

Give a Kidney Annual Conference
Saturday 23rd March 2019

Morning session

Patient Public Engagement in Action - Lisa Burnapp

The Living Donor Kidney Transplant 2020 (LDKT 2020) Public and Patient Engagement (PPE) Workstream was launched to focus on this agenda for the remaining 12-18 months of the current strategy, use the knowledge and expertise from donors and recipients to identify the priorities and involve them in delivering the agreed plan. JS has been part of this, representing Give a Kidney. So has Kirit Modi, for NKF; Fiona Loud, for Kidney Care UK and many others.

Work stream priorities are:

- To establish a distinct identity for living donation, separate from deceased donation
- To improve understanding of the living donation process
- To provide clear, consistent information for potential living donors
- To promote awareness of living donation
- To maximize non-directed altruistic donation
- To safeguard and support non-resident donors donating in the UK
- To increase LDKT in communities that are less likely to engage

Identity and branding has been revamped, with unique NHSBT branding created for living donation, which is aligned with the 'Yes I donate' imagery, on all website materials. Other resources will be updated as they are re-printed.

World Kidney Day on 14th March. NHSBT publicity focused on the success of the UKLKSS and the contribution of non-directed donors to the scheme: 'UK's living kidney sharing scheme to hit 1,000th transplants milestone this week'. Non-directed donors are 'game changers' in fight to cut the kidney transplant waiting list. Across the UK, over 700 people have donated a kidney to a stranger while they are alive.'

World Kidney Day itself saw a huge increase in traffic to NHSBT's website, with total visits up 78% on the previous year and downloading materials up 35% on the previous year. There were 3494 visits to the NHSBT website during the week 11th -17th March 2019

NHSBT has commissioned the National Black, Asian and Minority Ethnic Transplant Alliance (NBTA) to administer a Living Transplant Initiative for two years, with the aim to increase engagement with BAME communities. This funding ends at the end of March 2019. NHSBT has agreed to a £100k during 2019/20 to focus on engagement with people who may have less likely to have access to LDKT due to ethnicity and/or socio-economic situation.

NHSBT will administer the 2019 / 20 initiative, with the aim of bridging the gap between 'expression of interest' and commitment to the donor pathway. They will support initiatives that:

- Focus on individual / small group engagement, with recipients and donors
- Are already in place / easily established, ie feasible to deliver 'in-year'
- Are collaborative 'joint actions' between clinical colleagues, donor-recipient representatives, local KPA's / community groups

Outcomes will be evaluated using existing research-based methodology, in conjunction with colleagues at Bristol University.

From January 2019, a donor self-reporting outcome measures (DROMS) survey has been introduced. This is a 20-point questionnaire that is collected by the UK Donor Registry, administered by NHSBT. It includes pre-donation and post-donation assessments. It was piloted in three centres in 2018.

This year, Donor reported Experience Measures are being developed and piloted and will be introduced in January 2020.

The aim is to develop a portfolio of educational resources for donors that provide consistent information in both online and paper formats. The NHSBT website resources have been updated and expanded. FAQs are addressed and a range of more detailed factsheets have been and continue to be developed to cover specific issues in more depth., Guests were asked to let LB know if there are topics that should be included in future factsheets. The team is also working on guidance for individuals seeking donors through social media appeals.

LB thanked the Marketing and Comms team at NHSBT and all the other agencies and individuals who have helped with these initiatives.

Chain Reaction: personal insights - Joe Salvatore, Teresa Dobson & Carmel Dalby

Joe Salvatore had been attending the renal clinic for 10 to 15 years when he was informed that he need a kidney transplant urgently and must go on dialysis. Both his wife and daughter (Carmel Dalby) offered to donate, but his wife was unable to proceed with donation.

Unfortunately, Carmel was not a suitable match so both Joe and Carmel entered the UK Living Kidney Sharing Scheme. Carmel donated to someone on the waiting list as part of the donation 'chain' instead.

Through this Scheme, non-directed donor Teresa Dobson donated to Joe as the first 'link' in a chain and Carmel donated to someone on the waiting list.

Joe and Teresa kept in touch from time to time after the operation, anonymously, through their respective transplant coordinators. However, they became aware that some of their correspondence was not passed on and in 2018, Teresa suggested they meet up.

Teresa knew that such a meeting between donor and recipient was rare and took the opportunity to approach the Press Association to see if some publicity for living donation could be the result. Joe was happy to go along with this. The story was picked up locally as well as nationally by Sky News, the Telegraph and the Daily Mail, among others.

Carmel chose not to make contact with her recipient, although she did receive a thank you letter. She was happy to have donated but also to move on with her life.

Joe explained that the unit did not encourage him to write and thank his recipient, but agreed to pass on his thank you letter. However, more recently recipients are being encouraged to write. Some donors feel there is no need to make contact with their recipients, particularly as the importance of anonymity is stressed from the outset. Also that they shouldn't expect a thank you letter.

Unspecified Kidney Donation in the UK: Insights from the BOUNd study - Hannah Maple

BOUnD: Understanding barriers and outcomes of unspecified (altruistic) kidney donation
Chief investigator: Nizam Mamode

Where it all began

Numbers of altruistic donors rose from just a few in 2007 / 08 to over 100 annually in 2013 / 14. There was huge variation in donor rates across the 23 transplant centres, with 45% performed in just three centres (at Dec 2013).

Psychological findings showed little difference between specified and unspecified donors, when we might have expected specified donors to do better. The team wanted to know what that tells us about living donation?

Earlier studies had shown a drop-out rate of around 65%. Also that transplant professionals had 'mixed feelings' about unspecified living donation and there was anecdotal evidence from donors of barriers to donation.

BOUnD is a five year, nationwide, prospective study, using mixed methods of collecting data from donors - both specified (SKD) and unspecified / altruistic (UKD) and transplant professionals. It aims to discover whether variation in transplant professionals' practice and attitudes are preventing some unspecified donations; whether psychosocial and physical outcomes after UKD are equivalent to those after SKD and to determine the economic benefits of UKDD: what is an altruistic donor worth?

Challenges

UKD numbers have decreased slightly in recent years. Furthermore, the UK Living Kidney Sharing Scheme (UKLKSS) has resulted in fixed time points where donations take place. This means that there is a lot of activity at set time points. There are benefits: concentrated effort puts UKD on the radar; it's easier to identify donors we may have missed and the scheme ultimately results in more transplants.

Another challenge is that there is less awareness that the team also needs to recruit SKDs. Every centre does things slightly differently and everyone is very busy! As a result, the team has managed to recruit 72% of their target number; however only a fraction of the total living donor transplants are being referred to BOUnD.

Analysis of the first 418 donors demonstrate the following demographic profile:

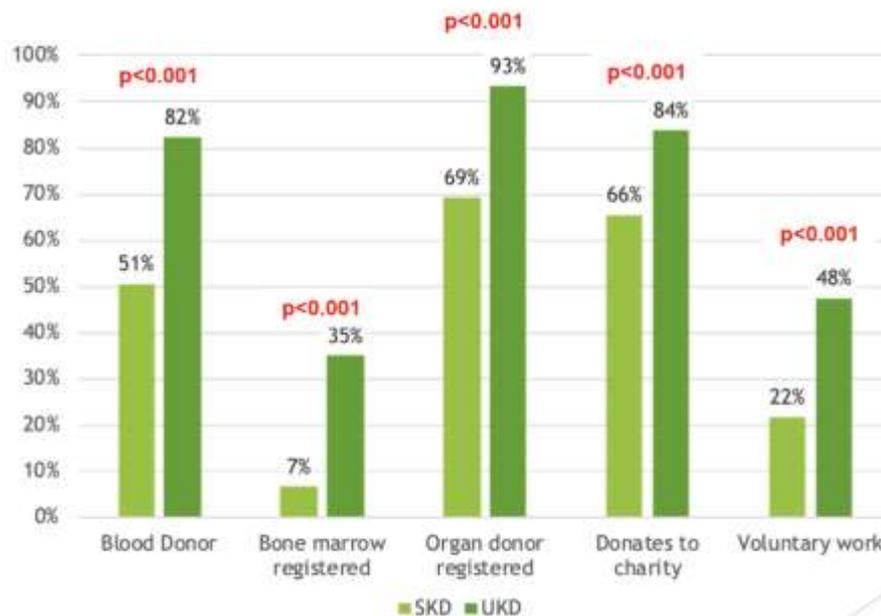
	Specified Kidney Donors (%)	Unspecified Kidney Donors (%)	P value
Age	49.2 years	48.5 years	0.610
Gender	92 (48.7) male	97 (51.3) male	0.082
Ethnicity (white)	157 (94.0)	168 (93.9)	0.951
In a relationship / widowed	143 (85.1)	94 (51.9)	<0.001
Children	131 (78.0)	95 (53.1)	<0.001
Religious beliefs (yes)	111 (73.0)	63 (36.6)	<0.001

- Current UKDs are significantly younger than data published in 2014, when the average age was 54yrs (now 48.5yrs).

- More SKDs hold religious beliefs than UKDs, so disputing claims by some that religion is a motivating factor.

UKDs display more consistent altruistic behaviours as shown by this graph:

Results - Altruistic behaviours



Of the 418 recruited, 236 completed the research pathway: 149 donated, while 87 withdrew. However, 124 were currently in work up and 58 were lost to follow up..

On studying timings, the team discovered that SKDs took 96 days but UKD 216 days on average. One factor is the mental health assessment that UKDs have to undergo; there is a lack of professionals able to assess patients. However, the two are hard to compare, as donors are referred at different times in the process. Also there is more likely to be a lag with SKDs due to recipient issues.

There was found to be no significant difference in number of UKDs vs SKDs donating or withdrawing.

Looking at centres in terms of volume of transplants carried out, time to donation was similar, whether in high or low volume centres.

Conclusions

Recruitment is ongoing and the study continues.

Interim analysis shows that

- There is no longer a significant difference in age between UKDs and SKDs; UKDs are getting younger
- There is no evidence that UKDs are more religious / motivated by religion
- UKDs take significantly longer to donate
 - UKLKSS is likely to be a contributory factor

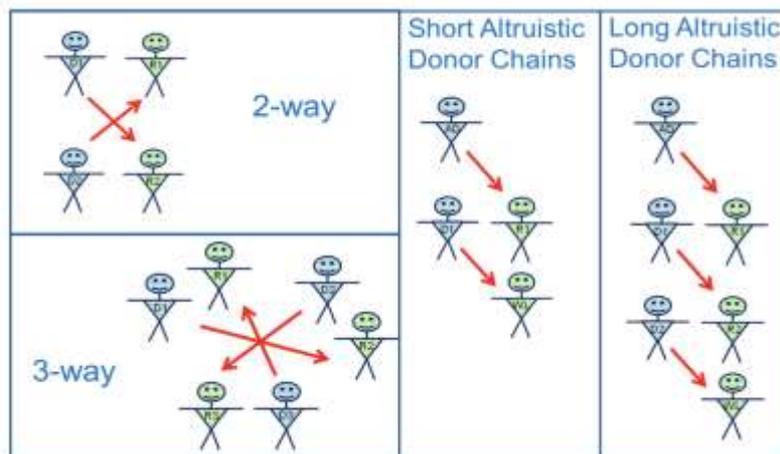
- May also reflect attitudes to UKDs or differences in workup (ie mental health assessment)
- Centre volume does not appear to have an impact on time to donation

More to follow...!

Afternoon session

Living Donor Kidney Transplantation Making Sharing Count – Lisa Burnapp

The UK Living Kidney Sharing Scheme(UKDKSS) matches donors and recipients in the following way:



Matching runs are co-ordinated every three months. In 2017 /18, 22% of adult living kidney transplants were achieved through the UK Living Kidney Sharing Scheme from kidney paired exchange or altruistic donor chains.

Reviewing donors' demographic, we see that altruistic donors tend to be older. 13% were over 70, compared with 1-3% in that age group of paired donors. 31% were 60-69, as opposed to 19% of that age group in paired donors. However, altruistic donors appear to be getting younger in comparison with previous statistics.

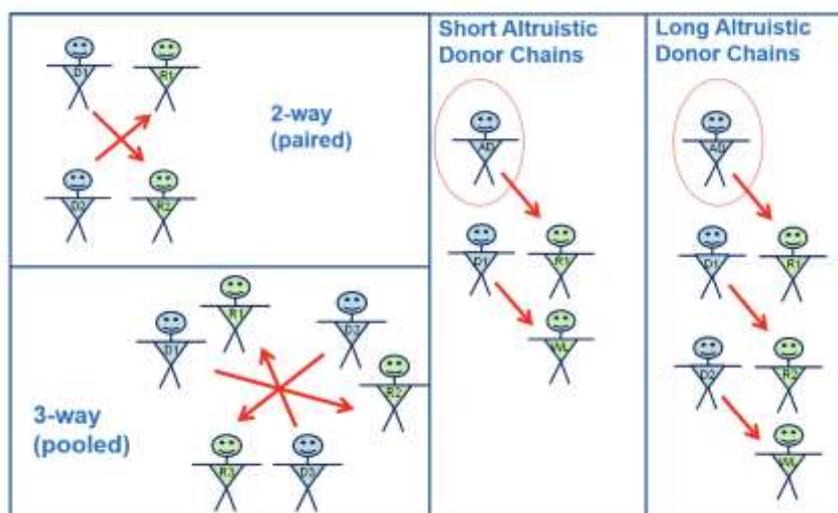
Considering ethnicity, 99% of ADs are white whereas only 78% of their recipients are white. 11% (paired) and 12% (altruistic) recipients are Asian.

Priorities for 2018 were as follows:

- To maximise transplants
- To increase flexibility in the scheme
- To tackle non-proceeding transplants
- To improve access and awareness

By inclusion of non-directed donors as a 'default', transplants from each altruistic donor (AD) have been maximized and the pool of donors within each matching run increased. Also by inclusion of incompatible pairs and with low-risk antibody removal for 'difficult to match' recipients. An increase in the number of transplants through the UKDKSS has led to a decrease in antibody incompatible transplants, which is good for kidney patients.

This diagram shows how the non-directed altruistic donor (NDAD) is key to 'triggering' a chain:



Some hospitals register more donors and recipient in the scheme than others. There are many reasons for this but it is important to ensure that all recipients and donors have the same opportunity to access the UKLKSS regardless of where they live in the UK.

AD numbers have fallen from their peak of 110 in 2014, to 87 in 2016 and 64 in 2018. However, in 2018, 48% of transplants from ADs were part of a chain (30% in 2017), so they went further, leading to 79 transplants (64 in 2017). The number of actual donors may appear lower in 2018 because most now enter a quarterly matching run and those who were fully assessed in 2018 may not donate until 2019 if they are registered in the October or January matching runs.

Not all can go into a chain: some donors expressed a preference to donate to the list, prior to January 2018 when chains became the default. Some donors are unmatched in the scheme and initially an increased proportion of kidneys were offered to 'high priority' recipients, due to the introduction of backdated waiting time points for recipients on dialysis on the national transplant list in 2018.

Flexibility is increasing, so non-simultaneous surgery can be arranged if necessary. There are designated weeks of surgery across all centres (up to 8 weeks post matching run). The aim is for 75% of transplants to proceed within eight weeks of being identified.

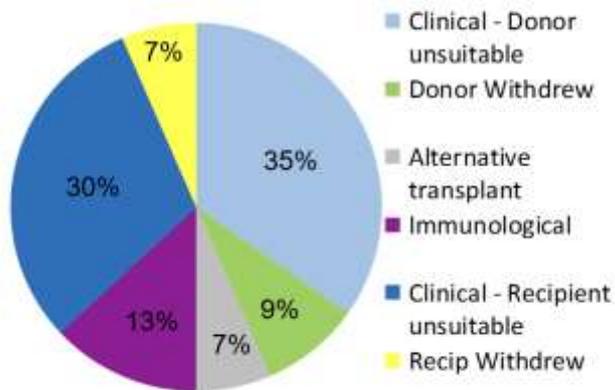
- 54% of identified transplants proceeded in 2007 - 2011
- 66% proceeded 2012 – present
- 60% proceeded since Jan 2017

Overall, the current rate of proceeding transplants is 62%

Whenever a transplant cannot proceed, an on-line survey is sent to the relevant centre to identify the cause and whether or not it could have been avoided. The summary findings are shown in the table below. The table includes all donors and recipients in the UKLKSS. There are many reasons why a transplant may not go ahead as planned. (E.g, the 'unsuitable donor' category may be due to a donor not being considered suitable for a particular recipient, which

we aim to identify as early as possible or because the donor becomes temporarily unwell and cannot proceed on the day).

October 2017- July 2018 (46 reasons)



The UK Living Kidney Donation Network was expanded in 2017 to improve communication and leadership for living donor kidney transplantation. NHSBT and the LDKT 2020 strategy implementation group encourage shared-learning and best practice by:

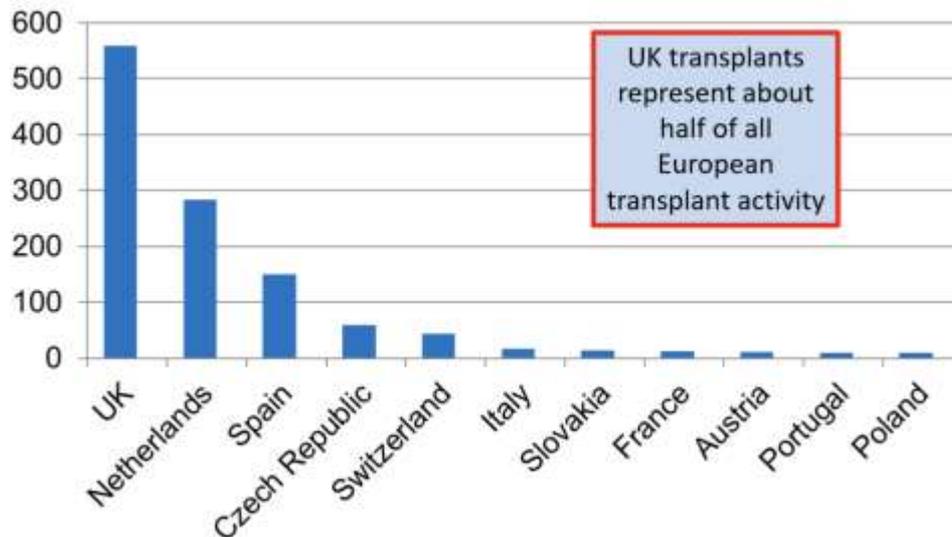
- Publishing Annual activity and centre specific reports
- Hosting and funding UK LKD Network meetings
- Collating and publishing quarterly newsletter and updates
- Providing key contacts within ODT to support the network

Online resources have been developed for the network: www.odt.nhs.uk/living-donation/ and there is an extended portfolio of donor-recipient information www.organdonation.nhs.uk/about-donation/living-donation/

As a result of this work, the number of patients in the quarterly matching runs has increased from 9 in April 2007 to 286 in October 2018. In 2016/17 and 2017/18, 85 of these were altruistic donors.

The European Network for Collaboration on Kidney Exchange Programmes (ENCKEP) has been established to collaborate internationally and discuss the scope of extending collaboration between countries for kidney exchange programmes. The group has already published on the current situation in Europe and there are further publications in development, including the principles for a legal and ethical framework.

Looking at the number of transplants from kidney exchange programmes by country, we can see that the UK is a leader in the field.



In summary, the scheme delivers effective kidney sharing across the UK, is the largest national scheme in Europe and has an international reputation. However, continuous innovation and improvement is vital to make the most of every transplant opportunity.

LB thanked her colleagues for their contributions and finished with the following quote:

NEVER UNDERESTIMATE YOUR ABILITY TO MAKE SOMEONE ELSE'S LIFE BETTER – EVEN IF YOU NEVER KNOW IT (GREG LOUGANIS)

What we can do better together – panel discussion

Lisa Burnapp, Fiona Loud, Kirit Modi

Bob Wiggins introduced the discussion with a reminder of how the landscape has changed since the charity was founded. The lines between directed and non-directed donation are blurred, for example: is a donor in a chain a directed or non-directed donor? They don't know their recipient, but they are donating so that a friend or family member will also receive a kidney. Similarly, donors and recipients who meet through a Facebook appeal don't know each other before the appeal. Do we need to reconsider the space we work in and where we can be most effective in supporting donors, however they might be categorised.

Fiona Loud (Policy Director, Kidney Care UK) received a kidney from her husband. Kidney patients are the focus for Kidney Care UK. She agreed that groups should work together, where they share a common goal. Through research, for example the BOUnD Study, we can see things through the eyes of health professionals and donors, as well as kidney patients. By sharing and evaluating this research, we can be more effective.

World Kidney Day was a good example of how different groups working together can make a greater impact. The result was a surge of interest in living kidney donation. Campaigning for the Organ Donation (Deemed Consent) Bill was another. However, now that the bill has passed, there is a danger that living donation will slip down the list of priorities, although the bill will not take effect until 2020. There is cross-organisational potential for Advocacy Officers, whose help with advice is invaluable.

Kirit Modi explained that his first kidney transplant, donated by his wife, lasted 15 years. He received another three years ago from a deceased donor. He notes that the profile of living donation is not the same in every unit and campaigns for greater consistency. He urged

everyone to join their local Kidney Patients Association and to offer peer support, so that anyone interested in living donation has readily available resources.

Lisa Burnapp stressed the importance of consistency of information across organisations. Ideally, collaboration between groups and charities would lead to several logos on the same information, rather than a variety of information, which can be confusing for interested parties. NHS BT have brought different groups together to work on this, creating a separate identity for living donation and expanding the available resources, online in particular.

Kidney Charities Together was set up to encourage collaboration. The group meets regularly to agree where they can best work together. Another is Kidney Health Partnership.

All agreed that influence can achieve a great deal, where money can't.

JS and LB agreed on the value of case studies and media stories; donors who are willing to tell their stories play a vital role in maintaining interest in living donation.

Attendees were urged to get in touch with Give a Kidney if they have any particular suggestions as to where they would like to see the charity focus. Give a Kidney is already involved with a large number of forums and would like to continue to ensure they can achieve the maximum impact, through collaboration.

BW closed the meeting by thanking all the speakers for giving up their time; Sanjiv Gohil for allowing the event to take place in his offices and for organising the catering; to Viv Calderbank for all her help throughout the year with newsletters and design work; and to fellow Trustees and members of the Steering Group.