# NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

## MINUTES OF THE FIFTY FIRST MEETING OF THE KIDNEY ADVISORY GROUP ON WEDNESDAY 18<sup>TH</sup> JUNE 2025

10:00 - 15:30

At The Wesley Hotel & Conference Venue, Euston House, 81-103 Euston Street, London, NW1 2EZ

#### **ATTENDEES**

Gareth Jones KAG Chair

John Asher Glasgow Representative

Atul Bagul KAG Deputy Chair/Leicester Representative

Richard Baker Clinical Governance Lead, NHSBT Jenni Banks Statistics & Clinical Research, NHSBT

Richard Battle
Catherine Boffa
Katy Brady

BSHI Representative
Portsmouth Representative
Recipient Coordinator, Leeds

Chloe Brown Statistics & Clinical Research, NHSBT

Lisa Burnapp AMD - Living Donation and Transplantation, NHSBT

Jo Chalker Regional Head of Nursing, NHSBT

Andrew Connor

Aisling Courtney

Dilan Dabare

Jack Galliford

Plymouth Representative

Belfast Representative

Birmingham Representative

North Bristol Representative

Oxford Representative

Nick Inston Lead CLU/Birmingham Representative

Katy Jones
Lazarus Karamadoukis
Usman Khalid
Nicos Kessaris

Newcastle Representative
Dorchester Representative
Cardiff Representative
Guvs Representative

Derek Manas Medical Director, OTDT, NHSBT
Miriam Manook Surgical Trainee Representative
Kirsty McNally Patient Safety Lead OTDT, NHSBT
Ismail Mohamed Royal London Representative
Zia Moinuddin Manchester Representative
Muir Morton Manchester Representative

Mike Nicholson Interim Chair of the ARCs Kidney National Steering Group

Laura Pairman Recipient Coordinator, Edinburgh
Matthew Robb Statistics & Clinical Research, NHSBT

Carla Rosser OTDT H&I Lead, NHSBT
Debabrata Roy Coventry Representative
Eleanor Sandhu Imperial Representative
Sapna Shah BTS/King's Representative

Jelena Stojanovic GOSH & Deputy Medical Rep. KAGPSG

Nick Torpey Cambridge Representative

### **IN ATTENDANCE**

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

## **APOLOGIES**

Lydia Ball, Raymond Braid, Chris Callaghan, Ian Currie, Hatty Douthwaite, Ben Hume, Helen Jones, Avneesh Kumar, Rose Lamb, Teresa Magirr, Sanjay Mehra, Anand Muthusamy, Sarah Plant, Aamer Safdar, Avinash Sewpaul, Smeeta Sinha, John Stoves, Madeleine Vernon, Julie Whitney, Anthony Wrigley

ITEM		ACTION
1	Welcome and Apologies. Declarations of interest in relation to agenda and responsibilities of KAG members.	
	G Jones welcomed all attendees to the second Kidney Advisory Group meeting of 2025. All members introduced themselves. The 'I have something to ask postcard' providing support for recipients asking about potential living donation was shared with members. The card was devised by Olivia Chapman in Brighton and has agreed to share the original pdf for adaptation, on the proviso that the East Sussex team is credited.	
2	Minutes of the meeting held on 29 <sup>th</sup> January 2025 - KAG(M)(25)01	
	2.1 Accuracy	
	There were no inaccuracies within the minutes of the last meeting, ratified as an accurate representation of the meeting. G Jones will document key points from this meeting, to be shared with centres.	G Jones
	2.2 Action points - KAG(AP)(25)01	
	All Action Points that were not complete from the last meeting were on the agenda for discussion today.  AP1 AP5 HTA B Forms/ Dashboard 18.10.2024	
	J Whitney was not present at the meeting to advise of the progress of this action point.  AP1 AP6 Paediatric Dialysis Capacity – Mitigation Options	
	with KOS 18.10.2024  M Robb confirmed that the changes to allocation will be in place for 18-24 months, in line with agreement at KAG meeting held on October 2024. Jelena Stojanovic commented that this change seemed to be making an impact on offers already.  AP1 AP8.7 CUSUM monitoring 18.10.2024	
	M Robb confirmed that the expected mortality and graft failure rates have been updated.	
	AP4 Waiting List Review G Jones informed members that he had heard from two centres following the review of patient suspended for greater than 5 years. Members confirmed that waiting lists had been reviewed and patients removed or reactivated with some ongoing	
	discussions with referring units.	
	A further review of long term suspended patients will be discussed at the KAG January 2026 meeting.	C Brown
	2.3 Matters arising, not separately identified	O DIOWII
	There were no matters arising.	
	2.4 KAG members and Deputy	
	G Jones thanked Atul Bagul, who has been appointed as KAG Deputy Chair.	
	2.5 Key learning points - KAG(25)09	
	An action point from the last meeting. Centres requested key	
	learning points from CUSUMs to identify common themes.	
	G Jones presented a paper on common themes and ask for brief,	
	succinct narrative reports from centres responding to CUSUM	
	requests which should include M&M discussions and what has	
	changed in units following the CUSUM requests. Frailty and vascular assessments and interaction between referring teams	
	and having an anti-coagulation protocol, scanning of the donor	
	kidney and delayed graft function and discharge and rejection	
	protocols and mentorship are common themes.	

	M Robb was asked to provide NHS number rather than NHSBT Transplant ID to make identification of patients easier. G Jones explained this may be an information governance issue but it	M Robb/ G Jones
	could be looked into.  N Torpey suggested a proforma with NHSBT data populated (including donor information) would be more helpful.  D Manas confirmed that there are 26 CUSUMs open currently.	
3	Medical Director's Report	
3	D Manas provided an update: New appointments - Carla Rosser H&I Lead, OTDT. Nick Inston is now officially appointed as the National Co-lead for CLUs. A new heart CLU has been appointed. There are plans to appoint an AMD for patient engagement following approval by SMT. A review of Lay Members and Patient Representatives is underway. Deputies for D Manas have been appointed; John Casey and Rommel Ravanan. The spending review was favourable; £3.6 million which will cover DCD Hearts, CLUs, ARCs and ANRP. A Programme Board has sub-groups for each organ. ARC steering groups - Interim Leads have been appointed for Liver, Kidney and Lung. Formal interviews will take place soon. Histopathology issues continue with a business case raised, NHS England refuse to pay histopathology staff with a pay freeze in place. This remains a patient safety issue. The formal NLOS review is almost complete. G Jones updated on collaboratives with a national meeting for the six collaboratives next week, to understand the workstreams. Three liver collaboratives have been established and a meeting will take place this year.	
	A Paediatric kidney transplant collaborative is being considered alongside NHSE work on Networked Models of Care. Cardo-thoracic North and South collaboratives will be created. D Manas also advised of a change in commissioning with a Transplant Oversight Group created to look at quality and emerging concerns. DCD donor consent remains low, having met with international colleagues discussions are continuing. OUG work continues. A pre-donation CT scanning working group has been set-up having had one meeting.	
	3.1 ODT Hub Update	
	J Whitney was not present at the meeting.	
	3.2 SCORE	
	J Whitney was not present. D Manas advised that this is progressing well. The offering and retrieval windows will change, with centres raising concerns on availability of theatre/anaesthetic support during the day. D Manas asked for centres to email Sarah Beale if they have concerns.	
	3.3 ARCs Programme: Kidney Workstream Proposal - KAG(25)10a, b	
	M Nicholson shared his presentation with members, providing an update with a plan to provide a national service. There is a 5-year strategy to develop the programme. A business case will be submitted to DHSC to introduce the national service. The ARC concept will collaborate across all organs.	

	The Kidney ARC pathway is under development and it is likely that organs will be considered for ARCs if not accepted after fast track. The final flow of organs has not been fully delineated. D Manas confirmed that there is funding for centres per organ under the ARC programme for perfusion.	
4	Waiting List Review	
	Centres have all reviewed their waiting lists and were reminded to maintain vigilance for suspended patients.	All
5	H & I update - KAG(25)11a, b	
	C Rosser provided an update, having provided papers for circulation prior to the meeting.  There were no discrepancies for HLA typing.  There is an electronic results system being developed nationally. There have been several incidents relating to how the HLA typing data for H&I is imported into the national database (NTxD). There should be some improvements by the end of 2025 and will update at future meetings.  An issue with Rapid Tier A offers to patients with a matchability score of 10 and low calculated reaction frequency (cRF) of 0-9%, was highlighted. It is likely this was caused by an update to the reference donor pool and matchability scores in March 2024. Since then, there has been a noticeable increase in the offers to this group of recipients, which was not anticipated. It is likely that rare or homozygous HLA types are achieving high matchability scores due to limited number of matches at Level I and II despite significantly higher matches at Level III and IV.  Recommendations to address this clinical issue were discussed, and members felt this issue needed further scrutiny due to the potential for inequity.  R Battle and C Rosser will update H&I colleagues to make them aware of the issue and the agreed recommendations.  Opening up the matchability score to include Level III mismatches was raised as a possible solution, or alternatively to remove matchability score 10 from the criteria for Tier A. M Robb agreed further modelling would be required to investigate possible solutions, which will be discussed in the KAG January 2026	R Battle/ C Rosser C Brown/ M Robb
	meeting.	
6	Commissioning Update - KAG(25)12a, b	
	Prior to the meeting G Jones approached all 4 nation Commissioners to ask if Imlifidase was commissioned for use with a live donor transplant that had beenallocated via the deceased donor allocation scheme (ie NDAD or end of chain donors from the NLKSS). The commissioners of all nations confirmed that this is not commissioned for a living donor transplant allocated through the deceased donor allocation scheme. Centres were asked to note the issue and inform NHSBT immediately if they are allocated such a donor but are unable to proceed without Imlifidase. A PPP for NHSE patients would be required for Imlifidase use in this situation and will be considered. D Manas confirmed that these cases can be discussed with the NHSBT Transplant Oversight Group.	All
	0.2 Changes to Commissioning - NAC(20) 13	

	There were no Commissioners present at the meeting but written updates were provided. G Jones asked if there have been any changes considered by the Commissioner prior to the meeting. Commissioning of kidney transplantation has been delegated to ICBs from 1st April 2025 within NHSE territory.  D Manas advised of no further changes in the immediate future. A Clinical Lead for Transplantation role in NHSE will be created and advertised.	
7	Outcomes of Fast Track Scheme - KAG(25)14	
	M Robb advised that the Fast Track Scheme was introduced by NHSBT in 2012, with 12 transplant centres included.  The analysis of 5-year graft survival from kidneys transplanted through the Fast Track Scheme has shown no significant difference when compared to kidneys transplanted via the national kidney offering scheme. Five-year patient survival was found to be lower in kidneys transplanted via the fast-track scheme at 82% vs 86% through the national kidney offering scheme, but no difference is observed after risk-adjustment. Graft survival remains the same for kidneys transplanted via the fast-track scheme and through the national kidney offering scheme in this study.  G Jones highlighted that adjusted outcomes of fast track kidneys were the same as non fast tracked kidneys but patients in 11 transplant units did not have access to 11% of transplanted kidneys which may lead to inequity.  Centres were asked whether all units should automatically be part of the to Fast Track Scheme, as occurs within liver and pancreas offering. Some centres expressed concern that they had limited resources to support membership of the fast track scheme with disturbed professionals not being available the next day.  Members were asked to consider two options:  1. Centres continuing to opt in to the Fast track scheme but centres not opting into the scheme should provide NHSBT with insight into why they are unable to join the scheme, on an annual basis.  2. All centres within the UK to be automatically enrolled into	All
	the Kidney Fast Track Scheme Centres voted for option 1 by a majority of 14:2.	
	Non fast track centres to consider joining the scheme. If they decide not to join, centres are asked to highlight the local barriers to joining the scheme to KAG chair before October meeting, in order to achieve a greater understanding of the limitations of KFTS.	Non fast track centres
8	Organ specific report	
	G Jones advised members that waiting time recorded by waiting time points will be added to the organ specific report for 24-25, in addition to the current active waiting time metrics.  NHSBT will consider other changes to the report, including longer (10 year) outcome data and non death censored graft survival.  G Jones asked members to advise him of any further data they would like to see in the report, although would have to consider the feasibility of requests.	All
9	Living Donation Update - KAG(25)15	
	L Burnapp advised members that 15 more living transplants have been completed compared with the previous year. Centres are	

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to ic cool cool N K see A w	viding data in a more timely manner.  urnapp asked centres to look at matches that don't proceed, dentify improvements. This data will be reviewed monthly with rdinators. Surveys are sent directly to living donor rdinators. essaris will feedback on what additional data he would like to from non-proceeding transplants. orking group are looking at what follow-up data will be ated within Primary Care.	N Kessaris
9.1	UKLKSS International Collaboration update	
Offe next	urnapp shared a presentation on the scheduling of the Kidney ering Scheme (KOS). The LKDC Ops. Group will have their t meeting next week, looking at clinical and scientific data on ors and recipients.	
mat cons NDA agre reas shot limit	O unplaced NDADs over the last year, none have been sched to paediatric recipients. The group were asked to sider whether to continue with the scheme for unmatched AD offers in the UKLKSS going to paediatric recipients. It was seed to continue for a further year, but investigation of the soning behind the lack of offering to paediatric recipients all be considered and whether there are recipient restrictions ting the offering. For discussion at the next KAG Paediatric p-Group meeting.	H Jones
	urnapp and M Robb will update Policy POL274 to reflect this ision.	L Burnapp/ M Robb
opti UKL L Bu The the	urnapp asked members for approval on an approach to mise theatre scheduling for transplants identified in the LKSS to avoid increased risk of collapsed exchanges. urnapp shared a presentation with the group. presentation will be sent to the Group with the minutes after meeting.	A Jakeman
Agr	If unable to conclude by the following Friday arrange MS Teams meeting to include LKD Coordinator and theatre calendar ree theatre dates within 2 chks MR (10 week window)  If unable to conclude by the following Friday arrange MS Teams meeting with all centres for the following Mon or Tues  MS Teams meeting to include LKD Coordinator and theatre allocation decision maker from centre	
Con with if a	proposal was supported. Insideration was also given to whether there is an SLA in place in the Trusts for patients/donors to be moved to another centre, local centre could not accommodate the exchange. L Burnappised members that further information will be provided.	
L Bu wee advi	National Focal Point (NFP) Update urnapp advised that she attended the Annual Meeting last ek, the network have highlighted points of concern. L Burnapp ised that The MEDLEAD Oxygen Blue website is visible in the for awareness to members.	
rem 20 c can	reports to the HTA, mostly people returning from outside the with a transplant. 14 have been referred to police and 11 ain under investigation cases remain under active review by HTA before a decision be made.  Robb advised that data on highly sensitised patients within the	

	LUZUZOO WILL be aliceved and at the consent IZA Compositions	
	UKLKSS will be discussed at the next KAG meeting.	
10	Patient Safety Update - KAG(25)16	
	The report was shared with members prior to the meeting. The number of reports remains stable, learning cases were shared with members. R Baker confirmed that there was previously no protocol for Core biopsies, this has now been agreed.  10.1 HHV-8 Update	
	R Baker provided an update, with a serology true positivity rate of just under 2%. Only 9 donors out of 3020 were PCR positive. This led to serious events within liver patients and one serious, non fatal, incident in a kidney recipient.  D Manas attended a recent SaBTO meeting reporting that only recipients of an organ from a PCR positive donor have been affected. All donors will be screened for antibodies and PCR but the test is only available retrospectively at present. The aim will be to develop a pre transplant PCR test, eventually.  10.2 Inc. 8734 - KAG(25)17  R Baker provided details of an incident on 3 <sup>rd</sup> February 2025	
	affecting two patients on the waiting list.  D Manas asked for all incidents to be reported to NHSBT.	
11	Imlifidase: Leicester case	
	A Bagul informed members of a transplant at Leicester centre with the patient on the Waiting List for 15 years. Her outcome remains good.	
12	KAG Paediatric Sub-Group Update	
	J Stojanovic provided an update on behalf of H Jones, thanking members for allowing paediatric patients to be prioritised more. KAGPSG are looking at 3 out of 10 tx centres have struggled with surgical staffing, adopting mutual aid for recipient work-up. Declined deceased donor offers are being analysed by a working group, with the lack of surgeons impacting the service. They hope to standardise the mutual aid service. D Manas confirmed that a summit will be held in October 2025, NHSE are involved with looking into this issue alongside Trusts and NHSBT.	
13	Recipient Coordinator Update	
	An issue whereby a centre accepted a kidney offered by the non- damage pathway was raised, with subsequent damage. D Manas will contact J Whitney for further discussion outside of this meeting.	D Manas
14	Lay Member Update	
	There was no Lay Member representation at the meeting.	
15	PAG Update	
	S White was not present at the meeting to provide an update.	
16	CLU Update	
	N Inston updated members on the organ review scheme and high quality organ declines, with recipient reasons highlighted with patients already being offered an organ or that they should have been removed from the Waiting List.	

	Denor work up is being looked at by an Abdominal Warking	
	Donor work-up is being looked at by an Abdominal Working Group for Cardio-Thoracic patients. A Donor Care bundle has been created by Intensivists.	
17	Feedback from Non-Transplanting Reps	
	L Karamadoukis asked members if they would like to keep Non- Transplanting Representatives on the Kidney Advisory Group. G Jones will send Expressions of Interest out with J Stoves and L Karamadoukis standing down from KAG this year.	G Jones
18	Feedback from Trainee Reps	
	H Douthwaite was not present, M Manook provided an update, advising members that some Trainees do not have access to certain Fellowships, the Herrick membership are very supportive to develop these.  D Manas confirmed that a workforce group are also keen to develop the Fellowships, historically Trusts were not keen to fund these. National TBDs for Trainees through individual Deaneries is proving challenging. An annual survey will be created.	
19	Any Other Business	
	The Anatomically Challenged Kidney Transplant Recipient	
	This paper from the West Midlands Collaborative was shared with members prior to the meeting. There is a small group of patients, often quite young, with a history of multiple transplants who may also be highly sensitised, have absent or poor vascular access or anatomy that is prohibitive to transplantation.  KAG members were asked to consider whether there is a significant need within the clinical community and whether a fixed term working group should be established to define the patient cohort and consider best practice for managing such cases.  D Roy advised that not all centres will participate. Members were in agreement to approve both recommendations. G Jones asked for volunteers for a Fixed Term Working Group to feedback to KAG at the next meeting. Members who will volunteer/nominate a volunteer will contact G Jones.  L Burnapp advised members that conversations amongst Surgeons at centres on whether to re-direct an organ for living	AII
	donation, included in the HTA Form, are increasing for them to have the donor asking for their organ back if it is not transplanted into a Recipient under the Living Donor programme. Lisa Burnapp asked for further feedback on the potential reasoning for this choice.	All
20	FOR INFORMATION	
20	19.1 QUOD Report - KAG(25)18	
	Date of next meeting: Wednesday 15 <sup>th</sup> October 2025 via MS Teams	