

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

**MINUTES OF THE EIGHTEENTH MEETING OF THE
KIDNEY PATIENT GROUP
HELD ON TUESDAY 4th JULY 2017
AT CITADINES HOLBORN/COVENT GARDEN
94-99 HIGH HOLBORN, LONDON**

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)
Peter Dutey-Magni	Population Policy and Practice Programme (UCL)
John Forsythe	Associate Medical Director (NHSBT)
Ruth Gilbert	Population Policy and Practice Programme (UCL)
Patricia Gooden	Kidney Research UK
Tess Harris	Polycystic Kidney Disease Charity
Fiona Loud	Kidney Care UK
Julia Mackisack	Lay Member, KAG
Lisa Mumford	Statistics & Clinical Studies (NHSBT)
Kirit Modi	National Kidney Federation/NBTA
Gavin Pettigrew	Addenbrooke's Hospital, Cambridge (attended PM)
Adnan Sharif	NBTA Representative
Jan Shorrock	Give a Kidney
Timothy Statham OBE	National Kidney Federation
Billy Stephens	Kidney Wales Foundation
Peter Storey	Kidney Research UK
Dominic Summers	Addenbrooke's Hospital, Cambridge
Mike Thompson	Communications (NHSBT)
Roy Thomas	Kidney Wales Foundation
Amanda Walduck	Kids Kidney Research
Sinead Wright	External Affairs Manager (NHSBT)

In Attendance:

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

Michael Abbott, Gloucestershire Kidney Patients' Association
 Debbie Adams, Kidney Patient Association (West Midlands)
 Yvette Bell, Kidney Research UK
 Chris Callaghan, National Clinical Lead for Organ Utilisation (Abdominal)
 John Champion, Six Counties Kidney Patient Association
 Jan Cooper, Kidney Research UK Trustee
 Sandra Currie, Kidney Research UK
 Elaine Davies, Kidney Research UK
 Sarah Harwood, Kidney Research UK
 Nicki James, Kidney Research UK
 Sarbjit Johal, British Renal Society
 Ewen Maclean, Scottish Kidney Federation
 Kathleen Preston, Lay Member, KAG

Rob Ryckborst, Kidney Patient Association – West Midlands
Richard Trompeter, Great Ormond Street Hospital

No feedback received from:

Danielle Angell, Kidney Wales Foundation
Nick Flint, KPA, West Midlands
Daniel Howarth, Diabetes UK
Surinder Jandu, NHSBT / British Renal Society representative
Betty Jennings, Secretary of Northern Ireland Kidney Research Fund
William Johnston, NIKPA – Northern Ireland Kidney Patient Association
Kevin Mashford, Transplant Association
Helen Lewis, Independent Researcher
Simon Lloyd, Six Counties Patient Association
Kieran Mullan, Patient Association
Kerriane O'Rourke, Diabetes UK
Emma Osbourne, Transplant Association
Patrick Tabor, British Kidney Patient Association
Melanie Wager, Kidney Wales Foundation
Tony Weaver
Robert Wiggins, Give a Kidney

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 – KPG(M)(16)1 and Action Points KPG(AP)(17)1

The previous minutes were agreed as a true and correct record. All actions completed or included on the agenda.

3 Medical Director's Report

J Forsythe updated the group regarding ongoing projects within NHSBT.

Organ allocation policies are under review. The Kidney Offering Scheme project is on-going, and the heart and lung allocation policy review has recently started. A new liver allocation scheme will begin at the end of 2017.

ODT Clinical website has undergone a significant change, this is to enable data and shared learning events to become more accessible. There have been initial teething problems, this is now up and running.

A Donor Characterisation review is taking place to look at current processes for donor characterisation, particularly for microbiology and tissue typing. Commissioning for this is complex due to certain areas which are funded by different commissioners. NHS England is aware that the proposed tariff may not cover the cost of this, however recognise NHSBT are keen to move this forward.

J Forsythe launched an Organ Utilisation Strategy at the British Transplantation Society which incorporated Clinicians around the country. The aim is to increase organ donor numbers and to ensure utilisation across units is the same. The consensus is to challenge why an organ has not been used in a centre. Organ utilisation is coming into focus not only in the UK but across Europe and USA.

F Loud asked if NHSBT have a statement explaining the use of patient data to

ACTION

ensure data collected is used in the appropriate way. J Forsythe agreed this is a priority and confirmed all data gathered is with patient consent.

F Loud would like to ensure data regarding patient consent is passed onto the British Renal Registry. L Mumford confirmed a document will be published on the ODT website, informing patients on how their data is used in current and future research projects.

K Modi asked regarding presumed consent in light of announcement that Scotland are to pursue this, following on from Wales. R Thomas feels more could be done within NHSBT to encourage the Government to adopt this idea in England.

4 **Informing Waiting list patients of organ offers – a pilot proposal**

J Forsythe presented on behalf of Chris Callaghan who is the National Clinical Lead for Organ Utilisation, a proposal and would like to gather views from the meeting, on patient involvement when a centre declines an organ offered.

Things to consider from the presentation are;

- Should the patient at the time of listing be asked if they would like to be informed of all organ offers at the time of offer?
- Should it become compulsory for centres to inform patients of all organs offered?

There followed a lengthy discussion about the pros and cons of patient involvement but the balance of opinion was that there should be patient participation in taking this forward.

J Forsythe requested attendees of the meeting take this proposal back to patient representatives and to let the Chairs of KPG know their thoughts regarding this proposal.

Patient Reps

D Marshall will send an email requesting feedback and cc S Tomkings in to collate this information. S Tomkings to circulate the presentation.

**D Marshall/
S Tomkings**

The proposal will be taken forward in Autumn 2017.

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

C Brown presented slides on organ donation and transplant activity over last financial year.

The presentation included;

- Organ donors have increased as have deceased donor transplants
- DBD & DCD donors have increased and are at their highest
- Living donors have slightly decreased
- Number of patients on the Kidney Transplant waiting list has decreased
- A small decrease in suspended patients in the last financial year
- Adult only DCD kidney transplants have increased. DBD kidney transplant have remained stable with a slight increase.
- UK is 3rd in living donor transplant rate across Europe, which has improved.
- 829 days is the median waiting time to receive a deceased donor kidney

K Modi asked as part of the ambitions for the 2020 strategy, there are 4 strategic targets which relates to deceased donation. A slight increase has been noted in consent and organ utilisation, transplant numbers and organ donations. The

ACTION

question was asked if at this stage this is where Organ Donation wanted to be. J Forsythe confirmed that there has been an increase in transplant and donor numbers which is a great accomplishment. Consent rates are currently at 62.7% and this is increasing yearly.

The Royal Free Hospital is holding an event to encourage the African Caribbean community to register to become an organ donor. A similar event has been held by NHSBT that is aimed at the Muslim community. L Mumford advised that a supplementary BAME report will be published on the ODT website.

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

L Burnapp presented an update on the implementation of the living donor kidney transplantation 2020 (LDKT 2020) strategy, including progress to plan and priorities for the coming year.

Members of the meeting supported the proposal to identify a Clinical Lead Nephrologist for LDKT in all transplant centres and referring units to work alongside surgical and specialist nurse leads. This has been endorsed by the British Transplantation Society and Renal Association and the network is currently being established. L Burnapp advised that a workshop will take place in October 2017 to implement further developments within the Living Kidney Sharing Schemes which will provide an opportunity for colleagues to network.

A series of short films (Let's Talk About....) covering all aspects of living kidney donation has recently been launched to add to the portfolio of information available for donors and recipients. The films are designed to encourage the conversation about LDKT between patients and their All these resources can be accessed via the following link: <https://www.organdonation.nhs.uk/about-donation/living-donation/>

F Loud advised KQUIP (Kidney Quality Improvement Partnership) will be holding local and regional meetings to bring together a range of medical and multi-disciplinary colleagues to discuss and plan further collaborative projects within UK Renal Registry, NHSBT and Public Health England.

7 **Express patient concern regarding Living Donor Donation numbers which have fallen for three successive years despite NHSBT target – KPG(17)5**

L Burnapp's presentation regarding living donor donation, confirmed donation numbers are declining. T Statham produced a paper which has been distributed to centres asking for responses on how to increase living donation numbers.

Attendees requested this paper is circulated to Kidney Advisory Group members.

Once responses are gathered, the wider perspective will be reviewed and a summit will be held in the House of Commons, to enable discussion with MPs regarding what requirements are needed and if there is a necessity for legislation to be changed.

S Tomkings

8 **NBTA's Living Donor Transplant Initiative –KPG(17)2**

A paper was received summarising the five projects which are taking place within NBTA.

A specific project is taking place within NBTA to increase the number of Living Kidney Transplants amongst the BAME community by targeting specific religions.

ACTION

K Modi, Chair of NBTA, would like the collection of religion on the National Transplant Database to be considered. At present no data on religion is collected due to data protection. L Mumford to liaise with Information Governance and take this forward.

L Mumford

9 Review of developments in policies

C Watson advised members that policies are published on the ODT website which are updated regularly.

A new policy regarding simultaneous Liver and Kidney transplantation was now available on the website for review.

10 PITHIA Trial

Dominic Summers presented slides regarding the National Histopathology Service for Transplantation (The PITHIA Trial).

This trial focuses on pre-implantation biopsies being taken to ensure the quality of kidneys being transplanted. Historic biopsies have shown biopsy scores, which can predict what may happen to the kidney and how it will perform.

The aim of the study was to evaluate prospectively the utility of having access to rapid histology prior to implantation.

A launch event will take place on 3rd October 2017; invitations for this event will be forwarded to all kidney organisations.

Each centre will be visited to inform patients and educate Clinicians of the trial which will be rolling out October 2017, with an end date of October 2020. Clinician's will require ongoing training which will take place in 22 transplant centres across the UK.

P Storey raised concern regarding the impact to a kidney once the biopsy has been taken and the increased cold ischemic time. D Summers advised pre-emptive biopsies have been taken and the risk of damage to a kidney is low. Increased cold ischemic time is a concern, however there are 6 centres which are geographically dispersed and which will provide the necessary service for processing the biopsies; the biopsy will be done at the donor hospital and transferred to the processing centre while the kidney is being transported to its destination, preventing delay.

11 Issue of large numbers suspended from the transplant list -KPG(17)3

L Mumford presented a paper showing data obtained from the UK Transplant Registry from 31 March 2008 to 31 March 2017.

This data has identified a reduction around 28% in the kidney only waiting list, however shows an increase in suspended patient waiting list over the same period, up to 2015/16, with a small fall in the last 12 months.

As there is a wide variation across the UK regarding suspended patients, NHSBT wrote to centres asking if there were any patients listed on the suspended list that shouldn't be, this resulted in a slight decrease in patients on this list, therefore letters will continue to be sent to centres ensuring numbers are always reviewed.

ACTION

J Forsythe advised, there has been a big drive by clinicians to improve this, this may be part of the reason numbers have decreased.

J Forsythe confirmed Roberto Cacciola has been involved with looking at suspended patient data and J Forsythe is keen to await the outcome of this. If required, J Forsythe will write to all units regarding suspended patient numbers and in particular, identify units which have high numbers on the suspended list.

R Thomas queried why a patient has to come off the waiting list if a patient is not in the country. C Watson advised if a patient chooses to travel far, it would be difficult to get a patient back in time for a transplant, however the patient could advise their co-ordinator of this. Being suspended for holidays does not result in loss of waiting time points.

L Mumford confirmed that the active list is published on the ODT website and a total waiting list is also published.

R Thomas asked who determined the rule that patients should be 6 months before going on dialysis before they could join the transplant waiting list. T Statham added that it is known that the results of a transplant done before dialysis are better than one done after starting dialysis. C Watson explained that there had been a lot of discussion regarding this. It is unfair to patients already on dialysis to prioritise pre-dialysis patients. In addition it is often not the fault of the patient that they have not been listed before starting dialysis – some patients “crash land” on a renal unit and require immediate dialysis without previous medical consultation. J Forsythe noted that a lot of work was done on this in 2006, highlighting differences in pre-emptive listing rates and these rates are still reported openly. Having a 6 month restriction was felt to be fair by the patients at that time. L Burnapp advised this is why patients are encouraged to consider a living donor transplant.

12 Progress with the new Kidney Offering Scheme

The current kidney allocation scheme has worked well and effectively, however a number of issues need to be reviewed.

The new scheme design aims to better identify the best kidney for a given recipient, and hopefully will reduce the number of declined offers

The scheme would take into account anticipated survival on the waiting list with the aim to try and ensure patients get appropriate offers in a timely manner,

The current offering scheme does not cater well for patients who have unusual tissue types and who are difficult to match. This is being reviewed as there may be certain ways that the scheme can be adjusted to help improve this.

12.1 Working towards a new Kidney Offering Scheme – matching donor and recipient more effectively

L Mumford presented slides showing the work which is taking place in the new Kidney Offering Scheme.

12.2 Update from Kidney Offering Scheme -KPG(17)4

From this paper, L Mumford talked through the 5 simulations and advised there is a further meeting taking place in July, after this, it is intended that future meetings will be open to include wider representation.

ACTION

R Thomas feels paediatric patients are not sufficiently considered in the scheme. C Watson said the aim was to manage a child throughout his life on renal replacement, to make sure he/she got the best kidney to ensure it would give the longest function but also not result in delays to getting a second transplant when that was required. The scheme was also looking at inequities around the transition at 18, from greatest priority to no priority if a patient joined the list aged 18 and one day. As part of this review, members of the group developing the scheme would like to ensure there is a smooth transition from paediatric priority to young patients awaiting a kidney.

R Thomas would like to see previous data showing paediatric waiting times. L Mumford will forward this.

L Mumford

13 Renal transplant data and welfare benefits data project

Professor Ruth Gilbert from University College, London, presented a welfare benefits data project.

The aim of the project is to look at the impact of renal transplant on the ability to return to work.

Data will be collected using unconsented none patient identifiable data, transferred to department of health and then UCL. Patients can opt out of this project.

The project will hope to benefit patients by improving the ability to work or return to work after a transplant. Data may indicate some centres are supporting patients in a better way. This data will only include people who have had a welfare benefit.

This project is not being commissioned, however Economic Research Council are enabling this, to encourage using administrative data in a more constructive way.

C Watson added it would be interesting to look at kidney donors in the same analysis. R Gilbert hasn't requested data from donors, however agrees this may be something to work towards. Concern was raised if information collated could be against patients, resulting in them losing benefits. R Gilbert confirmed it will not be individually identifiable.

S Tomkings to circulate slides.

S Tomkings

14 What would the Kidney Patient Group like the Kidney Advisory Group to do

C Watson asked the Kidney Patient Group if there is anything they would like to suggest the Kidney Advisory Group could improve. Members feel the ongoing projects and updates at the Patient Groups are valuable.

15 Any other business

It was queried if the public, when donating blood, are made aware of becoming an organ donor. It was confirmed this conversation takes place and L Burnapp advised a pilot is taking place across 10 static blood centres, where leaflets are available to raise awareness in becoming an organ donor. M Thompson added NHSBT communications team is looking to email all blood donors regarding organ donation.

Members feel it could be beneficial to have a glossary of terms for patients who are new to the Kidney Patient Group meeting. C Watson agreed, and would like to

ACTION

encourage people to ask if unsure on acronyms.

Date of next meeting:

Thursday 5th July 2018 venue tbc.