NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

THE FORTY SEVENTH MEETING OF THE KIDNEY ADVISORY GROUP
ON THURSDAY 18th JANUARY 2024
VIA MICROSOFT TEAMS

MINUTES

ATTENDEES

Rommel Ravanan	Chair, Kidney Group Advisory
John Asher	Glasgow Representative
James Barnes	Birmingham Representative
Katy Brady	Recipient Coordinator
Chloe Brown	Senior Statistician, Statistics and Clinical Research, NHSBT
Jo Chalker	Regional Manager & SNOD Representative, NHSBT
Andrew Connor	Plymouth Representative
Aisling Courtney	Northern Ireland Representative
Ian Currie	Associate Medical Director, Organ Retrieval, NHSBT
Hatty Douthwaite	Nephrology Trainee Representative
Jack Galliford	Bristol Representative
Abbas Ghazanfar	St George’s Representative
Paul Harden	Oxford Representative
Heidy Hendra	Nephrology Trainee Representative
Dela Idowu	Patient Representative
Maria Jacobs	Statistician, Statistics & Clinical Research, NHSBT
Helen Jones	KAGPSG Representative
Katrin Jones	Newcastle Representative
Avneesh Kumar	Sheffield Representative
Makis Laftsidis	Royal Free Representative
Debbie Macklam	Head of Service Development, Commissioning Team, NHSBT
Sanjay Mehra	Liverpool Representative
Zia Moinuddin	Manchester Representative
Pramod Nagaraja	Cardiff Representative
Jonathan Olsburgh	Guy’s Representative
Laura Pairman	Recipient Coordinator Representative
Gavin Pettigrew	Chair of Research & Development Steering Group
Paul Phelan	Edinburgh Representative
Benedict Phillips	Surgical Trainee Representative
Sam Richards	Statistician, Statistics & Clinical Research, NHSBT
David Roberts	Medical Director for Pathology and Clinical Lead for Genomics, NHSBT
Matthew Robb	Principal Statistician, Statistics & Clinical Research, NHSBT
Debabrata Roy	Coventry & Warwickshire Representative
Aamer Safdar	Lay Member Representative
Cinzia Sammartino	Royal London Representative
Shaminie Shanmugaranjan	Senior Statistician, Statistics & Clinical Research, NHSBT
Smeeta Sinha	National Clinical Director for Renal Services, NHSE
Olivia Shaw	BSHI Rep
Rupesh Sutaria	Portsmouth Representative
Nick Torpey	Cambridge Representative
Madeleine Vernon	Leeds Representative
Julie Whitney	Head of Service Delivery, ODT Hub Operations, NHSBT

Michelle Willicombe HLA selected red cell working group Representative

IN ATTENDANCE

Alicia Jakeman Clinical Support Services, NHSBT
Cherrelle Francis-Smith Clinical Support Services, NHSBT

APOLOGIES

R Battle, E Billingham, L Burnapp, F Dor, P Harden, L Karamadoukis, D Manas, P Mason, M Stokes, J Stoves, D Van Dellen, A Wrigley

ITEM		ACTION
1	**Declarations of interest in relation to agenda**	
	There were no declarations of interest from members.	
2	**Minutes of the meeting held on 11th October 2023 - KAG(M)(23)03**	
	2.1 Accuracy	
	The minutes were agreed as an accurate reflection of the meeting held on 11th October 2023.	
	2.2 Action points - KAG(AP)(23)03	
	AP2 - Suspended patients review R Ravanan advised that him and D Manas met up with two units who had over 50% suspensions. J Olsburgh and Z Moinuddin thanked R Ravanan and D Manas for attending recent meetings with their colleagues, confirming a new review process, including increased collaboration with their referring surgical centres to streamline the pathway to reduce numbers. **AP3 - Waiting time credit for non-UK dialysis start- Waiting time credit KAG(24)01** R Ravanan advised that, following on from discussions in the last KAG meeting, on non-UK citizens and the accurate recording of the dialysis start date for those patients starting dialysis out of the UK, he had met with D Manas and the NHSBT Legal Team. Relevant paper was circulated to members prior to the meeting. With members having read paper **KAG(24)01**, they made a unanimous decision that the dialysis start date in the UK is used as the accepted definition for 'dialysis start date' for all patients for the purposes of joining the UK deceased donor transplant waiting list. POL186 will be changed to reflect this change.	**R Ravanan/ C Brown**
	2.3 Matters arising, not separately identified	
	There were no matters arising.	
3	**Medical Director's Report**	
	R Ravanan provided an update on behalf of D Manas - Varuna Aluvihare is the new Liver Advisory Group Chair with Steven Masson appointed as Deputy Chair and Anya Adair is the new Surgical Lead. He thanked Tracey Rees for her contribution whilst in post as Chief Scientific Officer at NHSBT. He advised that Jen Lumsdaine has been appointed as Living Donor Support Clinical Lead upon Lisa Burnapp's retire and return. There are minimal funds available for 2023/2024 and 2024/2025. Lead CLUs have been funded. Local CLU funding will end mid 2024 with negotiations ongoing Histopathology has been funded for 2024/2025 and will be up and running from March 2024 – the service will cover exclusion of malignancy only (and not kidney quality assessment). G Pettigrew invited members to a meeting on 14th February 2024 to discuss the	

	results from the PITHIA Trial. Workforce shortages have affected paediatric transplantation predominantly in the Midlands. RINTAG has been disbanded, with Gavin Pettigrew appointed as Chair of the new Research & Development Steering Group. R Ravanan reiterated the message for Clinicians to register for TransplantPath.	
	3.1 ODT Hub update	
	3.2 HTA B Forms/Dashboard	
	J Whitney advised that the HTA B forms are being returned very well. There are 29 living forms outstanding from 2020. There is a significant backlog of three-month follow-up forms, with centres now having up to 41 forms outstanding. She thanked centres for recently completing these forms to reduce their backlog. She advised that another round of chasing will take place in four weeks for those centres with over 15 forms outstanding, as this impacts on reporting CUSUMs for their centres.	
	3.3 Sustainability and Certainty in Organ Retrieval (SCORE)	
	D Macklam presented details on the SCORE. Key area of focus is increasing efficiency across the whole pathway, over several workstreams. She asked all members to engage in SCORE scoping/definition in advance of the next KAG meeting and to share feedback via the SCORE@NHSBT.nhs.uk email address. She will provide her slides for circulation to members. I Currie presented information of the times of reperfusions on DBD abdominal organs between 2011 and 2021, proposing to move a quarter of transplants from overnight to daytime. The next KAG meeting scheduled for 16th April 2024 will be re-purposed to discuss and provide feedback to SCORE team and be open to clinical members of KAG from all 23 adult centres and KAG PSG members. R Ravanan asked members to share this information with their clinical colleagues with the recommendation each unit is represented by at least one surgeon, one nephrologist, one coordinator and H&I scientist.	**All** **D Macklam** **All**
	3.4 TransplantPath	
	J Whitney reminded members to request an account ready for go-live. She confirmed that there will be no option to pdf with the new system. J Asher requested information on centre specific data on who had already requested a TransplantPath account to help target clinicians who needed to be chased.	**J Whitney**
4	**Use of flights**	
	J Whitney proved an update following a recent email circulated to centres. There have been recent pressures with access to flights to transport organs. NHSBT have implemented a process to improve efficiency where two flights have been booked for the same donor or where three flights are booked within six hours of each other, to ensure we are maximising the use of resources where possible.	
5	**Live donor update - KAG(24)02**	
	M Robb provided an update on behalf of L Burnapp. He summarised that activity has remained stable with local constraints contributing to the plateau in activity. He reiterated that there is still a delay in centres reporting, with a three-month delay. He asked centres to continue to submit accurate data within seven days of surgery. Data detailing reasons for non-proceeding transplants from April 2023 to August 2023 MRs, highlighted that of 21 survey requests, there were 17 responses. 13 centres reported reasons that could not have been foreseen, whilst 4 centres reported avoidable causes and identified remedial actions. There were no offers to paediatric recipients of unmatched NDAD	**All**

	kidneys in the UKLKSS in 2023. He confirmed that a working group for the International Collaboration in Kidney Exchange Programmes will soon be convened. M Robb raised discussion on a query by a private sector hospital about the reoffering of a directed living donor kidney if it is retrieved in the private sector and cannot be implanted into the intended recipient. In section 4 of the Living Donor Kidney Transplantation Policy (POL 274, latest version https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/31150/pol274.pdf) there is provision, approved by KAG, for reoffering of directed donor kidneys in this situation within the NHS, to an identified local recipient. He asked members to approve the change within the policy to: 'In the event that a directed kidney retrieved in the private sector cannot be transplanted into the intended recipient, the following options could be considered: If the private sector organisation is associated with a NHS centre, a local recipient could be identified within this NHS centre, provided that complete donor information can be provided to inform the local offering process in the recipient centre. If the private sector organisation does not have an associated NHS centre, the kidney could be offered to a nearby NHS centre (as above) with same requirements for the accompanying information to inform the offering process in the recipient centre'. This was approved unanimously by KAG Representatives and will go to the next CARE Meeting for their approval. M Robb reported that in October 2023, the British Transplantation Society (BTS) published guidance on *'APOL 1 testing in potential living donors'* https://bts.org.uk/apol1-testing-in-potential-living-kidney-donors/ Since publication of the guidelines, financial pressures have meant that funding for all additional tests, including APOL1, previously approved for inclusion in the Nov 2023 iteration of 'National Genomic Test Directory', have been deferred for consideration until April 2024. Consequently, concerns have been raised that the clinical best practice guidance recommends APOL 1 testing in identified individuals (as above) but there is currently no provision for testing in the UK. This should go-live by spring/summer 2024. KAG representatives are asked to ensure that clinical colleagues are aware of the guidance and the interim advice about access to APOL1 testing pending further notification of the availability of testing in the UK. M Robb reported that NHSBT continues to work with the Human Tissue Authority (HTA), as the regulator, and others (Department of Health, Visas and Immigration, Police, National Crime Agency) to ensure that appropriate safeguards are in place to facilitate legitimate living donation and to support clinicians and patients with updated advice and guidance. NHSBT have provided interim guidance for patients and healthcare professionals at www.organdonation.nhs.uk/become-a-living-donor/ The Department of Health and Social Care (DHSC) are working towards introducing a 'Duty to Report' which will mean that all cases of travel for transplantation will have to be reported by clinicians. In the meantime, please contact the HTA for advice and guidance at transplants@hta.gov.uk regarding any matters of concern related to travel to transplantation, within the UK or outside the UK. KAG representatives are asked to ensure that clinical colleagues are aware of the work in progress and timeframes for implementation, the interim guidance and how to seek early advice from the HTA about	**M Robb** **All** **All**

	matters of concern.	
6	**Suspended patients review - KAG(24)03**	
	M Robb reported on 61 patients suspended for over 7 years as at 7th January 2024, by transplant centre. This data has been previously sent to centres. He asked all members to review their list of recipients who have been suspended for 7 years or more within 6 weeks of this meeting. Following this period for review, in the absence of a valid clinical reason to maintain patients in the suspended state, they will be removed from the list by NHSBT. There were no objections from members. He advised that approximately 20% of the WL (600-700 patients) had their first registration status as 'suspended'. There appeared to be no clinically justifiable reason for such a pathway. It was proposed that recipients are not registered with their first status as 'suspended' going forward. If agreed, a request to remove this option from the registration form will be logged at NHSBT. M Robb confirmed that these patients are not accumulating points. There were no objections other than for the group of recipients who are registered for the UKLKSS but are not to be activated on the transplant list. A further review of the implications of making this change will take place by M Robb, R Ravanan and C Brown out of this meeting. KAG members are also asked to consider a further review again in 12 months' time, where the length of suspension to be considered in the review would be reduced by 6 months so that in 2025, suspensions of over 6.5 years would be reviewed and so on. There were no objections from members. This will be capped to 5 years by 2028.	**All** **M Robb** **M Robb/R Ravanan/ C Brown**
7	**Urine dipstix - KAG(24)04**	
	M Jacobs presented the Urine Dipstick Testing paper investigating the completeness of urinalysis for deceased kidney donors and the association of urinalysis results with kidney offer acceptance and one-year graft survival, with the aim of assessing whether urinalysis results can meaningfully be used as a prognostic marker as part of organ quality assessment. In light of the analyses findings, KAG members were asked to support a recommendation for removal of mandatory urine dipstix assessment as part of deceased donor characterisation. R Ravanan confirmed that this question is to ensure that the information is used to make the best quality decision and not to decline an offer, following a request from Chris Callaghan during a review of the organ turn down process and highlighted similar findings in a recent peer reviewed publication. After extensive discussion the proposal was put to vote - 5 members voted for,11 members voted against this recommendation. In light of the voting results, urine dipstix will continue to be included in donor characterisation i.e. no change to current practice.	
8	**Governance update - KAG(24)05**	
	R Baker was not in attendance at the meeting. The Governance paper and review of CUSUM papers were circulated to members prior to the meeting. J Olsburgh asked for the Governance paper to be split into paper and Appendix for future KAG meetings.	**M Jacobs**
9	**Paediatric prioritisation since last KAG meeting**	
	H Jones reported that a paediatric prioritised patient at Evelina has been transplanted and is doing well now.	

10	**Matched blood for waiting list transplant patients - KAG(24)11)**	
	M Willicombe and D Roberts presented a proposal for the provision of HLA selected red cells for waitlist candidates and transplant recipients in the UK. M Willicombe advised that the aim of the working group is to assess if HLA selected red cells should and could be used in patients where HLA sensitisation is undesirable and blood transfusions cannot be avoided. A national steering group was proposed, M Willicombe asked KAG members to email her directly, should they wish to sit on the group. All members were in support of the proposed pilot due to be undertaken at Imperial followed by benefits analysis before more decisions made on rollout to other centres. S Sinha confirmed that NHSE commissioning for transplant does not include transfusion currently.	**All**
11	**KAG Paediatric Sub-Group update**	
	H Jones provided an update from the Paediatric Sub-Group, with dialysis capacity-demand concerns. R Ravanan had previously advised members of the workforce capacity issue earlier on the Agenda. H Jones advised that KAGPSG are looking into practice for choosing match grades to be harmonised nationally. Immunosuppression's has now been harmonised nationally, possibly moving to harmonise work-ups next with a Protocol to cover centres that buddy-up. H Jones asked members for advice on access to transplantation for refugee children. R Ravanan will speak to H Jones out of this meeting. R Ravanan advised members that the KAGPSG Chair role is out for expressions of interest.	
12	**Patient Representative/Lay Member/Recipient Coordinator update**	
	D Idowu advised members that patients have raised concerns with her over warnings in an article in the Mail Online on 7th January 2024 that the UK is on the verge of a kidney disease Public Health emergency. She questioned pre-emptive listing. She advised that patients in London have concerns on dialysis capacity and the issues on their kidney health. R Ravanan advised that he does not believe there to be concerns currently within Kidney clinicians. L Pairman and K Brady reported that no issues have been raised for discussion.	
13	**PAG update**	
	S White was not present at the meeting. The minutes from the last PAG meeting were circulated to members prior to the meeting.	
14	**CLU update - KAG(24)06**	
	N Inston had given his apologies for the meeting and provided an update, previously circulated as a paper to members.	
15	**Feedback from non-transplanting reps**	
	J Stoves and L Karamadoukis had provided their apologies for the meeting. R Ravanan provided a brief update on their behalf.	
16	**Feedback from trainee reps**	
	H Douthwaite and B Phillips were introduced as new members, they advised that they are discussing potential project ideas. B Phillips advised of a survey undertaken by 20% of 5000 surgical trainees which highlighted concern from surgical trainees about a diminishing access to training as a result of competition with physicians associates as well as safety related issues. The full report is published on Asset.org.	

17	**Any Other Business** 17.1 Imlifidase data form	
	S Shanmugaranjan advised members that no 30-day Imlifidase follow-up forms have been received by NHSBT.	
	Sam Richards, Statistician, NHSBT was introduced by R Ravanan, having produced the four-year KOS review paper with M Robb. Within the four-year review M Robb that there have been no major changes from the four-year review. He asked if members would wish for this report to be produced annually. It was agreed that this will be produced two-yearly. M Robb informed members that Rachel Johnson from NHSBT Clinical Research and Statistics is working on a tricontinental study comparing post-transplant graft outcomes, with colleagues in Australia and the US. They propose to share anonymised data with approvals in place under data sharing agreements. He asked if members had objections to sending anonymised date to Australia, no objections were raised.	
18	**FOR INFORMATION**	
	18.1 QUOD Report **- KAG(24)07**	
	18.2 PAG minutes **- KAG(24)08**	
	18.3 Annual review of offering scheme - **KAG(24)09**	
	18.4 Review of CUSUMS - **KAG(24)10**	

Date of next meeting: 16th April 2024 09:00 - 11:30 KAG SCORE meeting via MS Teams