

NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE THIRTY FIFTH MEETING OF THE KIDNEY ADVISORY GROUP PAEDIATRIC SUB-GROUP

**Thursday 8th May 2025
10:00 - 15:00 via MS Teams**

ATTENDEES

Helen Jones	KAGPSG Chair/ Paediatric Nephrologist, Evelina
Chris Callaghan	Evelina/GOSH Consultant Transplant Surgeon
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Mairead Convery	Consultant Paediatric Nephrologist, Belfast
Anusha Edwards	Consultant Transplant Surgeon, Bristol
Iram Haq	Surgical Trainee Representative, Manchester
Shuman Haq	Consultant Paediatric Nephrologist, Southampton
Nick Inston	Lead Kidney CLU, NHSBT
Maria Jacobs	Statistics and Clinical Research, NHSBT
Gareth Jones	KAG Chair/National Lead for Collaboratives
Katie Jones	Senior Programme of Care Manager, Women & Children,
Derek Manas	Specialised Commissioning NHS England
Joe McAllister	Medical Director OTDT, NHSBT
Mordi Muorah	Consultant Transplant Surgeon, Leeds
Rob Pearson	Consultant Paediatric Nephrologist, Birmingham
Sarah Plant	Surgical Trainee Representative, Glasgow
Ben Reynolds	Lead Nurse for Paediatrics, NHSBT
Carla Rosser	Consultant Paediatric Nephrologist, Glasgow
Julia Sanpera-Iglesias	OTDT H&I Lead, NHSBT
Vlad Shumeyko	Medical Trainee Rep./Nottingham
Jelena Stojanovic	Consultant Transplant Surgeon, Glasgow
Afshin Tavakoli	Deputy Medical Rep./Consultant Paediatric Nephrologist, GOSH
Julie Whitney	Deputy Surgical Rep./Consultant Transplant Surgeon,
Anthony Wrigley	Manchester
	Head of Service Delivery – ODT Hub, NHSBT
	Lay member

IN ATTENDANCE

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

APOLPOGIES

Jo Chalker, JJ Kim, Mordi Muorah, Mohan Shenoy, Kay Tyerman

ITEM		ACTION
1	Welcome and Apologies Declarations of interest in relation to agenda	

	H Jones welcomed all members to the meeting with introductions for new members.	
2	Minutes of the last meeting held on Thursday 21 st November 2024 - KAGPSG(M)(24)2 2.1 Accuracy 2.2 Action points arising - KAGPSG(AP)(24)2 2.3 Matters arising not separately identified	
	The minutes were approved, with outstanding/ongoing action points added to the agenda for discussion.	
3	KAGPSG Membership	
	H Jones updated the group of the new members appointed, there was no Birmingham, Cardiff, Liverpool or Newcastle representation.	
4	Medical Directors update 4.1 SCORE	
	D Manas advised that the Terms of Reference (ToR) for Advisory Groups are being reviewed. He welcomed C Rosser to the meeting as the newly appointed Deputy Head of H&I, NHSBT. There have been further new appointments across the clinical team, with a new Heart CLU Lead. A new AMD for patient engagement will be appointed following recommendations by the OUG. Applications are welcomed. Finance update: There has been an increase in baseline funding, providing funding for ARC project, NRP and CLU funding. The Collaboratives are working well, for further discussion on the agenda. The CT transformation is underway and is expected to take three years. A Transplant oversight group has been created to monitor CUSUMs, D Manas will chair the sub-group that sits within the main group. The OUG work is continuing. HHV-8 positive results have been problematic, a clinical working group will be set-up, with pre-transplant PCR testing recommended.	
5	UK renal transplantation status 5.1 Centres operating 5.2 Surgical Challenges	
	Bristol/Cardiff - A Edwards advised that the low number of offers is an issue at Bristol, they have not declined any offers. There has been one offer since February 2025. Workforce issues with surgical workforce but the service has remained open with mutual aid offered to Birmingham recently for a 2 week period. MDT discussions worked well, there were no transplants performed during this time. Offers for Cardiff patients are made to the paediatric Nephrologist at Bristol. Nottingham - M Christian advised that they have had two offers, one declined due to no availability of surgical cover. They have limited availability for a second surgeon which was required for the case. Living donor work-up is going well. They have plans in place to gain access to Theatres, D Manas	

	confirmed that NHSBT can engage with Trusts if required. A Tavakoli has been providing support. Nottingham has 23 patients listed (incl 2 suspended) and a dialysis population of 46. Manchester/Liverpool – A Tavakoli reported on a decline, with the kidney transplanted in another patient. The first patient had a very complex anatomy. Liverpool patients are on the Manchester waiting list, offers are discussed with the surgical team after coming to the paediatric Nephrologist with an SOP in place. A Tavakoli advised members of one decline on a 000 mismatch, with three offers since February 2025. One offer was declined as a NPM on the gallbladder was found on retrieval. There is no issue with access to Theatre with paediatric transplantation, only with adult patients. If there are surgical issues post-transplant for Liverpool patients they return to Manchester. He will share the SOP with the group. Belfast - M Convery advised that their living donation programme is going well. Urology patients are now treated at Belfast with the appointment of a new Consultant Urologist. Southampton/Evelina - S Haq advised that two patients are now on home haemodialysis, PD numbers are decreasing, they have had three offers. Patients over 16 are now having dialysis at Portsmouth which is working well. Two decline cases were discussed; S Haq advised that Evelina didn't contact Southampton to advise of the offer. This will be discussed at an Evelina Governance meeting in June. H Jones advised that a patient at Evelina was transplanted at the weekend. GOSH - J Stojanovic reported of no issues with surgical capacity, they have had three offers since February 2025, dialysis slots are always full, with 7/8 patients on home dialysis. Glasgow - B Reynolds confirmed that Glasgow have no issues with patients on the waiting list, their last deceased donor off was July 2024, they have 3 patients on the waiting list. They have never declined a DCD kidney. Leeds - J McAllister advised of staffing issues with haemodialysis nurses with one due to go on maternity leave. They have completed three transplants this year, one LRD, one offer was rejected by both surgeons and the Nephrology team. They have no issues with surgical staffing with three on the paediatric on-call rota. Birmingham – no representation at the meeting. Newcastle – no representation at the meeting. H Jones asked for those centres who have SOPs to share them with the group.	A Tavakoli - complete All
	6.2 Surgical Challenges	
	A Tavakoli supports the Nottingham team, with 4/5 transplants since October 2024. He advised members that NHSBT have reported that a lot of paediatric surgeons are retiring. For future transplant surgery there is a lot of initiative to engage. Hence there is more trainee representation in KAGPSG.	

6	NHSE Transplant network working group update from meeting held on 1 st April 2025	
	The first meeting was held on 1 st April 2025 on Networked models of care (NMC) further dates have been secured. The aims across both surgical and medical groups have been to identify the challenges and test solutions. The first meeting was focussed on identifying priorities, the data requirements will be discussed in the next meeting. A surgical summit will be held in September 2025. The group are looking to design an updated surgical specification, linking in with the adult renal service transformation programme. Conversation was held on how devolved nations can feed into this work, all have been invited to be involved at the meetings.	
7	Clinically urgent scheme https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/35789/pol186.pdf	
	M Jacobs advised of no clinically urgent patients registered in the 2024/25 financial year. The Policy was shared for information.	
8	Simultaneous liver and kidney transplantation	
	H Jones shared that some children waiting for simultaneous kidney/liver transplants on the combined list are waiting for a long time due to the liver offering pathway. The liver offering scheme will be reviewed by NHSBT, J Whitney confirmed that these patients can be prioritised by putting an appeal out to centres.	
9	Renal Transplant Collaboratives	
	G Jones shared a presentation on the Liver and Kidney adult collaboratives, with their aims and goals to deliver the recommendations of the OUG. NHSE are looking at Paediatric collaboratives and networks of care. There may be some duplication with at least 25 ICBs who commission renal transplant. K Jones confirmed that for paediatric renal transplantation the commissioning responsibility is retained within NHS England and hasn't been delegated to ICB. NHSE are BAU going forward following recent Government decisions, their Transplant network working group is split by South/Midlands/North with surgical and medical representation. D Manas suggested that a North and South Network may work with the new NHSBT Paediatric Clinical Collaboratives also including Belfast and Glasgow with Surgical and Nephrology representation. Opinion will be sought from all Colleagues including the Birmingham, Cardiff and Newcastle Representatives.	H Jones/ G Jones
10	HLA mismatch in paediatric grafts - KAGPSG(25)01	
	M Jacobs presented the regular paper, previously circulated to members. Since July 2001 recommendations have been made that paediatric patients who have a matchability score of 5 or less should not receive kidneys from non-favourably	

	HLA-mismatched donors within their first year of listing. There is a difference in mismatch grade registration practice across centres. There have been 6 non-favourably HLA-mismatched kidney transplants in paediatric patients in the 2024 financial year; one patient a waiting time of 298 days at point of transplant whilst the other five had waited more than 365 days. The patient waiting less than a year was listed at an adult centre. Change in terminology from non-favourably matched terminology is preferred. The group discussed that 'non-favourable' implies that the patient may not be receiving a 'good' kidney and if restriction on matching should be removed under the new allocation system. There is no agreed definition on what is favourable/unfavourable for each patient. Some work on pre transplant protocols and standardisation on listing patients will be undertaken as there a lot of variation. J Stojanovic is producing a paper on HLA mismatching, she will share the draft paper with the group. Discussion on levels and patient listing will be held outside of this group to produce recommendations to be taken to the wider group at BAPN. This paper will be discussed in the Spring 2026 meeting.	J Stojanovic M Jacobs
11	Harmonisation data – supplementary follow-up forms	
	H Jones questioned how the data collection is managed with low return rates and how this data will be analysed. M Jacobs advised that 150 forms have been submitted since the last meeting with forms being completed alongside the standard follow-up form. NHSBT are working to progress and finalise the analysis plan for the harmonisation study and looking at the next steps. M Jacobs will speak to Information Services, NHSBT to ask of the delay in uploading the forms and if a monthly email can be sent to centres to advise on the outstanding forms. This will be discussed further at the next KAGPSG meeting.	M Jacobs J Dudley
12	Centre specific organ decline rates - KAGPSG(25)02 12.1 Declining deceased donor offers KQuiP NHSBT QI project	
	M Jacobs presented the report to the group on transplants between 1st January 2015 and 3rd December 2024 and offers for paediatric patients for these transplanted kidneys. This paper details paediatric DCD and DBD offer decline rates by centres. N Inston confirmed that only two letters have gone to paediatric centres since the scheme started. Shared learning following the decline letters will be shared with the group at the next meeting.	N Inston
13	Patients suspended immediately after activation	
	This agenda item was previously discussed in November 2024 with 9 patients suspended, one patient remains suspended and has now been transferred to the adult service. Three are active, three have been transplanted and two were removed with condition improved.	

	Following this discussion the number of patients has reduced to one in the last six months. H Jones updated the group on an Evelina patient registered, offered a date for orthopaedic surgery and immediately suspended. He has not yet started dialysis and has now transitioned to adult services. This agenda item will now be removed for future meetings due to improvement in practice. This will also be considered in the standardisation of listing work to produce recommendations (discussed in agenda item 10)	
14	Paediatric use of the UKLKSS	
	M Christian presented two questionnaires on data collection on the Paediatric use of UKKSS. The forms will be sent to members for review.	M Christian - complete
15	Quality improvement & academic R and D 15.1 Kidney transplantation in anuric children without lower urinary tract problems	
	S Haq advised that he has 33 patients' data currently with further patients to be included, with the poster presented at IPNA.	
16	Any Other Business	
	H Jones advised that the CUSUM paediatric rates are being updated and an update on this will be circulated soon. B Reynolds will progress his Hep. C project.	
17	For information 17.1 Centre specific transplant list and transplant activity report - KAGPSG(25)03 17.2 POL186 - KAGPSG(25)04	
18	Date of next meeting - Thursday 6 th November 2025 Leonardo Hotel Nottingham, Waterfront Plaza, Station Street, Nottingham, NG2 3BJ	