NHS BLOOD AND TRANSPLANT

MINUTES OF THE THIRTY FIFTH MEETING OF THE KIDNEY ADVISORY GROUP HELD AT 10.30 A.M. ON MONDAY 10th JUNE 2019 12 BLOOMSBURY SQUARE, LONDON WC1A 2LP

PRESENT:

Prof. Christopher Watson	**Chair**
Mr John Asher	Medical Health Informatics Lead
Mr Atul Bagul	Representative for Leicester & Nottingham
Mr Adam Barlow	Representative for Leeds & Newcastle
Mr Stephen Bond	Recipient Co-ordinator Representative
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 Marc Clancy	Representative for Glasgow & Edinburgh
Mr John Casey	Chair of Pancreas Advisory Group
Mr Frank Dor	Representative for West London Renal Transplant Centre (WLRTC) and Oxford
Dr Jan Dudley	Chair – KAG Paediatric Sub Group
Prof. John Forsythe	Medical Director, ODT
Prof. Susan Fuggle	Scientific Advisor, NHSBT
Mr George Greenhall	NHSBT Clinical Research Fellow
Dr Sian Griffin	Representative for Cardiff & Bristol
Mr Jon Gulliver	NHS England (Specialist Commissioning) Representative
Dr Rachel Hilton	Representative for Guys' & St Georges
Mr Ben Hume	Assistant Director Transplantation Support Services, NHSBT
Mr Nicholas Inston	Representative for Birmingham and Coventry
Dr Gareth Jones	Representative for Royal Free & Royal London
Ms Julia Mackisack	Lay Member Representative
Dr Philip D Mason	Renal Association/Renal Registry Representative
Dr Jennifer McCaughan	BSHI Representative
Ms Lisa Mumford	Head of ODT Studies, NHSBT
Mr Ravi Pararajasingham	Representative for Sheffield and Cambridge
Mr Gavin Pettigrew	Representative for PITHIA Trial
Prof. Rutger Ploeg	NHSBT Principal Investigator for QUOD
Mrs Kathleen Preston	Lay Member Representative
Dr Matthew Robb	Statistic & Clinical Studies, NHSBT
Dr Imran Saif	Representative for Plymouth & Portsmouth
Ms Angie Scales	Lead Nurse: Paediatric and Neonatal Donation and Transplantation, NHSBT
Ms Clare Snelgrove	Recipient Co-ordinator Representative
Mr David Van Dellen	Representative for Liverpool and Manchester

IN ATTENDANCE:

Dr Richard Baker	National Clinical Lead for Governance, ODT – via teleconference
Ms Natalie Reeves	Recipient Co-ordinator (Observer)
Miss Sam Tomkings	Clinical & Support Services, NHSBT

APOLOGIES:

Prof. Lorna Marson, Ms Anusha Edwards, Mr Michael Stokes

ACTION

1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA – KAG(18)2

There were no declarations of interest.

2 Minutes of the meeting held on 27th November 2018– KAG(M)(18)2

2.1 Accuracy

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

Clarify section 5.5
Remove A Barlow from AP2

2.2 Action points – KAG(AP)(19)1

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

The English Opt-out legislation has been agreed. NHSBT are working with HTA as to how to enact it – there will be a consultation on this to which members are encouraged to contribute. Scotland was due to discuss Opt-out the day after KAG met. Legislation is also moving forward in Jersey, Guernsey and the Isle of Man.

NHSE have agreed that NHSBT can commission Donor Characterisation; Richard Baker will chair its implementation.

A joint innovation fund between NHS England and NHSBT has been agreed for DCD heart development which will be rolled out across the UK.

A successful regional collaborative meeting was held to discuss sustainability across the London region. From this, a Sub Group looked to develop a protocol to enable units to transfer the kidney and recipient to another unit in the event of a major incident or capacity issue. The Sub Group also considered organ declines particularly where a unit has declined an organ and another unit has transplanted, therefore a meeting has been set up to discuss the organ declines across London. The Sub Group will develop a questionnaire to look at current staffing across the London units and what is required in the future as the number of transplants increase. A meeting has been booked for 4th December to feedback on this work. This work has encouraged other units in different regions consider collaborative working, therefore R Baker will work with G Jones to learn from London and roll this out to other areas. Oxford and Coventry are also working collaboratively.

3.2 Update from Risk and Consent Working Group

J Forsythe provided an update from the Risk and Consent Working Group where there are 3 groups working together to take this forward.

Patient information is being developed. The group is working with the Winton Centre who have developed the PREDICT tool for prostate and breast cancer. A PREDICT tool will be developed by the end of the year initially for lung transplantation comparing waiting list and post transplant survivals, and once this is developed will be rolled out to other organs.

3.3 Governance Issues

3.3.1 Non – compliance with allocation

There are no non-compliance with allocation.

3.3.2 Incidents for review: KAG Clinical Governance Report – KAG(19)3 **ACTION**

R Baker presented the Governance Report.

R Baker drew attention to the two incidents raised where biopsy material had been taken and the results were received two weeks later. C Watson added it is the responsibility of the person taking the biopsy to tell Hub Operations and request this is processed urgently. R Baker suggested this is formalised and to ensure it is properly recorded. R Baker will be writing to centres regarding this in the next few weeks. **R Baker**

3.3.3 QUOD punch biopsy

There have been 68 formal incidents relating to QUOD biopsies recorded at NHSBT. Since November 2018, there have been 6 serious adverse events including a reported graft loss. It was agreed for a survey to be circulated to all centres to obtain units' perception of the biopsies taken. R Baker encouraged members to complete the survey which was circulated on 4th June ASAP. **All Centres**

Since then, an emergency teleconference was held including senior members of NHSBT who decided to suspend biopsies taken for the use of QUOD and PITHIA until a safer way to continue is identified.

C Watson added that the PITHIA trial is in place to help decide whether a kidney is suitable for a recipient and was thus being done for the recipient's benefit. R Baker concurred and advised this was stated during the telecon.

G Pettigrew expressed his concern and felt that stopping the trial is unfortunate and highlighted that a provisional kidney offer was accepted over the weekend but later declined because of biopsy availability. He also highlighted the conflict in governance for the trial, which rested with the trials data safety monitoring committee.

C Watson asked members of KAG whether they felt there was a concern with QUOD and PITHIA biopsies. A Barlow had received a kidney where the biopsy was taken close to the hilum. The kidney suffered a significant arterial bleed on perfusion which was stopped, however there was an AV fistula at the site afterwards and concern around re bleeding therefore the aneurysm was coiled but the following day the kidney had thrombosed. It was felt the biopsy was not taken from the correct place. The cause of graft loss had to be explained to the recipient who was not aware that a biopsy had been taken from the kidney.

R Ploeg stated that biopsy training for QUOD began in February 2018 where surgeons were taught the procedure for punch biopsy and a video was created to ensure proper competency was achieved.

In order to reduce risk, it was agreed to downsize the PITHIA biopsy for pathology and to reduce the punch biopsy to 2mm.

Members agreed that the transplanting surgeon will close the biopsy site, not the retrieving surgeon.

K Preston and J Mackisack felt this should be resolved as quickly as possible and ensure that the appropriate people are involved in the conversations and decisions made.

ACTION

C Watson reminded centres to ensure that their patients are made aware of QUOD and that it is possible for patients to opt out of QUOD biopsy.
C Callaghan felt it would be helpful for centres to be made aware at the time of offering whether a QUOD biopsy had been taken. **All Centres**

J Forsythe suggested meeting with G Pettigrew and R Ploeg to produce a solution which is safe for patients and to allow this research to continue. **J Forsythe/ G Pettigrew/ R Ploeg**

3.3.4 Summary of CUSUM monitoring of outcomes following kidney transplantation – KAG(19)4a KAG(19)4b

M Robb presented the CUSUM monitoring paper.

Since the last Kidney Advisory Group, there have been 5 signals in kidney transplantation.

An investigation which is still outstanding was undertaken at St George's following a signal in the CUSUM monitoring of 30-day patient mortality following adult deceased kidney transplantation.

Four signals in the CUSUM monitoring were identified at Bristol, Birmingham, Cardiff and Edinburgh. Investigations were undertaken for Bristol, Birmingham and Edinburgh where no underlying issues were identified. An investigation remains to be undertaken for Cardiff.

Paper 4b showed updates of the expected mortality and graft failure rates.

J Dudley advised that Bristol had suspended its service as a result of 3 failed living donor transplants which will have affected the figures for Bristol.

C Watson advised that the Kidney Advisory Group CUSUM monitors against the unit's own activity, in contrast to other organs where events are monitored against the national activity. Members were asked if the Kidney Advisory Group should remain monitoring as is or move to monitoring against the national rate.

L Mumford confirmed the signal for CUSUM triggers is not risk adjusted but the underlying data is.

L Mumford was asked if the new allocation scheme will make a difference to the centres which have a higher proportion of elderly patients on the waiting list. L Mumford advised that in the current scheme, older kidneys are allocated to older patients therefore a similar pattern should be seen within the new scheme.

The suggestion was made to implement both ways of monitoring, against the centre and the national rate. It was agreed to run CUSUMs against each baseline and review this after a short period. **M Robb**

3.4 Hub Update

B Hume presented an update from Hub Operations.

The overall donor activity is not as high as ODT expected, therefore Hub Operations will look at the donor pool and the reasons for this through the donor audit.

Julie Whitney has been appointed as Head of Service Delivery. Julie will focus on the experience of offering and look at the method of offers and organ specific donor criteria.

4 Developments in IT

4.1 Organ Quality eForms update

There has been an increase in the use of the electronic form B which replicates the paper form. 41% of forms received have been electronic. The plan is to cease paper forms by July. Centres have experienced IT problems most of which have now been resolved.

Phase 2 of this, to implement feedback for organ quality, has been put on hold due to lack of resource while IT issues with the blood service are resolved.

4.2 Recording reasons for kidney decline or non-use – KAG(19)5

Members received a paper showing the categorised reasons for decline. Additional categories have been added such as consent and authorisation and logistical issues.

It was felt that 'centre already transplanting' is a useful code, however to be decided is at what level of activity would this be a reasonable code to use.

J Dudley advised the KAG Paediatric Sub Group (KAG PSG) are interested in this area and the data which is captured on the form. As there is a 60% decline rate in children and young people KAG PSG feel there is a large variation in centre decline and would like to do a smaller piece of work to look at the individual comments on reasons for decline. J Asher advised the data recording for declines is poor. J Dudley asked if there is flexibility to break down the free text information. L Mumford advised the statistical team has analysed this for previous categorise to help develop the list of declines.

5 Scientific Advisor's Report

5.1 Donor discrepancy monitoring – KAG(19)6

S Fuggle presented a summary of the discrepancies detected last year which remains low.

There was 1 data entry error identified within ODT before allocation and 6 errors were detected after allocation.

With the implementation of the donor characterisation review it is anticipated more electronic submission of data and the aim is to have end to end transfer of data.

C Watson queried why it is not possible to achieve end-to-end electronic data transfer. S Fuggle advised that the laboratory systems are quite different which makes electronic to electronic difficult, but this is something which will be considered.

5.2 Summary of donor discrepancies – KAG(19)7

A summary of the donor discrepancies was provided.

5.3 Minimum resolution for donor and recipient HLA types – KAG(19)8a & KAG(19)8b

When the 2006 Kidney Allocation Scheme was developed a minimum resolution for reporting donor and patient HLA type was introduced as this specification was required at the time. This now needs to be increased and will be developed as part of the donor characterisation review.

ACTION

J Forsythe acknowledged this is S Fuggle's last advisory group meeting and thanked her for her dedication and hard work. The advisory concurred and thanked her for her contributions over the years.

5.4 BSHI/BTS guidance on XM prior to deceased donor kidney transplantation – KAG(19)9

A request was made at the previous KAG meeting to develop guidelines for the cross matching (XM) for deceased donors.

The group decided the three main points to consider were:

- Timing of the XM results and to ensure these are available to prevent a delay for the patient going to theatre.
- The key importance of a XM is to facilitate a safe transplantation particularly for highly sensitised patients who will require prospective wet cross matching.
- Where additional donor material such as blood is required, to ensure this is requested in a timely manner.

C Callaghan asked how this can be audited to identify what units are doing to drive improvement and practice. J Forsythe suggested this will be a part of the donor characterisation commissioning.

6 Transplant Centre Profiles update – KAG(19)10

An updated Transplant Centre Profile was received incorporating the changes suggested at the last meeting.

The following suggestions were made:

- Belfast is not in the correct location on the map
- The total number of transplants per year heading could be misleading as the total number the number refers to deceased donor only on this chart, with a separate profile for living donor transplants
- Consider changing 'graft' as patients may not understand this term **M Robb**
- Change tissue type to HLA type
- Availability of right size organ is not required for kidney
- Remove the speech bubble of information altogether

7 Allocation

7.1 Kidney Offering Scheme – IT update

The launch of the Kidney Offering Scheme was planned to be alongside the changes made to the Pancreas Offering Scheme, however the IT development for the incorporation of the pancreas scheme is still undergoing troubleshooting. It has therefore been agreed that the provisional date for the Kidney Offering Scheme to go live will be 3rd September 2019.

7.2 Liver and kidney registrations – KAG(19)11

M Robb presented a review of the revised ODT Hub Operations process for access to transplant for liver and kidney patients.

Figure 1 shows the number of kidney and liver transplants which had increased in November 2014 and April 2016 with a decrease subsequently. In the most recent 6 month period there were 7 liver/kidney transplants and there was 1 highly sensitised patient on the kidney matching run, however this patient did not receive the offer of the kidney because they already had another offer from a different donor.

7.3 Living Donation Transplant Policy – KAG(19)12 **ACTION**

The policy for Living Donor Kidney Transplantation went live last year. A few amendments will be made to clarify the blood group matching for the living sharing scheme and what happens if a kidney is *en route* to a transplant centre and cannot be implanted. M Robb asked members to review the policy and feedback their comments.

J Gulliver asked what information is provided to the patient in terms of waiting times. C Watson clarified that centres can inform patients about the different types of kidneys available to them, considering their level of sensitisation.

An error was noted on page 3 'core antigen' should read 'core antibody' under the medical history section. **M Robb**

8 Outcomes of transplanted kidneys that were previously accepted with the pancreas – KAG(19)13

M Robb presented a paper on the outcomes of transplanted kidneys that were previously accepted with the pancreas.

Concerns have been raised where the kidneys were accepted with the pancreas as an SPK offer but the pancreas was later declined and the kidney offered on, with a consequent longer cold ischemic time (CIT) for the kidney.

M Robb undertook an analysis to look at the effect on the kidney offered on after declined pancreas. He stated that it was difficult to identify which kidney was offered with the pancreas, however 359 kidneys were identified as offered and 312 kidneys were transplanted.

The median CIT time for kidneys offered with the pancreas was 19.3 hours and the median time for the kidney not offered with the pancreas was 12.8 hours. While there is evidence showing that the kidney offered with the pancreas but subsequently declined had a longer CIT, there was no evidence that kidney graft survival outcomes were any different between the two kidneys.

G Jones highlighted that half of the data could not be analysed due to not knowing if the kidney was offered with the pancreas whether this was something NHSBT want to look at in more detail. M Robb confirmed this will be addressed and advised that it was agreed at PAG to go through a selected number of cases in more detail.

J Casey added that the pancreas transplant centres are very aware of the implications of accepting SPK offers and then declining again and have emphasised that the pancreas should be inspected as soon as it arrives at the implanting centre. J Casey feels that the introduction of the pancreas imaging pilot which will allow pancreas transplant centres to have images of the pancreas will help centres make a decision sooner.

It was also suggested to look at GFR after 1 year in addition to graft survival.

9 Review of infant donors < 2 years – KAG(19)14

M Robb presented a review of allocation scheme for infant donors.

There was 1 case where offering deviated from the protocol with Nottingham being offered a donor kidney pair for a named patient, but this was subsequently declined.

ACTION

A Scales and the SNOD identified this error and this was raised through governance reporting. Since then the policy has been reviewed and a mechanism has been put in place.

J Mackisack stated this is the second time this has happened, and that this happened after the policy had been reviewed. A Barlow confirmed a very clear protocol was developed after the last KAG meeting and suggested this recent error could be an administration error at Hub Operations. B Hume will follow this up and report back at the next meeting. **B Hume**

K Preston suggested receiving some follow up from the outcomes of the transplants. Of the three transplanted at Manchester, the one in question at the last meeting was reported to be working.

The suggestion was made to include comparative figures over a longer period which will be added to the next report. It was also suggested to receive this report every 6 months and to stratify the information by age. **M Robb**

A later suggestion was made to consider adding a minimum and maximum donor age to allow only Guy's and Leeds to appear on the matching run for those offers from donors under 2 years of age. If those units decline, the offer would be made on a first come first serve basis. Members agreed this should be trialled. L Mumford will discuss this with Hub Operations. **L Mumford**

10 Update on A2 donors for B Recipients

An update for this item will be sought for the next meeting.

11 Statistics and Clinical Studies update – KAG(19)15

M Robb provided an update from the NHSBT Statistics and Clinical Studies.

L Mumford has been appointed to head of ODT studies and Helen Thomas has been appointed as head of clinical trials and statistics.

There have been 8 presentations presented at the British Transplantation Society (BTS) Annual Congress.

Work has begun on the centre specific organ reports and living donor kidney transplantation report.

12 Organ utilisation

12.1 Declined offers due to logistical reasons – KAG(19)16

A paper was received following feedback from patient groups and transplant units. It was agreed at the Transplant Policy Committee (TPRC) and the NHS Blood and Transplant Board that there should be a process established for notifying patients when an organ has been declined on their behalf solely due to lack of resource.

J Forsythe ran through the process and informed members that NHSBT will write to all units to inform them of the new process.

From the information available, kidney has the fewest cases where units experience lack of resource, with pancreas having the highest number.

The question was raised from the 2016 NHS England review of units (peer review) whether the actions and recommendations from the review have been followed. J Gulliver advised the QST who led the peer review process confirm

ACTION

the delivery of actions involved from the peer review. It was felt a mechanism should be in place to ensure follow up on actions from the reviews. NHS England are working on the terms of reference to look at a review of renal services across the board where capacity is likely to be part of the process.

J Gulliver stated that the paper received does not specifically mention incident reporting. It was suggested the process must be clear to ensure consistency across centres. It was noted that KAG encourage incident reporting.

12.2 CIT and XM practices – update

Covered under item 5.4.

12.3 KAG STWG offer scrutiny schemes – KAG(19)27

C Callaghan provided an update from the oversite committee which was set up by KAG.

The remit of the committee is to examine and grade written responses from units after being contacted by the offer review scheme (ORS). Grading will be red/amber/green. C Callaghan went through the process.

C Callaghan advised there has been some confusion around the term 'ideal' donor therefore proposed to change the name to higher quality donor. A Bagul suggested the term higher quality organs could suggest other organs are sub quality. The suggestion to refer to the organs as high expectation of use instead of quality was made and including standard and extended criteria was also suggested.

Discussion took place regarding obtaining a second opinion and who the appropriate person is to obtain this from. It was highlighted that as this would be a Tier A patient, that it would be worth discussing the offer with the nephrologist who looks after the patient. The suggestion was made to re word the paragraph to 'an appropriate second opinion e.g. preferably the nephrologist looking after the patient'. **C Callaghan**

An update from this will be provided in November.

12.4 Organ imaging pilot

On 28th March the kidney imaging pilot started for deceased donors over 65 and organs which are damaged. C Callaghan would like to obtain feedback from SNODs and Hub Operations to identify how well this is being used.

12.5 Provisional offering of pancreas from MVT blocs – KAG(19)17

A paper was presented by C Callaghan on behalf of Cambridge who perform multi-visceral transplants in adults. The proposal is for when Cambridge accept a multi-visceral bloc for a patient with PV thrombosis, a pancreas matching run be initiated, and the pancreas be provisionally offered via the offering scheme. However, it is often possible to transplant a liver alone in such patients, and so not use the donor pancreas which could then be offered on. A kidney would be held back from offering until the destination of the pancreas was known.

C Callaghan asked KAG depending on the tier of the patient involved, if it is possible to have a kidney and pancreas provisional offers to facilitate and improve organ utilisation of these pancreases.

It's expected there will be approximately 10 multi-visceral offers a year, therefore it was suggested for those 10 to be offered provisionally as an SPK.

As there are around 10% of pancreas only patients on the national transplant list, R Ploeg suggested offering the pancreas as a PTA.

C Callaghan recommended running a matching run incorporating the kidney along with the pancreas and holding back one kidney if indicated by the matching run, (unless the matching run indicated the top patient on the run was a pancreas only patient) – this would then form a provision pancreas ± kidney offer. The kidney would only be held until cross clamp, after which it would be a full offer. C Callaghan proposed this pathway will only be followed if Cambridge can make a decision before cross clamp.

C Callaghan, L Mumford, M Stokes and B Hume will hold a telecon to ensure a clear process for this is defined. **C Callaghan L Mumford M Stokes B Hume**

12.6 Out of hours transplant vs in hours transplant outcomes – KAG(19)18

M Robb presented a paper summarising the transplant results where surgery occurred during the day time and night time and compared the 5 year outcomes of the two groups.

Between April 2014 and March 2019 overall, the proportion of transplants performed during the night time is 35%. Over the further time periods, the majority of transplants occur between 8pm and 4am.

Of the transplant performed between April 2010 and March 2014 the graft survival outcomes split between day time and night time with no evidence of difference in graft survival between the two groups. Figure 3 show 5 year patient survival outcomes which show no difference. A small difference was shown in the delayed graft function.

In summary, there was no evidence of a difference in 5 year graft survival between transplants that occurred during the day and night. Over the last 5 years, 65% of transplants were performed in the day time hours.

M Clancy asked if the total transplant includes living donor transplantation or if this is a survival analysis of deceased transplants. M Robb advised that the total transplants included both living and deceased to give an idea of activity, but the survival analysis focussed on deceased donor transplants.

M Robb advised CIT was analysed and that there was a difference between day time hours and night hours. The average CIT during the day was 13.4 hours and the night time was 15.3 hours.

M Clancy raised the concern that this data could undersell the amount of out of hours work done.

12.7 PITHIA update

Recent events regarding biopsies were noted as discussed above.

G Pettigrew advised positive feedback has been received from the 9 centres with access to PITHIA.

13 Living Donation

13.1 UK Living Kidney Sharing Schemes (UKLKSS): Update and impact report – KAG(19)19

L Burnapp presented the update and impact report for the Living Kidney Sharing Schemes.

ACTION

A higher proportion of non-directed donors are entering the scheme and are now responsible for up to 60% of all transplants in each matching run. L Burnapp highlighted that of the donors which remain unmatched, they are predominantly blood group A. The highest number of non-directed donors were in the April matching run with almost 100 transplants identified.

Non-simultaneous exchange applies to recipients within a pair whose paired donor has donated on a separate date from the recipient operation. There have been 11 non-simultaneous exchanges completed from the October and January matching runs resulting in 30 transplants. L Burnapp highlighted the two cases where a recipient had missed out on a transplant due to a non-proceeding non-simultaneous donor but have subsequently received a transplant. Both recipients were on the deceased donor transplant list who were due to complete a chain.

There has been no request for recipient prioritisation in the past 6 months.

91% of transplants proceeded in the designated weeks of surgery for the January matching run, which was an improvement on the October run. Two transplants are yet to proceed from the January matching run. 23 out of 27 self-reports were received in response to requests for clarification about non-proceeding and delayed transplants, which is slightly lower than the responses received in the past. 35% of those non-proceeding transplants were considered preventable. In the last 6 months 40% of transplants did not proceed which impacted on 16 exchanges in the October matching run.

50% of preventable non-proceeding transplants are attributed to donor recipient registration and the completeness and accuracy of information provided. L Burnapp asked ODT to look into this and it was confirmed 70% of donor registrations received require some sort of clarification. L Burnapp requested members go back to their centres and feed this back and for each centre to review the data for non-proceeding transplants to ensure that all preventable causes are addressed. **All Members**

Figure 4 provided the data which shows the delayed transplants due to logistical issues and access to theatre. It was recognised that the option of these pairs being transplanted in an alternative centre could be considered more often.

Section 6 refered to an incident where the identity of a donor was inadvertently disclosed to the recipient. It has therefore been agreed when completing the request form for H&I crossmatching to limit the information to the donor ID, exchange ID and date of birth. It was also agreed to include the NHS number and if this is not available an equivalent. J Asher added that centres must not provide the recipient with the location of the donor hospital. **L Burnapp**

Members were asked to note the recommendations made and to ensure that they are brought to the attention of colleagues in the centres that they represent. **All Members**

13.2 Letter re: direct pairs – KAG(19)20

A letter was received by C Watson from Edinburgh with the request to prioritise living donor potential recipients where the recipient's transplant does not take place because of medical reasons.

C Watson highlighted that this was previously discussed, and it was decided at that stage not to give priority to a recipient where their donor had donated but

ACTION

they were unable to receive a transplant. It was pointed out by members that this scenario was different from that when the recipient's transplant failed

After a lengthy discussion it was agreed that if a donor has donated their kidney and the recipient is unable to receive the kidney, and the donor's kidney goes on to be transplanted to a recipient on the transplant list that the paired recipient will be prioritised for a deceased kidney transplant.

The following statement will be included in the living donor transplantation policy 'if the prospective donor has donated and the recipient was unable to receive the kidney, but the kidney facilitated a transplant, that recipient can be prioritised.' **M Robb**

14 KAG Paediatric Sub-Group

14.1 Report from KAG paediatric Sub-Group: 20th March 2019 – KAG(19)21

J Dudley provided an update from the KAG Paediatric Sub Group Meeting held in March.

The national consent forms are available for use and on the Renal Registry website.

The harmonisation project is underway to align centres' immunosuppression regimens.

A small study is taking place looking at volumes of intravenous fluids and there is a proposal for a larger research study looking at composition of intraoperative fluids.

UK position statement was circulated and as there currently is no licensed antivirals for children it was suggested that children would currently not receive HCV positive organs.

C Watson asked J Gulliver when will an opinion be received from NHS England for HCV treatment for adults. J Gulliver responded advising the policy proposal will be taken to the clinical panel this month and once the clinical panel have signed this off there is a process of policy development which has to be followed. J Gulliver advised if there are exceptions for children and young people, that will need to be reflected in the policy. J Gulliver will let C Watson know of the anticipated time scale for the development of this policy. **J Gulliver**

J Forsythe suggested that the KAG Paediatric Sub Group consider young donors whose best opportunity may be to accept an HCV organ and treatment with DAAs could be the right form of treatment for some patients.

15 Pancreas Advisory Group

15.1 Report from Pancreas Advisory Group: 1st May 2019 – KAG(19)28

J Casey presented an update from the Pancreas Advisory Group Meeting.

It was agreed that a short-term working group would look at the logistical reasons for decline in pancreas transplantation and look at defining what would trigger raising a declined offer with the potential recipient.

The pancreas imaging pilot will begin in July.

A number of cases will be looked at in more detail to identify the late SPK declines and the kidney CIT.

ACTION

All pancreas units would consider accepting HCV positive donor organs for HCV negative recipients however funding has not been secured in England for the DAAs.

Three working groups have been agreed within PAG, one to look at simultaneous SIK transplants, another to look at medium to long term outcomes in pancreas transplantation and how this is recorded and a third working group to look at quality of life measures in solid organ transplantation.

16 Patient for dual Kidney Transplant Listing – KAG(19)22

F Dor submitted a request for a giant male patient to receive two kidneys instead of one. Members agreed with the request made.

17 Organs and tissues to be excluded – KAG(19)23

Members were encouraged to read and submit comments on a consultation document on "Organs and tissues to be excluded from the new system of organ tissue donation in England" by 22nd July. **All Members**

18 Any Other Business

18.1 Patients who died on the waiting list following deceased donor kidney offer decline – KAG(19)24

C Callaghan presented a paper which informs KAG of incidents where a patient has died on the waiting list following a deceased donor offer decline.

This information will be circulated to units on a 6-monthly basis which will include the primary reason for decline, free text and any other reasons.

NHSBT do not record the renal unit for pre-emptive patients.

J Dudley requested the paediatric data is collected within this. J Dudley will circulate an email to the sub group informing them of the data inclusion. **C Callaghan J Dudley**

The suggestion was made to include crossmatch positivity incidents. **C Callaghan**

A Bagul received a DCD kidney treated with NRP perfusion but was not aware of this. The suggestion was made to inform centres if a donor has been treated with NRP perfusion. M Ryan will let the SNODs know of this request. **M Ryan**
It was noted that Glasgow presented their data on NRP kidneys at the BTS recently and showed better graft function after NRP.

19 Date of next Meeting:
Thursday 21st November, 10:30AM, 12 Bloomsbury Square, London.

20 FOR INFORMATION ONLY

20.1 Transplant Activity report: April – KAG(19)25

Noted for information.

20.2 QUOD statistics 2019 – KAG(19)26

Noted for information.