NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

MINUTES OF THE NIGHTEENTH MEETING OF THE
KIDNEY PATIENT GROUP
HELD ON THURSDAY 18th JULY 2019
AT THE ROYAL COLLEGE OF ANAESTHETISTS
CHURCHILL HOUSE, 35 RED LION SQUARE, LONDON WC1R 4SG

PRESENT:

Chris Watson	Chair of NHSBT Kidney Advisory Group – **Co-Chair**
Lisa Burnapp	Lead Nurse for Living Donation, NHSBT
David Coyle	Kidney Patient Involvement Network
John Forsythe	Associate Medical Director, NHSBT
Tess Harris	Polycystic Disease Charity
Fiona Loud	British Kidney Patient Association
Kirit Modi	National Kidney Federation
Matthew Robb	Statistics & Clinical Studies, NHSBT
Rob Ryckborst	Kidney Patient Association, West Midlands
Charlotte Silver	Senior Communications Officer, NHSBT
Maria Tennant	Kidney Research UK
Douglas Twenefour	Diabetes UK
Robert Wiggins	Give a Kidney Charity

In Attendance:

Sam Tomkings	Clinical & Support Services, ODT (NHSBT)

ACTION

Apologies:
Andrea Brown, National Kidney Federation
Chris Callaghan, National Lead for Organ Utilisation (Abdominal)
Helen Lewis, Independent Researcher
Julia Mackisack, Lay Member
David Marshall, Co Chair
Maggie Pratt-Heaton, Six Counties Patients' Association
Kathleen Preston, Lay Member
Adnan Sharif, NBTA Representative

1 Welcome and Introduction

C Watson welcomed everyone to the meeting and thanked them for coming. Introductions were completed.

2 Approval of minutes of previous meeting – KPG(M)(18)1 and Action Points KPG(AP)(19)1

The previous minutes were agreed as a true and correct record. Actions with a verbal report are listed below;

AP2 – There have been two meetings for the All Parliamentary Kidney Group. There is ongoing work within this group which is focusing on areas such as the BAME strategy and living donation. K Modi advised a follow up meeting was held to discuss the BAME strategy and has since received a letter from the MP which has been circulated to the group.

ACTION

3 Medical Director's Report

J Forsythe provided an update on the current developments taking place within NHSBT.

NHSBT has introduced a board policy regarding lack of resource for transplantation. Part of this policy will include if a kidney offer is made for a named patient and declined solely due to lack of resource. NHSBT feels that the patient should be informed of the declined offer. Departments of Health and Commissioners have been made aware of the development which is to be implemented in the next three months. It was agreed that it would be useful to have a set of words provided to patients to inform them of what this means, and perhaps a template of action open to the patient but this latter needs to come from patient representatives, not ODT.

Discussion took place regarding how this information would be communicated to patients who are already on the waiting list, the suggestion was made for centres to write to the patients who are already listed. It was agreed for future patients who will be listed, that this will be part of the discussion between the patient and the Recipient Coordinator.

J Forsythe stated this will only apply to deceased donation as clearly the patient knows of a postponement in living donor transplantation.

The suggestion was made to make the local Organ Donation Committee aware of this plan. **J Forsythe**

The legislation for Opt-out has been implemented since 1st July in Jersey. In England, it will take effect in Spring 2020 and thereafter will take effect in Scotland. The statistics team have created models of low medium and high prediction levels associated with Opt-out and have provided the information to Commissioners to allow them to plan for the need for an increase in resources. Without new technologies such as machine perfusion and NRP, the publicised increase in numbers of transplants will not be achieved.

NHSBT have commenced work on the post 2020 strategy and as part of the development will request assistance from the patient groups. C Silver added this will be discussed at the Organ Donation Forum taking place on 14th August.

In the past, Hepatitis C has been a virus which has been difficult to treat. With the advent of new medications collectively termed direct acting antivirals (DAA) it is possible to transplant HCV positive organs into HCV negative recipients with treatment afterwards; it is important that the patient has been properly consented. The use of DAA for this purpose has been agreed in Wales and Scotland but there is an indication that this will be agreed in Northern Ireland. NHS England had indicated that a decision will not be provided until the next calendar year but it is hoped that the decision could be expedited. The Kidney Patient Group discussed if there is a possibility for a decision from NHS England to be provided sooner.

4 Latest Statistics relating to Organ Donation and Transplantation

M Robb provided the latest statistics for Organ Donation and Transplantation.

The transplant waiting list across organs show a decrease in the past 10 years with a slight increase in the last financial year, with 6077 currently on the waiting list. There has been variation in living donation over the past 10 years but DBD and

ACTION

DCD donors have increased.

The number of organs transplanted from DBD donors show 82% and 82% were transplanted from DCD kidney donors.

The active kidney transplant list has slightly decreased over the past 10 years with 4954 patients at the end of the financial year. Suspended patients over the last 10 years have increased but in the last 4 years there has been a slight decrease. 16% of patients being suspended before activation.

The number of antibody and incompatible transplants have decreased over the last 10 years, and the use of the sharing scheme has increased.

The 5 year graft survival rate by transplant shows for living donors unrelated or related have the highest graft survival rate between 91.8%-93.6%, compared to deceased donors

The centre specific monitoring data has been sent to centres for checking and will be published at the end of the month.

The median average waiting time to transplant from 1 April 2013 – 31 March 2016 show some variation across centres with the average overall being 674 days.

There are no outlying centres with poor survival rates. The 10 year patient survival after listing for a kidney transplant on average is 75% with some outlying centres. M Robb added this data is over a wide time period and therefore if there is a change over the last year, this would not be reflected in this data. The form return rate can contribute to this data. Some data is available from the national register to look at death in patients.

The cause for the slight increase in deceased donors but slightly fewer transplants is not known, however the utlisation by organ type shows the number of kidney transplants has risen commensurate with the number of donors, although this is not the same across all organs.

The question was asked how well it works challenging outlying centres. C Watson advised the biggest changes came when data started to be published identifying centres. Pursuing outlying centres had prompted visits to some centres which responded by changing their practices. Raised after the Liver Patient Group meeting was to consider writing to each centre requesting their response to their results, therefore a generic paragraph could be created for kidney centres.

It was asked whether Getting It Right First Time (GIRFT) has impacted organ transplantation. J Forsythe advised it has not but L Burnapp highlighted that discussions have taken place regarding the length of pathway for living donor transplantation and pre-emptive listing.

It is anticipated on behalf of the Quality Surveyance Team as part of NHS England will run another peer review across transplanting and non-transplanting centres which will look at the pathway to renal replacement including decisions for the choice of treatment and when those decisions are made.

K Modi suggested reviewing the content of the latest statistics on kidney donation and transplantation and consider including things such as Opt-out and the new kidney offering scheme. Another suggestion made was to include more detail of the suspended patients on the list in the annual report.

M Robb

M Robb

5 Update on living donor kidney transplantation 2020 strategy

L Burnapp presented an update on the Living Donor Kidney Transplantation 2020 strategy from 2018.

ACTION

There has been a slight reduction in activity in the past year but, overall, it has plateaued over the past 3 years. Last year saw an increase in pre-emptive transplants, however this year has fallen, particularly for children.

There has been a 15% increase in activity for the UK Living Sharing Scheme (UKLSS). 64 non-directed actual donations have taken place 'in -year', which suggests an apparent dramatic drop in activity. However, this may under represent the total number of donors who are ready for donation due to clustering around the quarterly matching runs. L Burnapp confirmed that in April there were 25 non directed donors included in the matching run. In previous years, many would have donated 'in-year' instead of being deferred to the next matching run. L Burnapp advised the number of transplants non-directed living donors have facilitated can be found in the kidney specific report which will be available this month online.

The biggest change made to the UKLSS is registering as a default all the non-directed donors which has been successful. The aim is to create longer chains. Donors will still donate directly to the transplant list if there is a suitable highly sensitised, long waiting patient. Overall the number of patients and matched pairs have increased.

Every 6 months an update from the UKLSS is provided to KAG which shows centre specific -activity and non-proceeding/delayed transplants and centre variation. This allows individual centres to identify areas for improvement.

The UKLSS is exploring options for international collaboration to allow patients from another country to be included in our scheme to facilitate transplantation.

The donor reported outcome measure has been initiated and rolled out in January 2019 and the aim is for the donor reported experience measure to be added to this in January 2020.

From next year, deceased and living donor transplantation will be combined in the 2025 strategy, which is currently under development.

The question was asked if the UKLSS would go beyond Euro Transplant.
L Burnapp explained it would be a challenge to be part of a global collaboration but the network NHSBT is contributing to is called the ENKEP project which is a European funded collaboration looking at the potential for a transnational collaboration for kidney exchange programmes within Europe. The proposal is that a fix term working group will produce some statistical modelling between the Netherlands and the UK as the schemes are similar. Three other countries have approached the UKLSS to explore the possibility to omit a pair through the scheme, and as a result this has opened opportunity for UK patients. For this, a memorandum of practicalities and understanding between countries would have to be developed. Members agreed a larger pool of donors will enable more and better matched transplants.

The question was raised whether there is a predicted effect on living donation associated with the change in the legislation to an opt-out system. L Burnapp highlighted this is an important point and encouraged members to keep up the awareness of living donation, given that there may be a perception that living organ donation would not be required if opt-out generates more deceased donor organs

ACTION

for transplant.

F Loud asked if the capacity issues are being captured in the same way as deceased donation. L Burnapp confirmed that every non proceeding transplant in the UKLKSS is highlighted and if it is an incident it is reported via ODT online. Give a Kidney charity will report any concerns raised to them from non-directed altruistic kidney donors to L Burnapp which is helpful in addressing improvements that need to be made.

The suggestion was made to include another years data within the report to Kidney Patient Group (KPG). **L Burnapp / M Robb**

6 Development of a BAME strategy on organ donation: post 2020 – KPG(19)3

K Modi informed members that a conference will take place on 16th October 2019 co-hosted by NHSBT and NBTA focusing on BAME issues in relation to the new strategy.

K Modi drew members attention to several documents available focusing on BAME and a letter received from the MP. The Minister supported the requirement for BAME to be a part of the strategy. K Modi requested that the Kidney Advisory Group (KAG) consider access to transplant for BAME and low socioeconomic groups. C Watson stated that equity of access was a priority for KAG already and agreed and the ATTOM study did highlight the factors involved in poor access; the results of this study had been presented to all kidney centres. **C Watson**

7 Kidney declines

Half of standard criteria kidneys are declined by a centre but go on to be transplanted at another centre. To understand the reasons for this, C Watson informed members of the two initiatives which have been put in place. Every centre will receive a summary of the kidney offers which have been declined. Approximately 36 letters have been sent to 21 centres requesting the reason why the kidney offer had been turned down. Some offers will have been declined due to logistical reasons and therefore NHSBT will write to the Medical Director for that centre.

C Watson was asked who makes the decision to decline the offer. Members were advised that in some centres offers to via a Recipient Coordinator and for some centres the offer goes direct to the surgeon; the decision to transplant is usually made by the surgeon who may discuss this with the on call nephrologist or another colleague.

Another initiative taking place in London is if a centre does not have capacity, that centre can consider sending the patient and organ to another centre as part of a reciprocal agreement. Oxford and Coventry work collaboratively to provide cover at weekend of which patients were very supportive. Members encourage collaborative working and will feed this back to their patient groups. L Burnapp will suggest raising this at the British Transplantation Society (BTS) to discuss as part of the system and organisations of care. **L Burnapp**

8 Kidney Patient Involvement Network

D Coyle presented an overview of the Kidney Patient Involvement Network which is a network of charities and individuals committed to quality public involvement and engagement who are willing to work together collaboratively on initiatives to improve standards and develop patient leaders of the future.

		ACTION
	The aims are to increase the impact of patient and carer voices through meaningful involvement and to provide practical examples from strategic framework. The network would like more service and research organisations to help provide a consistent approach with involvement of patients at different levels.	
	The network is developing a research library and plans to incorporate practical ''how to guides'', training and education of patients and in some cases chairs of committees, expanding the network and benchmarking.	
	C Silver informed D Coyle of the organisation Donation Forum which the network may find useful.	
9	**New Kidney Offering Scheme update** The provisional go live date for the Kidney and Pancreas offering schemes is 3rd September 2019.	
9.1	**Kidney Allocation Policy – KPG(19)1** Members received the Kidney Allocation Policy which has been reviewed.	
9.2	**Patient Communications – KPG(19)2a & KPG(19)2b** A summary of the key principals of the Kidney Offering Scheme and FAQs was circulated. M Robb requested members feedback their comments.	**All Reps**
	Lisa Mumford is looking to produce a set of short animated cartoons providing information to patients on the Kidney Offering Scheme.	
	Members asked how the information will be disseminated and how patients currently on the waiting list and new patients will be informed of the new scheme. The suggestion was made to consider adding information into the Kidney Care and National Kidney Federation (NKF) magazine and consider making the information more user friendly.	**M Robb**
	L Burnapp suggested disseminating the information through Recipient Coordinators and renal units.	
10	**Transport services for dialysis patients** R Ryckborst raised concerns regarding the transport services for dialysis patients resulting in some patients not being collected and missing their appointments.	
	The question was asked if there is a similar pattern across the country which members confirmed there is. F Loud highlighted a piece of work that had taken place within the Renal Association who developed a range of recommendations regarding transport which was sent to NHS England. F Loud will send this work to S Tomkings for circulation to KPG.	**F Loud / S Tomkings**
	K Modi advised of a project taking place within Devon CCG involving patients who arrange their transport with funds provided.	
11	**What would the Kidney Patient Support Group like the Kidney Advisory Group to do?** F Loud requested inviting a member from NHSBT to attend a Renal Registry patient council meeting to discuss the use of collaborative data within UK Renal Registry and NHSBT. M Robb volunteered to attend a meeting.	**M Robb**

ACTION

12 Any Other Business

Give a Kidney would like to work more closely with other charitable organisations to raise awareness of non-directed living kidney donation. Lines are becoming blurred between non-directed and directed kidney donation and where Give a Kidney can support the different types of donation and whether the charity could make a bigger impact.

T Harris queried why the data by renal diagnosis is not available from NHSBT as this data is collected on the renal registry. M Robb advised a proportion of the data does not get reported or is unknown but what is available could be added to the next statistical report. **M Robb**

Date of next meeting

TBC