

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

**MINUTES OF THE NIGHTEENTH MEETING OF THE
KIDNEY PATIENT GROUP
HELD ON TUESDAY 10th JULY 2018
AT MEDICAL SOCIETY OF LONDON, LETTSOM HOUSE, 11 CHANDOS ST,
LONDON W1G 9EB**

Present:

David Marshall	National Kidney Federation – Co-Chair
Chris Watson	Chair of NHSBT Kidney Advisory Group – Co-Chair
Andrea Brown	National Kidney Federation
Chloe Brown	Statistics & Clinical Studies (NHSBT)
Lisa Burnapp	Lead Nurse for Living Donation (NHSBT)
John Forsythe	Associate Medical Director (NHSBT)
Tess Harris	Polycystic Kidney Disease Charity
Fiona Loud	Kidney Care UK
Julia Mackisack	Lay Member
Kirit Modi	National Kidney Federation
Lisa Mumford	Statistics & Clinical Studies (NHSBT)
Paula Ormandy	British Renal Society
Kathleen Preston	Lay Member
Rob Rijckborst	Kidney Care UK – West Midlands
Emma Stapley	Senior Communications Officer – NHSBT
Peter Storey	Kidney Research UK

In Attendance:

Sam Tomkings	Clinical & Support Services, ODT (NHSBT)
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Apologies:

Chris Callaghan, National Lead for Organ Utilisation (Abdominal)
Patricia Gooden, Patient Representative
Helen Lewis, Independent Researcher
Adnan Sharif, NBTA Representative
Patrick Tabor, Kidney Care UK
Roy Thomas, Kidney Wales Foundation
Martin Wood, Six Counties Patients' Association

No feedback received from:

Diabetes UK Centre Office
Nick Flint, KPA, West Midlands
Northern Ireland Kidney Patient Association
Transplant Association
Scottish Kidney Federation
South Asian Health Foundation
Swindon Kidney Patients' Association

1 Welcome and Introduction

C Watson welcomed everyone to the meeting and thanked them for coming. Introductions were completed. C Watson advised the Kidney Patient Group (KPG) that Timothy Statham Chief Executive of the National Kidney Federation was retired and wanted to express thanks for Tim's contribution to the KPG over the years.

ACTION

ACTION

2 Approval of minutes of previous meeting – KPG(M)(17)1 and Action Points KPG(AP)(18)1

There were two errors highlighted in the previous minutes. These errors will be corrected. Once corrected, the minutes can then be approved.

Action points**AP1 – Informing waiting list patients of organ offers – a pilot proposal**

This work is ongoing and is being discussed across the patient groups. The feedback received so far from patient groups is there is a requirement for increased communication with patients regarding retrospective organ offers. The aim is to have an agreement in place with centres by 2019.

AP3 – NBTA's Living Donor Transplant Initiative

Following the meeting held in 2017, L Mumford liaised with Information Governance and Sally Johnson regarding the collection of religion data to be included on the National Transplant Database. This request constitutes sensitive data and any organisation would need to justify why this information should be collected. K Modi requested if a pilot could be considered within an area with a significant BAME population. L Burnapp agreed to explore the feasibility within the NBTA Living Donor Transplant Initiative.

L Burnapp

3 Medical Director's Report

J Forsythe provided an update on the achievements and current projects within NHSBT.

The current consent rate which is at its highest is 66%. In the last year, there have been 1574 donors and, including live donor transplants, the total number of transplants is 5075 which is also at its highest. Over the last ten years there has been a 95% increase in donation. A snap shot of data from the waiting list in 2010 identified there were 8012 patients on the active waiting list and in 2018 the number of patients on the waiting list had reduced to 6044.

J Forsythe outlined the developments around the UK regarding the opting out consultation. Deemed consent legislation is in place in Wales. A draft bill for opting out is going through parliamentary process in Scotland. A consultation exercise has taken place in England and the Government's response will be available in the near future. Claire Williment from NHSBT is working alongside the Department of Health.

A joint initiative with the British Transplantation Society (BTS) has begun to assist clinicians and patient groups manage increased risk donor profiles and to define the core information regarding the donor and when that information should be given to patients. Lay Members have been involved in this project and helped consider various tools which will be available on the ODT website.

The 95% increase in donation in the last 10 years has resulted in additional pressure on the system and on the retrieval teams. A joint BTS/NHSBT summit was held recently where various options to improve capacity were discussed as well as discussing the potential impact of opt-out legislation. F Loud asked what the outcome was from the capacity survey which took place in 2016. J Forsythe confirmed units were contacted which highlighted the concern regarding capacity

from increased transplant activity which lead to the summit meeting. Prior to the summit meeting, a questionnaire regarding capacity was completed by each centre. The questionnaire and summary from the summit will be available once finalised.

ACTION

K Modi requested the capacity issue is raised at the All Parliamentary Kidney Group provided the summary from the summit is available. J Forsythe confirmed this will be circulated as soon as possible.

D Marshall
J Forsythe

4 **Outcome from the Living Transplant Initiative – KPG(18)2**

K Modi presented an update on the Living Transplant Initiative.

A manifesto was published in January 2018 and there were seven recommendations which have initiated responses and once these are gathered, will be presented to the All Parliamentary Kidney Group.

A Living Transplant Initiative interim report is now available on NBTA website and will be available on the ODT website.

NHSBT have agreed further funding to NBTA until March 2019.

Three projects have begun, one is under discussion and a final report with recommendations will be published next year. Further publication will take place through NBTA and the living donor network for additional funding.

K Modi made a request to KAG to help publicise the Living Transplant Initiative interim report and to assist with publicising the request for funding. C Watson agreed for K Modi to send these requests including a brief explanation to S Tomkings for circulation to KPG members.

K Modi

K Modi confirmed once NBTA have completed these projects, a national sustainable model could be considered and that there is a possibility to extend this to donation after death. NHSBT would be happy to support communities and local groups to encourage taking this forward and to assist with applying for funding if funding is not available through NHSBT.

5 **Latest Statistics relating to Organ Donation and Transplantation**

C Brown presented information on organ donation and transplant activity over the last financial year. J Forsythe is keen for this information to be disseminated amongst patient groups.

DBD, DCD and living donors have increased in the last year and the number of patients on the transplant waiting list has decreased. The UK is listed as 4th in the living donor transplant rate across Europe.

NHSBT are keen to produce a risk adjusted waiting time report by centre. All reports will be published on the ODT website.

The donor rate per million population (pmp) for 2017/18 is known for the UK but the data across Europe has not yet been published. The UK rate for living donor kidney transplant is 15.2 pmp which is slightly less than last year due to the increase in population.

NHSBT are in the process of publishing the living donation rates pmp by transplant and renal centre and when completed, these will be available on the ODT website. A new initiative taking place is, if centres have declined a good kidney offer, that

centre will receive a letter from Chris Callaghan (National Organ Utilisation Lead, Abdominal) requesting further details regarding why the organ had been declined. The responses received has helped identify logistical issues within centres.

ACTION

F Loud highlighted that a patient report experience measure is available on the renal registry website. This is a national annual survey of kidney patients which provides an insight into their experience.

T Harris asked why transplant data isn't reported by primary renal diagnosis. L Mumford advised in 30-40% of cases the underlying renal diagnosis is unknown, therefore it would be challenging to report on this as a large amount of data would be unknown. If further information regarding primary renal diagnosis is required, L Mumford would be happy to provide the information that is available.

6 **Update on living donor kidney transplantation 2020 strategy**

L Burnapp presented an update on the progress made with the living donor kidney transplantation 2020 strategy.

Since the beginning of 2017/18 there have been 88 living donor transplants per month which is below the projected activity of 114 living donor transplants. The results taken from the latest activity report show a variation in LD pmp rates across regions within England and between UK countries.

The 2020 oversight group met in January 2018 to identify ways to increase living donor kidney transplant activity across all four UK countries. The LDKT 2020 Strategy Implementation Group (SIG) has included the outcomes of the meeting in the action plans for 2018/19 and ensured that they were aligned with the APPKG manifesto, which was published later in January.

A UK Living Kidney Donation Network was established in Scotland in 2016. In 2017 this was extended across the UK, with an identified nephrologist in every transplant and referring centre to add to the existing network of transplant surgeons and living donor coordinators.

A list of useful resources is circulated to the network quarterly including links to recipient and donor information. Any additional information members feel should be shared, can be added to this list. All reports are available on the ODT website and, the Living Donation area on the website is in the progress of being updated. L Burnapp expressed thanks to Matthew Robb, Senior Statistician within NHSBT for producing a Living Donor Policy for LDKT which recently went live.

The LDKT 2020 SIG identified a short fixed term work stream for patient and public engagement. An interactive workshop including key charities met for the first time at the beginning of July to identify some key priorities, which will be embedded in the SIG action plans. LDKT promotional resources are now available on the promoting donation hub, including resources from the LTI, and educational resources are regularly updated and extended to include relevant information.

A donor reported outcome measure tool will be disseminated to all centres this year alongside the requests for annual clinical data for the UK Living Donor Registry. A tool to measure donor experience will be developed this year. An online expression of interest form for non-directed altruistic donors has been developed and will be launched with the new corporate website.

A UK wide workshop for the UK Living Kidney Sharing Scheme was held in October 2017. This included representation from all units to consider current issues and how these can be addressed. The actions and outcomes identified

were approved by KAG in December and implementation will be completed by July.

ACTION

NHSBT are involved in a European project which is being led by the European Union. This project is considering potential international collaboration in kidney sharing schemes across European countries.

The question was raised as to whether historical data are available on donor reported outcome measures. L Burnapp advised the reported outcome measure that has been developed will collect prospective information from previous donors who attend for follow-up, regardless of their year of donation.

K Modi requested the names and contact details of the Clinical Lead Nephrologists for LDKT in all transplant centres and referring units to allow communication between the Kidney Patients' Association, Nephrologists and Coordinators. L Burnapp advised that the network has been contacted to gain permission to share contact information. Once all responses are received, this information will be made available.

7 Review of developments in policies

C Watson advised the policy for accepting donors with a positive virology such as hepatitis B, C or HIV may change as recipient centres will opt in to receive those donors.

8 Issue of large numbers suspended from the transplant list – KPG(18)3

A paper was presented at KAG which made the request for transplant centres to review their centre's suspended list to identify if patients who had become unfit for transplantation should have been removed from the national waiting list rather than simply suspended. Following that, there has been a slight decrease in numbers, however there are still a large number of patients on the suspended list.

There is a wide variation in the proportion of patients that are suspended at each transplant unit. At Manchester, more than 54% are suspended from the waiting list compared to 26% at Plymouth. Some centres have a practice of registering patients on the transplant list as suspended while getting worked up for a transplant and then only activate the patient once the patient is ready for transplant. A large proportion of patients are being suspended due to their condition deteriorating or NHSBT not being notified of the patient's death. Centres have been asked to check the suspended list on a regular basis and to notify NHSBT.

C Watson requested that to make the data clear, to consider removing patients listed prior to activation and to consider including some retrospective data with this adjustment to inform trend analysis.

L Mumford

C Watson confirmed if a patient is listed and suspended immediately, this would not count towards waiting time points, therefore there is no benefit to being listed and suspended, it is purely a way of centres working. F Loud highlighted patients may not be aware they are listed as suspended and assume they have been listed on the active waiting list. C Watson suggested that the patient groups advise patients to enquire if they are on the active waiting list at the time of listing. L Mumford added there will be a future project investigating causes of death related to suspended patients which links in with the Hospital Episode statistics (HES) data.

This information will be taken back to KAG for further discussion regarding the variation in the way centres work across the country and to try and identify an optimum way of working.

ACTION

K Modi asked if it is possible to incorporate the suspended figures in the main data shown for active patients which is reported in the latest statistics relating to organ donation and transplantation. Members felt a unified figure is possible, however the figures which are currently reported separately is more accessible. L Mumford confirmed the suspended figure is included in the kidney annual report.

P Ormandy asked if a pre- activation or pre- work up phase has been considered as a separate category. C Watson advised transplant centres have individual ways of working and often have a local work up list in centre. C Watson stated that he thought we should work towards patients only being able to join the active waiting list, rather than being listed as suspended first.

9 Progress with the new Kidney Offering Scheme

The Kidney Offering Scheme was presented and discussed at the last KPG. Since then, the new scheme has been out for consultation and wide presentation at BTS, RTSM and through KAG.

9.1 Working towards a new Kidney Offering Scheme

L Mumford presented an update of the Kidney Offering Scheme.

The new scheme has moved towards longevity matching which will better match kidneys to recipients. HLA matching will be better tailored by age. Geographical equity of access has been considered to help ensure no matter where a patient is registered, patients will have equal access to receive a kidney. The new scheme will help tackle long waiting times. Patients will receive waiting time from the start of their dialysis date. It was agreed as part of the new scheme that age should be a continuous factor.

From the suggestions made, 29 simulations were produced using real data. The simulations used in the past helped predict a very accurate outcome. The new scheme will consist of a two-tiered system tier A and tier B. Tier A are patients who are extremely difficult to match. All other patients will be allocated in Tier B. From the changes made to the scheme, BAME patients waiting time will be in line with white patients.

Final sign off was received at KAG in June and the new scheme will be implemented in January 2019.

A FAQs is in development. L Mumford will forward the draft questions available and requested any FAQs the group feel should be added to forward these to L Mumford.

**L Mumford
Patient Reps**

The question was raised who will be at a disadvantage by the development of the new scheme. L Mumford advised the scheme has been developed to be more equitable, but older patients may have to wait slightly longer. C Watson confirmed L Mumford modelled a simulation which reduced waiting time to transplant older patients, however this raised the transplant waiting times for children and younger adults. KPG members felt the reasons for developing the scheme and the impact this will have on certain patient groups should be available. L Burnapp added

increased conversations are essential to allow older patients the decision to wait for a living donor transplant.

ACTION

J Forsythe asked L Mumford what could be tweaked in this new scheme to improve waiting times for older patients. L Mumford recently attended a Transplantation Society congress where this was discussed and highlighted that it was believed that rejection rates in older patients would be less, however potentially poorer matches in older patients with poorer quality kidneys may not produce such a good outcome. This will be analysed using NHSBT data and depending on the outcome, this may suggest an adjustment of the HLA/age equation; the possibility of giving extra points to elderly patients could be another option.

9.2 Kidney Offering Scheme Documents – KPG(18)4

A paper was received provided a summary outlining the key objectives and proposed offering scheme.

10 What would the Kidney Patient Support Group like the Kidney Advisory Group to do?

C Watson confirmed the actions and items raised at the Kidney Patient Group meeting are discussed at the Kidney Advisory Group meeting.

11 Any Other Business

• **Transplant Centre Profiles – KPG(18)5**

NHSBT are keen to introduce information on Organ Donation and Transplantation that is more accessible to the public. J Forsythe requested feedback from KPG members on this newly developed infographic.

The following suggestions were made;

- Consider listing the number per million population.
- Incorporate text explaining the number of donor transplants comparison with the national figure.
- Indicate the average waiting times for both local and national data.
- Include the average life span of the kidney transplant.
- Use absolute numbers instead and consider using percentages in brackets as percentages are more difficult to interpret.

A request was made if possible for Statistics and Clinical Studies to encourage other health professionals when presenting to use the most current data available.

Date of next meeting

Thursday 18th July 2019 - London.