

## kidney disease

### Report on the United States experience of living kidney donation based on visiting the University of Minnesota and the Mayo Clinic submitted to UK Transplant.

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**T**he Kidney Disease Modernisation Initiative, funded by Guy's and St. Thomas' Charitable Foundation, seeks to improve the delivery of renal care for the population of Lambeth and Southwark. In order to seek out examples of good practice two representatives of the project visited two large transplant centres in the United States (US) to examine their living donor programmes. The two institutions were chosen after discussion with the Medical Director of UKT, Mr. Chris Rudge, as each have large and active living donor programmes. The University of Minnesota has one of the most mature and best-established programmes in the US. It performs approximately 130 living kidney donor transplants per year and is renowned for its pioneering work in pancreatic transplantation. The Mayo Clinic programme is younger and historically small but, during the last five years, has increased from 40 to 205 living donor grafts per year.

The following analysis is based on the authors' understanding of the differences between the living donor programmes in the US and the United Kingdom (UK). It is not intended to be a comprehensive review but is designed to highlight

key issues, which may facilitate a better understanding of the disparity in living kidney donation between the UK and the US. General comparisons are made between the programmes in each country based on collective experiences rather than an attempt to analyse the activity in each centre individually. The intention is not to be prescriptive about specific changes that should be made. The authors apologise for any inaccuracies or omissions that may have arisen as a result of their interpretation of the information provided.

One of the UK representatives also acts as Nurse Consultant Adviser to the Living Donor Schemes supported by UK Transplant (UKT) and will furnish information from the visit to UKT. The Modernisation Initiative is grateful to the staff at both the University of Minnesota and the Mayo Clinic, not only for their time and the quality and depth of information that they provided, but also for the warm welcome that was extended to the visiting representatives. It is especially grateful to Dr. Raja Kandaswamy at the University of Minnesota and Dr. Mikel Prieto at the Mayo Clinic for coordinating the visits at each centre.

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# Key Issues

## The Overview:

### National and Local Frameworks

There has been an increase in the number of living donor transplants performed over the last ten years in the US. Whilst the UNOS (United Network for Organ Sharing) scheme oversees cadaveric kidney allocation it has no role in the living donor programmes. There is no specific legal framework or regulatory body governing the practice of living donation. Individual units have ethics committees that determine local practice. This means that potential donors and recipients do not need to demonstrate the same 'emotional' relationship which is required by ULTRA (Unrelated Live Transplant Regulatory Authority) in the UK in order for the donation to proceed. For instance, a valuable source of living unrelated donors in the US is from workmates or members of the same religious organisation who are accepted as donors. In the UK they may not fulfill the necessary requirements under the Human Organ Transplant Act 1989. Non-directed (altruistic stranger) donation is not felt to significantly contribute to the numbers of living donor transplants performed. However, both centres accept the principle and have used these donors. Both have robust frameworks in place for managing these donors and ensuring the anonymity of donor to recipient. Interestingly, there is an absolute requirement by Medicare that dialysis physicians should refer their patients for transplantation in the US. The only caveat is that the patient should be considered as a potentially suitable candidate prior to referral. There is no similar mandatory arrangement in the UK.

The growth in the number of living donors has been achieved by individual hospitals increasing their numbers rather than by a national campaign. Institutions which do not

have a living donor programme are now unlikely to be viable if they are solely dependent upon cadaveric transplantation activity. Thus, there is a competitive pressure for transplant units to establish living donor programmes. In the US system there is flexibility for individual patients to access programmes which are geographically distant if they choose to do so or if living donor transplantation is not offered at their local centre. Potentially, recipients with significant co-morbidities can access larger or more experienced programmes which are able to take their case if the local programme cannot provide the service. This has provided a financial incentive for centres to offer living donor transplantation. This is significantly different from the traditional referral patterns in the UK. Neither programme felt that the active projection of the living donor programme had a detrimental effect on the cadaveric programme.

### Funding

The living donor programmes are funded separately from any provision for dialysis treatment. There is greater clarity around the costs for the living

donor assessment programmes. The two institutions have slightly different methods of accounting but both attribute the real costs of living donor work-up to the recipient funding stream. Thus, costs arising from individuals who are assessed and subsequently found to be unsuitable to donate are still billed to the recipient. At present in the UK many units only have a single charge category for assessment and surgery, which attracts funding once the donor nephrectomy has been performed. This may mean a significant financial penalty to the UK unit where there is a high donor attrition rate. In the US the total costs of the process are transparent and transplant units are not financially penalised for recipients who need a number of individuals to be assessed before a successful transplant occurs.

### Local infrastructure and resources

Both institutions offer an attractive environment and each centre has significant capacity dedicated to the living donor programme; availability of daily assessment appointments for donor and recipient and operating time to accommodate up to four

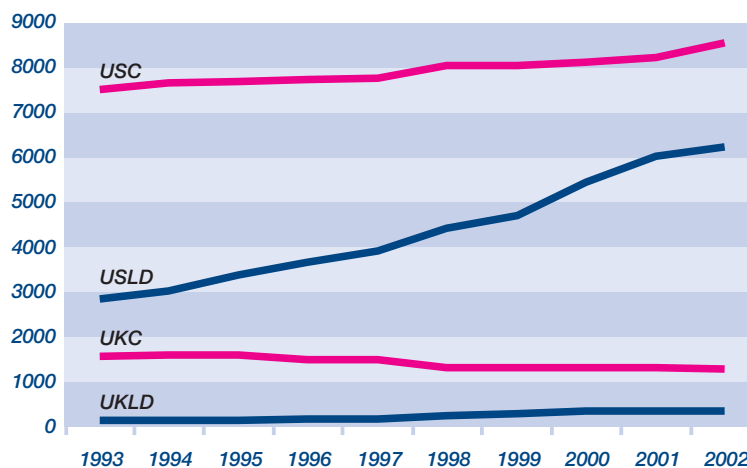


Figure 1. UNOS and UKT data for transplant donor origin for 1993-2002. UKC- UK cadaveric, UKLD UK living donor, USC US cadaveric and USLD US living donor.

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transplants per week. The concept of providing an excellent service is at the centre of their philosophy of care. There is unlimited access to a large number of local hotel beds. This means that the length of in-patient stay is dramatically reduced for individuals who travel to the centres for assessment and ultimately transplant/donor surgery, by enabling patients to be discharged to a local hotel. There is emphasis upon rapid donor and recipient assessment and results retrieval over one to two days with a decision on progression to donation/transplantation being given to the potential donor or recipient at the end of the consultation. A living donor may leave hospital after two days and be reviewed at one week before return to their home town.

Both centres have the facility for laparoscopic donor nephrectomy with almost 100% uptake of this procedure. There is differing opinion about the impact of the laparoscopic programme on increased donor rates, but everyone involved felt that no US living donor programme could survive without laparoscopic donation because of the expectations/choice of the potential donors. Current fellows in transplantation are no longer routinely trained to perform open donor nephrectomy and view it as an exception rather than a rule. The understanding is that laparoscopic donation is now the universally established procedure of choice in the US. Both programs have a group of surgeons who perform laparoscopic donor nephrectomy, although not all. Donor in-patient stays of two days post-operatively were reported in both centres.

A system of 'remote' follow-up is established; accepting that follow-up of recipients may not involve direct clinic visits after the initial post-discharge period of 2-3 weeks. Local testing with results forwarded to the transplant centre is accepted, with significantly more onus upon the

patient to be responsible for retrieving and acting upon blood results and initiating contact with the transplant centre. Telephone follow-up and triage of problems through dedicated co-ordinators is much more the norm than in the UK.

Both centres favoured the use of Spiral CT scanning over MRI scanning for optimal definition of the vascular anatomy. This is not universal practice in the UK. Some concern has been expressed at the ability of MR angiography to define the distal vascular anatomy completely in such conditions as donor renal artery stenosis.

### Recipient issues

In the US, prospective recipients are given very clear information about the best option for transplantation, i.e. a living donor kidney transplant before dialysis or listing on the cadaveric transplant waiting list. This is explained as being optimal in terms of both death and morbidity in comparison with dialysis and cadaveric transplantation. *A poorly matched living donor kidney is always better than a well matched cadaveric kidney*' is how it is expressed to potential recipients. There is transparency about the mortality expected on dialysis treatment: for example, *'a Blood Group B patient put on the cadaveric transplant list was as likely to die on dialysis as to have a transplant'*. The average wait for Blood Group B is 5 years and there is



Mayo Clinic

an approximately 10% annual mortality on dialysis treatment. The recipients are also given a living donor kidney half life of approximately 20 years, twice that of a cadaveric kidney. This information is shared with the recipient and their family. It is explained that those individuals who go onto dialysis will live less long than those who have a living donor transplant, which mirrors the UK practice. However, it is not apparent that the information is delivered to all patients in the UK with the same degree of clarity in comparison with the practice in the US. The values for outcome are not identical to those in the UK but in many respects are very similar. Pre-emptive transplantation is the preferred option. There is an estimated rate of up to 70% for achieving this. A vital part of the success of this aspect of the

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programme rests with the level of awareness and agreement on behalf of referring physicians. These physicians in Minnesota may be 500 miles away!

Tissue typing is not considered to be important in either the adult or paediatric programmes, with the exception of sibling HLA identical donors. In fact, other than a positive crossmatch tissue typing is relatively inconsequential in the context of living donor transplantation. One centre offers a protocol-driven desensitization and blood group incompatible programme, which contributes to the overall numbers of transplants performed from living donors.

The approach to recipient co-morbidity differs from the UK practice. Death with a functioning kidney for older recipients is regarded as a success if their quality of life has been enhanced in the interim: this is not necessarily the prevailing view in the UK. The information that older recipients with significant co-morbidities such as diabetes mellitus have a high mortality on dialysis is shared with the patients. Whilst the mortality rate for older recipients with co-morbidities is higher than for younger recipients without co-morbidities, it is still better than it would be if the same individual commenced dialysis. Older recipients are commonly transplanted from their offspring. The view of the transplant surgeons at both centres is that if a living donor transplant is the best option for the recipient then they are prepared to proceed. The risks for the recipients are made absolutely clear to the potential donors. It is accepted that the concept of increasing the living donor rate for more patients who are approaching end stage renal failure offers more of them a better prognosis but that the absolute outcome data for living donor transplantation may be worse as a result of broadening the inclusion criteria. For both centres, 'What is

best for the recipient' is a clear guiding principle. Recipient weight/Body Mass Index (BMI) is another borderline area which is viewed differently in the US: although the peri-operative morbidity is higher in living donor recipients with high BMIs this is perceived as a small problem compared with the morbidity/mortality risks for these patients on dialysis. An exclusion of a BMI of 40 or above was discussed although exceptions to this rule had been observed! It is possible that the average BMI range of individuals within the general population in the US has influenced this more pragmatic approach.

One centre offers the option of a living donor transplant followed by cadaveric pancreas transplant for their diabetic recipients. In the UK many diabetic patients have the choice between either a living donor kidney alone or simultaneous cadaveric kidney-pancreas transplant. In the centre concerned, it is anticipated that the diabetic living donor recipient will receive a pancreas transplant within a few months after renal transplantation. In some instances it is possible, although unusual, to synchronise living donor kidney transplantation and cadaveric pancreas transplantation if a suitable organ becomes available and the recipient and their living donor are willing to be 'on-call' for this eventuality once assessment is complete.

### Donor Issues

Donors are held in high regard and highly-valued. One programme referred to the process of donation as 'Your Gift', whilst one gives a certificate to all donors on the morning after surgery, which is presented to the donor by his/her surgeon.

Interestingly there is no 'Norwegian approach' to donation. In Norway physicians, with the consent of the potential recipient, may approach potential donors directly. These units do not approach donors directly but recipients are actively encouraged to do so.

There is excellent information available for potential donors, which is presented in a variety of formats. One unit has an excellent 'talking head' video produced at a small cost. This is sent to potential donors and then returned. One unit makes a video of the laparoscopic procedure available to potential donors should they wish to watch it. Whilst almost all donors opt for laparoscopic surgery, for a donor with a raised BMI, a hand assisted laparoscopic donation is considered the option of choice. The criteria for consideration of obese donors are more liberal than the UK approach but careful consideration is given to this group because of the impact on future renal and general health. In one centre, potential donors from the United Kingdom would be excluded because of the risk of Creutzfeldt-Jacob Disease!

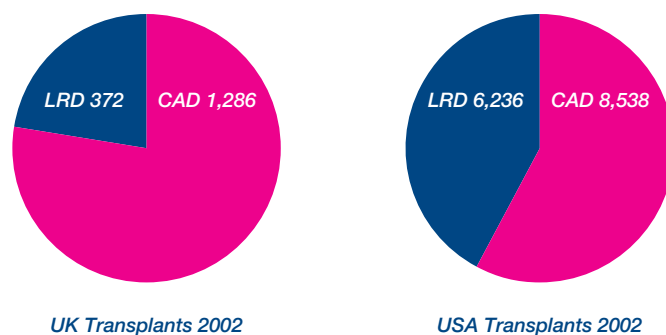


Figure 2. Proportion of cadaveric and living donor transplants for 2002.

### Variations

There are some caveats to the experience in Minnesota. For example, Minnesota has a stable population and is less ethnically diverse than that of Lambeth and Southwark. Whilst there are many similarities in philosophy and practice between the UK and the centres in Minnesota, some of the obvious

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variances reflect significant disparity in the community, cultures and ethnic diversity. However, these do not completely explain the proportional differences between the cadaveric and living donor transplant activity as seen in *Figure 2*. The main differences are in approach rather than statutory obstructions. The following represent the key differences in practice that were identified:

- There is a significantly more active approach to promoting living donor transplantation from the healthcare team of which they are proud because it is considered to be ‘best for patients’.
- Offering a clinically excellent service is central to the success of individual programmes in the context of the competitive market-place.
- Patient choice is the ‘rule’ rather than the ‘exception’ in determining referral patterns into transplant centres.
- There is no specific legal framework governing the practice of living donor renal transplantation.
- There are clear mechanisms to recognise and attribute the real costs of donor work-up. These include the costs which arise from the assessment of donors who are subsequently found to be unsuitable or cannot be used, i.e.; where multiple donors are assessed for one recipient.
- Physicians have a statutory obligation to refer potentially suitable patients to a transplanting centre for consideration.
- Early education of potential recipients to the possibility of living donation as the treatment of choice before dialysis.
- Clear, realistic information to the recipient-families-carers-friends from the outset about.
  - The best option for renal replacement therapy.
  - The risks of dialysis treatment.
  - Waiting times on the cadaveric transplant list.
  - Choices for older patients or those with significant co-morbidities: a kidney from a living donor is a better option with a better outcome than either cadaveric transplantation or dialysis.
- Inclusion criteria for potential transplant recipients are less restrictive. It is accepted that poorer outcomes in terms of longevity of patient survival compared to present practice in high risk recipients is balanced against better outcomes for the individual patients.
- Desensitisation and ABO incompatible programmes are well established in one centre.
- Large centres have the capacity and flexibility to provide both rapid assessment and surgery to potential donor and recipients.
- Laparoscopic surgery is an option for all living donors and is almost exclusively used as the procedure of choice for donor nephrectomy.
- Excellent information/literature is available to potential donors and recipients in a variety of formats/presentations.
- Strong culture of ‘remote’ telephone assessment and follow-up for donors and recipients in conjunction with local physicians as the norm.

## Summary

From their observations, the authors conclude that the growth in living donor transplantation within these specified centres in the US is multi-factorial. Whilst it may not be possible to mirror the experience exactly, aspects of the model could be successfully translated into UK practice to enhance the clinical effectiveness and expand the scope of existing programs. If such an initiative was to be embraced, a package of measures would need to be established in order to manage the concomitant increase in activity throughout the patient’s transplantation pathway. It is anticipated that this document will provide a platform for further discussion and consultation in order to facilitate the modernisation agenda in this area.

**For further information and discussion please contact:**

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