NHS Commissioning Board

Commissioning Policy Statement: Reimbursement Of Expenses For Living Kidney Donors

April 2013

Reference: NHSCB/A07/PS/a









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First published: April 2013

Prepared by the NHS Commissioning Board Renal Transplant CRG

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POLICY STATEMENT: Reimbursement Of Expenses For Living Kidney Donors

Policy Ref: NHSCB/A07/PS/a

Purpose:	This Policy is designed to inform healthcare professionals and commissioning authorities about the principles and processes that underpin financial reimbursement for living kidney donors. It is envisaged that it will be compatible with practice in the other UK countries.				
	This policy has been developed jointly by NHS Blood and Transplant and NHS Kidney Care				
Background:	The purpose of this policy is to endeavour to ensure that the financial impact on the living kidney donor is cost neutral. Reimbursement of expenses must be proportionate and fair for the individual and administered in a consistent and timely manner. Best practice must be congruent with the Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006.				
	The following points summarise the policy in England (but with a view to being compatible with policies from the other UK countries – Wales, Scotland, Northern Ireland) for the reimbursement of costs associated with undertaking a living kidney donation. This could either be a directed kidney donation (to a relative, friend or other), or as part of the National Living Donor Kidney Sharing Schemes (i.e. paired/pooled donation or non-directed altruistic donation and altruistic donor chains):				
Commissioning position:	 a) The principle of reimbursement is founded on the premise that there should be no financial incentive or disincentive in becoming a living kidney donor; 				
position.	 b) A robust, stratified claims assessment process based upon the level of risk and proportionality is required i.e. in line with the donor's earnings, in order to assess claims accurately across the spectrum of costs. 				
	 c) The financial reimbursement will reflect the loss of earnings and other relevant expenses except where exceptions apply (see g) 				
	d) The calculation of reimbursement will be agreed in principle in a transparent and consistent manner before donation.				

Policy review date:	April 2014			
Date approved by NHSCB Board:	March 2013			
Responsible CRG:	Renal Transplant CRG			
Equality impact:	The NHS CB has a duty to have regard to the need to reduce health inequalities in access to health services and health outcomes achieved as enshrined in the Health and Social Care Act 2012. The NHS CB is committed to ensuring equality of access and non-discrimination, irrespective of age, gender, disability (including learning disability), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex (gender) or sexual orientation. In carrying out its functions, the NHS CB will have due regard to the different needs of protected equality groups, in line with the Equality Act 2010. This document is compliant with the NHS Constitution and the Human Rights Act 1998. This applies to all activities for which they are responsible, including policy development, review and implementation.			
Evidence summary:	N/A			
Effective from:	1 April 2013			
	See Appendix A for the full policy and associated documentation			
	g) Potential donors who are deemed unsuitable to proceed to donation may be eligible to claim for reimbursement of travel expenses, including parking costs. Under exceptional circumstances, additional reimbursement costs may be considered on a case by case basis.			
	f) The NHS Commissioning Board (NHS CB) will reimburse donors directly to avoid delay caused by indirect payment processes (i.e. via individual Trusts).			
	e) Special arrangements (e.g. retrospective consideration of claims) may need to be considered where overseas donors are involved or those that relate to the National Living Donor Kidney Sharing Schemes, if the timeframe prior to donation precludes prospective agreement.			

Appendix A

POLICY FOR REIMBURSEMENT OF EXPENSES FOR LIVING KIDNEY DONORS

RECOMMENDED BY





Kidney Care

REIMBURSEMENT OF EXPENSES FOR LIVING KIDNEY DONORS POLICY DOCUMENT

This Policy is designed to inform healthcare professionals and commissioning authorities about the principles and processes that underpin financial reimbursement for living kidney donors. It is envisaged that it will be compatible with practice in the other UK countries.

1. Aim

The purpose of this policy is to endeavour to ensure that the financial impact on the living kidney donor is cost neutral. Reimbursement of expenses must be proportionate and fair for the individual and administered in a consistent and timely manner. Best practice must be congruent with the Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006 (see Appendix 3).

2. Summary

The following points summarise the policy in England (but with a view to being compatible with policies from the other UK countries – Wales, Scotland, Northern Ireland) for the reimbursement of costs associated with undertaking a living kidney donation. This could either be a directed kidney donation (to a relative, friend or other), or as part of the National Living Donor Kidney Sharing Schemes (i.e. paired/pooled donation or non-directed altruistic donation and altruistic donor chains):

- h) The principle of reimbursement is founded on the premise that there should be **no financial incentive or disincentive** in becoming a living kidney donor;
- i) A robust, stratified claims assessment process based upon the level of risk and proportionality is required i.e. in line with the donor's earnings, in order to assess claims accurately across the spectrum of costs.
- *j)* The financial reimbursement will reflect the **loss of earnings and other relevant expenses** except where exceptions apply (see g)
- k) The calculation of reimbursement will be agreed in principle in a **transparent** and consistent manner before donation.
- l) Special arrangements (e.g. retrospective consideration of claims) may need to be considered where overseas donors are involved or those that relate to the

- National Living Donor Kidney Sharing Schemes, if the timeframe prior to donation precludes prospective agreement.
- m) The NHS Commissioning Board (NHS CB) will reimburse donors **directly** to avoid delay caused by indirect payment processes (i.e. via individual Trusts).
- n) Potential donors who are deemed **unsuitable to proceed** to donation may be eligible to claim for reimbursement of travel expenses, including parking costs. Under exceptional circumstances, additional reimbursement costs may be considered on a case by case basis.

3. Key Principles for Reimbursement

The key principles that underpin the application and approval processes to prevent delay in settling claims are:

- I. Individual claims should be submitted and settled in a timely fashion to prevent unnecessary financial hardship to the donor as a consequence of the donation.
- II. Claims will be settled by the NHS CB on an individual basis according to agreed criteria specified within the governance structure (see 9- Governance Structure).
- III. Early identification of potential claims during the donor assessment period is essential to facilitate prior approval in principle and to ensure timely settlement (see 10, 11 Process/Responsibilities).
- IV. Early notification to the NHS CB of a potential claim must be made and, whenever possible, prior to the date of donation to facilitate timely settlement. However, provision should be available for considering claims retrospectively if, for genuine reasons, it has not been possible to highlight a prospective claim to the NHS CB (see 1 e).
- V. Donor expectations about the nature and size of claims that will be approved must be appropriately managed.
- VI. Donors must be provided with appropriate and specific information about criteria for application, approval processes and timeframes at an early stage of the assessment process.
- VII. Income and alternative sources of reimbursement, (e.g. salary, statutory sick pay) must be declared and supporting evidence (e.g.; pay slips, social security certificates) provided by the donor at the time of application for reimbursement.

4. Potential Living Donors from Overseas

There are instances when the individual wishing to donate lives overseas. It is possible for claims to be made for reimbursement for overseas donor expenses such as flight costs, loss of earnings and reasonable accommodation costs incurred during their stay in the UK.

There are UK guidelines that specify best practice for the evaluation of donors living overseas. A protocol has been agreed between the key stakeholders within the wider transplant community, UK Border Agency and Human Tissue Authority (HTA). (see Section 1, Introduction, Background Information Document and Appendix 1).

Ideally costs will be reimbursed directly to the donor. There may be circumstances where this is impractical because the donor does not have a UK Bank Account. The HTA has confirmed that it is reasonable for there to be flexibility, provided that costs are appropriately reimbursed and relate to the expenses incurred as a result of the

donation process. Hence, in such circumstances, the costs may be reimbursed to another family member, including the recipient if necessary.

The Living Donor Coordinator must notify the recipient's commissioners of a potential overseas donor as soon as the visa application has been approved.

Should the donation be unable to proceed due to circumstances that could not have been foreseen prior to arrival in the UK, then consideration should be given to reimbursing the travel expenses incurred.

5. National Living Donor Kidney Sharing Schemes (NLDKSS)

The NLDKSS is the collective term used to describe the scheme in which donated kidneys are "shared" across the UK. These include paired/pooled donation (PPD), non-directed altruistic donation (NDAD), and altruistic donor chains (ADC).

Prospective agreement of donor costs from the NHS CB may not be feasible in cases of NDAD and ADC donation because the recipient may live anywhere in the UK and arrangements outside England may apply. The living donor coordinator should have prior knowledge of a claim and the proposed amount that the NDAD intends to claim prior to donation so that donor expectations can be managed. It is recommended that the appropriate paperwork and application is prepared in advance so that, when a NDAD is matched to a recipient, a claim can be expedited as quickly as possible according to the agreed process (see section 10).

5.1 Paired/Pooled Donation

In cases of PPD where kidneys are exchanged between recipient and donor pairs in either two-way (paired) or three-way or more (pooled) exchanges, the reimbursement of the donor will be agreed locally with the recipient commissioners. This facilitates prospective agreement and works on the basis of reciprocity (i.e. all recipients ultimately receive a transplant when matched).

5.2 Altruistic Living Donors (non-directed altruistic donation, including altruistic donor chains)

This is where a person volunteers to donate a kidney to an unknown recipient, that is, someone they have never met before and who is not known to him/her. They may donate directly to the national waiting list to a single recipient, or create an altruistic donor chain in which donor recipient pairs within the paired/pooled scheme may benefit from donation from an altruistic donor with the end of the chain being a kidney donated to the national transplant list. (Appendix 2)

6. Child Tax Credit and Working Tax Credit

A person's entitlement to Child Tax Credit will not be affected by the fact that (s)he is a living donor. A short absence (see-12) from work should not affect a donor's entitlement to Working Tax Credit, including the child care element, because, assuming the donor plans to return to work as soon as (s)he has recovered, HM Revenue & Customs would not regard the absence as affecting the donor's "usual working hours". When entitlement to either or both of the tax credits is assessed, only taxable income is taken into account. So if donors receive non-taxable income,

they are not required to report it to the Inland Revenue. Donors who need further information should contact the Tax Credit Helpline on 0845 300 3900 for further advice.

7. Travel Expenses

Any reasonable claim for travel expenses should be considered on an individual basis and documentation to support the claim for these expenses will be required.

Appropriate travel costs should be calculated on the basis of the cheapest and/or most appropriate mode of public transport (including any promotional or concessionary fares) available to the patient. Mileage will be at the agreed standard NHS rate.

If the donor is claiming tax credit, they may claim travelling expenses directly from the Trust. Although it is preferable for donors to comply with the process outlined in this document, in cases of financial hardship reimbursement of travel expenses at the point of need is likely to be more appropriate. However, if expenses are claimed from the Trust, the claim cannot be duplicated as part of this process.

8. Miscellaneous Expenses

It is possible that a donor may incur additional expenses as a direct result of the donation (e.g. additional child care costs/additional employment/ accommodation). Claims for reimbursement of these costs will be considered on an individual basis by designated personnel in the NHS CB (see-9 Governance Structure). Documentation to support the claim for these expenses must be provided by the donor and accompany the application.

These expenses must be considered reasonable and proportionate. Where possible these should be anticipated prior to donation.

9. Governance

A governance structure has been agreed to provide the appropriate level of scrutiny for all claims. This is designed to support the timely and consistent payment of legitimate claims and to provide a robust risk management strategy to underpin the policy.

9.1 Evidence to support claims (to be provided by the claimant)

The best evidence available should be submitted i.e. receipts, invoices, statements. In the absence of direct evidence, supplementary documentation e.g. letters of confirmation, testimonies, may be considered to support claims.

LOSS OF EARNINGS

Salaried Donors

- Payslips ideally 6/12 but at least 3/12
- Overtime look at overtime patterns and claims as a whole OR P60 from closest financial year.
- Stipulate that "additional income will be considered on a case-by-case basis" and that "by signing this application form, you are providing authorisation for the commissioner to contact your employer to clarify any payments".
- Payment will be processed on presentation of medical certificate for proceeding donors.
- Donors must provide evidence of any SSP (statutory sick pay) received they will be entitled to top-up if SSP is lower than their salary.

Self-employed Donors

- Copy of latest tax return.
- If a new business (operating for under 12/12), their accountant will provide details of net earnings to date.
- Evidence of Employment and Support Allowance received

Unemployed Donors

 If donors believe that they have lost benefits through donation, relevant information should be submitted. Liaison with the benefits and/or other agencies will be required to endorse claim.

DONOR OUTGOINGS

<u>Travel</u>

- Travel will be reimbursed for the donor ONLY.
- Standard class travel claims only will be considered for reimbursement.
- Mileage will be reimbursed at the standard NHS public transport rate. Current rates can be confirmed at
 - http://www.nhsemployers.org/payandcontracts/agendaforchange/pages/afcmileageallowances.aspx
- Parking, toll and congestion charges will be reimbursed.
- Taxis will be reimbursed only when used by the donor in the post operative period.

Accommodation

 Donors may claim accommodation costs on the basis of the actual room/per person rate paid up to a maximum of £85 per night (total cost based upon The Institute of Hospitality average room rate for 2011) at www.instituteofhospitality.org/news/2011-news/april-issue/uk_hotels_forecast

Other Expenses

- The commissioners will consider claims for expenses incurred by the donor as a direct result of donation. These costs include reimbursement of expenses incurred through the evaluation process, in-patient stay and for up to 12 weeks postoperatively.
- Care of a dependent will be considered on an individual basis. The donor is responsible for exploring entitlement to support from Social Services in this situation
- Backfill cover for business this will be linked to loss of earnings but assume that, if cover is in place, earnings have not been 'lost'.
- Donation-related prescription costs.

OVERSEAS DONORS

 Overseas donors (proceeding and non-proceeding) will be entitled to reimbursement for travel, accommodation and visa costs (including extension), but not for "living expenses" or loss of earnings.

9.2. Risk Management

Claim applications will be reviewed by designated personnel within the NHS CB.

Each claim will be assigned a Red-Amber-Green (RAG) rating. Claims can be escalated through the scale, e.g. from amber to red if there is concern that the claim is fraudulent.

The claim form must be signed by the responsible commissioner within the NHS CB and will reflect the workings/decision-making process, e.g. overtime calculations

All panels can be virtual (i.e. discussions via telephone/e-mail)

Green - single commissioner sign-off

- Value of up to £999
- Straight forward claims, e.g. clear relevant evidence provided
- Commissioner should be comfortable/authorised to sign off

Amber - virtual panel of e.g. three people.

- Value of £1000 to £4999
- Complex claims, e.g. bonuses/overtime, carers, or where claim is subjective
- Overseas and non-proceeding donors

Red – extended panel, e.g. to include expert advice from another area/discipline

- Value of greater than £5000
- Complex, contentious claims
- Potentially fraudulent claims
- Altruistic donors/shared kidneys

10. Claims Process

Best Practice Model for Reimbursement of Living Donor Expenses*

* adapted from BTS/RA 'UK Guidelines for Living Donor Kidney Transplantation', May 2011.

Identify potential reimbursement requirements with donor at early stage of assessment, i.e. loss of earnings, travel expenses.

Provide donor with information pack & application form to apply to NHS Commissioning Board (NHS CB). NHS Trust writes to NHS CB using template letter to register donor interest in submitting a future claim

Donor collates relevant documentation to support claim, i.e. evidence of net pay earnings, monthly/weekly payments, sick pay entitlement, travel, accommodation, child care etc.

Donor completes claim form with supporting evidence, identifying other relevant sources of funding/entitlements for expenses e.g. statutory sick pay (SSP), incapacity benefit. Some travel claims may be directly reimbursed from the Trust on the day of appointment/investigation (such as for donors who are in receipt of income support).

A social worker is helpful in assisting at this stage.

NHS Trust applies directly to NHS CB, enclosing relevant information, to seek approval for the claim.

Claims should be submitted in accordance with National Policy.

If claim approved, the NHS CB pays directly to the donor. Initial agreement should be for maximum of 12 weeks with flexibility to apply for extension if required.

Retrospective reimbursement maybe considered if unforeseen circumstances prevent a prospective claim being identified.

Initial payment for 6 weeks, extendable when supported by Medical certs to 12 weeks if still off work. Claims to be submitted -within an absolute maximum of 28 days from the end of the claim period.

Payment plan to be established prior to planned date of surgery following receipt of most recent supporting documentation i.e. 3-6 months payslips or similar. NHS Trust issues first medical certificate to donor on admission.

EMPLOYED DONORS

- Medical certificate submitted by donor to employer for SSP
- 1st payslip showing loss of earnings post surgery forwarded by NHS Trust to NHS CB with copy of medical certificate
- Payment processed

SELF-EMPLOYED DONORS

- Medical certificate submitted by donor to Department of Works and Pensions for incapacity benefit
- Copy of medical certificate forwarded by NHS Trust to NHS CB
- Payment commences as per sum agreed by prior approval

11. Responsibilities

11.1 Claimant (donor)

- a) In order to achieve prospective approval from the NHS CB, it is the responsibility of the claimant (donor) to ensure that:
 - The donor's Trust is alerted at an early stage that he/she wishes to submit a reimbursement claim.
 - An estimated assessment of the claim is submitted by the donor via the NHS Trust representative, to the commissioners at an early stage in the process.
 - All paperwork related to the estimated claim is submitted to the Trust representative (living donor co-ordinator (LDC)/Social Worker (SW)/ Administrative Support (AS)).
 - All claims need to be made within 28 days of the end of the claim period.
- b) It is the responsibility of the claimant (donor) to ensure that, when the transplant has been scheduled:
 - All claim forms are fully and accurately completed before submission
 - All supporting evidence is available
 - Checklist is completed
 - All information is submitted with the claim including confirmation of support from claimant's employer in a timely fashion (usually when the transplant has been scheduled assuming that this may be within four to six weeks).

Pending the appropriate paperwork to support this, the claim will be paid within 28 working days of receipt.

11.2 Trust Representative (see above)

- a) In order to achieve prospective approval from the NHS CB, it is the responsibility of the Trust Representative (LDC/SW/AS) to:
 - Provide the Donor Information Pack (Appendix 4) to the potential claimant at an early stage in the donor evaluation.
 - Check that the claimant's information corresponds with outpatient and inpatient dates.
 - facilitate prospective approval of a potential claim.
 - To write to the NHS CB notifying of them of all potential claims.
- b) To progress a claim, it is the responsibility of the Trust representative to:
 - check information submitted by the Claimant correlates with outpatient and inpatient dates.
 - Send information collated by Claimant to the NHS CB.

11.3 Commissioner (NHS Commissioning Board (NHS CB))

- a) For prospective notification of claims, it is the responsibility of the NHS CB to ensure that:
 - The claim and prior approval letter are acted upon as soon as possible.
 - acknowledgement is sent to the donor and the LDC that the claim has been received.
 - Confirmation or otherwise of prior approval by return where possible.
 - b) To facilitate the final claim, it is the responsibility of the NHS CB to ensure that:
 - Acknowledgement is sent to the donor and the LDC that the claim has been received.

- The claim form is acted upon in a timely manner so that payment is approved within 28 days of receipt of the claim.
- Points of clarification are asked directly of the claimant (donor) re the content and supporting information in the application but clinical queries are directed towards the LDC.
- The claim is approved to commence payment from the scheduled date of donation.
- the donor is reimbursed directly from the NHS CB in a timely manner.
- Appropriate contact details for designated personnel dealing with claims are provided to Claimants and Living Donor Coordinators

12. Timelines

The following are guidelines for the recovery process. These are total recovery times from admission to anticipated return to normal activity.

- Return to normal lifestyle or work activity within 6-12 weeks depending upon lifestyle and work commitments i.e. sedentary/physically strenuous. This may also apply to donors recovering from open nephrectomy as opposed to minimally invasive procedure.
- Caveats will apply if there are post-operative complications, e.g. wound infection, hernia etc, which may extend the anticipated inpatient stay/readmission/further procedure and/or recovery time.

13. Declaration

The donor **MUST** take personal responsibility for their own care and to follow reasonable medical advice or expenses may not be met.

The information included in each claim will be strictly validated to ensure that it is reasonable and appropriate. Renal Units and Transplant centres (see Governance, section 9) will be required to provide the necessary mechanisms to ensure that ALL information is correct and legitimate. It should be noted that all claims require the signature of the donor, agreeing to the following declaration:

"I declare that the information given is correct and complete. I consent to the disclosure of relevant information for the purposes of checking this and in relation to the prevention and detection of fraud. I understand that if I knowingly withhold information or provide false information, I may be liable for criminal prosecution and/or civil proceedings."

14. Appeals

- A national database will be developed by the NHS CB to record all claims.
- Appeals will be considered in accordance with NHS CB policies and protocols

Appendix 1: Best Practice Model Donors from Overseas	for the Management of Liv	ing Donor Transplant	s from
			1.1

Once initial enquiry has been initiated from either potential donor or recipient, the living donor co-ordinator (LDC) provides educational information for the donor and health questionnaire/request for initial investigations in country of

Donor returns medical information/health questionnaire to LDC for review by transplant team. Recipient transplant assessment reviewed and updated (i.e. suitable to proceed to transplantation within 3-6 months)

If deemed suitable to proceed, LDC liaises with donor and, if appropriate, agrees a provisional date for commencement of donor evaluation (4-12 wks ahead). LDC writes to the donor using the template letter to confirm arrangements; detailing roles, responsibilities and entry visa application process. Commencement date of the entry visa is requested for a few days prior to the planned date to facilitate travel to the UK. The recipient, also needs to receive a copy of the letter. If recipient requires further assessment for transplantation, this should be performed prior to initiating further contact

On arrival in the UK, donor assessment performed as per UK Guidelines and potential plan for surgery and recovery, pending outcome of assessment, is established to ensure that this can be achieved in principle within 6 months

Unsuitable Donor

- Return to country of origin with advise for future follow-up if appropriate
- May be eligible for travel and visa reimbursement costs

Suitable Donor

- Proceeds to donation as planned
- Reimbursement claim for donor expenses made to commissioners
- Returns to country of origin following appropriate period of convalescence with long-term

*From BTS/RA 'UK Guidelines for Living Donor Kidney Transplantation', May 2011. (see sources, Background Information)

Appendix 2*

Figure 1: Paired (2-way)/Pooled (3-way) Donation

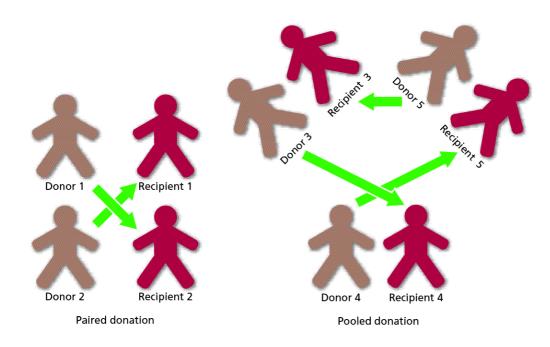
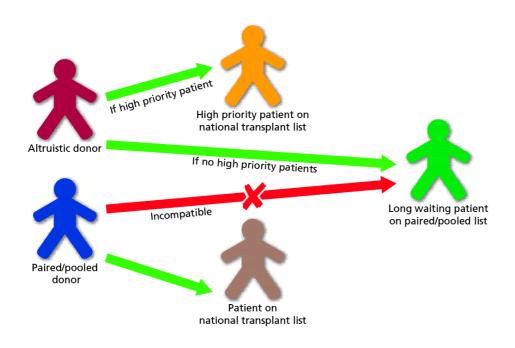


Figure 2: Altruistic Donor Chain



^{*} Figures courtesy of NHS Blood and Transplant

Appendix 3a

BACKGROUND INFORMATION TO SUPPORT POLICY DOCUMENT

1. Introduction

Transplantation is widely accepted as both a clinically and cost effective treatment for end stage kidney disease (ESKD) and recent analysis shows that the benefit to the health economy is as much as £100,000 per patient over 5 years in comparison with the average costs of maintenance dialysis therapy¹.

The enhanced patient and transplant outcomes associated with living donor kidney transplantation (LDKT), together with the potential for planned pre-emptive LDKT prior to the onset of dialysis has meant that LDKT has become the renal replacement therapy (RRT) of choice for many patients². Avoidance of dialysis and an increase in the number of transplanted years versus years on dialysis per patient contributes to additional cost savings, making LDKT an attractive option for patients, healthcare professionals and commissioners. Activity has trebled in the UK in the last decade with more than 1000 kidneys transplanted each year from living donors. This accounts for over 50% of annual kidney transplant activity currently across the UK³. NHS Blood and Transplant has developed a UK Strategy for Living Donor Kidney Transplantation, which supports the development of the service across the UK and outlines the importance of working closely with commissioners to achieve optimum outcomes⁴.

During the development period, the profile of LDKT in the UK has changed dramatically resulting in an increasingly complex recipient case-mix and extended donor pool. Changes in clinical practice have been influenced by the introduction of a new legal framework ^{5,6}. novel technologies and professional guidelines that reflect growing expertise in the field ^{2,7}. In particular, the advent of the National Living Donor Kidney Sharing Schemes (NLKDSS) which, from January 2012, will include altruistic donor chains (ADC) as well as the existing paired/pooled donation (PPD) and non-directed altruistic donation (NDAD), have added another layer of complexity to the logistical planning of transplants as kidneys are shared across all the UK countries. Of the four countries that make up the UK, there is significant ethnic diversity in parts of England which presents challenges when facilitating donations from donors who live overseas. The recently revised UK Guidelines provide guidance in addressing some of these logistical issues with solutions that have been agreed in collaboration with the Human Tissue Authority (HTA), UK Border Agency (UKBA) and healthcare professionals ².

2. Context

The concept of reimbursement of legitimate expenses incurred by the donor, including loss of earnings, which are directly attributable to the organ donation has been supported by legislation prior to the implementation of the Human Tissue Act (HT Act) and continues under the current framework. It does not conflict with the primary mandate prohibiting payment or inducement for the supply of a human organ ^{5,6,8.} Guidance from the Department of Health (DH)⁹ supports NHS Organisations to

administer such payments where the donation does not contravene the HT Act. Although there is no legal obligation for them to do so, NHS Organisations have agreed in principle that payment of legitimate donor expenses is justified on the premise that, within reason, donors are no worse off as a result of the donation but neither should they gain financially. For the purposes of health economics, the calculation for *'the proposed reimbursement should be considered in light of the gross cost saving through the provision of a transplant as a result of the donation'* 10. In this context, the sum of a reimbursement claim will rarely exceed the cost saving of transplantation versus dialysis which equates to approximately £20,000 per year. 1

By way of example, analysis of a single regional network in England, with a catchment population of 4.359 million, showed that in 4.25 years a total of 115 donors were reimbursed, at a total cost to the Regional Sector of £240,000. The average cost per patient based on these figures was £2,110 with a range from £70 to £7,200. 15% (n=17) received £5,000 or more (Appendix 3b).

The limitations on this data are:

- Prior to 2009/10 when the budget was then held at regional level, some payments would have been paid directly from Primary Care Trusts (PCT) and will not be accounted for in the analysis.
- The region has an indicative "cap" of £5,000 but each case is reviewed individually. This may have limited the amount of some claims.

Historically, each UK country has developed individual protocols to facilitate the reimbursement of living donors. This has been an evolving process and some areas of the UK have mature policies in place which facilitate best practice and streamlined administration so that payments are made to donors at the appropriate time, at the point of need. Although considerable effort has been made to address these requirements, the range of policies in existence has created inequity of access to funding for claimants (donors) and administratively time-consuming processes for healthcare professionals and commissioners. In England, there is no single pathway for claiming reimbursement and it is subject to local arrangement between different regional networks. Wales, Scotland and Northern Ireland each have an agreed pathway in place which is country specific. Although many of these challenges are not new, the need for robust reimbursement arrangements that are fit for purpose to underpin a UK-wide service has been highlighted in recent years by the advent of the National Living Donor Sharing Schemes. Cases of PPD and NDAD where donors and recipients donated and received organs in different UK countries and were subject to different reimbursement arrangements, demonstrate the urgent need for a single coherent policy to ensure that the patient experience is seamless and that the risk of adverse events is minimised. Future developments within the NLDKSS are dependent upon the generosity of altruistic donors and public confidence in the donor reimbursement scheme is of primary importance.

The Policy document was compiled by a Steering Group (Appendix 3c) and was widely consulted upon throughout the transplant community.

References/Sources:

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- 2. United Kingdom Guidelines for Living Donor Kidney Transplantation, British Transplantation Society/Renal Association, 3rd version, May 2011. www.bts.org.uk/
- Annual Activity Report for Organ Donation and Transplantation, NHS Blood and Transplant, 2010/11 http://www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/transplant_activity_report.jsp
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- 5. Human Tissue Act 2004 www.opsi.gov.uk/acts/acts2004/ukpga_20040030_en_1
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- 10.Live Donor Expenses Commissioning Policy, version 1, March 2007
 http://www.wales.nhs.uk/sites3/Documents/898/CP30%20Live%20Donor%20Expenses.pdf
 (Revised document seen in draft August 2010-awaiting publication)

Appendix 3b: Example of Donor Reimbursement Activity

SEC Analysis of Donor Reimbursement Costs

Financial Year	Values Total Reimbursement	No. of Donors	Average Reimbursement
2007-08	18,478.03	10.00	1,847.80
2008-09	26,682.94	17.00	1,667.68
2009-10	113,705.98	43.00	2,644.33
2010-11	55,313.88	30.00	1,843.80
2011-12	25,660.99	15.00	1,710.73
Grand Total	239,841.82	115.00	2,103.88

Appendix 3c: Membership of Steering Group

Lisa Burnapp	Lead Nurse, Living Donation, NHSBT
	Consultant Nurse, Living Donor Kidney Transplantation
	Guy's & St. Thomas' NHS Foundation Trust
Emma Billingham	Senior Commissioning Manager, NHSBT
Nicky Bentley	Associate Director, South East Coast SCG
Rebecca Campbell	Renal Network Manager, Yorkshire and Humberside SCG
Laura Corner	Greater Manchester Kidney Care Network Manager,
	Greater Manchester Kidney Care Network
Nanette Grant	Programme Lead and Network Manager, Renal Services, West Midland Renal Network.
Carol Willis	Lead Nurse, West Midlands Renal Network
Wendy Hope	Network Manager, East Midlands Renal Network
Lynda Smith	Network Manager, Cumbria and Lancashire Kidney Care Network
Julie Hill	Living Donor Coordinator, Hull
Georgina Speak	Living Donor Coordinator, Leeds Teaching Hospitals
Anne Theakstone	Living Donor Co-ordinator, Nottingham City Hospital
	Emma Billingham Nicky Bentley Rebecca Campbell Laura Corner Nanette Grant Carol Willis Wendy Hope Lynda Smith Julie Hill Georgina Speak

Appendix 4a: Donor Information

Reimbursement of Expenses for Living Kidney Donors

Donor Information

This information pack is designed to:

- 1. Advise you how to make a claim
- 2. Answer frequently asked questions
- 3. Inform you about what to expect

How do you make a claim?

STEP 1

- The living donor co-ordinator will inform you during your clinic visit about the reimbursement process and what you will need to do to make a claim
- An Information pack will be provided which will include frequently asked questions and a claim form
- Please note that you will need to complete the claim form yourself and supply relevant documentation/evidence to support your claim

STEP 2

 The living donor co-ordinator will inform the NHS Commissioning Board (NHS CR) that you are likely to make a claim

STEP 3

- You will need to accurately complete the claim form and return it to the living donor co-ordinator along with the relevant evidence to support your claim
- The living donor co-ordinator will check and confirm your attendance dates on the claim form, sign and forward your

Responsibilities

Donor /Claimant

In order for your claim to be considered, you must:

- Inform the live donor co-ordinator as soon as possible if you would like to submit a claim for reimbursement.
- Provide a letter from your employer confirming the level of sick pay you will get if you go ahead to donate
- Ensure you are claiming any other benefits you may be entitled to e.g. statutory sick pay or help with travel costs etc.
- Ensure the claim form is fully and accurately completed and signed before submitting it to the live donor co-ordinator
- Ensure all supporting evidence / documentation is collected and submitted with the claim.
- Complete and return the checklist
- Submit the claim form in a timely fashion (within a maximum of 28 days of the date of donation) once the donation date has been scheduled.
- Inform the NHS CB if you return to work whilst you are receiving reimbursement or if you have been overpaid.

Hospital Trust Representative / Living Donor Co-ordinator / Social Worker

The Hospital Trust Representative will:

- Provide a donor information pack at an early stage.
- Inform the NHS CB of any potential reimbursement claims
- Check and confirm the inpatient / outpatient appointments on the submitted claim form.
- Send the claim form and relevant evidence provided by the donor to the NHS CB

NHS Commissioning Board (NHS CB)

The NHS CB Representative will:

- Confirm prior approval of the claim in principle initially.
- Acknowledge receipt of the reimbursement claim to the donor and Living Donor Co-ordinator.
- Approve payment of the claim within 28 days.
- Contact the donor directly if further information is required regarding the submitted supporting evidence.
- Ensure the claim is approved to commence payment from the scheduled date of donation

Reimbursement Information for potential living kidney donors

You are currently undergoing tests to assess your suitability to become a living kidney donor.

Your Living Donor Co-ordinator will have explained that you will be required to attend hospital for several appointments and investigations as part of the work up process. If you are found to be suitable to go on to donate your kidney you will also need a period of time after the operation to recover and recuperate.

It is possible to submit a claim for reimbursement of loss of earnings, travel costs and other relevant expenses that have occurred due to the donation process. Any claims submitted by a donor will be assessed on an individual basis by the NCB in line with the reimbursement of expenses for living donor's policy document.

Frequently asked questions

What is donor reimbursement?

Under the Human Tissue Act 2004 payment for donating a human organ is illegal. However, the Act does support the reimbursement of reasonable expenses for travel, loss of earnings and other expenses if directly attributable to the organ donation process.

When should I start to think about my reimbursement claim? As soon as possible.

The Living donor co-ordinator will provide you with an information pack at the early stage of your testing to assess your suitability as a donor. Read the information provided and start to gather the evidence required to support your reimbursement claim. For example, train tickets, parking receipts and letter from your employer confirming the level of sick pay you will get if you go ahead to donate.

What happens if I have had investigations and have found out I am not suitable to donate my kidney? Can I still make a claim?

You may submit a claim for reimbursement of travelling expenses and parking. In exceptional circumstances additional reimbursement costs may be considered.

I am in the paired / pooled list as part of the national living donor kidney sharing scheme (NLDKSS) can I still make a claim for reimbursement?

Yes, you can make a claim. Depending upon where you live in the UK, this will be submitted to the relevant NHS CB/Health Board.

I am an altruistic donor can I make a claim for reimbursement?

Yes, you can make a claim. The relevant NHS CB/Health Board for the recipient of your donated kidney will be responsible for dealing with your claim.

What do I need to make a claim?

You will need to provide proof of:

- Current employment status / income / pay slips
- Details about any benefits you currently receive or may receive following the donation / confirmation of loss of benefits.
- If employed, you will need to obtain a letter from your employer confirming the arrangements for work absence, sick pay, unpaid leave, partial pay.
- If self employed, you will need to provide details of gross income (before tax) from the last year
- Travel tickets / receipts or mileage travelled by car.
- Miscellaneous receipts, e.g. accommodation

You will need to submit the completed claim form and checklist

I am coming from overseas to donate my kidney. Can I still make a reimbursement claim?

Yes you can make a claim. The Living donor co-ordinator will need to inform the NHS CB as soon as your visa application has been approved.

Who makes the final decision on a reimbursement claim?

The NHS CB will make the final decision on any reimbursement claim after looking at the evidence you have supplied with your claim form.

Can my claim be rejected?

All claims will be scrutinised to prevent fraudulent or inappropriate claims being authorised. If evidence submitted with your claim is insufficient you may be asked by the NHS CB to provide further information or evidence.

How much will I be reimbursed?

This will vary according to your individual circumstances. You should not be financially worse off as a result of the donation process, but neither should you make any financial gain as this would constitute payment for donation which is illegal Travel costs for donors can be reimbursed and will be calculated on the basis of the cheapest and most appropriate mode of public transport.

Reasonable reimbursement of accommodation charges will be made up to the national average cost of a room

When will I receive my reimbursement?

The NHS CB will process your claim in a timely manner and aim to have it approved within 28 days. Payment can be made following the scheduled date of donation.

What if I return to work while I am still being reimbursed?

If you return to work during your period of reimbursement you must inform the NHS CB. You will need to repay the appropriate amount of reimbursement

Who can help me make a reimbursement claim?

The living donor co-ordinator will inform you about the donor reimbursement process at an early stage of your assessment to donate. You will need to complete the claim form yourself and obtain all the relevant documentation to support your claim.

Appendix 4b: Template letters and Claim Forms

Template letter number 1: to inform NHS Commissioning Board of potential donor registration of interest in claiming for reimbursement of living donor expenses

[Date]	[Trust Headed Paper]
To whom it may concern [NHS CB],	
Re: Reimbursement of Living Donor Exp	penses for
Donor name:	Date of Birth:
Hospital No:	NHS No:
Address:	
The above named person named is being a donor.	assessed as a potential living kidney
He/she * (delete as necessary) has register of expenses. In accordance with National F he/she* (delete as necessary) is eligible to	Policy, a full application will follow if
We would be grateful if you could confirm remail address].	eceipt of this letter by email to [insert
Please do not hesitate to contact me if you stage.	require any further information at this
Yours faithfully,	
Living Donor Coordinator	
Cc: potential donor	

Template letter number 2 and claim form for reimbursement of living donor expenses

[Date]	[Trust Headed Paper]
To whom it may concern [NCB],	
Re: Reimbursement of Living Donor Expenses for	or
Donor name:	Date of Birth:
Hospital No:	NHS No:
Address:	
As per our previous correspondence, please find atta and relevant attachments in respect of the above.	ached a completed claim form
Please do not hesitate to contact me if you have any hearing from you.	queries. I look forward to
Yours faithfully,	
Living Donor Co-ordinator	
Cc: potential donor	

LIVING KIDNEY DONOR CLAIM FORM FOR REIMBURSEMENT OF EXPENSES

This form must be completed in full. Missing information will delay your claim. Please complete all relevant sections before submitting the form to your Trust Representative for signature and final submission.

Please attach all supporting evidence to this claim form (see 'Donor Information' Frequently Asked Questions)

For the purposes of completing the form:

- The 'Claimant' is the donor
- The 'Trust Representative' is the Living Donor Co-ordinator/Administrative Assistant/Social Worker
- The 'Commissioner' is the NHS Commissioning Board

Section 1: DONOR AND RECIPIENT INFORMATION.				
To be completed by the Claimant.				
Name of donor:				
NHS Number:				
Date of Birth:				
Address:				
Email:				
Telephone number/s:				
Name of recipient (If applicable):				
NHS Number:				
Date of Birth:				
Address:				

Section 2: RELEVANT APPOINTMENTS/HOSPITAL ATTENDANCES. To be completed by the Claimant and confirmed by the Trust Representative. Hospital/clinic **Initials of Trust Date** Reason for appointment representative to confirm each entry Signature of Trust Representative to confirm attendances:

Section 3: TRAVEL EXPENSES.

To be completed by Claimant. NB: only complete this section if you have not been previously reimbursed for your travel expenses by the Hospital Trust. Mileage is paid at 24 pence /mile (NHS Public Transport Rate).

Date and time	Journey To/From	Mileage (if driving)	Amount claimed	Evidence attached Yes/No*
Total				
Total				

^{*} see section 6

If you have been informed that you are unable to donate a kidney, please go directly to Section 6

Section 4: PREDICTED LOSS OF EARNINGS (IF DONATION IS PLANNED TO PROCEED)					
To be completed by the Claimant.					
Proposed Date of Donat (if agreed)	ion				
Dates	Am	ount claimed		Evidence attached Yes/No*	
Total					

Section 3: OTHER EXPENSES.

To be completed by Claimant. NB: only complete this section if you have incurred/are likely to incur other expenses that are directly related to your donation.

Dates	Type of expense	Reason	Amount claimed	Evidence attached Yes/No*

^{*} see section 6

Total		

^{*} see section 6

Section 6: SUPPORTING STATEMENT.		
To be completed by Claimant. Please provide any additional information that you wish to be considered e.g. if supporting evidence cannot be provided and/or anything else that may affect your claim.		

Section 7: DECLARATION			
To be signed by the Claimant.			
I declare that the information given is correct and complete. I consent to the disclosure of relevant information for the purposes of checking this and in relation to the prevention and detection of fraud. I understand that if I knowingly withhold information or provide false information, I may be liable for criminal prosecution and/or civil proceedings.			
Signed:	Date:		
Print Name:			

Final Checklist

Please ensure that you complete the following checklist before submitting your claim form:

To be completed by Claimant to accompany claim form.		
Have you:	Please initial to confirm	
1. Completed all relevant sections on the form?		
2. Enclosed all relevant supporting evidence/information?		
3. Signed and dated the declaration?		

Please submit your completed form, supporting information and attached checklist to your Trust Representative to sign the relevant sections. He/she will send your application the NHS Commissioning Board.

Section 7: CONFIRMATION BY TRUST REPRESENTATIVE			
To be signed by the Living Donor Co-ordinator.			
I confirm that the above person has (**delete as applicable):			
**Been assessed as a kidney donor and is suitable to donate a kidney.			
**Been assessed as a kidney donor but is unsuitable to donate and will not be proceeding to donation.			
Signed:	Date:		
Print Name:			
Hospital Trust:			

For office use only section to be included to reflect claims approval process