



## Discussion Paper

### Challenges facing Living-Donor Kidney Transplantation in the UK

Kirit Modi, Life Vice President, NKF - June 2017

#### 1. Introduction

This discussion paper is published by NKF with the view to encourage debate about the challenges facing Living-Donor Kidney Transplantation (LDKT) in the UK. The two key challenges are:

- To identify the reasons for the drop in the number of LDKTs in the UK over the last three years.
- To agree on and implement measures to reverse this decline so that the targets set in the Living Donor Kidney Transplantation 2020 Strategy may be met.

NKF would be grateful for responses to this paper, by no later than the end of August 2017. Please send them to: [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk)

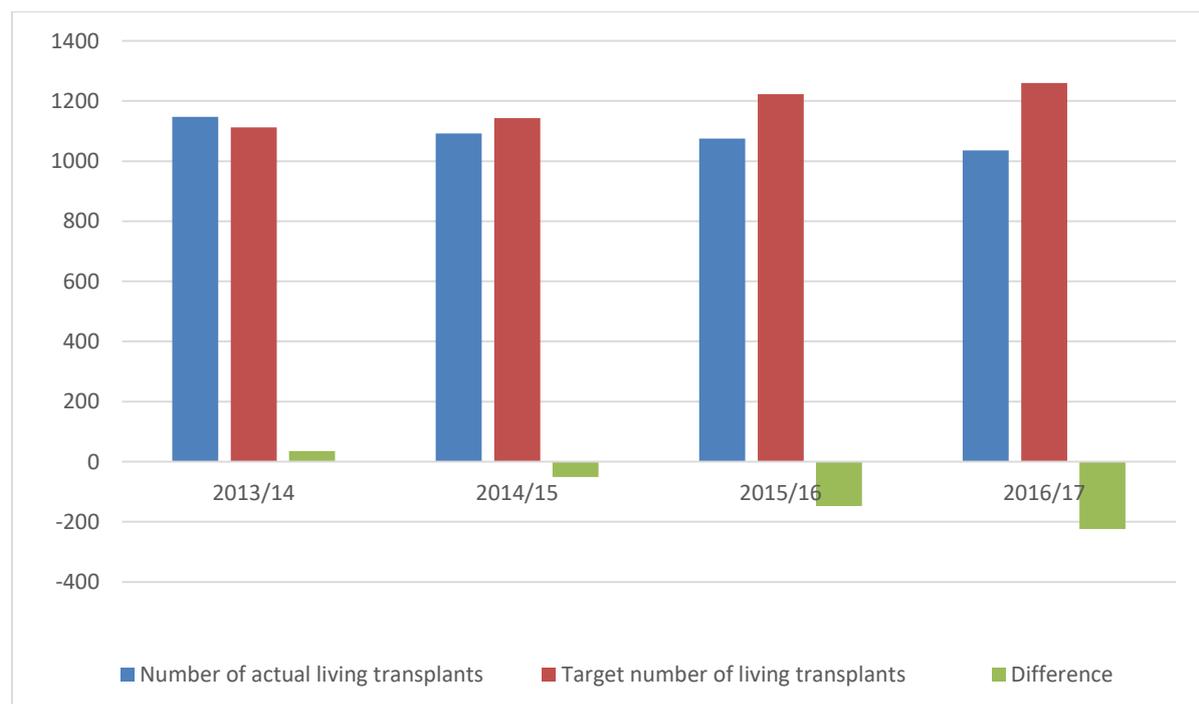
#### 2. Living-donor transplants in the UK

The number of Living-Donor Transplants (LDT) - mainly kidneys (97% in 2016/17) - carried out in the UK over the past four years, compared with targets set:

	<u>Actual number</u>	<u>Target</u>	<u>Difference</u>
<b>2013/14</b>	1148	1112	+ 36
<b>2014/15</b>	1092	1143	-51
<b>2015/16</b>	1077	1223	-146
<b>2016/17*</b>	1043	1260	-217

(\*2016/17 'actual number' figure is provisional)

The 'actual living-donor transplants' provisional figure for the year 2016/17 indicates a reduction of 105 transplants (nearly 9%) compared with the 2013/14 figure. The bar chart below shows the increasing gap between the 'actual numbers' compared with the targets set. If this trend continues it is highly unlikely that the target of 1728 living-donor transplants set for 2020 will be achieved.



An alternative measure of LDT activity is the number of LDTs per million of local population per year (pmp). In 2013/14 the figure for the UK was 17.9 living donor transplants pmp compared with the provisional figure of 16.0 in 2016/17. If this downward trend continues then it is likely that the 2020 target of 26 pmp will also be missed.

This measure is also effective in determining LDT statistics by Transplant Centres. Provisional data indicates that there is a significant level of variation in the pmp among the transplant centres in the UK. Provisional data for 2016/17 confirms the variations across different regions in the UK as follows.

<b>Regional area</b>	<b>Provisional pmp for 2016/17</b>
North England	15.4
Midlands and East	12.5
London	15.9
South England	13.7
Wales	16.5
Scotland	15.5
Northern Ireland	41.6

It is important to consider these figures for living donor transplants alongside figures for transplants from deceased donors. Provisional figures for 2016/17 indicate that deceased donor activity reached record levels in 2016/17. NKF welcomes these impressive results, but is concerned that the key 2020 target related to deceased donation, consent rate, is increasing very slowly and we may not reach the 2020 target set out in the Strategy.

Also, it is important to note that the UK is doing very well in relation to the living donor kidney sharing scheme in terms of the number of registered patients receiving a transplant through the scheme. Many of these recipients are immunologically complex and a high proportion are from BAME communities.

However, the focus of this paper is living donor transplantation and the next section explores possible reasons for the drop in numbers.

### **3. Possible reasons for the drop in numbers.**

As a result of discussions with interested parties over the past few months, a number of possible reasons for the drop in numbers of LDTs have emerged. These are listed below. This list is by no means complete and should be considered trigger points for discussion only, with the full expectation that the

list will increase as this discussion progresses. Your views on this list along with potential additions to the list will be greatly appreciated. It should be noted that there is limited hard data available to clearly identify the underlying causes.

#### **4. Unexplained variation in the number of living-donor transplants undertaken by transplant centres.**

Given the variable socio-economic, ethnic and other demographics across the UK it would be highly unusual if there were no variations in the number of LDTs carried out in the 23 transplant centres in the UK. However, the variations in the LDT rates are significant and this suggests that other factors may be influential.

NHSBT are currently working on improving the way in which LTD pmp is calculated by transplant centres. This review is a welcome development. NKF is grateful to NHS England for their support in using the commissioning process to help address this variation. Appropriate commissioners of LDKT services in Scotland, Wales and Northern Ireland also have an important role to play in ensuring that the commissioning process is used effectively to address this unexplained variation.

We have examples of excellent protocols in place in supporting living-donor transplantation within the UK. These need to be publicised widely so that others may learn from it. Members of the LDKT 2020 Strategic Implementation Group have been involved in shared learning events across the UK and will soon complete visits to all transplant centres. It would be most helpful to consider the outcomes from these events, both locally and nationally.

Two examples of excellent LDT practices are included below and are listed as appendices.

One is the transplant centre at Belfast (which reported the highest number of LDTs carried out in the UK in 2015/16). NKF is grateful to Dr Aisling Courtney, Consultant Nephrologist, the Belfast Transplant Centre, for outlining their work in Appendix 1.

The second is from a referring unit at James Cook Hospital in Middlesbrough. NKF is grateful to Dr Caroline Wroe, Consultant Nephrologist for sharing their work in Appendix 2.

It is not surprising to note that in both cases, strong leadership has resulted in a cultural change in the approach to living donor transplantation.

#### **5. Some hospitals do not employ sufficient Living-Donor Coordinators (LDC)**

There is some evidence suggesting there may be a correlation between the number of LDCs employed at a transplant centre or a referral unit and the number of LDTs achieved. Peer Review visits of Kidney and Pancreas Transplant Centres in the UK led by the NHS England Quality surveillance team,, identify five transplant centres at which the number of LDCs is a concern. This issue is also highlighted by NHSBT who has developed a tool for calculating the number of LDCs needed at both Transplant Centres and referral hospitals, according to the complexity of their individual programmes. It would be most helpful to know the impact of these important initiatives.

The contribution of the LDC in engaging with potential living-donors and recipients so that a transplant takes place, is critical. NHS England's specification for living-donor kidney transplantation can help raise the importance of sufficient LDCs being employed. NKF welcomes the support of the Renal Services Clinical Reference Group, in taking this forward.

#### **6. The support provided by LDCs in encouraging potential living donors from within the patient's family and close friends may need to be reviewed**

For a variety of reasons, it is sometimes difficult for patients waiting for a kidney transplant to discuss living donation from someone within their family or from close friends. Currently no formal guidance exists to support the patient in navigating this process. Practice across the country varies; some hospitals offer one to one meetings with those interested in becoming a living donor, while some offer group sessions attended by both patients and their potential donors. Some hospitals also encourage potential donors and

recipients to talk to those who have successfully donated or received a living-donor kidney. Most hospitals provide written information on the living donation process. While each of these approaches has merit there is no evidence to indicate their relative effectiveness.

The key area of development seems to be exploring ways in which the patient waiting for a kidney can be supported in finding a potential living donor. NHSBT has recently commissioned National Black, Asian and Minority Ethnic (BAME) Transplant Alliance (NBTA) to undertake an innovative initiative to encourage more living-kidney donation from targeted BAME groups. Five projects, aimed at the Hindu, Jain, Sikh, and African and African-Caribbean communities in London and Leicester have been established. The focus is on how more living donors from these communities may be encouraged to come forward through work by and within the targeted communities, development of culturally sensitive resources as well as providing support to the patient through arranging sessions at home with extended family and friends. Details of this Living Transplant Initiative are available from the NBTA web-site ([www.nbta-uk.org.uk](http://www.nbta-uk.org.uk)). Also, during 2015/16, NHSBT sponsored a one-year pilot study from Kidney Research UK, to encourage living kidney donation through a peer volunteer home education initiative. It would be helpful to find out the outcomes from this pilot. In June 2017, NHSBT developed a series of short films, called “Let’s talk about.....” to encourage living donation.

NKF welcomes all these initiatives and has supported them. It would be helpful to find out their impact in due course with a view to extending this work across the country.

## **7. Some kidney patients may prefer to receive a kidney donated after death rather than one from a living donor**

There is some anecdotal evidence which suggests that some kidney patients waiting for a transplant do not wish to “burden” family members or close friends with having to consider the possibility of becoming a living donor or having to undergo surgery. The reduction in the average waiting time to receive a kidney donated after death (now 2.5 years; and 3 years for BAME patients) may also be a consideration for some patients.

It is important that patients waiting for kidney transplant and potential living donors fully understand the advantages and disadvantages of receiving a living donor kidney, compared to one donated after death. There is no national guidance available at present and NKF is pleased that NHSBT is considering developing such guidance.

It is also important that patients waiting for a kidney transplant and potential living donors fully understand the risks and benefits of donation and transplantation, both short term and long term. Transplant surgeons and nephrologists seem to have differing approaches to how they assess the risks and benefits. It would be helpful to review current practice among hospitals in the UK with a view to achieving parity in this assessment.

## **8. Important research findings**

A recent research finding, the Access to Transplants and Transplant Outcome Measures study (ATTOM) –( <https://www.renalreg.org/research/access-to-transplantation-and-transplant-outcome-measures-attom> ) provides an insight into living donation and transplantation in the UK. NKF is most grateful to Dr Gabriel Oniscu, Consultant Transplant Surgeon, Royal Infirmary Edinburgh and Dr Diana Wu, Research Fellow, Royal Infirmary Edinburgh, for their help in developing this summary of the research.

This UK-wide study was conducted as part of the ATTOM research programme, funded by the National Institute for Health Research (NIHR).

This study adds new and important knowledge about factors associated with LDKT compared to Deceased Donor Kidney Transplantation (DDKT) among UK patients who are suitable to undergo transplantation. LDKT, and in particular pre-emptive LDKT, provides best clinical outcomes for patients with End Stage Renal Disease (ESRD). This study has identified specific patient groups with a lower likelihood of undergoing LDKT compared to DDKT.

Among patients undergoing kidney transplantation in the UK, there are significant age, ethnic, socio-economic and geographical disparities in the

utilisation of LDKT. The likelihood of LDKT compared to DDKT is significantly reduced if the recipient:

- is older
- is from a Black or Asian background
- is divorced, separated or widowed
- has lower educational attainment
- experiences socio-economic deprivation (no car or not a home owner)

In addition, among those who undergo LDKT, the chances of pre-emptive transplantation compared to LDKT after dialysis has started, are reduced if the recipient:

- is from Asian background
- is unemployed
- experiences greater socio-economic deprivation

These findings demonstrate that social factors play a role in influencing access to LDKT in the UK. The demonstrated disparities may reflect both barriers in certain patient groups as well as important positive factors in others. Improving access to LDKT will not only benefit individual patients, but will also have favourable effects for the wider ESRD population by effectively increasing the overall pool of available organs.

This study is essential in directing further work into appropriate interventions. Several studies in the USA and Netherlands have explored targeted interventions, with promising results for reducing disparities in LDKT.

NKF welcomes these important research findings which provide an opportunity to review the current LDKT services and explore ways of increasing access for all patient groups. It is important that the whole kidney community considers ways of addressing these disparities and involves patient groups in the process.

## **9. Who champions living donation in hospitals?**

It is not clear who champions living donation in hospitals. Clearly the LDCs promote living donation, but they may not always be able to influence the

approach to living donation within the hospital. For donation after death, hospitals are expected to have Organ Donation Committees with overall responsibility for the number of these donations and for monitoring progress on a regular basis. There is no such arrangement for living donation.

The Chair of the LDKT 2020 Strategic Implementation Group has visited all 23 Transplant Centres in the UK as part of the shared learning events described previously, and one of her conclusions is that a Lead Nephrologist for Living Donation (LNLT) should be appointed at each Transplant Centre. It would be appropriate to consider appointing a LNLT at each hospital, including referral centres. NKF welcomes this development and looks forward to NHSBT and the clinical community taking this forward.

## 10. Conclusion

NKF wishes to encourage an informed debate on the reasons for the downward trend in living-donor transplantation in the UK, and to explore ways in which we can address this well before 2020. We would be grateful for responses to this paper from all interested parties and will continue to work with NHSBT, representatives of the four UK governments, NHS England, staff in hospitals, professional associations, kidney patients' associations, patient charities and individuals to respond to the current challenge we are facing. NKF is confident that, with the support and commitment of all interested parties, this trend can be reversed.

Please send all responses to [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk) by no later than the end of August 2017.

### **Acknowledgements:**

The NKF is most grateful to valuable contributions from many colleagues in the development of this Discussion Paper. The views expressed are, of course, those of the NKF. We are delighted to thank the following for their support:

Dr Aisling Courtney, Dr Caroline Wroe, Lisa Burnapp, Dr Richard Baker, Jon Gulliver, Dr Diana Wu, Dr Gabriel Oniscu, Dr Adnan Sharif, Prof David Wheeler, Deborah Duval, Sue Lyon, David Marshall ( NKF Chair ), Tim Statham (NKF CEO) and Andrea Brown (NKF Office Manager).

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## **Appendix 1**

### **Northern Ireland living donor kidney transplant programme**

Dr Aisling E Courtney, Consultant Nephrologist - Belfast City Hospital, Belfast Health & Social Care Trust.

#### **Background**

Kidney services are provided for the 1.85 million residents of Northern Ireland (NI) in six adult and one paediatric hospital. All kidney transplant operations take place in the Belfast City Hospital, where the transplant programme began in 1968.

Prior to 2010, NI had a low rate of living donor (LD) kidney transplantation (mean 4.3 pmp per annum (pa) 2000-2009) with few kidney transplants performed pre-emptively (before dialysis treatment is required). This was despite the knowledge that transplantation is the optimal treatment for end stage kidney disease with regard to both patient survival and quality of life, and that living versus deceased donation offers superior outcomes (in terms of both how long the transplant and the patient survive). Additionally, patients in NI were waiting longer than their counterparts in almost every other region in the UK for kidney transplantation, resulting in poorer outcomes after transplantation and some becoming unsuitable to ever be transplanted.

#### **Current position**

There has been a significant and sustained increase in LD transplantation in NI, the mean LD rate over 2011-2016 was 33.4 pmp pa, with >40 pmp in 2016. This compares to 15.1 pmp in England, 15.0 pmp in Scotland, and 14.9 pmp in Wales for 2015/16; and exceeds the LD rate in all other European countries. Over the same time period the number of patients on dialysis in NI has fallen substantially (Figure 1), and the number of people on the active waiting list has reduced by 50%.

Multiple factors were involved in this transformation; the three considered most influential are detailed below.

### **Looking after the donor**

The philosophy in NI is 'to make it as easy as possible to for people to donate'. Previously a major disincentive to donation was a lengthy donor work-up process. With multiple assessment stages and hospital visits the entire journey could take two years. Unsurprisingly, this resulted in donor fatigue and subsequent drop-out.

There was a radical change in the potential donor pathway with those deemed to be suitable after a screening questionnaire, now attending a '1-day' assessment where all investigations, that were previously requested sequentially, are scheduled for one visit. This is a more compressed approach than any other transplant centre in the UK is universally well received by potential donors, and regular audit has repeatedly demonstrated it to be safe as well as efficient.

In addition to streamlining the assessment process, we do our utmost to care for each donor so that throughout the journey to beyond donation they feel important and valued, with careful consideration of the timing of surgery, ease of expenses reimbursement, accessibility to the team for advice or queries, all contributing to a very low drop-out rate. Thus donation in NI is typically a very positive experience indeed, and this has facilitated a cultural change within communities which is influential in sustaining a phenomenally high number of people volunteering.

### **Addressing institutional barriers to living donation**

In NI one of the major limitations to living donation was the availability of surgeons with the skills to perform the donor surgery. However, given that the LD programme was very tiny it was impossible to attract a suitable transplant surgeon to Belfast to solve this problem. An innovative solution was found with the forging of a partnership between Belfast and Birmingham Trusts; two of their surgeons came regularly to Belfast to carry out the donor surgery, this allowed us to develop our LD programme to a stage where we could recruit potential transplant surgeons and facilitate their training (also as part of this partnership).

While this particular issue may not be a common problem, the key point is that in most institutions there is something that is the major barrier to further development or expansion of the LD programme, and that there will be a way to overcome it. Often 'lateral' thinking is required and persuasion of others of the necessity of innovation is essential.

### **Changing the philosophy**

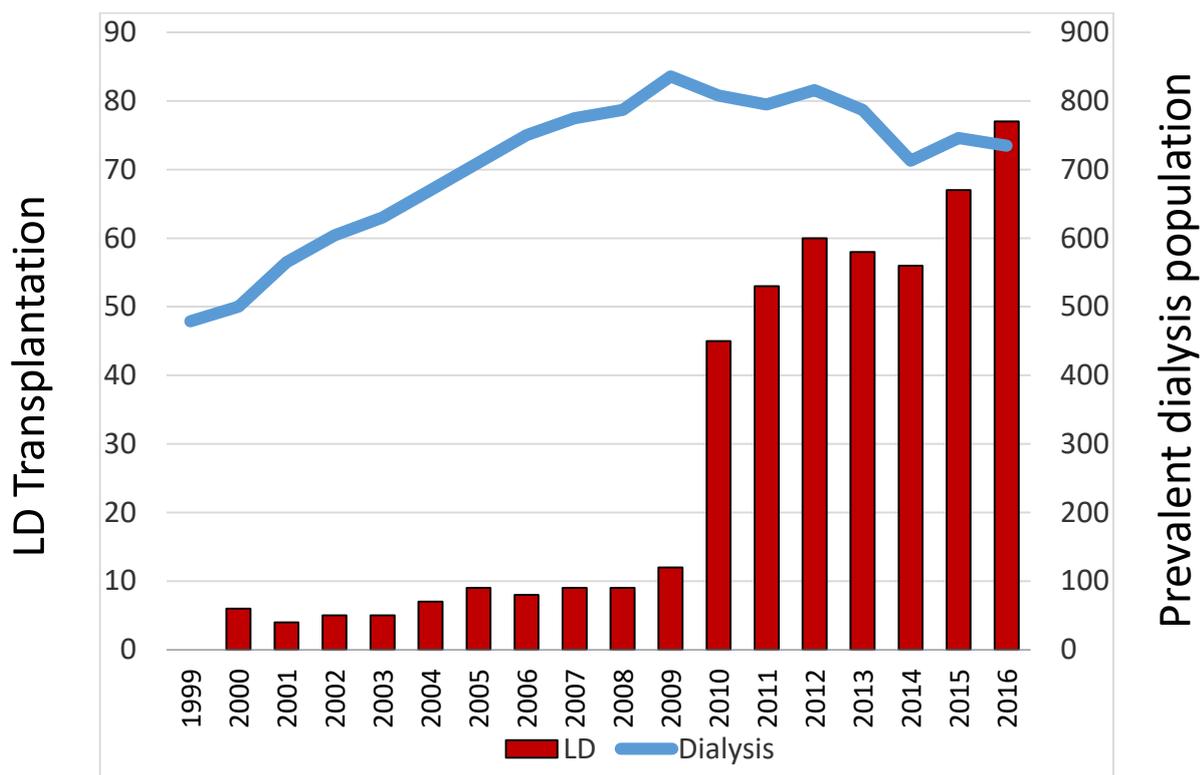
Traditionally in NI nephrologists prepared their patients for dialysis. This was entirely appropriate since the chances of a pre-emptive transplant were extremely tiny. There had to be the ability to deliver a timely LD transplant programme first, and then a change in mind-set across all of NI to prepare suitable patients for transplantation. Multiple small incremental changes have led to our current position, but one of the most important is the discussion of transplantation at a very early stage with those who inevitably will require it. If patients and their families are aware that the ultimate goal will be transplantation, ideally avoiding dialysis altogether, and that this is realistic if there is a suitable living donor, when they approach end stage kidney disease it is much more probable that there will be a volunteer.

A similarly important change in philosophy within the transplant team also took place. This was a realisation that a donor's perception of a reasonable risk is often quite different to ours, and a patient (and their families) consideration of what is success can also be dissimilar. Transplant programmes should not be judged solely by graft and recipient survival (the standard parameters) but by the outcomes in the entire end stage renal disease population. The latter is much harder to measure, but by the focus on the former potentially disadvantages higher risk donors and recipients from transplantation.

### **Conclusion**

We acknowledge that we are privileged in NI (despite what our history suggests), to have relatively cohesive communities where altruism thrives. However, this is certainly not a new phenomenon that has only developed since 2010. The changes made in structure and approach to living donation has facilitated the increase in LD transplantation. None of these need to be exclusive to NI.

**Figure 1**



## **Appendix 2**

### **Teesside Living Kidney Donor Service**

Dr Caroline Wroe, Consultant Nephrologist, Clinical Lead for Living Kidney Donation - The James Cook University Hospital, South Tees Hospitals NHS Foundation Trust.

### **Background**

South Tees Hospitals NHS Foundation Trust covers a population of 1.01 million and provides the Living Kidney Donor service for Middlesbrough, Stockton, Hartlepool, parts of North Yorkshire and South County Durham (see map below).

There are high levels of deprivation with more than 50% of the population in the lower 2 quintiles of deprivation (IMD). Ethnicity is typically 95-97% white with the exception of Middlesbrough (15% Asian). Potential living kidney donors complete medical assessment at The James Cook University Hospital, prior to referral to the local transplant centre for actual surgery, which is based

at The Freeman Hospital in Newcastle. After surgery they are then discharged back for follow up at 6 weeks, and for lifelong annual reviews.

There are 23 Renal Transplant Centres and 38 Non-transplant Renal Units in the UK, each group covering roughly half of the UK population. Establishing Living Donor Services within referral centres, with close ties to their local transplant centre is therefore key to improving equitable access across the UK and reaching national targets for living kidney donor numbers.

At The James Cook University Hospital, the Living Donor Services evolved out of a well-developed deceased transplant pathway as the benefits of living kidney transplantation, and of pre-emptive transplantation, became established (in terms of quality of life, life expectancy and health economics). A transplant specialist nurse was appointed in 2006 working with both recipients and potential living donors and in 2011 a specialist Living Donor Clinic was established with one Nephrologist leading the service for Living Donation. This clinic was designed with capacity to accommodate an expansion in Living Donor numbers over 5 years, and allows for the additional work up of altruistic donors and donors whose recipients are cared for by other hospitals (for example donors for paediatric kidney patients and donors for recipients managed out of area) without compromising the service for local patients.

### **Improved outcomes for donors and recipients**

Since 2011 the service has been evaluated annually and the following outcomes observed:

- A reduction in waiting time to complete living kidney donor work up (by  $\frac{1}{3}$ ).
- A 50% reduction in the number of hospital visits required by the donor, avoiding additional time off work or away from family.
- A sustained increase in the number of local patients receiving living donor transplants (from 14 pmp in 2010 to 19 pmp in 2016-reaching the National target).
- An increase in pre-emptive living donor transplant rates (from 27% in 2011 to 63% in 2016).
- An increase in the number of altruistic donors and donors worked up for non-local recipients (representing an additional 5-10 donors per year).

- Positive donor experience: in a donor survey in 2012 100% of patient were positive about their experience of living kidney donor work up (76% rated their experience as excellent, 12% as good and 12% as fair).

We believe this has been achieved by the following:

### **Having early conversations**

The option of living kidney donation needs to be in the first conversation we have with patients when we talk about kidney failure, so the whole team need to be confident in starting the conversation. We acknowledge the difficulties faced by patients when talking about living donation with their friends and relatives and offer advice about how and when to start that conversation.

*“We have had a huge shift in attitude over the last 10 years or so. We’ve moved from a position of waiting to have people approach us to discuss donating to their relatives and friends to one in which we raise the issue at an early point”*

Dr David Reaich Clinical Director, South Tees Hospitals NHS Foundation Trust Renal Unit.

*“I think the most important issue is that our unit has a strong culture to the concept of ‘Transplant first, dialysis second’ whenever it is at all possible. We constantly ask ourselves and our colleagues “Is this patient suitable for a transplant?” from an early point in clinic, and the second question we ask is “Do they have a potential living donor?”*

Dr Steve Kardasz, Consultant Nephrologist, South Tees Hospitals NHS Foundation Trust.

### **Simplifying the donor experience and focus clinical expertise**

The commonest concerns raised by donors remains the time taken to establish if they are fit to donate and the ability to get prompt answers to their questions about health and risk. Cutting waiting time for tests and combining several tests into one visit offers huge benefits, as does identifying a clinical lead for living donation to develop skills and confidence in dealing with the issues raised during living donor work up. Introduction of a standardised

pathway also creates a framework for regular audit and allows comparison between units facilitating regional dialogue and further quality improvement.

*'Fewer visits mean potential donors move the process far quicker and therefore it is less stressful for everyone concerned as it is difficult waiting for tests to come back bit by bit', 'It is better for all concerned that the suitability for donation is assessed quickly, less time is needed off work and the information is still fresh in your mind.'*

Donor Survey 2012.

*"Reducing the time and number of investigations required for donors to go through makes the donor pathway more palatable"*

Mr Alistair Rogers, Consultant Urologist and Donor Surgeon, Freeman Hospital Newcastle.

### **Peer education and donor involvement**

Potential donors value the opportunity to discuss donation with previous donors and recipients. Donors are hugely motivated and articulate, and are usually willing to share their story when asked. Peer support is offered to all potential donors in Teesside and is provided either on a one to one basis, or in a group setting over coffee at bi-annual open days. Potential transplant recipients are also encouraged to bring their family to these events to open up the discussion around living donation. In addition to peer review, donor stories are publicised on the unit website and through the hospital magazine, radio, TV and public lectures.

### **Partnership with the local transplant team and donor surgeons**

Good communication between the referral centre (James Cook) and transplant centre (Freeman Newcastle) makes the transition for the donor and recipient easier. The information given to potential donors about risk and surgical complications has been agreed with the local transplant centre and the same information sheets are used in both centres. This helps to introduce and acclimatise the donor to what will happen and sets realistic expectations about timing, surgery and recovery which is an important factor in interpreting the process as a success. In addition the local transplant centre is open and transparent in reviewing complication rates; enabling the donor to be quoted

both national and regional outcomes. This level of communication strengthens the confidence the referral centre team has in donor outcomes and facilitates the progression of complex, as well as, simple cases.

