

NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

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

Thursday 21st November 2024

10:00 - 15:00 via MS Teams

ATTENDEES:

Helen Jones	(Chair) Consultant Paediatric Nephrologist, Evelina
Martin Christian	Consultant Paediatric Nephrologist, Nottingham
Martin Drage	Consultant Transplant Surgeon, Evelina & GOSH
Jan Dudley	Consultant Paediatric Nephrologist, Bristol
Shuman Haq	Paediatric Nephrologist, Southampton
Maria Jacobs	Statistics and Clinical Research, NHSBT
Joanna James	Donor Transplant Co-ordinator, Leeds
Jon Jin Kim	Consultant Paediatric Nephrologist, Nottingham
Derek Manas	Medical Director, OTDT
Omar Masood	Consultant Transplant Surgeon, Leeds
Grace McCall	Consultant Paediatric Nephrologist, Belfast
Jenny O'Gorman	Paediatric Nephrologist, Guy's & St. Thomas (trainee)
Ben Reynolds	Consultant Paediatric Nephrologist, Glasgow
Julia Sanpera	Paediatric Nephrologist, Guy's & St. Thomas (trainee)
Jelena Stojanovic	Consultant Paediatric Nephrologist, GOSH
Yincent Tse	Consultant Paediatric Nephrologist, Newcastle
Julie Whitney	Head of Service Delivery – ODT Hub
Anthony Wrigley	Lay Member

IN ATTENDANCE:

Liz Armstrong	Head of Transplant Development, NHSBT
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APOLOGIES:

Rose Lamb, Sarah Plant, Khalid Sharif, Mohan Shenoy, Kay Tyerman

ITEM		Action
1	Welcome and Apologies Declarations of interest in relation to agenda Apologies were noted. There were no declarations of interest from members.	
2	Minutes of the last meeting held on 8th May 2024 - KAGPSG(M)(24)1 2.1 Accuracy	Gareth Jones KAG chair to be invited to

	The minutes of the last KAG - PSG meeting held on 8th May 2024 were approved, with no inaccuracies. 2.2 Action points arising - KAGPSG(AP)(24)1 2.3 Matters arising not separately identified. There were no matters arising.	future KAGPSG meetings
3	KAGPSG Membership Welcome to Julia Sanpera and Jenny O'Gorman trainee Nephrology representatives and Alba Bueno & Iram Haq Surgical trainee representatives for KAGPSG. Yincent Tse is standing down as dep KAGPSG Co-Chair. Thanks were given to him for his support in this role for the past 3 years. Grace McCall is representing Belfast at today's meeting in place of Mairead Convery.	Deputy KAGPSG chair to be appointed via expressions of interest
4	Medical Directors update All decisions re clinical advice, best practice, changes to policy etc. need to be endorsed by Advisory Groups. New appointments: -R Ramanan has completed 2nd term as KAG chair. Gareth Jones has been appointed into the role and will commence as KAG chair 1st December. G Jones will continue in National Collaborative lead role. -R Venkateswaran is leaving his CTAG heart chair role due to him securing a position in the US. A Ranasinghe has been appointed to the CTAG Heart chair and will commence in post 1st December, S Pettit will become the CTAG Heart Deputy chair. -A 6-month pilot has concluded whereby OTDT H & I support has been provided by H & I Clinical Services. Following discussion at OTDT September 2024 it has been agreed that OTDT H and I support will continue to be provided to OTDT by H and I Clinical Services under the leadership of K Latham. All SOAG will have H and I representation in future from a NHSBT H and I Consultant and BSHI rep to strengthen the H and I contribution to the SOAG. -Lead Heart CLU role will be appointed to in due course following A Ranasinghe's appointment to CTAG Heart chair role. -D Garcia Saez has stood down from her National Clinical Lead in Cardiothoracic Organ Utilisation post. V Gerovasili has agreed to undertake the role for an interim period until spending review decisions are made and communicated re future CLU finding.	

	-M Wellberry Smith appointed in to Environmental Sustainability in Transplantation (ESiT) Lead role. Role will include engagement within NHSBT will overlap with SCORE program including transport task force and other external groups. -Spending review baseline bid includes aNRP/ DCD heart and CLU funding. Funding is essential to maintain/ improve OU, expect to hear funding decision by end of 2024. - ARCS bid submitted to DHSC, likely to receive notification of decision by April 2025. -Matching and offering business case if funded will enable IT changes to be actioned in a timelier manner. -Histopathology interim solution in place with funding identified. Aim will be to reduce the loss of organs due to lack of histopathology, pithia scanners will be used to process samples for reporting. -ISOU sub groups, Xeno, ARCS and H & I due to report and conclude over the coming months. -Trust engagement, Stakeholder engagement and Patient engagement sub groups established and supporting the delivery of OUG recommendations. - ICE report published, next steps will be for the Cardiothoracic Transformation Programme to convene, Marius Berman and Anna Reed have been appointed as clinicians on this Programme. https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/34815/report-on-uk-heart-and-lung-transplantation-services.pdf -Consent summit planned for 2025 in recognition of decreasing consent rate. -Diagnosis of death new guidance goes live Jan 2025. https://www.aomrc.org.uk/publication/2025-code-of-practice-for-the-diagnosis-and-confirmation-of-death/ HHV8 monitoring continues, low number of cases.	
5	Centre specific transplant list and transplant activity report - KAGPSG(24)06 Number of active patients listed on 31 March 2024 - 119. Highest number of patients compared to previous 10 years. DBD donor transplants in paediatric patients, 2023/2024 - 33 Lowest no of transplants compared to previous 10 years. DCD donor transplants in paediatric patients, 2023/2024 -10 Living donor transplants in paediatric patients, 2023/2024 – 76	

	Kidney transplants (all donor types) in paediatric patients, 2023/2024 - 119 Changes (temporary) to the kidney offering scheme may hopefully increase paediatric offers and alongside reducing donor offer declines may result in an increase in paediatric transplantation over time. Scheme will be reviewed at 9 and 18 months. Time frames for implementation/ IT changes Spring 2025.	
6	UK renal transplantation status 6.1 Centres operating GOSH & Evelina – offer to other centres to spend time with GOSH and Evelina. Some logistical /HR challenges, 1 centre charges for training opportunities, Jelena Stojanovic (JS) will explore the possibility of training fee to be waivers for UK kidney colleagues and will prioritise applications. GOSH -Living donation numbers are positive, looking forward to increasing deceased donation activity in 2025 following kidney offering changes. 2 recent deceased donor transplants. Evelina- Living donor programme is strong. Southampton – HD full to capacity. Home HD service re launched. Recipient co-Ordinator vacancy has impacted on living donation workup, now resolved. Bristol – Living donor programme strong, some challenges accessing theatre time, likely to improve in 2025. Some challenges with staffing/ on call. HD capacity stable. Birmingham – HD capacity a challenge recently. Mutual aid no longer required. Transplant offers and activity moderate over the past year. Nottingham – Stronger position than last reported in May 2024. Grateful for partnership with Evelina/ GOSH and Manchester. Asfin Tavakoli (AT) supporting transplantation at Nottingham. Policy in place 2 consultant transplant surgeons undertaking paediatric transplants. Paed living donation coordinator in post, collaboration with other centres has resulted in learning with regards to smoother pathways. Grateful to GOSH for supporting complex paed transplant soon. Divisional restructure within the trust a concern. Glasgow – No patients on hospital HD. 4 patients on PD. Newcastle – No of highly sensitized patients listed. Hopefully should benefit from changes to the kidney sharing scheme. Belfast- 2 transplants 2024, 1 deceased and 1 living donor transplant. Recent retirement of urologist resulted in challenges for paediatric requiring bladder surgery to support transplantation. Locum urologist	Clinical Urgent Scheme listing to be added as a regular agenda item to KAGPSG

	now in post. HD service is fragile due to workforce challenges. Offer of support from Glasgow. Leeds – 14 patients active on the W/L. Kidneys declines this year included family declines due to high-risk social history and donor age (DCD) has led to discussion with regards to consenting discussions. Adult colleagues supporting paediatric rota this has improved resilience. Offer of support to other centres. Manchester/ Liverpool/ Cardiff – no representation at this KAGPSG meeting. Standardisation of workup supportive for mutual aid. Derek Manas suggested learning from Living Donor proctor team may be useful in supporting and formalising mutual aid/ training.	
7	Renal Transplant Collaboratives G Jones is the National Collaborative Lead. London Collaborative set up in 2018 and integral during the pandemic. OUG report detailed the importance of Regional Collaboratives (Recommendation 4.) National Renal Collaborative Inaugural meeting 9th December. Similar meeting for Liver Collaboratives in 2025. Collaboratives are to be multi-disciplinary; will include public voice representatives. KAGPSG wish paediatric collaboratives to be separate from adults due to complexity and unique challenges associated with renal transplantation. Paediatrics is working as a national collaborative currently.	H Jones to report at Regional Collaborative meeting consensus from KAGPSG for there to be a paediatric collaborative
8	Harmonisation Data - KAGPSG(24)07 Supplementary follow-up forms to collect immunosuppression data for children and young people receiving a kidney transplant were introduced in September 2021 following UK standardisation of immunosuppression prescribing. These forms are sent on a weekly/monthly basis for 3 month and annual follow-up respectively. Centres using ODT online or NTN receive an email report detailing which recipients are due a supplementary form and are expected to complete and return a PDF supplementary form for each recipient for the relevant follow-up period. Centres completing paper returns are sent the supplementary form via post along with the standard follow-up forms. Paper summarises supplementary follow-up form return rates and data completeness of these forms. It was agreed at KAGPSG in May 2024 that supplementary forms should be completed for paediatric transplants from 1 September 2021 only. Forms for transplants prior to 1 September 2021 have been excluded from the analysis.	

	Supplementary follow-up returns have been completed at 3 months, 1,2 and 3 years, with return rates of the transplants meeting the inclusion criteria ranging from 20% to 44% Some discussion with regards to form completion, some units believe return rates are higher than stated in the report. Enthusiasm within the group to continue form completion to inform future guidance. B Reynolds asked why Glasgow wasn't showing up on the table so this will be looked into. Copy of the supplementary form to be circulated with the minutes for information.	M Jacobs M Jacobs/ L Armstrong
9	Centre specific organ decline rates - KAGPSG(24)08 9.1 Declining deceased donor offers KQuIP NHSBT QI project This paper routinely monitors the offer decline rates for paediatric patients over the past 10 years, where the kidney declined was ultimately transplanted. Offer decline rates are monitored by donor type and centre in this paper. There have been actions taken in the past 10 years to review offer declines and minimise variation across centres. Two prospective audits (2014, 2017) examined reasons for declining offers of kidneys for paediatric patients. National guidelines for offer acceptance for paediatric patients have also been produced. On 11 September 2019 the UK Kidney Offering Scheme was introduced. The scheme was designed to address some of the inequities observed in the 2006 scheme. Simulations of the scheme indicated that paediatric offers would initially decline whilst highly sensitised and long waiting patients are prioritised. Since September 2014, the national DCD kidney allocation scheme and subsequent 2019 Kidney Offering Scheme has enabled paediatric patients to receive more offers from DCD donors. Summary Since 2014, the national DBD paediatric offer decline rates have fluctuated around 40%. For paediatric DBD kidney offers, Manchester had a decline rate lower than the lower 95% confidence limit and Nottingham had a decline rate higher than the upper 95% confidence limit. The national decline rate for DCD offers over the last 10 years was 56%. There is also variation in paediatric DCD declines across centres, however as the numbers are small it is difficult to say if these differences are significant Recommendation	

	While it is accepted that offer decline rates do not necessarily impact on kidney utilisation, significant variation in these rates is likely to lead to delays in the offering process and inequities in access to transplant for children listed at centres with notably higher offer decline rates. For this reason, it is important to ensure centre practice is consistent. Members are asked to regularly review their reasons for declining kidney offers in order to minimise offer decline rates within their individual transplant centres. Discussion with regards to mandating a discussion between nephrologist and surgeon prior to declining a kidney offer. SaBTO aide memoir should be accessed prior to decline. Decline meetings, opportunity for centres to pair to share learning. Need to see a change in culture /behaviour. Utilisation going up and decline rate decreasing, culture change in adult centres and discussions is making the difference in acceptance. Donor demographics are changing, DCD organs not as marginal as they have been previously. There is a variance across centres declining and accepting kidneys.	
10	SCORE feedback SCORE team will be visiting Liver Centres over the next few months, Paediatric Kidney colleagues would be welcome to join meetings. SCORE aims to deliver nighttime retrieval, to enable daytime transplantation. Retrieval will take place when required for super urgent liver retrievals and complexities with regards to paediatric donation acknowledged. Offering 08.00 – 10.00 Cardiothoracic Offers & Tier A kidney offers 10.30 – 12.30 Liver and Bowel Offers 13.00 – 15.00 Renal and Pancreas simultaneous offering (3 centres) 16.00 Planning of logistics for overnight retrieval NORS Model Workstream Planned Arrival Window (PA) will give more predictable retrieval times. Reduced travel times through better allocation of resources Modelling 1 retrieval per team per night Fewer delays in accessing donor theatres anticipated overnight data shows more delays in day time. NORS planned arrival team 8pm – 3am All centres will need to plan for SCORE changes, daytime transplantation and daytime offering. Focus for all transplant centres: • Organ coordination	

	• Organ arrival • Implant Implementation not for another 12 months at least. Consideration needs to be given with regards to dialysis of patients prior to transplantation. Day time offering may enable more discussion with regards to organ acceptance/ decline.	
11	Patients suspended immediately after activation. Concern re patients suspended immediately after activation and gaining waiting time points whilst suspended. Highlighted by Leeds at a previous meeting and therefore MJ has provided details of cases. Variation in practice re activation and immediate suspension across centres, group agreed that consensus would be helpful to ensure equity. Patients should only be listed whereby there is intention to transplant although acknowledgement that this is a difficult equation trying to time right for a child and not straight forward. Discussion re listing of patients awaiting living donation and transplantation, practice is confusing as children with a living donor are listed on the deceased list whereby there is no intention to transplant with a deceased donor. Discussion with regards to whether there should be an external review if patients are activated and then suspended for an ongoing period. There is no current review mechanism to review suspensions. Consensus re the need to harmonise with adult practice although making a policy will be complicated. D Manas will speak with G Jones and then H Jones. G Jones and D Manas will agree a way forward with regards to a fixed term working group.	G Jones/ H Jones/ D Manas
12	CUSUM Monitoring - KAGPSG(24)09 Updating expected mortality and graft failure rates. For CUSUM monitoring to remain informative, expected 30-day mortality and 30-day graft failure rates need to be updated to keep them relevant to current practice. Current expected rates are based on centre-specific performance between 1 January 2012 and 31 December 2016 and the revised rates will be based on performance between 1 January 2017 and 31 December 2021. As with current expected rates the calculation to determine the revised rates will give greater weight to the most recent performance. The monitoring period will also be brought forward so that it remains independent of the period used to calculate the baseline rates.	

	Revised centre-specific expected mortality rates for deceased and living donor paediatric transplantation have been set to the default minimum of 1% as there were no paediatric deaths during the updated baseline period. There has been an increase in the revised expected graft failure for deceased donor transplantation following three graft failures at 2 units during the baseline period. There has also been an increase in the revised expected graft failure rate for living donor transplantation following one graft failure at 1 unit during the baseline period. Expected mortality and graft failure rates have been updated to ensure CUSUM monitoring is relevant to current practice and the revised rates will be incorporated into the next CUSUM reports. Any new historical signals which appear as a result of these amendments will not be investigated retrospectively.	
13	Paeds-specific updates to the NHSBT website Work underway devising content for patient information website pertaining to paediatrics. infoKID resources will be updated over the next year and will be a valuable resource that the patient information website will include a link to https://infokid.org.uk. infoKID website is PIF TICK certified. Request for a trainee rep to join H Jones in devising content for the patient information website.	J Sanpera/ J O’Gorman/ A Bueno/ I Haq
14	Paediatric use of the UKLKSS - KAGPSG(24)10 Paper looks at use of the UK Living Kidney Sharing Scheme (UKLKSS) for pairs registered from 1 January 2020 – 8 October 2024. Matching runs take place quarterly, with matching runs not going ahead in April and July 2020, and January 2021. 43 paediatrics recipients (49 pairs) have joined the UKLKSS since 1 January 2020. 23 (47%) of the paediatric pairs registered were blood group incompatible, 26 (53%) blood group compatible. 12 (24%) were known HLA incompatible, 32 (65%) HLA compatible and 5 (10%) not reported. In the same period, 1066 adult recipients forming 1128 pairs joined the UKLKSS. 590 (52%) of the adult pairs registered were blood group incompatible, 538 (48%) blood group compatible. 454 (40%) were known HLA incompatible, 563 (50%) HLA compatible and 111 (10%) not tested. Discussion that as the scheme expands and becomes less novel there is a need to factor in how service will be provided in a robust way. Need to actively encourage use of the scheme with low numbers of deceased donors. Opportunity to publish data in the public domain.	

15	Quality improvement & academic R and D projects 15.1 Joint Adult Paediatric Workshop on Kidney Allocation Workshop held in response to long waiting times for paediatrics. Workshop attendees included clinicians and patients. Acknowledgment that that landscape is changing with donor age increasing and recipients becoming more complex. Opportunities for centres to increase understanding of declines and information on outcomes of subsequent transplants. 15.2 Molecular HLA project Develop and validate risk categories to predict rejection. Longitudinal analysis of immunosuppression data. 15.3 Cell-free DNA as a barometer of allograft injury – call for research planning committee Next steps partner with Cambridge H & I lab. Form research group to design study and apply for funding. 15.4 HCV work Presented at Transplant Challenges meeting in Glasgow and can proceed in principle for children, documentation to be prepared. 15.5 Kidney transplantation in anuric children without lower urinary tract problems Poster presentation at ESPN.	
16	Surgical challenges Meeting with NHSE w/c 25th November 2024.	
17	Any Other Business Request from Martin Drage to support clinical meeting, D Manas suggested emailing with detail of meeting or exploring commercial sponsorship.	M Drage
18	Date of next meeting 2025 date TBC. Face to face (no hybrid option)	