To be ratified **KAG(M)(18)2**

NHS BLOOD AND TRANSPLANT

MINUTES OF THE THIRTY FOURTH MEETING OF THE KIDNEY ADVISORY GROUP HELD AT 10.30 A.M. ON TUESDAY 27th NOVEMBER ODT, STOKE GIFFORD, BRISTOL BS34 8RR

PRESENT:

Prof Christopher Watson	**Chair**
Prof Lorna Marson	Deputy Chair and British Transplant Society Representative
Mr John Asher	Medical Health Informatics Lead & Representative for Glasgow & Edinburgh (deputy)
Mr Titus Augustine	Representative for Liverpool & Manchester
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 John Casey	Chair of Pancreas Advisory Group
Ms Joanna Chalker	Specialist Nurse – Organ Donation Representative
Ms Natalia Diaz-Burlinson	BSHI Representative (deputy)
Dr Jan Dudley	Chair – KAG Paediatric Sub Group
Ms Anusha Edwards	Representative for Cardiff & Bristol
Prof John Forsythe	Medical Director, ODT
Prof Susan Fuggle	Scientific Advisor, NHSBT
Mr Jon Gulliver	NHS England (Specialist Commissioning) Representative
Dr Rachel Hilton	Representative for Guys' & St Georges
Mr Ben Hume	Assistant Director TSS, NHSBT
Dr Maria Ibrahim	Clinical Research Fellow, NHSBT
Mrs Rachel Johnson	Assistant Director Statistics & Clinical Studies, NHSBT
Dr Gareth Jones	Representative for Royal Free & Royal London
Ms Julia Mackisack	Lay Member Representative
Prof. Nizam Mamode	Clinical Lead for Transplantation, Guy's Hospital (adhoc member)
Dr Philip D Mason	Renal Association/Renal Registry Representative
Dr Adam McLean	Representative for Oxford and WLRTC
Ms Lisa Mumford	Statistics & Clinical Studies, NHSBT
Mr Ravi Pararajasingham	Representative for Sheffield and Cambridge
Mr Gavin Pettigrew	Representative for PITHIA Trial
Prof. Rutger Ploeg	National Clinical Lead for Organ Retrieval, ODT
Mrs Kathleen Preston	Lay Member Representative
Dr Matthew Robb	Statistic & Clinical Studies, NHSBT
Mr 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

VIA TELECONFERENCE:

Dr Richard Baker	Representative from Clinical Reference Group (CRG)

IN ATTENDANCE:

Ms Lizzie Abbot-Davies	Clinical & Support Services (observer)
Mr George Greenhall	Clinical Research Fellow, NHST
Ms Rachel Hogg	Statistic & Clinical Studies, NSHBT (observer)
Miss Sam Tomkings	Clinical & Support Services, NHSBT

APOLOGIES:

Mr Marc Clancy	Representative for Glasgow and Edinburgh
Prof John Dark	National Clinical Lead for Governance, ODT

Mr Frank Dor Representative for Oxford & WLRTC
Mr Nicholas Inston Representative for Birmingham & Coventry

ACTION

1 Declarations of interest in relation to the agenda – KAG(18)1
There were no declarations of interest.

2 MINUTES OF THE MEETING HELD ON 7th June 2018– KAG(M)(18)1(Am1)

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

2.2 Action points – **KAG(AP)(18)2**
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.

The Scottish bill for Opting Out has been published and it is anticipated this will come into force by April 2020. The English Opt Out legislation has past the Commons and has now moved to the House of Lords where a debate took place on 23rd November; no amendments were made. A committee debate will take place in December and if there are amendments suggested, it is likely the legislation will be timed out for this Parliament. Impact assessments have been completed for both legislations which has suggested the requirement for additional resources for communications, retrieval and novel technologies.

The donor characterisation strategy is moving forward with a potential solution regarding the issues with the HLA laboratories and microbiology laboratories.

A separate working group including representation from all advisory groups has been put together to consider HCV positive to negative transplantation. The direct acting anti-viral agents are available in Scotland and Wales for this but no agreement yet is forthcoming by NHS England. Centres will be asked if they would consider organs from HCV positive donors to HCV negative recipients.

Regional meetings will be held to discuss sustainability and to identify the resource required to move forward. The first meeting will be held in London beginning on 28th November and will be rolled out more widely across the country.

3.2 Update from Risk and Consent Working Group
The Risk and Consent working group is a joint project involving NHBST and the British Transplantation Society (BTS). The aim of this project is for the organ specific working groups to produce a quantum of information that should be delivered to patients who go on the waiting list. The Winton Centre is involved to develop an interface which will be available on the website for clinicians and patients to use.

ACTION

A Barlow advised the tacrolimus brand managers are interested in funding aspects of transplantation, particularly involving consent and decision-making tools. L Marson, President of the BTS felt this should not be an industry labelled project, a point agreed by all.

3.3 Governance Issues

3.3.1 Non – compliance with allocation
There have been two incidents raised where patients were potentially at a disadvantage (refer to item 5.3). These incidents are being investigated.

3.3.2 Incidents for review: KAG Clinical Governance Report – **KAG(18)29**
J Forsythe presented the Governance Report received from J Dark.

INC-3173 - was raised at PAG where it was emphasised the anatomy of the kidney must be reported to the transplanting centre as soon as possible to help increase utilisation of the pancreas.

INC-3281 - The transplant centre requested an additional donor microbiology test to be carried out as a result of new post donation information, however the request was made against the incorrect donor number. The centre has since formalised a better handover procedure when they have multiple donor organs.

3.3.3 Summary of CUSUM monitoring of outcomes following kidney transplantation – **KAG(18)30**
A CUSUM summary paper was received.

Since June 2018 there has been four CUSUM signals in kidney transplantation.

Two 30 day graft failures were identified, one at the Royal Free Hospital and one at Newcastle Hospital, however there were no underlying issues identified. There was a 30 day patient mortality at Cardiff and Liverpool, though no underlying issues were identified.

J Forsythe reassured members the usual CUSUM response process was followed and all CUSUM signals are raised at each Advisory Group meeting.

3.4 Hub update
B Hume provided an update on behalf of Hub Operations.

IT developments have commenced for the new Kidney Offering Scheme which will be completed in January 2019. The Pancreas Allocation Scheme will be completed in March 2019 and the schemes will be tested together for a period of eight weeks. A launch date will begin in early June.

4 Positive virology and HLA typing – KAG(18)31
Raised at the last KAG meeting was the increase in out of hour calls to the regional managers, requesting permission to fast track a set of kidneys without HLA type where there was positive virology of the donor. An agreed action to bring to this meeting was the data to quantify how often positive virology kidneys are offered and accepted and the details of the positive virology.

Of the 27 positive virology cases, one was offered without the HLA.

ACTION

It is therefore proposed in the exceptional cases where HLA is not available at the point of offering, to fast track kidneys without HLA type, where there is a positive virology of the donor, and offer on a first come first served basis via the positive donor virology scheme to avoid delay.

C Watson added that NHS England are yet to agree funding for the treatment for HCV positive organs which may alter the way these organs are offered. J Gulliver confirmed this is not yet at the approval stage.

No objections were received to fast track the infectious risk kidneys before the HLA is available.

C Callaghan asked which centres preformed the transplants from donors with positive virology. Once the centres have been identified, C Watson will write to the centres and suggest they present their data at a national forum. **L Mumford** **C Watson**

5 Allocation

5.1 Proposed change to the Kidney Offering Scheme – **KAG(18)32**

The proposed offering scheme was disseminated for final consultation in April 2018 and agreed final sign off at the Kidney Advisory Group in June 2018. Concerns were raised at the Kidney Patient Group and during UK kidney week regarding the length of time older patients must wait to receive a high-risk kidney.

An additional ten simulations were considered to alter the HLA and age term points to offer alternative suggestions to allow older patients a slightly reduced waiting time.

The final proposal was taken to the KAG Paediatric Sub Group as this alteration will have a slight increase in waiting time for paediatric patients.

The concern was raised that this proposal will benefit patients who are least likely to gain a survival benefit. C Watson reminded members that there is an increased chance older patients will die on the waiting list waiting for a transplant, therefore this will be a better survival rate for the older patients from the point of listing.

L Mumford will circulate the national survival benefit to members. **L Mumford**

K Preston suggested clear justification is required for younger people having to wait longer for a transplant. L Mumford confirmed the increase for younger patients waiting is approximately 22 days.

J Asher suggested emphasising within communications for a patient to be eligible for a transplant they must have 50% 5 year survival post transplant.

Members agreed with the proposed scheme, however acknowledged the need for good communication for the justification of the changes.

5.2 Waiting time from start of dialysis – **KAG(18)33**

In 2014 it was agreed at KAG that the waiting times should be calculated from the patient's date of starting dialysis to increase equity for patients due to the differences in listing practices across UK.

During February, March and April 2018, ODT Hub Information Services manually back dated waiting time points from the start of dialysis for patients

ACTION

on the national kidney waiting list which continued for patients joining the list between May and August. A system implemented by IT means this will now be automatically calculated when a patient is registered on the waiting list.

The change has resulted in a 13% reduction in patients receiving a pre-emptive transplant. Concern was raised regarding pre-emptive listing and the time it takes for a patient who is pre emptively listed to start dialysis as the policy states the patient should require dialysis within 6 months of being listed. NHSBT does not collect dialysis start date post registration, however the Renal Registry does, but the data captured is between 12 and 18 months behind what is required. This information should be available and presented at the next KAG meeting.

L Mumford added the median time between pre-emptive listing and pre-emptive transplantation is 235 days.

5.3 Liver and Kidney registrations – **KAG(18)34**

A paper was received following concerns raised about 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. This paper shows the impact of the change.

Since the new National Liver Offering Scheme was introduced, this has altered how the livers are offered with the kidney which has resulted in a reduction in liver and kidney transplants. The overall active and suspended patients on the waiting list has fallen by 27.

Four high priority kidney patients were ranked 2 – 5 on the matching runs and did not receive an offer of a kidney. Potentially 2 of these 4 patients were disadvantaged and could have been transplanted but for a clerical error, therefore an incident has been raised at NHSBT and further training will be undertaken.

J Forsythe requested further clarification on how the incidents occurred. L Mumford advised the kidney was offered with the liver before the kidney matching algorithm is run and, although it is in the kidney policies, ODT Hub Operations must remember to offer the kidney back to any high priority kidney patient if there are two or more on the kidney run. C Watson suggested this is something which should be automated. L Mumford added ODT Hub Operations are moving towards an interactive matching run which B Hume confirmed will be implemented for three organ groups in March 2019.

J Asher suggested as an interim measure to incorporate a free text box to tier A. **L Mumford**

5.4 Choice of kidneys for pancreas and kidney recipients

Discussed and agreed at the KAG meeting in June 2017 was that the centre with the recipient who has the most points on the national kidney allocation scheme would receive the left kidney; the centre could request the right kidney if the left kidney was deemed unusable or if they were accepting on behalf of a paediatric recipient, a highly sensitised patient, or a patient who has been on the waiting list for over 5 years.

ACTION

C Watson requested that representatives relay this information to their centres again. **All representatives**

5.5 Priority for the contralateral kidney when the kidney allocated to an SPK is unusable
Agenda item covered under item 5.4.

6 Review of infant donors < 2 years – KAG(18)35

Following recommendations from a short term working party in 2017, a proposal was accepted at the Kidney Advisory Group in June 2017 that Leeds and Guy's will be the national centres for implanting kidneys from small paediatric donors (under 2 years of age). This proposal was implemented in November 2017.

11 *en bloc* kidneys were offered from donors under the age of 2 years in the last 12 months. Of the 11 *en bloc* kidneys offered, 6 (55%) were accepted and transplanted. Two are reported as functioning, one failed on day 0 and three currently have no follow-up reported. Some transplants took place outside of the two designated centres.

C Watson asked C Callaghan and T Augustine for an update regarding the transplants which took place where no follow up has been obtained.
C Callaghan reported the kidney recipient at Guy's is doing well. T Augustine advised of the 3 transplanted in Manchester, one recipient who was pre-dialysis is doing well and the kidneys are perfused and the GFR is improving. Unfortunately, for another recipient one kidney thrombosed the next day and for the third recipient the kidney functioned for 14 days but later ruptured.

K Preston expressed concern that practices have deviated from the recommendations made by the working group, with different centres performing the transplants and highlighted that reporting follow up is essential. C Watson agreed with the concerns raised. L Mumford advised NHSBT only receive information from the 3 month follow up form which is usually received around 4 months post transplant.

A Barlow raised concern from Leeds previous experience that 5 out of 16 transplants from donors under 1 month of age had failed early which suggests this practice cannot be supported. He therefore asked whether a limit should be considered, and only kidneys over 1 month be offered.
C Watson advised it had been agreed that those kidneys could be fast tracked, but this did not seem appropriate given the results.

Members suggested for C Callaghan, A Scales, A Barlow and K Preston to go through the agreed system to ensure communication of this is correct. **C Callaghan / A Scales / A Barlow / K Preston /**

C Watson requested more information regarding why the donors weren't referred to and by the nominated specialist centres. **L Mumford**

7 Update on A2 donors for B recipients – KAG(18)36

N Mamode presented a paper proposing that a pilot scheme be undertaken for the use of Blood Group A2 deceased donor organs for Group B recipients, with centres and patients deciding whether to enter the scheme. The aim of this is to improve access to transplants for ethnic minority groups where Blood Group B is more common.

ACTION

G Jones raised concern regarding the logistics of keeping Blood Group B patients' antibody titres suitably low. A McLean advised that this was trialled in London where administrative issues were experienced and it also identified sharp rises in anti-ABO antibodies in blood group B patients following a septic episode.

L Mumford advised this has been modelled and the outcome suggested it did benefit highly sensitised blood group B patients, however the blood group A donors were not always being typed for A2 across the country.

J Gulliver was asked as some patients may experience acute humoral rejection whether NHS England would support treating those small group of patients with eculizumab. J Gulliver advised this is something which would have to be considered.

L Burnapp suggested considering this for blood group A non-directed altruistic donors that are matched within the kidney sharing scheme and therefore only require managing the recipient side.

N Mamode / G Jones / A Barlow / A Bagul / L Burnapp / J Dudley

C Watson requested an implementation group to look at the issues raised and within the paper. N Mamode, G Jones, A Barlow, A Bagul, L Burnapp together with a member from Birmingham and a member from KAG PSG will take this forward and feedback at the next meeting.

8 Statistics and Clinical Studies update – KAG(18)37

An update from Statistics and Clinical Studies was received.

L Mumford has been appointed to Head of ODT Studies and colleague Helen Thomas as Head of Clinical Trial Statistics.

M Robb will be taking over as statistical lead for kidney transplantation.

L Mumford and Chloe Brown received the Research and Development award for best translation of research into clinical practice for developing the Kidney Offering Scheme.

9 Small renal masses and NORS teams – KAG(18)38

A paper originally presented at the National Retrieval Group (NRG) detailing the recommendation for how the retrieval teams should preform biopsies of a small renal tumour noted at the time of retrieval. The aim is to avoid future incidents regarding an incision being made into a tumour in the first kidney, then using the same equipment to pack the second kidney and thus contaminating it resulting in both kidneys being discarded.

10 CIT and XM practices – KAG(18)39

A paper was received and presented by C Callaghan regarding an DBD donor kidney transported to centre a 100 miles away. The Hub was notified that the cross match was positive. The organ was then offered on to Guy's for a paediatric patient but was declined due to prolonged cold ischemic time. The organ was entered into the kidney fast track scheme (KFTS) and the organ was accepted and transplanted by the fourth centre. C Callaghan questioned whether this could be avoided by a centre doing a cross match on peripheral blood from the donor before the kidney was removed.

A survey of all 21 UK H&I laboratories linked to kidney transplant units was performed in October 2018 asking about the capacity of laboratories to

ACTION

complete a peripheral blood lymphocytes (PBL) cross match. The results show the majority of laboratories can complete these cross matches out of hours, however the data shows it can take laboratories up to 4-6 hours. The response also suggests the clinicians are making the decision to request a PBL/LN cross match, not the laboratories.

In light of this variation between units, KAG was asked to consider if specific national guidance was required to get peripheral blood cross matching, and, if so, how best to take these issues forward.

N Diaz-Burlinson advised Manchester does not complete the PBL cross matches since a splenic lymphocyte cross match is preferentially performed for a highly sensitised patient due to the better sample quality.

It was also noted that the absence of a full donor HLA type may necessitate a formal crossmatch where, for example, DP antibodies existed.

S Fuggle noted that DP typing will be part of the new offering scheme and is available for most donors, and stressed the importance of the DQ typing both of which should be included within the offering algorithm as soon as possible.

T Brown raised concerns for Northern Ireland where PBL would need to be flown to the local laboratory and noted the impact this has on DCD cold ischemia time, and the substantial financial impact of transporting samples. C Watson noted that once full donor typing is rolled out and built into the offering scheme there will be fewer issues. G Jones suggested storing serum for highly sensitised patients in the mainland laboratory to which PBL samples could be shipped more readily.

J Chalker added it is necessary to have a clear policy built into the process to ensure the additional samples are available.

KAG fully support the requirement for national guidance. C Watson requested C Callaghan, S Fuggle and N Diaz-Burlinson to devise a set of guidelines available by the next meeting which would sit within professional guidelines. **S Fuggle / C Callaghan / N Diaz-Burlinson**

11 KAG STWG offer scrutiny schemes – KAG(18)40

The report of a short term working group was considered; the group had been set up to examine the following:

1) how to categorise responses from centres to letters querying organ utilisation decisions
2) defining a 'trigger' to take the next step in the process
3) deciding what the next step in the process should be, if there were recurrent concerns about organ utilisation decisions in some units
4) oversight for any process
5) 'duty of candour' issues for units, i.e. the need to retrospectively inform patients if there were concerns about organ utilisation decisions

R Hilton asked for an example of the categories and how these are defined. C Callaghan advised they proposed system of a red, amber and green responses.

G Pettigrew asked how often this is an issue. C Callaghan advised a letter is sent 3-4 times a month.

Discussion took place regarding duty of candour. J Forsythe clarified that feedback from patient representatives and lay member representatives suggested that patients do not want to be advised of every offer. However, if an offer was declined due to lack of resources, patients must be made aware. This had also been raised at the Transplant Policy Review Committee (TPRC) where it was resolved to include a statement in the policy ensuring duty of candour to patients is fulfilled. **ACTION**

To take this forward a code of practice has to be agreed and a group to implement this. C Watson requested C Callaghan, J Mackisack and other volunteers to contact C Callaghan to draw up an appropriate code breach of which would result in further investigation. **C Callaghan / J Mackisack /**

12 Organ imaging pilot

C Callaghan updated KAG with the progress made on kidney imaging at retrieval which had been delayed due to issues with sending images securely, issues which had now been resolved by IT.

The Pancreas Advisory Group had requested to implement the pancreas imaging pilot at the same time as kidney. Due to the delay in implementation, retraining of the SNODs on taking images is required and this affords the opportunity to implement both pancreas and kidney imaging together in Spring 2019.

C Callaghan will liaise with R Ploeg to develop an SOP for pancreas. **C Callaghan / R Ploeg**

13 Analyses of kidney CITs and outcome – KAG(18)41

M Ibrahim presented a report of the impact of cold ischemia times (CIT) on DBD and DCD donor kidney transplant outcomes, and to investigate how often organs are declined due to perceived prolonged CIT.

Since the introduction of the 2006 Kidney Allocation Scheme, CIT has been reducing and in 2017 only 20% had a CIT greater than 18 hours with 40% having a CIT of less than 12 hours.

A Barlow highlighted the graph suggests there is not a significant difference for DBD donor kidney transplant outcome between 18-24 hours and over 24 hours. M Ibrahim confirmed 12-18 hours produced a better outcome than 18-24 and over.

M Ibrahim advised the delayed graft function data has not be analysed. Primary non-function rate was looked at and confirmed less than 3% of all kidney transplants suffer primary non-function.

C Callaghan noted a slight caveat within table 2 and advised further work will take place analysing this data.

G Pettigrew asked for clarification for the impact of DRI – more marginal (higher DRI) kidneys would be expected to be more susceptible to longer CITs, however this was not the case. M Ibrahim confirmed this is correct and this was analysed over time. L Mumford advised within figure 5 that 75% of the D4 kidneys are around 18 hours CIT.

L Mumford advised although not stated in this paper, 5% of DCD kidneys were transplanted using novel technologies. C Watson suggested those data must be captured.

ACTION

C Callaghan added this data could be interpreted in several ways, however advised kidneys should be transplanted as soon as possible particularly if more than one offer is made. Additionally, these data imply kidneys are being declined due to longer CIT, L Mumford added the median time between pre-emptive listing and pre-emptive transplantation is 235 days.
but the aim of this paper is to provide centres with the confidence within selected recipient groups to transplant kidneys with longer CIT.

14 PITHIA trial

G Pettigrew presented an update on PIHTIA.

This started in October 2018 and the 4 centres who will receive access to the service are Belfast, Glasgow, Coventry and Portsmouth. This will be rolled out to another 4 centres from March 2019.

15 International Kidney Outcome Comparisons

R Johnson gave a presentation on International Kidney Outcome Comparisons based on a paper published earlier in the year using an analysis from the UK, Australia, New Zealand and the US.

The analyses took place on 380,000 recipients focusing on graft failure rates across the continents. Over a period of 27 years, follow up is available until 2014 for the kidney only transplants.

The UK short term graft survival rate was not as good compared with Australia who had the best outcomes at 1 year, however long term graft survival identified the US as the outlier. The data highlighted improvement in graft survival over time and the short term graft survival improved across the continents.

J Dudley asked if analyses had taken place for patients with diabetes vs non-diabetes. R Johnson advised this was examined and the results are consistent.

J Asher suggested one of the reasons longer term outcomes are not as good in the US is the affordable health care.

R Johnson advised the length of time for dialysis was not considered.

16 Developments in IT

16.1 Organ quality eForms update

J Asher gave an update on the organ quality replacement forms.

A pilot electronic HTA-B form will begin for pancreas in December and the development of HTA-A form is scheduled to start in April 2019. The pilot is to ensure clinicians are able access the form. The new HTA- B form will integrate the retrieval surgeon and transplant surgeon's assessment of anatomy, quality and damage.

The additional fields incorporated for kidney will be improved recording of when the kidney was moved onto ice.

The biggest change to the prototype is the questions regarding anatomy which has been rephrased and will allow additional fields to appear as relevant.

L Mumford added additional information will be recorded for NRP and machine perfusion. **ACTION**

J Dudley requested paediatric representation is part of this group. J Dudley will ask KAG PSG for a volunteer and get back to J Asher. **J Dudley**

17 Living Donation

17.1 UK Living Kidney Sharing Schemes: Update and monitoring report – **KAG(18)42**

A paper was produced providing an update on the impact of continuous improvements within the UK Living Kidney Sharing Schemes (UKLKSS).

The report identifies since May 2018, 26 non-directed altruistic donors have donated a kidney, 12 (46%) initiated an altruistic donor chain and 14 donated directly to the National Transplant List and the minority of those previously stated a preference.

Since July, no exceptions have been made for non-directed donors expressing a preference to donate to the list instead of donating to a chain.

There were 18 non-directed donors registered in the October matching run which is the highest number to date. Of those, 16 were matched and therefore 43 transplants were identified which accounted for 51% of all transplants.

Concerns have been raised due to non-simultaneous surgery and the impact of non-proceeding transplants. Intervals between exchanges has dramatically reduced and most have been discussed with L Burnapp prior to scheduling and referred to Chair of KAG as necessary. 13 transplants were identified from 5 non-simultaneous exchanges since the last report to KAG.

There has been no request for recipient prioritisation for transplant from the April or the July matching run, however questions have been raised to consider what may happen if non NHS entitled patients, including those from the private sector were involved in exchanges and if a recipient from the private sector were to miss out from a transplant within the scheme due to problems with the paired donor, what would be offered to that recipient.

L Burnapp highlighted an incident has been reported within the sharing scheme which is currently under investigation and the outcome will be reported back at the next KAG meeting.

A survey has been sent to centres when there has been non-proceeding transplant to improve centre-specific data and feedback. 97% of surveys have been completed and a quarter of cases identified through self-reporting could have been prevented.

In summary, the improvements to the scheme have been successful. The following recommendations were approved by KAG:

A donor decline report will be sent out quarterly to each transplant centre to encourage local/regional review and action.

If centres do not positively confirm the acceptance of complex donors for potential recipients following the pre-matching run, those donor-recipient combinations will be excluded from the matching run to avoid late withdrawals after transplants have been identified.

ACTION

If non-directed donors request to donate directly to the national transplant list instead of into the UKLKSS, such requests will be sent to L Burnapp for consideration by the Chair of KAG.

The recommendation within this paper proposed that non-entitled NHS/private patients who wish to participate with their donors within this scheme are not given prioritisation if they were to miss out on transplant.

After a lengthy discussion and divided opinion, the advice from KAG is not to include such patients within the sharing scheme given that there were ethical concerns about the absence of mechanism in place to offer such prioritisation on the National Transplant List.

17.2 ABO blood group incompatible transplants in the UK Living Kidney Sharing Scheme – **KAG(18)43**
M Robb presented an update on ABO incompatible (ABOi) and HLA incompatible (HLAi) transplants within the kidney sharing scheme. It is now felt that the potential benefit of ABOi transplantation through the scheme should be further explored and perhaps practised more widely.

Using the 2018 October matching run, 85 potential transplant were identified and if excluding ABO would result in losing 1 transplant. On allowing ABO transplants, this would identify 120 transplants (40%) increase.

C Watson suggested an implementation group is set up to discuss logistics and feedback at the KAG meeting in June. **L Burnapp**

18 KAG Paediatric Sub-Group

18.1 Report from KAG Paediatric Sub-Group: 17th October 2018 – **KAG(18)44**
J Dudley reported on the main points of discussion from the KAG Paediatric Sub Group teleconference.

Members of the Paediatric Sub Group supported the proposed changes to the Kidney Offering Scheme.

The first draft of the initial manuscript of ATTOMIC is available.

A project looking at harmonisation of transplant immunosuppression is taking place to identify the variety used across centres within the UK

18.2 National Consent Form – **KAG(18)45a & KAG(18)45b**
The final draft of the national consent forms for paediatric kidney transplantation has been circulated. These forms were signed off by the KAG PSG in October.

J Dudley requested endorsement by NHSBT. J Forsythe would be happy to support this, however applying a logo can be a lengthy process.

J Forsythe suggested liaising with Matthew Wellberry-Smith who is leading on kidney within the risk analysis and communication working group which is taking place to ensure there is no duplication of work.

J Asher highlighted the forms do not mention donor transmitted disease or donor transmitted malignancy.

ACTION

N Mamode suggested including the ability to add free text to include specific things for specific patients.

19 Pancreas Advisory Group

19.1 Report from Pancreas Advisory Group: 15th November 2018
J Casey reported on the main points discussed at the Pancreas Advisory Group meeting (PAG).

As part of the new IT platform, it was agreed to introduce appropriate changes to Pancreas Allocation Scheme to bring in line with the changes made to the Kidney Offering Scheme. Tier A of the Pancreas Offering Scheme will include highly sensitised patients and be the same as tier A of the kidney scheme; the BMI exclusion criteria has been amended.
PAG agreed that pancreases would not be offered via the fast track scheme if the cold ischemia time of potential fast track offers was more than 8 hours.

20 **KAG representation on QUOD to replace C Callaghan**
QUOD is a national consortium which discuss national bioresource and requires representation for all advisory groups.

C Callaghan will be stepping down as KAG representation for QUOD and C Watson requested representation from another member. J Asher volunteered to represent KAG. **J Asher**

21 **Special request – KAG(18)46**
C Watson received a letter from a Nephrologist requesting special listing for a patient who they felt falls outside of the standard listing criteria.

The request received was for compassionate listing to allow the patient to have a kidney transplant. The patient had a GFR just over 20 so was not eligible to be listed. However they wished to start a family and could not do so at the level of renal function they had. After a long a detailed discussion it was acknowledged that this was a common scenario, and also that there were scenarios other than pregnancy that could be argued fell into the same category. It was therefore agreed that such compassionate listing could not be permitted in the index patient's case as it would set a difficult precedent.

J Gulliver suggested this may not be the decision for KAG to decide and highlighted any application for a special request requires an individual funding request submitted to NHS England to guarantee fairness to patients who fall within a similar cohort. J Forsythe clarified that in fact NHSBT has a statutory role for allocation of organs and therefore it was very much a decision for KAG.

22 **Any Other Business**
L Burnapp highlighted that the company (GEE) who supplies isotope used for measuring donor GFR are ceasing trade in December. Oncologists who mainly use this are moving towards using DTPA. A short term working group will consider the implications and dissemination of information and if there is a requirement to adapt existing guidelines. This information will be available in the quarterly newsletter.

A Barlow requested clarification that if a local centre and screening centre declines an offer should those organs not be offered, as they are being offered via fast track. A Barlow will forward the occurrences to B Hume. **A Barlow**

ACTION

It was acknowledged Leicester's offer decline rate has significantly reduced and the centre's representative was congratulated on the hard work in achieving this.

C Callaghan encouraged units and individual surgeons to register and accept fast track offers; currently only half of all centres accept fast track offers and a third of all deceased donor kidneys are offered through the fast track scheme.

23 Date of next Meeting:
Monday 10th June 2019, 10.30am at 12 Bloomsbury Square, London

24 FOR INFORMATION ONLY

24.1 Transplant Activity report: October 2018 – **KAG(18)47**
Noted for information.

24.2 QUOD statistics 2018 – **KAG(18)48**
Noted for information.