**Approved 9.6.2017** **KAG(M)(16)2**

**NHS BLOOD AND TRANSPLANT**

# MINUTES OF THE THIRTIETH MEETING OF THE KIDNEY ADVISORY GROUP HELD AT 10.30 A.M. ON MONDAY 5TH DECEMBER 2016 AT ODT, BRISTOL

## PRESENT:

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| **Prof Chris Watson** | **Chair** |
| Ms Lorna Marson | Deputy Chair |
| Mr John Asher | Medical Health Informatics Lead, ODT (Part meeting) |
| Mr Titus Augustine | Representative for Liverpool & Manchester |
| 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 Marc Clancy | Representative for Glasgow & Edinburgh (Part meeting) |
| Mr John Connolly | Representative for Northern Ireland |
| Prof John Forsythe | Associate Medical Director, ODT |
| Prof Susan Fuggle | Scientific Advisor, NHSBT |
| Mr Paul Gibbs | Representative for Plymouth & Portsmouth |
| Ms Alison Glover | Recipient Co-ordinator Representative |
| Dr Sian Griffin | Representative for Cardiff & Bristol |
| 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 | Head of Organ Donation & Transplantation Studies, NHSBT |
| Dr Gareth Jones | Representative for Royal Free & Royal London |
| Mrs Julia Mackisack | Lay Member Representative |
| Dr Stephen Marks | BAPN Rep/KAG Paediatric Sub Group Chair |
| Dr Philip Mason | Renal Association / Renal Registry |
| Ms Roseanne McDonald | NSD Scotland Representative (Part meeting) |
| Dr Adam McLean | Representative for Oxford and WLRTC |
| Mrs Bethan Moss | SNOD Team Manager – South Wales (Deputy for Mr P Walton) |
| Ms Lisa Mumford | Statistics & Clinical Studies, NHSBT |
| Mr Gavin Pettigrew | Representative for Leicester and Cambridge |
| Prof Rutger Ploeg | National Clinical Lead for Organ Retrieval - ODT |
| Mrs Kathleen Preston | Lay Member Representative |
| Mr Keith Rigg | Representative for Sheffield & Nottingham |

## IN ATTENDANCE:

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| Miss Olivia Jones | Content Designer for NHSBT Digital Team, NHSBT |
| Miss Sophie Hughes | Statistics & Clinical Studies, NHSBT |
| Miss Trudy Monday | Clinical & Support Services, ODT |

## APOLOGIES:

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| Dr Richard Baker | British Transplantation Society |
| Dr Alison Brown | Representative for Leeds & Newcastle |
| Mr Roberto Cacciola | Associate Clinical Lead for Organ Retrieval, ODT |
| Prof John Dark | National Clinical Lead for Governance, ODT |
| Ms Sally Johnson | Director of Organ Donation & Transplantation – NHSBT/ODT |
| Mr Iain Harrison | Statistics & Clinical studies – Business Analyst NHSBT |
| Mr Ben Hume | Assistant Director TSS - NHSBT |
| Dr Tracey Rees | BSHI Representative, Cardiff |
| Mrs Anne Sheldon | Head of Referral & Offering, ODT |
| Mr Anthony Snape | Head of IT Service Management, NHSBT |
| Mr David Stagg | BTS, NHSBT |
| Mr Mick Stokes | Duty Office Services Manager, ODT |

Ms Helen Tincknell Lead Nurse – Recipient Co-ordination
Mr Phil Walton SNOD Regional Manager – South Wales & South West

**ACTION**

**1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA – KAG(16)29**

There were no declarations of interest.
The Chair welcomed the two Lay Member Representatives, Kathleen Preston and Julia Mackisack, to the meeting.

**2 MINUTES OF THE MEETING HELD ON 9TH JUNE 2016 – KAG(M)(16)1(Am)**

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

2.2 **Action points – KAG(AP)(16)2**
All action points were either completed or included on the agenda.
Action point 7: a response is awaited from Prof Mamode.

2.3 **Matters arising, not separately identified**
There were no other matters arising.

**3 ASSOCIATE MEDICAL DIRECTOR'S REPORT**

3.1 **Developments in NHSBT**
**Appointments in the last six months**
J Forsythe reported on two items:

- People should be aware via the Associate Medical Director's Newsletter that there is currently a Donor Characterisation Project in progress. Refer to minute 3.3 also.
- The length of the donation process is being worked on in order for this to be improved – there is a meeting this week, and also a stakeholder meeting (26th January 2017) to include representatives from different groups.

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(16)30**
Members received the KAG Clinical Governance Report which stated that there were 101 incidents identified with the Key Word 'Kidney' in the six-month period April to September 2016. J Forsythe explained that he believed it was good to see the number of incidents being reported rising since it showed that incidents are actually being reported – this in turn aids shared learning for the future. Members are asked to forward any comments they have to J Forsythe. It was highlighted that positive fungal cultures and other organisms should also be reported.

3.2.3 **Summary of CUSUM monitoring of outcomes following kidney transplantation - KAG(16)31**
Members received this quarterly report. Monitoring will continue and a further report will be submitted to the next KAG meeting.

3.3 **Donor characterisation**
A review of Donor Characterisation is currently being undertaken. The review is a specific action from the TOT2020 Strategy and includes review of the processes for donor characterisation both for Microbiology and HLA typing,

**ACTION**

and is being chaired by Prof Susan Fuggle. A Stakeholder Event was held in London on 5th October and there was wide representation from the transplant community and other stakeholders, including commissioners. The project is being taken forward through the working group which is scheduled to meet in January. The final report will be submitted by the end of April.

3.4 **Health Informatics update**

3.4.1 **ODT Microsite – KAG(16)32**

Olivia Jones is the Content Designer for the ODT medical website. As part of the project, research has been conducted in order to learn what the website visitors look at and use. 150 people from a variety of departments have completed the survey, and contributions from transplant clinicians are particularly encouraged and would be gratefully received. Members are asked to email Olivia Jones with any comments msliviajones@gmail.com and/or complete the survey using the following link: https://www.surveymonkey.co.uk/r/J3GGWJM
It was noted that the calculators are very useful so they will remain. The deadline for comments is 31st March 2017.

3.4.2 **Transplant consent form app – KAG(16)33**

A web application has been developed by clinicians in Glasgow to generate a bespoke consent form for each patient. The pilot of the web application can be viewed at: www.glasgowtransplant.com/pilot
Members are encouraged to visit the link and 'test' it, and to forward any comments to J Asher. Patients must be informed of their options, even if a patient does not show interest, therefore, an 'educated' format, and a 'user-friendly' format is available of the information around consent. J Mackisack offered to help with the language side from a lay perspective, if it is needed. S Marks raised the issue of the need for a national consent form app for paediatric patients as well. C Watson reminded the group that NHSBT guidelines on consent for transplantation were available on the ODT website.

3.4.3 **Electronic replacements for HTA form A and B – KAG(16)34**

There have been longstanding calls for an electronic replacement for the HTA Form A and Form B. J Asher is currently looking at using a model used in the Netherlands which collects more detailed information, and is easier for the surgeon to complete it as it is electronic. A prototype of the interface has been built and can be previewed at www.txtools.net/odtpilot/ It allows for additional comments to be submitted in detail, in a timely fashion, and therefore supports the quality cycle.

R Ploeg agreed to liaise with J Asher regarding the possibility of linking the retrieval and transplant side together to enable the communication of discrepancies, and also the prompting of an incident form. It was noted that it would be of benefit to have an HTA A Form also designed for living donation, however at present, these forms are only being designed for deceased donors; L Burnapp agreed to liaise with J Asher regarding this.

**R Ploeg / J Asher**

**L Burnapp / J Asher**

3.5 **Hub Update**

The Hub development teams will start work on the liver matching scheme in the Spring, with plans to go live in the late Summer of 2017.

J Asher reported that the new liver allocation scheme is being implemented in Summer 2017.

3.6 **KPIs for KAG – KAG(16)35**

C Callaghan presented data on graft outcome for use in NORS KPIs. Analyses showed that DGF, PNF and graft survival were not influenced by retrieval team, and therefore KAG agreed that kidney graft survival would not be included as a KPI for NORS.

3.7 **Investigation into timings of the donation process – KAG(16)36**
Members received a paper investigating the timings of the donation process between 1st April 2010 and 31st March 2016, which seems to have been increasing overall. It was highlighted that the time from referral to formal approach has almost doubled over the six year period, and the time from approach to the start of the retrieval operation has increased from around 13 hours to around 19 hours.

R Johnson referred to the heat maps showing the distribution of retrieval operation start times for consented DBD donors for each financial year; it has become apparent that in recent years these times have shifted to be more spread out. For DCD, overall this process has also increased.

It was also highlighted that over the years, treatment is being withdrawn later. Families tend to withdraw consent because of the length of time for the process. There is an internal meeting on 6th December 2016, and another on 26th January 2017 to discuss these issues in detail and how the whole process can be improved.

3.8 **Update on plans for introduction of allocation algorithms**
J Forsythe explained that the plan was for the sequential introduction of offering algorithms onto the new IT platform. Hearts have been split into the urgent and super-urgent allocation scheme (went live on 26th October 2016), and to date the introduction has gone well; the next project is to introduce the new liver allocation scheme. This will be phased with DBD livers first, and then DCD. It is hoped to continue the allocation schemes for the other solid organs in the same way. When the new kidney offering scheme is ready to go live, there will be a system of review and clinicians will be asked to check the information for their patients.

3.9 **Update on Patient Consent Scheme – KAG(16)37**
The NHSBT Patient Consent Scheme has been in place since October 2005. Of the 29950 patients across the UK that have been listed for a kidney transplant at some point in time since April 2008, 98% have given their consent for the use of their personal data recorded on the UK Transplant Registry. For centres with consent rates lower than 98%, representative members are kindly requested to feed this audit back to the centre. **Centre Reps**

## 4 Allocation

4.1 **DCD Kidney Allocation Scheme update – KAG(16)38**
Members received the two year review of the National DCD Kidney Allocation Scheme. The following points were highlighted:

- on 1st September 2016 the age range for offering of the second kidney regionally increased from 5 to 54 years, 5 to 59 years;
- one kidney remains local; one goes out for regional offering, except in London where both are offered regionally;
- during year 1 of the scheme there were 58 DCD SPK transplants – this has decreased to 40 in year 2;
- There has been a higher proportion of highly sensitised patients being transplanted – HLA matching has improved;
- There is better HLA matching and more long waiters being transplanted in London where both kidneys are shared;
- CIT for the second kidney has reduced from 15.8 hours to 14.9hours;
- Fast track allocation has not changed;
- L Mumford reported that centres will be asked in June 2017 if the age range should be changed again, as originally planned; **L Mumford**
- DCD screening: there is a review taking place of which centres are best to

remain as a screening centre.

L Mumford presented a review of the allocation zones with particular reference to Belfast. Belfast had expressed concern that DCD kidneys had a longer CIT when transferred to them. The analysis suggested that they could reasonably be moved into the Midlands zone from the Northern zone without affecting the Northern zone while benefiting their own ischaemic time. This was likely to be due to the proximity and frequency of air services to Northern Ireland in the Midlands.

4.2 **Recognition of waiting time for patients when coming into the UK from another country**

It was reported that occasionally patients do come into the UK needing to transfer from their previous transplant waiting list to the UK transplant waiting list. Members agreed that waiting time should be accrued from time of starting dialysis, assuming that they are NHS eligible.

**5 Update from Kidney Offering Scheme Meeting held on 30th September 2016 – KAG(16)39**

Three working groups were set up, which each reported back to KAG in June 2016. The following were highlighted:

- work plan to explore effect of matching poor kidneys with poor recipients;
- donor monitoring – looking at how donors and kidney are matched in the quartiles;
- work plan to look at transplant benefit advantages eg. apply risk index to waiting list;
- work on declines: model declines, and the reasons for them;
- mandatory typing – increase the repertoire for which a donor is typed;
- issue around some offers for highly sensitised patients being turned down (now they are being flagged at the time of offering which is better);
- brief outline of early data from the ATTOM meeting.

This group is meeting again on 22nd December. The aim is for something to be drawn up by the middle of 2017, however, it was noted that it was unlikely that IT could implement anything in 2017.

**6 Advisory Group Chairs feedback**

The item on QUOD biopsies has been tabled at most of the Advisory Groups. 80% of kidneys are now getting a QUOD biopsy. It is important that recipients are made aware that their kidney is likely to have been subject to a biopsy at the time of retrieval.

R Ploeg suggested that a patient information leaflet would be of benefit to explain the purpose of the biopsy and what it does.

Members were reminded that all incidents re. QUOD biopsies must be reported to the HTA. NHSBT have stated that it would be useful to have photographic documentation of biopsies for each donor, showing the angle at which it was taken, etc, although it was acknowledged that a photo does not necessarily prove at which angle the biopsy is actually taken. Clinicians are responsible for ensuring that QUOD biopsies are documented.

**7 Statistics and Clinical Studies update – KAG(16)40**

Members received a paper providing an update from Statistics and Clinical Studies, summarising recent presentations, publications, current and future work. R Johnson highlighted the short survey re. the Report on Kidney Transplantation, and encouraged members to complete this survey and disseminate to colleagues for their responses. **All**

**ACTION**

## 8 Offering

8.1 **Audit of DBD and DCD fast track kidney offering scheme – KAG(16)41**

An audit of the DBD and DCD Kidney Fast Track Schemes (KFTS) was received by members. L Mumford reported that a lot more kidneys are being implanted as a result of these schemes. The centres who are already registered in the KFTS appear on the monthly centre report, however, L Mumford agreed to separate the fast track offers on the monthly and quarterly reports to enable better interpretation of the data. **L Mumford**

8.2 **Outcomes of declined deceased donor kidneys that are subsequently implanted elsewhere – KAG(16)42**

Members received a report which analyses centre comparisons of declined kidney offers through the National Kidney Allocation Scheme between 1st January 2010 and 31st December 2014. There was no apparent difference between centres.

14% of patients for whom an offer was made were subsequently removed from the waiting list or died. Centres are encouraged to note the high incidence of declined offers for kidneys that go on to be transplanted successfully.

8.3 **Proposed pilot re. attaching organ images to selected kidney offers – KAG(16)43**

C Callaghan reported that a previous analysis looking at discarded kidneys concluded that more transplants could have taken place if the kidneys were offered more swiftly. In light of this, C Callaghan set up a small working group to look at these findings.

A regional pilot study will commence in January/February 2017 with the London and South eastern teams within centres. Images will be emailed securely to the Duty Office, and then forwarded to an NHS email address for governance reasons. The NRG (National Retrieval Group) have given their support.

8.4 **Kidneys for combined liver and kidney transplants - KAG(16)44**

Members received a report giving an overview of waiting list and transplant activity for patients awaiting a liver and kidney transplant from 1st November 2013 to 31st October 2016. The new policy of delaying offering of one of a pair of kidneys until the liver centre had decided whether to accept the kidney for a combined liver and kidney transplant was reviewed. No high priority patient had been disadvantaged since this policy was introduced.

Concern was expressed that a liver centre had requested a kidney after it had been accepted by a kidney centre. L Mumford agreed to check that the kidney is offered to a kidney centre only once the liver has been through the offering process (and within 60 minutes of the offer). **L Mumford**

**Simultaneous Liver/Kidney Transplant (SLK) - KAG(16)53a**

A report describing work of the LAG Fixed Term Working Unit on Simultaneous Liver/Kidney Transplant (SLK) was received by members. SLK was to be considered in liver recipients with an eGFR<30ml/min for >3 months, or on chronic renal failure. C Watson reported that the current proposals were unlikely to change the number of kidneys being offered for SLK transplants. It was agreed to accept this proposal but to keep activity under review, particularly as the liver offering scheme changes.

**ACTION**

## 9 LIVING DONATION

### 9.1 Strategy for Living Donor Kidney Transplantation

There have been 598 living donor kidney transplants carried out so far in the latest financial year. There will be a transition of funding in April 2017 to NHS England and the Health Departments in other UK countries. L Burnapp will circulate information on slides, and any questions should be directed to L Burnapp or J Gulliver. **L Burnapp**

A lot of work has been carried out on campaigns, with the public and in particular BAME groups, raising awareness of living donation. Additional funding will enable focus projects and shared learning events. By the end of March 2017 it is envisaged that every centre would have been visited and had an opportunity to draw up local action plans. The key points of shared learning will be presented at the RTSM in February 2017.

There has been a particular focus on the living kidney sharing schemes; registrations are increasing, and there has been a rise in two and three-way exchanges. What is not so successful is the timeliness of the transplant within the agreed 8-week standard. There is more work to do collectively to reach this target across all centres, but it is increasingly more difficult as more transplants are identified within the scheme. Currently two thirds of non-directed altruistic kidney donors are still donating to the waiting list in preference to forming an altruistic donor chain. Work needs to be done towards improving the uptake of the chains.

The Living Donor Transplant Centre specific report (found under activity reports on the ODT website) now includes detailed information re. living donor kidney transplants, showing comparison of centres to which patients can refer. This is the first time that this information has been published. Feedback was encouraged to be sent to L Burnapp.

### 9.2 Eligibility of a previous living donor for priority for transplantation – KAG(16)45

There have been cases of living donors who have themselves gone on to require a kidney transplant, resulting in the policy for 'Living organ donors who require a transplant as a direct consequence of donation' being written. Following discussion it was agreed that all previous donors who require a kidney transplant, whether as a direct consequence of donation or not, should be eligible for the same prioritisation for the new and subsequent transplants. L Mumford and L Burnapp will amend the policies as appropriate to reflect this. **L Mumford / L Burnapp**

### 9.3 UK Living Kidney Sharing Schemes

#### 9.3.1 Update on non-simultaneous surgery - KAG(16)46

Members received an update on non-simultaneous surgery for the period from June 2016 to date. L Burnapp reported that it offers more flexibility within the sharing scheme.

On review, it appears that non-simultaneous surgery remains a safe and effective option to maximise utilisation within the UKLKSS; the risk of non-simultaneous exchanges not proceeding to completion remains low. It is recommended that in addition to the existing safeguards, all cases where clinical considerations impact on the decision to consider non-simultaneous surgery must be referred for approval to the Chair of KAG. Non-simultaneous surgery will continue on a case by case basis going forward.

**ACTION**

9.3.2 **Proposal for prioritisation of patients who miss out on a transplant when an identified paired/pooled donation or altruistic donor chain does not complete - KAG(16)47**

Occasions where patients who miss out on a transplant when an identified paired/pooled donation or altruistic donor chain does not complete are more likely to happen in non-simultaneous surgery. L Burnapp presented options and recommendations for prioritisation. Option 1 was prioritisation for a deceased donor kidney; option 2 was prioritisation for an altruistic living donor kidney. Members agreed that both options would be good to have, and the current allocation rules should be followed as they are in option 1; if option 2 is favoured then blood group B recipients may receive O kidneys, and blood group AB recipients may receive A kidneys as per current allocation protocol.

**10 Renal Transplant Services Meeting – draft agenda - KAG(16)48**

The Renal Transplant Services Meeting is being held on Thursday 2nd February 2017 at the Geological Society, London. Members received a draft agenda for information, and are asked to email C Watson if there are any other issues which need covering.

**11 KAG Paediatric Sub-Group**

11.1 **Report from KAG Paediatric Sub-Group: 19th October 2016**

J Forsythe confirmed that he would approach the Head of Quality Surveillance Team at NHS England re. inclusion of paediatric peer review.

S Marks highlighted the following from the KAG Paediatric Sub-Group meeting on 19th October:

- Centres may still be offered an organ they have not requested due to virology. If offered and declined on virology this would still count as a declined offer. In the future allocation scheme, it is hoped this will change;
- there have been no major incidents reported from the paediatric side;
- ATTOMIC Child study: application is in progress;
- National consent form being considered;
- Meetings of Subgroup – agreement to try annual face to face meeting with a telecon meeting in between, in place of two face to face meetings a year.

**12 Pancreas Advisory Group**

12.1 **Report from Pancreas Advisory Group: 2nd November 2016**

J Casey reported that the allocation scheme is working generally very well, but there are a few areas being monitored. There is a working group looking at the pancreas allocation scheme, in particular, three broad areas: utilisation for islet and solid organ transplants, BMI, and allocation for highly sensitised patients.

**13 Any other business**

G Pettigrew raised the issue of which kidney goes to which recipient. L Mumford confirmed that the existing policy states that whichever centre accepts the kidney first has the choice. However the proposal had been made that there would be no choice in order to speed up allocation, since there have been instances where centres have delayed in making their preference known. Concern was expressed regarding the preference for kidneys for children, for large adults where long vessels were preferred, and where on retrieval only one kidney was viable and the non-viable kidney had been allocated to a high priority (e.g. highly sensitised) patient. It was agreed that a small working group should be convened by C Watson to discuss **C Watson**

further.

**14** **Date of next Meeting:**
Thursday 8th June 2017, London venue tbc
Thursday 14th December 2017, Bristol venue, tbc

**15** **FOR INFORMATION ONLY**

15.1 **Transplant Activity report - KAG(16)49**
Noted for information.

15.2 **Kidney Selection & Allocation Policies for review – KAG(16)50 a and b**
Noted for information.

15.3 **IT Progress Report – KAG(16)51**
Noted for information.

15.4 **Review of long waiting patients – KAG(16)52**
Noted for information.

**Organ Donation & Transplantation Directorate** **December 2016**