepted into the programme.

Referrals into paediatric programmes remain at an almost steady state or have minimally increased because the size of the patient cohort is relatively stable. However, within these limited cohorts, there is variation in practice with regard to LDKT between centres so there is potential for expansion within the national programme.

There is significant variation in rates of attrition of donor-recipient referrals from the programme, i.e. the pairs who do not proceed or exit the programme. Between centres, this varies from 25-75% of all referrals. The influencing factors (as above) may account for some of this variation but the point at which referrals are considered to enter the programme impacts upon how activity is counted and this is inconsistent across all centres. If the point of referral is taken from when a potential donor has had some meaningful discussion/interaction with the LDC, it is likely that the average rate of attrition will be between 30-50% for most programmes. This should be considered in future capacity and workforce planning to ensure effective triage and progression of donor-recipient referrals.

Programmes vary in capacity and capability. These can be categorised as follows:

**Mature programmes** i.e. those that are offering the full range of living donor options to their patient cohort (new technologies, National Sharing Schemes, pre-emptive LDKT). These centres have reviewed their dialysis populations to ensure that LDKT has been offered and are achieving close to maximum pre-

emptive transplantation rates for their local population. These programmes are unlikely to show big step increases in activity but will show a slow upward trend/steady state year on year through 'fine tuning' their services. Such centres may not offer the full range of options 'in-house' but are prepared to refer donor-recipient pairs to other centres e.g. for incompatible transplantation. These programmes have a high profile and priority within their own Trusts.

**Maturing programmes** i.e. those that have been through a recent re-organisation or re-appraisal of their service and have implemented significant changes, facilitating significant short-term expansion and increased activity over the next 1-2 years before reaching steady state. These programmes are also well supported by their corporate Trust colleagues.

**Developing programmes** i.e. those that have work to do to reach their potential but significant activity potential in these centres is unlikely to be realised unless changes are implemented. This includes capacity issues, developing infrastructure and engagement between colleagues in referring DGH nephrology units and the transplant centre. With the exception of theatre capacity, which will address an instant backlog for those centres, there will be a lead time for changes that are implemented within this financial year and increased activity will only be realised next financial year (2012/13). These programmes typically tend to have a lower profile or priority within their individual Trusts.

All centres have developed clinical pathways to optimise donor and recipient management to the point of transplantation. There is variability about success and functionality, particularly across complex models of care e.g. 'hub and spoke'. The most effective pathways are those in which

- The multi-disciplinary team (MDT) is fully engaged with the philosophy of LDKT, roles and responsibilities are clearly defined and there is good communication between MDT members.
- There are separate lead clinicians involved with donor and recipient pathways who work with lead nurses to ensure that donor and recipient pathways run in parallel to one another to achieve timely transplantation
- There is appropriate infrastructure established in key professional roles i.e. nephrology, surgery, nursing in order to deliver the current service and to resource future expansion.
- Key support services e.g. Histocompatibility and Immunology (H&I) and administrative support, particularly for pivotal nursing roles, are well resourced
- These principles are mirrored both in the transplant centre and in units that refer donor-recipient pairs to the centre for LDKT. Shared responsibility for donor-recipient assessment in accordance with

agreed pathways/protocols strengthens working relationships between 'hub and spokes' and builds capacity for future expansion

The concept of pre-emptive LDKT is well established and all centres, both adult and paediatric, aspire to maximise activity. Currently, there is no meaningful comparative measure between centres because of confounding factors (as previously outlined) but it is clear that a strong MDT ethos and teamwork, effective clinical pathways for both donor and recipient and early identification of potential recipients who may benefit from a pre-emptive LDKT are key to success.

The units that trigger a referral for consideration for pre-emptive LDKT at a recipient eGFR level of approximately 20 mls/min.1.73m<sup>2</sup> achieve better pre-emptive transplantation rates (eGFR between 10-15 mls/min.1.73m<sup>2</sup>) because they are able to initiate a pathway that is relevant to the recipient disease and decline in function and donor availability.

Access to clinical investigations and consultations has an impact on the speed at which clinical evaluations can be achieved and needs to be factored into local models. The guidance for pre-emptive deceased donor listing at six months prior to dialysis is inappropriate in the context of LDKT because sufficient time must be allowed for the attrition of unsuitable donors.

A significant rate-limiting step is the variation in practice between transplant hubs and referring spokes which are identifiable at regional, local and individual clinician level and is accentuated in more complex models where more than one DGH nephrology unit refers to a transplant hub.

Minimally invasive donor surgery techniques are offered in all centres and are considered integral to improved donor outcomes and future sustainability of LDKT.

Some centres, by virtue of their infrastructure and/or donor-recipient cohort have developed expertise in certain areas of LDKT (e.g. recipients with HIV, Sickle Cell Anaemia).

The majority of adult centres either provide/aspire to provide antibody removal programmes for ABO blood group incompatible (ABOi) LDKT. The minority of programmes have made a decision not to commence this programme and have either postponed the commencement because of capacity issues within the general LDKT programme and/or decided to refer donor-recipient pairs to other centres on a long-term basis.

Fewer adult centres offer antibody removal for HLA (immunological) incompatibility (HLAi) although a minority of centres (n=2) have started such programmes in preference to ABOi in the first instance. Whilst centres do refer such pairs to other centres for HLAi LDKT if the service is not provided locally, it is likely that there is an under-detection rate and thus potential to expand activity for suitable patients.

The success and long-term outcomes from these programmes is multi-factorial, regardless of the perceived complexity/degree of incompatibility between donor and recipient. These are:

- Dedicated clinical expertise across the MDT
- Robust support services for both H&I and haematology monitoring
- A critical mass of patients to develop clinical expertise, ameliorate the learning curve effect and streamline services more economically
- Outcome monitoring through all participating centre contributing data to the NHSBT Antibody Incompatible Transplant Registry (AiT)

All centres are involved with and have growing confidence in National Living Donor Kidney Sharing Schemes. There was unanimous support to amalgamate NDAD and paired/pooled schemes from October 2011 and to achieve improvements in clinical pathways to optimise the productivity of the schemes. Typically, the decision to enter donor-recipient pairs into the existing paired/pooled scheme is based upon clinical criteria which are discussed with the donor-recipient pairs on a case by case basis.

There are some specific considerations related to black and minority ethnic (BME) groups which have a direct impact on activity and account for centre variations in achieving LDKT in BME donor-recipient cohorts. These are worthy of further exploration but include ethnic origin and associated co-morbidities, level of education, social standing and financial security.

National patient information materials (e.g. NHSBT leaflets, '*Gift of Life*' materials) supplemented by local, centre-specific patient information and the publication of the 3<sup>rd</sup> version of the '*UK Guidelines for Living Donor Kidney Transplantation*' are seen as a positive contribution to achieving consistency in LDKT practice across the UK.

### **3.2 Organisational**

Adult LDKT is delivered within different models of care across the UK

- Transplant centre (hub) alone
- Small 'hub and spoke': transplant centre (hub) and single DGH nephrology referring unit (spoke)
- Complex 'hub and spoke': transplant centre (hub) and multiple DGH nephrology (spokes)\*
- 'Extended family': transplant centre (hub) and multiple satellite dialysis centres staffed by transplant centre
- 'Hybrid': transplant centre (hub) with extended family units and DGH spokes

\* Some DGH 'spokes' refer to more than 1 transplant 'hub'

Paediatric LDKT services are organised as a 'spoke' associated with an adult transplant centre 'hub' and serve broader regional patches. With one exception, all paediatric centres are situated geographically apart from the adult centres, even when they are within the same Trust.

Clinical pathways are locally agreed to meet the needs of the region. In 'hub and spoke' models, donor and recipient evaluation and long-term follow-up are usually shared between the transplant centre and referring units according to agreed protocols. In 'extended family' models, responsibility for donor and recipient pathways are assumed by the transplant centre. However, such arrangements are subject to local variation and under-performing DGH nephrology units may be masked by centralisation of services in the transplant centre in an effort to streamline activity. This may be onerous for the transplant centre and may not present an ideal model for future expansion.

Control, organisation and flexibility of theatre capacity on more than one day of the week are essential for transplant centres to sustain a viable LDKT programme and to fully participate in the National Living Donor Sharing Schemes. The ability to organise and to accommodate simultaneous donor-recipient lists in a recommended timeframe<sup>3</sup> will be pivotal to future capacity planning.

### **3.3 Commissioning**

There is a lack of consistency in current commissioning and funding arrangements for LDKT. The majority of transplant centres are funded by activity but some centres are still subject to block funding. All transplant centre Trusts (n=24) and 11 DGH referring centres receive investment from NHSBT into LDKT until financial year end 2011/12 (as outlined above). Referring DGH nephrology units are also subject to variable funding streams and the most robust models are based upon activity, negotiated with the transplant hub, so that a proportion is paid to the DGH for the work that is contributed to the overall transplant process.

In the absence of a National Tariff that accurately reflects donor and recipient evaluation costs, including H&I, and competes favourably with the recent dialysis tariff, LDKT and particularly pre-emptive LDKT is vulnerable. Both transplant centres and referring DGH units will rely upon the Transplant Tariff to negotiate activity-led funding streams.

Antibody removal programmes for recipients of ABOi and HLAi living donor transplants are also subject to local funding and commissioning arrangements. The majority are agreed on a case by case or limited cohort basis but some centres absorb the costs within their routine LDKT programmes. One centre is commissioned to enter all incompatible pairs into the National Sharing Scheme for two matching runs (6 months) prior to

commencing antibody removal but most centres are at liberty to make this decision on clinical grounds (see above).

The recent implementation of a MDT Tariff from DH will offset some costs for both donor and recipient evaluation. Further communication about this Tariff from DH to the wider transplant community will help to inform effective implementation in the context of LDKT.

The cost of clinical investigations (excluding H&I) can be redeemed but only if the GP is identified as the 'commissioner'. With the exception of one centre, donor referrals are not generated via the GP but from Consultant to Consultant referral in order to facilitate a streamlined evaluation process and timely transplant. This will need to be considered in negotiating future commissioning arrangements for living donor pathways.

There is widespread anxiety across the transplant community about the uncertainty in National Commissioning arrangements, the potential financial shortfall under new tariff arrangements and the overall impact on the sustainability of LDKT. This is the primary risk to the successful implementation of a National Living Donation Strategy.

#### **4. Recommendations**

In light of this comprehensive review, the following recommendations are proposed in order to develop a living donor programme across the UK that is clinically excellent, financially viable and has future sustainability.

1. Key stakeholders within the wider transplant community should be invited to participate in and contribute to:
  - A launch event for the NHSBT UK Strategy for Living Donor Kidney Transplantation
  - An implementation Steering Group for the Strategy
  - The optimum service delivery model for a responsive and sustainable LDKT programme
  - The work-streams that are required to deliver the above
  
2. Commissioning arrangements for LDKT must be supported by a Transplant Tariff that facilitates/incentivises activity-led funding streams to be developed that accurately reflect the costs of donor and recipient management in both transplant and referring DGH nephrology units. Such arrangements must reflect the multi-disciplinary nature of the service and the infrastructure that is required to support a complex recipient-donor case-mix and a rapidly evolving service, including adequate theatre capacity and flexibility for centres to meet local need and to participate effectively in the National Living Donor Kidney

Sharing Schemes. Particular consideration must be given to the commissioning and provision of LDKT for donor-recipient pairs that are immunologically complex and/or blood group incompatible in terms of the clinical expertise and infrastructure that is required.

3. Workforce development and planning across the multi-disciplinary team that reflects the requirements of a contemporary living donor service needs to be considered as a priority.
4. The development of clinical and organisational pathways based upon contemporary professional guidelines and evidence base<sup>3</sup> that are applicable across complex models of care are required to maximise the potential of all aspects of LDKT practice. This is particularly relevant to pre-emptive LDKT and the National Living Donor Kidney Sharing Schemes.
5. A communication strategy that includes the provision of generic, up to date information for donors and recipients that is available in a variety of formats and accessible through the internet must underpin clinical practice.
6. Research and audit must be integral to any future developments and evaluation of the programme. Such activity should be directed towards areas that require particular development and reflect the overall Strategy for LDKT such as pre-emptive transplantation and black and ethnic minority (BME) communities.

## Appendix

Transplant centres participating in living donor kidney transplantation activity.

**Table 4.7 Adult living donor kidney transplants in the UK, 1 April 2008 - 31 March 2010, and percentage of active transplant list at 31 March, by transplant centre/region**

Transplant centre/region	2008-2009			TOTAL		2009-2010			TOTAL	
	Directed	Paired/pooled	Non-directed	N	% list	Directed	Paired/pooled	Non-directed	N	% list
Belfast	8	0	0	8	4	15	2	0	17	7
Birmingham	61	0	1	62	10	76	0	1	77	13
Bristol	36	0	0	36	10	35	1	2	38	12
Cambridge	40	4	0	44	16	40	1	1	42	15
Cardiff	31	0	0	31	14	37	1	0	38	14
Coventry	35	2	1	38	28	33	1	0	34	23
Edinburgh	18	0	1	19	7	21	2	2	25	8
Glasgow	27	0	1	28	9	20	1	0	21	7
GOS	1	0	0	1	0	0	0	0	0	0
Leeds	37	2	0	39	11	37	1	1	39	11
Leicester	45	0	1	46	12	42	0	0	42	12
Liverpool	28	0	0	28	12	29	1	2	32	14
Manchester	37	4	0	41	7	53	5	0	58	10
Newcastle	39	0	2	41	17	41	0	1	42	17
Royal Free	19	0	0	19	8	43	0	0	43	17
Royal London	38	0	1	39	15	44	0	1	45	16
WLRTC	87	0	2	89	20	81	2	1	84	17
Nottingham	15	0	0	15	6	15	0	0	15	7
Oxford	42	1	1	44	10	48	3	1	52	12
Plymouth	15	0	1	16	18	17	0	1	18	18
Portsmouth	20	1	0	21	9	16	3	0	19	9
Sheffield	19	0	1	20	9	22	0	1	23	11
Guy's	88	1	2	91	22	103	5	1	109	28
St George's	42	1	0	43	15	49	3	0	52	17
<b>TOTAL</b>	<b>831<sup>1</sup></b>	<b>16</b>	<b>15</b>	<b>862<sup>1</sup></b>	<b>12</b>	<b>920<sup>1</sup></b>	<b>32</b>	<b>16</b>	<b>968<sup>1</sup></b>	<b>14</b>

<sup>1</sup> Includes 3 transplants performed at The London Clinic

Source: NHSBT Transplant Activity Report 2009-2010.  
[http://www.organdonation.nhs.uk/ukt/statistics/transplant\\_activity\\_report/current\\_activity\\_reports/ukt/activity\\_report\\_2009\\_10.pdf](http://www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2009_10.pdf)