

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE**

**MINUTES OF THE SIXTH MEETING OF THE
KIDNEY PATIENTS' SUPPORT GROUPS AND NHSBT,
HELD ON TUESDAY, 28 JULY 2015
AT BIRKBECK, UNIVERSITY OF LONDON,
MALET STREET, LONDON WC1E 7HX**

PRESENT:

Mr Jim Higgins	National Kidney Federation / Northampton KPA – Co-Chair
Prof Chris Watson	Chair of NHSBT Kidney Advisory Group – Co-Chair
Mrs Lisa Bradbury	Statistics & Clinical Studies (NHSBT)
Ms Lisa Burnapp	Lead Nurse for Living Donation (NHSBT)
Mr John Champion	Six Counties Kidney Patient Association
Mrs Jan Cooper	Kidney Research UK Trustee
Ms Sarah Harwood	Kidney Research UK
Ms Tess Harris	Polycystic Kidney Disease Charity
Ms Nicki James	Kidney Research UK
Ms Surinder Jandu	Antibody Incompatible Transplant Co-ordinator, NHSBT / British Renal Society representative
Mr Ewen Maclean	Scottish Kidney Federation
Prof James Neuberger	Associate Medical Director, ODT (NHSBT)
Dr Rob Ryckborst	Kidney Patient Association – West Midlands
Mr Timothy Statham OBE	National Kidney Federation

In Attendance:

Mrs Kathy Zalewska	Clinical & Support Services, ODT (NHSBT)
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ACTION**Apologies:**

Ms Debbie Adams, Kidney Patient Association (West Midlands)
Mr Ian Hampton, Head of Campaigns and Partnerships, NHSBT
Ms Fiona Loud, British Kidney Patient Association
Ms Louanna Prince, External Affairs Manager, Communications, NHSBT
Ms Jan Shorrocks, Give a Kidney
Ms Melanie Wager, Kidney Wales Foundation

No feedback received from:

British Organ Donor Society
Diabetes UK
Kidney Cancer UK
National Kidney Federation (West Midlands)
Northern Ireland KPA
Northern Ireland Kidney research Fund
Royal Free KPA
Royal London Hospital KPA
South Asian Health Foundation
Swindon Kidney Patients' Association
Transplant Association

1 Welcome and Introduction

Introductions were completed and C Watson & J Higgins welcomed everyone to the meeting.

ACTION

2 Approval of minutes of previous meeting**2.1 Accuracy**

The previous minutes were agreed as a true and correct record.

3 Review of actions outstanding:**3.1 Progress achieved with a dual signature donor card and extent of proposed distribution in the UK**

I Hampton was unable attend to present an update on this item and had agreed to provide his presentation for circulation to attendees.

I Hampton

3.2 ODR – Quality management system at SNOD and RTC level

J Neuberger reported on changes within the ODT Specialist Nurse workforce. This work includes changes to training in approaching families for consent to donation. NHSBT is evaluating the concept of a designated requester role for Specialist Nurses to ensure donation occurs whenever appropriate. This evaluation will take place in two regions to see if there is an improvement in consent rates.

A workforce review for SNODs is also taking place looking at team and regional structures to identify inefficiencies in working practices in order to reduce unnecessary or cumbersome administrative processes.

Work is being undertaken with commissioners and Trusts on reviewing working practices of recipient co-ordinators who are employed by Trusts rather than by NHSBT. Currently there are variations in practice around the country in working practices of recipient co-ordinators.

4 TOT2020 Strategy

- 4.1
- J Neuberger reported on the TOT2020 Strategy for the UK. A number of issues are being addressed by a variety of organisations including NHSBT, commissioners, the BTS and other stakeholders.
 - Two Clinical Leads for Organ Utilisation have been appointed – Andre Simon from Harefield who will be working with cardiothoracic teams on appropriate utilisation of cardiothoracic organs and Chris Callaghan from Guys who will be working with abdominal teams. The two main areas for loss of organs are at the consent stage and utilisation. As accountability for the use of organs lies with surgeons, NHSBT will work to provide information and support.
 - In conjunction with NHS England which has a very effective peer review process, NHSBT conducted a peer review of cardiothoracic centres, the final report for which is awaited. It is hoped to roll out similar reviews for other organs following discussion with NHS England.
 - Work is taking place with Andrew Haigh, acting on behalf of the Chief Coroner, to ensure that organ donation proceeds whenever appropriate when the death of a potential donor has to be reported to the Coroner/Procurator Fiscal.
 - NHSBT is working with academics to develop a long term strategy with a view to changing public behaviour towards organ donation. Members highlighted the effectiveness of advertising campaigns promoting organ donation in Scotland such as 'Kill Jill'.
 - Discussions are taking place with commissioners in order to look at the evidence available on machine perfusion.
 - Various streams of work are being undertaken around BAME donation. This includes a peer educator trial, meetings with Imams, and developing links with the MOHAN foundation (a deceased organ donation not-for-profit organisation in India).

ACTION

- In Scotland there is a Maastricht 2 trial on DCD donors. There has been only one donor so far so it is too early to carry out any evaluation.

- 5 Latest Statistics relating to Organ Donation and Transplantation**
L Bradbury presented the latest statistics relating to Organ Donation and Transplantation to the group (**see attached presentation**). Members noted a fall in the number of patients on the waiting list but an overall rise in the number of suspensions. L Bradbury agreed to investigate this. **L Bradbury**
- 6 Issues raised by members**
6.1 Improvement in BAME Communities donation rates
I Hampton was unable to attend to present an update on this item and had agreed to provide his presentation for circulation to attendees. **I Hampton**
- 7 Review of current selection and allocation policies**
The revised selection and allocation policies were received and noted. The only change made during this revision was the addition of an Appeals Panel whereby a centre can appeal against a patient selection decision. In answer to a query as to whether patients are aware of the appeals process, C Watson confirmed that clinicians are aware and will initiate the appeal on behalf of their patient.
- 8 Update on DCD Allocation**
L Bradbury presented an update on the DCD allocation scheme (**see attached**).
- 9 Review of developments in policies**
The main developments are the addition of an Appeals Panel and establishment of a DCD allocation scheme, both previously mentioned. Another change awaiting IT input is the establishment of a process for recording waiting time from dialysis. Patients who were listed after starting dialysis will have that waiting time included in their waiting time points' calculation.

If a patient is on dialysis rather than on the transplant waiting list through choice, then if and when they wish to move on to the transplant waiting list then this rule will still apply.
- 10 Consideration as to the causes of the drop in transplant numbers**
Following publication of the NHSBT Annual Activity Report 2014/15 the NKF responded to the NHSBT press release making the following comments:
- The fall in transplant numbers is regrettable
 - NKF asked that the circumstances in which people die is reviewed to ensure the opportunity to become a donor is not missed
 - Stakeholder groups need to engage more in campaigns for public awareness on the consent issue
 - Whilst the ODR is clearly more efficient now, the issue is that the register does not have a visual appeal to the public which could be rectified with the use of organ donor cards
 - The card needs to be a dual signature card to indicate that the conversation has taken place
 - The TOT2020 strategy needs to have more specific targets. Statements such as 'world class performance' lack meaning.
 - Variability between regions needs investigation although it was acknowledged this is already being reviewed
 - Reaching 21 million people in the UK on the ODR is good news but is pointless if this doesn't result in an increase in transplant numbers

- The number of patients on the waiting list has fallen and should be investigated

The question of clinicians over-riding the wishes of the next of kin to refuse consent if the potential donor is on the ODR was raised. J Neuberger explained that if the potential donor is on the ODR in the UK then the Human Tissue Authority has indicated that this is legal consent for donation. In reality, however, if the family is very distressed about the donation proceeding, clinicians and others will respect the grief of the family and will not override that decision. NHSBT works hard to encourage families to respect the wishes of the donor. There is also the added difficulty that if the family is unwilling to co-operate then vital information on the donor is not forthcoming.

13 **Update on the LDKT 2020 Strategy**

L Burnapp gave a presentation (**see attached**) on the Living Donor Kidney Transplant 2020 Strategy. Since July there has been continued engagement with stakeholders; five year plans have been established for each work stream; developed key performance indicators; and implemented changes to the national living donor sharing schemes (NLDKSS) to maximise transplant activity, improve utilisation of the shared donor pool and perform statistical modelling to develop the schemes. Over 1,000 patients a year are benefiting from living donor kidney transplantation with the percentage of proceeding transplants through the NLDKSS rising from 35% to 60% in five years. Areas for improvement include increasing awareness about non-directed altruistic donations, which fell 9% last year; overall living donor activity, currently 19% behind projected activity; and the number of non-proceeding transplants in the national sharing schemes.

T Statham highlighted the power of TV advertising in increasing awareness of altruistic donation. It was acknowledged that advertising is expensive but other ways to raise awareness include storylines on popular TV soaps. L Burnapp added that one of the biggest influences on altruistic donation has been the Give a Kidney charity. There are plans within LDKT 2020 to increase public engagement about all aspects of living donation.

E McLean reported on a TV documentary for BBC Scotland called Transplant Tales which covered transplants from altruistic donors as well as from deceased donors. These programmes stimulated interest in donation, particularly on social media. It was noted that a dedicated leaflet on altruistic donation will soon be available in blood donor sessions.

14 **What would the Kidney Patient Support Group like KAG to do?**

C Watson updated the group on the points raised at the last meeting:

- Living donation: provide more centre identifiable information – This is available by transplant centre but not by dialysis centre
- Decision support: How a patient can be given information regarding a less than perfect kidney – J Neuberger is leading a programme to establish an App or website to improve information to enable patients to better interpret risk
- Transition period for young ones so they are helped to become compliant – The KAG Paediatric sub-group is looking to produce guidelines on compliance. Guys' Hospital is currently looking for stories for a project and N James agreed to find out more information on workshops for young people leaving Evelina for adult units and pass this information to C Watson for the Chair of the Paediatric sub-group.

ACTION

In answer to a question on risk averse behaviour following the Cardiff incident it was acknowledged that although there was no evidence to this effect it was likely that there is probably a tendency to more risk aversion as well as a greater awareness of the guidelines on consent. J Neuberger reported that outcomes of high risk donors as well as survival from listing is published on the ODT website and there is a need to ensure that recipients and families are advised of extremely rare risks to ensure that consent is properly informed. Centres are also changing their consent practice to ensure there is more informed consent.

T Harris referred to the behaviour change strategy and that TOT2020 mentions getting organ donation on the school curriculum. Discussions on this have started in Scotland with the production of a pack for schools. Work is ongoing with the Department of Education but there is competition with other subjects to incorporate into the school curriculum. NHSBT can provide the information for schools but is unable to mandate its inclusion in the curriculum. J Higgins emphasised that stakeholders should also take responsibility for campaigning for this to take place and K Zalewska was asked to contact I Hampton for resources that stakeholder groups can use within the community, possibly an area on the ODT website where groups could download for packs for school visits.

K Zalewska

15 Any other business

Jan Shorrocks (Give a Kidney) was unable to attend but asked via email if NHSBT would consider increasing the profile of living donation within their campaigns to increase public awareness. Currently the focus appeared to be exclusively on deceased donation. This is a huge missed opportunity particularly as outcomes are better for kidneys donated from living donors, now that non-directed living donation can trigger up to three transplants in their chain, providing an opportunity to improve flagging transplant rates. L Burnapp responded, stating that the NHSBT Communications policy concentrates on two large projects on living donation p.a. Earlier this year there was a radio piece, in collaboration with Give a Kidney, as research shows that radio has influenced people to consider altruistic donation. Another opportunity is Transplant Week events and looking where stories on living donation can be included.

It was recognised that although social media is a powerful tool in increasing awareness of altruistic donation there is a large drop-out rate following receipt of detailed information.

16 Date of next meeting

To be agreed.