

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

**MINUTES OF THE SEVENTH MEETING OF THE
KIDNEY PATIENT GROUP
HELD ON THURSDAY, 21ST JULY 2016
AT THE ROYAL COLLEGE OF ANAESTHETISTS,
CHURCHILL HOUSE, 35 RED LION SQUARE, LONDON WC1R 4SG**

PRESENT:

John Forsythe	Associate Medical Director, NHSBT – Co-Chair
Chris Watson	Chair of NHSBT Kidney Advisory Group – Co-Chair
Danielle Angell	Kidney Wales Foundation
Lisa Bradbury	Statistics & Clinical Studies (NHSBT)
Andrea Brown	National Kidney Federation
Lisa Burnapp	Lead Nurse for Living Donation (NHSBT)
Rebecca Cooke	Kidney Wales Foundation
Ian Hampton	Head of Partnerships & Campaigns, NHSBT
Tess Harris	Polycystic Kidney Disease Charity
Sarah Harwood	Kidney Research UK
Fiona Loud	British Kidney Patient Association
Kate Martin	Statistics & Clinical Studies (NHSBT)
Kirit Modi	National Kidney Federation
Rob Ryckborst	Kidney Patient Association – West Midlands
Timothy Statham OBE	National Kidney Federation
Peter Storey	Kidney Research UK
Bob Wiggins	Give a Kidney

In Attendance:

Trudy Monday	Clinical & Support Services, ODT (NHSBT)
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Apologies:

Michael Abbott, Gloucestershire Kidney Patients' Association
Debbie Adams, Kidney Patient Association (West Midlands)
John Champion, Six Counties Kidney Patient Association
Daniel Howarth, Diabetes UK
Nicki James, Kidney Research UK
Betty Jennings, Secretary of Northern Ireland Kidney Research Fund
Sarbjit Johal, British Renal Society
William Johnston, NIKPA – Northern Ireland Kidney Patient Association
Helen Lewis, Independent Researcher
David Marshall, National Kidney Federation
Kevin Mashford, Transplant Association
Emma Osbourne, Transplant Association
Jan Shorrocks, Give a Kidney
Richard Trompeter, Great Ormond Street Hospital

No feedback received from:

Yvette Bell, Kidney Research UK
Caryl Bryant, Sec Royal London Hospital KPA
Jan Cooper, Kidney Research UK Trustee
Elaine Davies, Kidney Research UK
Nick Flint, KPA, West Midlands

Surinder Jandu, NHSBT / British Renal Society representative
 Simon Lloyd, Six Counties Patient Association
 Louanna Lubega, Communications, NHSBT
 Ewen Maclean, Scottish Kidney Federation
 Kieran Mullan, Patient Association
 Kerriane O'Rourke, Diabetes UK
 Ray Pearson, British Organ Donor Society
 Jacqueline Pratt, ODT Lay Member
 Patrick Tabor, British Kidney Patient Association
 Roy Thomas, Kidney Wales Foundation
 Melanie Wager, Kidney Wales Foundation
 Mick Walker, National Kidney Federation
 Tony Weaver

1 **Welcome and Introduction**

J Forsythe welcomed everyone to the meeting and thanked them for coming. Introductions were completed.

2 **Approval of minutes of previous meeting**

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

3 **Election of a representative to act as a co-chair**

J Forsythe explained that the previous Chair had stood down and therefore it was appropriate for today's meeting to be Chaired by himself. Going forward however, attendees were asked to think about how these meetings should be Chaired – by one Chair or two Co-Chairs (elected from one of the kidney patient support groups).

This group provides a platform for information sharing between NHSBT and patient groups, and should include ongoing contact with the Chair of the Kidney Advisory Group (KAG). It was confirmed that once the TOT2020 Strategy has concluded, this group will continue.

Frustration was expressed that these meetings only happen once per year and that there was an underlying concern regarding issues not being taken forward after the meeting.

T Monday will email the Terms of Reference to attendees for comment and ask for feedback on how these meetings should be chaired going forward and by whom (patient, transplanted patient or patient group representative) with a deadline for responses.

T Monday

4 **Plans for a new kidney allocation policy in the United Kingdom**

The current kidney allocation scheme has worked very effectively, however a number of issues have been identified that need addressing, for example, the detail of the tissue type could be increased to avoid positive crossmatches. Three groups were established to explore changes in histocompatibility matching (tissue typing), the philosophy underlying allocation, and reviewing the current scheme to identify its strengths and weaknesses. For example, the following have been discussed: accruing waiting time points from the date a patient starts dialysis, rather than from when they are actually listed; prioritising younger recipients for younger donor kidneys; the age limit for paediatric patients (currently 18 for kidneys, but 16 for livers).

C Watson explained that a research project called ATTOM (Access to Transplantation and Transplant Outcome Measures) has characterised most new

patients starting dialysis, joining the transplant waiting list or having a transplant over a 12 month period, providing detail on comorbidity such as heart disease, quality of life, quality of health and so on. These data will be combined with data from NHSBT and the Renal Registry in drawing up the new scheme. The overall aim of a new allocation scheme would be to allocate the most appropriate kidney to each recipient. The revised (or new) scheme could be finalised for consultation by the end of 2018, but its implementation would be determined by NHSBT IT – who are currently implementing a new liver allocation scheme.

5 Review of actions outstanding:

Progress achieved with a dual signature donor card and extent of proposed distribution in the UK

I Hampton reported on a different tack taken – the focus has been on building the customer relationship with people on the ODR through emailing them with reminders of the importance of having conversations with their families about their choice. There is a limited budget with which to progress new initiatives, and the last six months of testing different interventions has resulted in a poor response generally. The key is to get the subject talked about and become the norm. Three to four messages are posted per week on Facebook, enhancing the ‘talking’ of the subject using free social media which is a powerful tool. Therefore, for the time being, the dual signature donor card will not be pursued.

6 Review of legislation regarding organ donation in the United Kingdom

D Angell reported that the Kidney Wales Foundation was a key driver in helping to establish the Welsh Organ Donation ‘opt out’ legislation which has been in place since December 2015. Talks began between patient groups and the government in 2012. It is too early to evaluate the effect that this new legislation has had, however the system is being monitored and will be reported on. It is hoped that if it is successful it will prompt discussions for the same ‘opt out’ legislation to be adopted across the whole of the UK.

In terms of planning implications, it was noted that there is increased pressure on resources at transplant centres, impacting on teams, and that this could impact on donor organ offers. Discussions are taking place within centres across the UK through ‘peer review’, which include trying to identify pressures.

Regarding Brexit, J Forsythe reported that NHSBT are already looking at the possible implications. Some of the regulatory powers have come from the EU side, but most, if not all, were already established within the UK.

7 Update on living donor kidney transplantation (LDKT) 2020 strategy

L Burnapp explained the three main objectives which have been acted on with work streams, and that this is ongoing work with the transplant centres. NHSBT continues to engage with Departments of Health and Commissioners to ensure that funding supports the development of the LDKT programme. A revised policy for reimbursement of expenses for living donors has been approved and will be published by NHS England in the near future. It was highlighted that the ‘National Living Donor Kidney Sharing Scheme’ sharing scheme has been re-named the ‘UK Living Kidney Sharing Scheme’ (UKLKSS).

There has been an increase in the different types of living donation since 2007 but overall donor numbers have fallen below projected activity in the last two years. Currently LDKT forms an average of 32% of the transplant activity of each centre. There is now more confidence with the UKLKSS scheme amongst patients and clinical teams, with a 52% increase in transplants in the last year after new

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changes were introduced. Although the number of non-directed altruistic donors has decreased slightly, the number of transplants per donor has increased due to the impact of altruistic donor chains. In order to achieve the targets for the 2020 strategy, public engagement campaigns are planned throughout the year and professional engagement is on-going through shared learning events using NHSBT LDKT centre-specific reports, NHS England kidney transplant peer review (September to November 2016) and donor presentations (national/international meetings and congresses). A pilot project across two sites focusing on family donation in BAME groups commenced April 2016, with an aim to achieve a template by the end of this year to roll out to centres.

It was acknowledged that there are many actions to address between now and 2020 and that patient, public and professional engagement are key to changing attitudes and shifting culture. Attendees were reminded that the UK is performing 1,000 transplants a year which is the third highest rate per million population, and that NHSBT is absolutely committed to improving the number of transplants. There is some evidence that transplant centres are stretched and some may be under-resourced.

The slides from this item will be emailed out to attendees along with the minutes.

T Monday**8 Update from Give a Kidney/Non-directed altruistic kidney donation**

Give a Kidney is a registered charity founded in 2011 by a group of people (mostly patients) committed to promoting altruistic or non-directed living kidney donation. The charity now has approximately 400 members. It supports potential donors, and aspires to influence change within transplant centres, NHSBT, and the mindsets of both clinicians and the public, raising awareness and challenging resource and where it should be focused. National media is more difficult nowadays, and to help with this a new ambassador's programme has been launched this summer.

9 Latest Statistics on Kidney Donation and Transplantation

K Martin presented slides on kidney donation and transplant activity over the last ten years. The following were highlighted:

- donor and transplant numbers have increased, while living donor transplant numbers and the number of patients on the 'active' list have decreased;
- there has also been an increase in suspended patients;
- DBD and DCD donor numbers have increased;
- There have been more blood group incompatible transplants than HLA incompatible transplants.

Concern was expressed over the varying data amongst centres, and it was explained that such variations can arise through different issues within individual hospitals, for example understaffing, different criteria for accepting donor organs. By producing the 'Annual Report on Kidney Transplantation' which analyses data at a centre level, centres can reflect on their performance and address areas where they are outliers. The introduction of a peer review scheme very soon will enable more shared learning amongst centres. It was also noted that the UK results compare well internationally with other countries, in particular with the US and Australia. These slides will be emailed out to attendees along with the minutes.

T Monday

Concern was expressed at the variation in utilisation rates for donor kidneys. It was explained that naturally some clinicians were more risk averse than others. Attendees were advised that two donor organ utilisation leads had been appointed

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to address this: Chris Callaghan for abdominal organs and Andre Simon for cardiothoracic organs.

J Forsythe confirmed that NHSBT is working on different projects to help achieve the strategic objectives of the TOT2020 Strategy.

It was highlighted that the ODT website, although designed for clinical access, is not very user-friendly for patients as it is often difficult to locate specific types of information. J Forsythe accepted that this is a problem and confirmed that John Asher (in NHSBT) is going to be reviewing that particular part of the website. The importance of having transparent and meaningful data which is easily accessible to patients was noted. J Forsythe asked patient groups to liaise with J Asher in advising how this may be taken forward.

Patient Groups

10 UK Renal Research Strategy

P Storey from Kidney Research UK presented the UK Renal Research Strategy which was launched in April 2016. It has been produced by a multi-stakeholder steering group, looking at UK renal research and describes 4 strategic aims that overarch a set of 13 recommendations, with suggestions for their implementation. This document aims to identify the gaps in current research activity and promote further research.

11 Improvement in BAME Communities donation rates

I Hampton reported on two objectives relating to donation which he is currently overseeing: to improve the number of people on the ODR, and to increase their consent rates. The first audience targeted is the over 50s, the age group more likely to become donors; the second target audience are those people who lead chaotic lives; the other audience are children as change makers (children are more likely to talk to their parents and generate debate).

Two interventions have been explored with respect to BAME communities: to engage with Muslim scholars (religious community based) to develop a new Fatwa; to engage with African-Caribbean communities. I Hampton would like to use the patient group memberships to communicate his messages, and noted that it would be of benefit to have some kind of communication device to share information (maybe a 'communications' group which is campaign focused). It was agreed that an improved information flow between patient groups and NHSBT is required.

12 Review of developments in policies

The only development relating to renal transplantation in the last year is the exemptions panel. The exemptions panel (made up from members of KAG) has been in place for one year, and assesses individual cases which may be disadvantaged by the current policies for access to and allocation of kidney transplants.

KAG are looking at developing a policy for allocation of kidneys from very small (under 10kg) donors.

13 Issue of large numbers suspended from the transplant list

L Bradbury presented a paper investigating the increase in the number of suspended patients on the kidney transplant list. The numbers of suspended patients has varied widely across the 23 adult transplant centres; a reason for this could be down to how the centres are managed – some centres register patients on the transplant list before they are 'active' (no waiting time is accrued until a patient is 'active'). It was noted that a large proportion of patients are being

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suspended due to their condition deteriorating and NHSBT may not have been notified of their death. KAG were not concerned about the practice of listing patients as suspended since there was no evidence that this was an attempt to gain extra priority. It was keenly awaiting the available of mortality data from the Office of National Statistics which should give further insight into the outcomes of patients who remained suspended. L Bradbury agreed to report on the numbers of suspended patients after the data cleansing exercise upon receipt of ONS data.

L Bradbury

14 Fluctuating Organ Transplant numbers over the past 24 months (Kidney)

Refer to minutes 7 and 9.

15 The current dependency on Living Donors (Kidney)

Refer to minute 7 and accompanying slides.

16 Failing to be able to match or reflect the increase in registered donors, with the numbers of Cadaveric Organ Transplants over the past 15 to 20 years

Refer to minute 7.

17 High Profile Availability of the new Organ Donor Card – the lack of

Refer to minute 5.

18 A proposal for non-elective donor-ship

Refer to minute 6.

R Rijckborst raised a proposal for non-elective donorship in the UK. C Watson referred to the Welsh law of deemed consent which will provide evidence for the rest of the UK and may prompt a national change in practice if successful.

NHSBT was not able to lobby for a change in national policy, but it was emphasised that lobbying efforts are most effective when they come from patient groups. R Rijckborst was encouraged to communicate this proposal to 'Transplant 2020', which is a coalition of patient groups, clinical organisations and industry, dedicated to raising the rate of consent to organ donation in the UK.

19 What would the Kidney Patient Support Group like KAG to do

It was noted that these meetings were useful, and that there is a shared understanding with the framework within which all the attendees work, which is very important. It is however, difficult to maintain communication once per year so maybe an interim report would be useful.

T Harris asked if NHSBT were to be linked with the renal registry in the future.

L Bradbury confirmed that NHSBT is monitoring the current development of a UK data collaborative, but that they were not members of this at present due to lack of spare IT capacity at the moment. However it is proposed to join the collaborative in due course.

20 Any other business

None.

Date of next meeting

To be agreed.