To be ratified **KAG(M)(17)2**

NHS BLOOD AND TRANSPLANT

MINUTES OF THE THIRTY-SECOND MEETING OF THE KIDNEY ADVISORY GROUP HELD AT 10.30 A.M. ON THURSDAY 30th NOVEMBER 2017 AT ODT, STOKE GIFFORD, BRISTOL

PRESENT:

Prof Christopher Watson	**Chair**
Ms Lorna Marson	BTS Representative and Deputy Chair
Mr John Asher	Medical Health Informatics Lead & rep for Glasgow & Edinburgh (deputy)
Dr Richard Baker	Renal Clinical Reference Group
Mr Simon Boyes	Representative for Cambridge & Sheffield
Mr Jeremy Brown	Specialist Nurse – Organ Donation Representative (deputy)
Mr Tim Brown	Northern Ireland Representative
Ms Lisa Burnapp	Lead Nurse for Living Donation, NHSBT
Mr Chris Callaghan	National Clinical Lead for Organ Utilisation (Abdominal)
Mr John Casey	Chair of Pancreas Advisory Group
Mr Frank Dor	Representative for Oxford and WLRTC
Dr Jan Dudley	Representative for KAG Paediatric Sub Group (deputy)
Ms Anusha Edwards	Representative for Bristol & Cardiff
Prof John Forsythe	Associate Medical Director, ODT
Prof Susan Fuggle	Scientific Advisor, NHSBT
Mr Paul Gibbs	Representative for Plymouth & Portsmouth
Mr Jon Gulliver	NHS England (Specialist Commissioning) Representative
Dr Rachel Hilton	Representative for Guys' & St Georges
Mr Nick Inston	Representative for Birmingham & Coventry
Mrs Rachel Johnson	Assistant Director Statistics & Clinical Studies, NHSBT
Dr Gareth Jones	Representative for Royal Free & Royal London
Dr Philip Mason	Renal Association / Renal Registry
Ms Lisa Mumford	Statistics & Clinical Studies, NHSBT
Mr Gavin Pettigrew	Representative for PITHIA Trial
Mrs Kathleen Preston	Lay Member
Dr Matthew Robb	Statistic & Clinical Studies, NHSBT
Ms Angie Scales	Lead Nurse: Paediatric and Neonatal Donation and Transplantation, NHSBT
Ms Clare Snelgrove	Recipient Co-ordinator Representative

IN ATTENDANCE:

Dr Milos Adamec	Observer from Czech Republic (observer)
Dr Premsyl Fryda	Observer from Czech Republic (observer)
Ms Catherine McDonald	Quality Assurance, NHSBT (observer)
Ms Claire Mitchell	Clinical Governance Manager, NHSBT (observer)
Mr Imran Saif	Future representative for Plymouth & Portsmouth (observer)
Miss Sam Tomkings	Clinical & Support Services, ODT
Ms Dana Vasickava	Observer from Czech Republic (observer)
Ms Debbie Sutton/ Trudy Monday	Clinical & Support Services, ODT

APOLOGIES:

Mr Titus Augustine	Representative for Liverpool & Manchester
Dr Alison Brown	Representative for Leeds and Newcastle
Prof John Dark	National Clinical Lead for Governance, ODT
Ms Sally Johnson	Director of Organ Donation & Transplantation – NHSBT/ODT
Mrs Julia Mackisack	Lay Member
Ms Laura Ramsay	Lead Nurse Recipient Co-ordination
Dr Tracey Rees	BSHI Representative, Cardiff
Mr Mick Stokes	Head of Hub Operations

ACTION

1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA – KAG(17)2

There were no declarations of interest.

2 MINUTES OF THE MEETING HELD ON 8th JUNE 2017– KAG(M)(17)1(Am)

2.1 **Accuracy**

The minutes of the previous meeting were agreed as a correct record.

2.2 **Action points – KAG(AP)(17)2**

All other action points were either completed or included on the agenda.

2.3 **Matters arising, not separately identified**

There were no other matters arising.

3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

3.1 **Developments In ODT**

J Forsythe updated members on the current developments within ODT.

- There has been a 9% increase in donor and transplant numbers so far this year and this is likely to impact on the retrieval teams and transplant centres.
- The new lung allocation scheme has increased activity by over 20%.
- The new liver allocation scheme is due to begin in March 2018. As a result from the lessons learned from the implementation of the lung allocation process, the liver allocation process will be piloted more thoroughly.
- The length of donation and retrieval process is still far too extensive; further actions taking place to try to make a significant difference over timings for donations.

3.2 GOVERNANCE ISSUES

3.2.1 **Non-Compliance with Allocation**

There were no instances of non-compliance with allocation to report.

3.2.2 **Incidents for review: KAG Clinical Governance Report – KAG(17)27**

J Forsythe reported on behalf of Prof John Dark on incidents related to kidney.

Previously highlighted, there are issues surrounding pathology type 2 testing, which is where a lesion in the organ or donor needs to be examined. Some issues relate to lack of communication, and a suggestion has been made for a form to be used by SNODs and surgeons providing guidance and information to be used when a biopsy is taken.

A meeting took place in Scotland involving representation from pathologists to find out how many would be willing to be involved in an on- call system for pathology to be digitally processed and then read by a pathologist at home. Twelve pathologists agreed to be involved. J Forsythe and J Dark are liaising with the Royal College of Pathologists.

ACTION

The report produced also highlights damage at retrieval which resulted in a kidney lost for transplantation. J Forsythe asked if members feel further investigating should take place, requesting additional information when an organ has been damaged and resulted in discard.

It was noted at the Pancreas Advisory Group (PAG) meeting, a request was made for all pancreas surgeons to complete an incident form if an organ is retrieved and discarded.

The suggestion was made at the National Retrieval Group, for organ damage rates to be made publicly available and to incorporate a response from the NORS team.

It was acknowledged that the reporting of an incident of damage should be used as a learning tool, not as a punitive measure or as part of a blame culture. The group agreed the need for more dialogue with the retrieval teams.

3.2.3 **Summary of CUSUM monitoring of outcomes following kidney transplantation - KAG(17)28**

A CUSUM summary was produced of outcomes following kidney transplantation in the last 5 months. There have been four signals identified and following investigation, no underlying issues were found.

L Mumford advised the CUSUM summary will no longer be uploaded to the ODT website, however CUSUM will continue to be monitored and discussed at KAG.

3.3 **Letter to centres on offer declines for high priority patients**

At the previous KAG meeting, it was noted that a large number of kidney offers to long waiting and highly sensitised patients were being declined, however those kidneys went on to be transplanted.

It was agreed a letter will be sent to the Clinical Director / Director of Kidney Transplant Units, requesting a reason why the kidney was discarded or declined. This is likely to be up and running at the beginning of 2018.

3.4 **The discard of kidneys from 'ideal' donors – KAG(17)29**

A report presented by C Callaghan describing an approach to identify kidneys offered from 'ideal' donors and analyse the frequency of non-use and underlying reasons.

An analysis over the course of the last year identified that seven letters would have been produced, as discards are fairly low. C Callaghan advised members to prospectively record reasons for declining "ideal" kidneys to assist with responding if a letter is sent out.

J Forsythe requested this information is disseminated to colleagues. **All Members**

3.5 **Deceased donor kidney imaging pilot – KAG(17)30**

Previous papers to KAG have proposed a pilot study by which selected deceased donor kidneys are photographed at retrieval (and/or at benching); with the aim of reducing kidney discard rates.

The paper received, proposes a larger national pilot to assess the impact on organ utilisation and to modify the entry criteria to donors over 65.

ACTION

Members agreed this project should proceed. C Callaghan and J Forsythe will liaise to decide how best to move this project forwards. **C Callaghan / J Forsythe**

4 **Kidney Offering Scheme – KAG(17)31**

A presentation was given by L Mumford updating members on the progress made with the new Kidney Offering Scheme. Following the presentation, the following questions and comments were made.

It was confirmed Bernadette Lee has looked at various possible national schemes looking at cost and QALY; her assessment of the 2006 NKAS suggested this to be a good compromise between cost effectiveness and fairness. As part of the assessing, K Preston suggested if not taken place already, that the new scheme is quality impact assessed.

C Callaghan requested L Mumford advise what percentage of donors over 70 years of age would fit into the D4 category of the new scheme. **L Mumford**

The various simulations produced means the median waiting time is 608 days and reducing. Further simulations will take place to incorporate other organs, SPK offers and outcomes, and will analyse further, the outcomes of putting an older kidney into an older recipient.

J Casey explained at the last PAG meeting, it was suggested to begin reviewing the Pancreas Allocation Scheme which may have an impact on the work KAG are doing, therefore initial thoughts and ideas from KAG would be beneficial. **All Members**

C Callaghan asked how the number of declined kidneys would affect the simulations. J Forsythe advised the simulations designed in the 2006 scheme could not take into account declines but the results of the scheme mirrored the prior simulations.

T Brown asked if the travelling and cold ischemia time and the impact this has on the organ and graft survival had been considered. L Mumford advised the geographical location has stayed the same to try and avoid nationally shipping kidneys.

John Forsythe highlighted that split HLA matching was currently taking place in France and asked if we should consider this. S Fuggle explained that previous analysis had shown that split matching was not shown to be beneficial except in cases which are DR6.

It was indicated that for patients with blood group O, there is a concern over accrual of more patients being on the waiting list. L Mumford confirmed there would be an increased waiting time of around 20 days.

The proposed scheme will be discussed further at the Renal Transplant Services Meeting in January.

ACTION

5 Allocation

5.1 **Short term working group to discuss Group 2 patients – KAG(17)32**

Discussion took place at the previous KAG meeting regarding Group 2 patients not entitled to NHS care.

A small working group will be convened to look into the best way to optimise Group 2 patients and how they access kidneys in the fast-track scheme. **C Callaghan / G Jones / F Dor & Lay Members**

C Callaghan, G Jones and F Dor volunteered to look into this, together with the Lay Members.

J Forsythe requested members with any comments to discuss this with the short term working group, J Forsythe or C Watson.

5.2 **Screening/allocation for small paediatric kidney donors – KAG(17)33**

At the last KAG meeting, a proposal was made for St James, Leeds and Guy's to be the national centres for implanting kidneys from small paediatric donors. Since the proposal, the following developments have taken place.

A team from Guy's visited Leeds to identify the processes and pathways and how organ offering should take place, which Adam Barlow is leading on in Leeds. To incorporate the NORS support, the geographical model of allocation appears to be the most appropriate.

Adam Barlow looked at the Leeds experience. From this, it has been decided to not accept offers from a donor under one month as there is only a 25% chance of kidney survival. This information will be presented at the British Transplantation Society (BTS).

It was agreed if both Leeds and Guy's decline an offer, the organ should be offered via fast-track. Discussion took place how likely will the paediatric kidney be utilised if the agreed national centres has declined, however it was acknowledged centres may decline if there is no suitable recipient on their waiting list. The suggestion was made to have a limited pool of centres, C Callaghan confirmed this has been considered; however this increases the complexity for centres looking after another centres patient.

This work will continue.

5.3 **Liver and kidney registration – KAG(17)34**

Following concerns regarding potential disadvantage for patients needing a combined liver/kidney transplant, the Liver Advisory Group (LAG) and Kidney Advisory Group (KAG) agreed a slight change in the ODT Hub Operations processes to more readily facilitate combined liver/kidney transplant.

In summary, the impact for kidney patients overall has been small; however one patient has missed out on the offer of a kidney who was highly sensitised.

C Callaghan queried why the figure shown in table 1 is not what is currently active on the waiting list for Guy's and King's. L Mumford explained that a large number of kidney and liver patients that are registered are suspended for the kidney and active for the liver, this is why both suspended and active patients have been presented.

ACTION

The reason for the introduction of the change was because the HLA is generally not known at the point of liver offering. It has now been agreed that the liver and kidney patient offer will be provisional until the HLA is available and no highly sensitised or long waiting patients are identified on the kidney matching run.

J Forsythe asked Clinical and Support Services to advise on the agreed changes to the combined liver/kidney registration. **Clinical & Support Services**

Post meeting note: The following amendments to the liver allocation policy was agreed at the TPRC meeting

Current wording
Centres must declare within the 60 minute offering time if they wish to accept a kidney to accompany a liver. Beyond the 60 minutes, kidneys will only be allocated by the kidney allocation scheme and the pancreas allocation scheme.

Revised wording
Centres must declare within the 60 minute offering time if they wish to accept a kidney to accompany a liver. This offer is provisional and subject to there not being highly sensitized or long waiting patients on the National Kidney Waiting List (Tiers A to C) to whom both kidneys should be allocated by the national kidney offering scheme.

Beyond the 60 minutes, kidneys will only be allocated by the kidney allocation scheme and the pancreas allocation scheme.

6 Recording reasons for kidney decline – KAG(17)35

A paper was received incorporating the list of recording reasons for decline. The following suggestions were made to be added to the list.

Under section B

- Organ unsuitable should include tumour
- Chronic changes to be included
- Poor perfusion to be included

Under section D

- Recipient already received a transplant to be included

Any further changes to contact J Asher.

7 Recipient specific criteria – KAG(17)36

A paper on recipient specific matching criteria was presented at KAG in June. These will only take effect once the new waiting list management tools are built for the Hub.

The suggestion was made to consider weight mis-match as additional decline criteria. R Hilton highlighted, as the recipient criteria may change, a responsive listing/alert system is required.

ACTION

8 Update on National Renal Histopathology Service

G Pettigrew updated members on progress with the PITHIA trial.

An inaugural event with presentations about the trial was held in October in London.

R&D approval is required, once approved; centres will be informed when they have access to the service.
Twenty two centres will be involved in the trial, which is planned to begin in January 2018.

9 Statistics and Clinical Studies update – KAG(17)37

The Annual Activity Report on Organ Donation and Transplantation has been published on the ODT website. All annual reports, including the living donor kidney annual report will also be available on the website.

Professor Dave Collett has retired but will continue to visit ODT on a Tuesday until the end of February 2018.

NHSBT contract with NHS England funds two clinical fellows to support our programme of audits and analyses. One of these is an ongoing post in cardiothoracic transplantation and is based in Papworth. The second post is currently vacant and will be advertised in December/January as a fellow to work in abdominal organ transplantation.

10 Increase in suspended patients on the National Kidney Transplant list – KAG(17)38

The proportion of patients listed on the national waiting list as suspended is increasing. This has been a cause for concern for both patient groups and NHSBT.

It was agreed for M Robb to look into patients who have been suspended for a long period of time and review them a year after being listed. **M Robb**

Members agreed it would be beneficial for NHSBT to be notified when a patient begins dialysis. L Mumford confirmed it is a priority to look into patient waiting times to the start of dialysis which will hopefully be completed before the new allocation scheme is introduced.

Further discussion will take place at the Renal Transplant Services Meeting.

11 Living Donation

11.1 **UK Living Kidney Sharing Schemes**

11.1.2 **Outcomes and actions from the UKLKSS workshop – KAG(17)39**

A paper was produced highlighting the actions and outcomes. L Burnapp requested this paper is circulated amongst colleagues.

A UKLKSS workshop was held in October. L Burnapp expressed thanks to the ODT Hub, Statistical Department and all centres that were represented.

From this workshop, it was identified with increasing activity, it is challenging for centres to align themselves to accommodate all the identified transplants with the existing 'shared weeks' of surgery. It is proposed that, from April 2018, three weeks are designated to this activity at 5, 6 and 8 post matching run. Members of KAG agreed to trial this proposal.

ACTION

L Burnapp sought approval for any transplants identified in a matching run where dates of surgery exceed an interval of 14 days. It was agreed for this timeframe to remain the same.

11.1.3 **Prioritisation for transplant: recipient and previous donor requirements and outcomes – KAG(17)40**

L Burnapp produced a report identifying that there have been 9 non-simultaneous exchanges within the UK Living Kidney Sharing Schemes.

A discussion took place around patients who missed out on a transplant where one donor in a paired scheme donates and the other does not. After a lengthy discussion, KAG agreed that where a patient misses out on a transplant because their intended paired donor does not donate, while their own donor does donate to the paired recipient, the patient will be entitled to prioritisation within their tier on the national matching scheme. It was noted that for non-sensitised recipients, this may mean a transplant will be forthcoming in a relative short time period, but that it is unlikely that a sensitised patient will get a kidney offer quickly.

Members are asked to take this into account when consenting patients for the UK Living Donor Kidney Sharing Scheme. All cases where the paired scheme is not successful are to be discussed at KAG.

Patients on the national transplant waiting list who miss out on a kidney at the end of a short non-directed altruistic donor chain will not get priority for a transplant.

11.2 **Prioritisation for transplant in the event of immediate graft failure in the Living Donor recipient – KAG(17)41**

A paper was produced highlighting a case where a recipient received a paired kidney in the UK Living Kidney Sharing Scheme but had immediate graft failure due to technical difficulties.

KAG agreed, where a paired donor kidney that suffers immediate graft failure there will be no compensatory prioritisation. However if the recipient is pre-dialysis and was deliberately not listed on the deceased donor list because the living donor kidney was planned, he/she is entitled to retrospective waiting time points from the point at which they were deemed fit to undergo a transplant.

J Forsythe reminded members it is important for patients to be aware of this risk at the beginning.

11.3 **De-listing a patient from the Deceased Donor Waiting list in case of a Living Donor transplant**

A discussion took place regarding a national policy for delisting patients prior to receiving a living donor transplant.

Forthcoming BTS guidelines on Living Donation were not able to reach consensus on this. It was also noted that there was a need to respect donor and recipient choice in this matter.

It was acknowledged that most centres suspended the recipient from the national list once a date had been given. KAG left it for individual centres to agree their own policy.

ACTION

12 KAG Paediatric Sub-Group

12.1 **Report from KAG Paediatric Sub-Group: teleconference 18th October 2017– KAG(17)42**

J Dudley provided feedback from the KAG Paediatric Sub-Group teleconference held on 18th October.

A National Consent form which has been trialled in Bristol has been completed and will be circulated by the end of 2017.

S Marks is co-ordinating a paper on HLAi transplantation data and the first draft is being circulated.

The ATTOMIC data are being collated and abstracts and manuscript will be circulated.

13 Pancreas Advisory Group

13.1 **Report from Pancreas Advisory Group: 1st November 2017**

J Casey provided an update from the PAG meeting held on 1st November.

J Casey and S Fuggle will be looking at the definition of sensitisation for patients. **J Casey & S Fuggle**

It was confirmed at the PAG meeting that dual listing could be achieved and it would be ideal to incorporate this into the new Kidney Offering Scheme. Details would need to be finalised before implementing. Members agreed it would be sensible for dual listing to take place at the pancreas centre.

It's likely that development to move the Pancreas Allocation Scheme across to the new ODT Hub IT platforms will commence in 2018/2019.

14 Utilisation of Hepatitis C kidneys – KAG(17)43

A paper was delivered by Gareth Jones highlighting the underutilisation of kidneys from donors with Hepatitis C. It was noted that 71% of kidneys from such donors are declined; however the introduction of effective anti-viral drugs capable of achieving a cure of hepatitis C in over 95% of treated individuals, opened the opportunity to use kidneys from HCV positive donors in HCV negative recipients. Such a practice was reported at the 2017 ATC and in the NEJM.

J Forsythe added that a working group chaired by Ahmed Elsharkawy involving SaBTO and NHSBT will be producing guidelines for using organs from Hepatitis C donors. These guidelines will be included in the BTS annual congress in March 2018. It was noted, there has been no agreement to fund HCV treatment by NHS England, although discussions are ongoing.

15 Any Other Business

The Renal Transplant Services Meeting (RTSM) will be taking place on Wednesday 24th January.

16 Date of next Meeting:
Thursday 7th June 2018, 12 Bloomsbury Square, London

17 FOR INFORMATION ONLY

17.1 **Transplant Activity report: Sept 2017 – KAG(17)44**
Noted for information.

17.2 **Update on consent rates for patient data held within ODT – KAG(17)45**
Noted for information.

17.3 **QUOD KAG Application tracking –KAG(17)46**
Noted for information.

Organ Donation & Transplantation Directorate **November 2017**