# NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

## MINUTES OF THE FORTY FIFTH MEETING OF THE LIVER ADVISORY GROUP HELD ON 29<sup>th</sup> NOVEMBER 2023, 11:00 - 15:30, Mary Ward House, 5-7 Tavistock Place, London, WC1H 9SN AND VIA MS TEAMS

### **ATTENDEES**

Doug Thorburn Chair, Liver Advisory Group/Royal Free Hospital

Anya Adair
Mike Allison
Varuna Aluvihare
Matt Armstrong
Sarah Banks
Royal Infirmary of Edinburgh
Addenbrookes Hospital, Cambridge
Kings College Hospital, London
University Hospitals Birmingham
Recipient Co-ordinator Representative

Joan Bedlington Patient Representative

Will Bernal King's College Hospital, London

Lisa Burnapp AMD for Living Donation and Transplantation, NHSBT Andrew Butler MCTAG Chair/ Addenbrookes Hospital, Cambridge

Lee Claridge St James's University Hospital Becky Clarke Regional Head of Nursing, NHSBT

Matthew Cramp University Hospitals Plymouth/BLTG Representative National Clinical Lead for Organ Retrieval, ODT

Bobby Desari University Hospitals, Birmingham Audrey Dillon St Vincent's Hospital, Dublin Ewan Forrest Glasgow Royal Infirmary

Paul Gibbs Addenbrookes Hospital, Cambridge
Tassos Grammatikopoulos
Pam Healy Chief Executive, British Liver Trust
Jade King Statistics and Clinical Research, NHSBT

Andrew Madden Lay Member

Derek Manas Medical Director, OTDT, NHSBT Aileen Marshall Royal Free Hospital, London

Steven Masson The Freeman Hospital, Newcastle upon Tyne

Joerg Matthias-Pollock Royal Free Hospital

Krish Menon Kings College Hospital, London

Marumbo Mtegha Paediatric Representative, Leeds Teaching Hospital

Suzie Phillips Statistics and Clinical Research, NHSBT Peter Robinson-Smith Recipient Co-ordinator Representative

Ian Rowe Chair of the National Liver Offering Scheme Monitoring

Committee

Ken Simpson Royal Infirmary of Edinburgh

Sanjay Sinha National Surgical Lead, Clinical Governance, NHSBT

Rhiannon Taylor Statistics and Clinical Research, NHSBT

Dhakshina Vijayanand Leeds Teaching Hospital Chris Watson University of Cambridge

Sarah Watson Commissioning Manager, Highly Specialised Services, NHSE

Gwilym Webb Addenbrookes Hospital, Cambridge

Steve White PAG Chair/The Freeman Hospital, Newcastle upon Tyne

Julie Whitney Head of Service Delivery - ODT Hub, NHSBT

#### IN ATTENDANCE

Alicia Jakeman Clinical Support Services, NHSBT

### **APOLOGIES**

Maria Jacobs, Tracey Rees, Khalid Sharif, Craig Wheelans

ITEM	Welcome	ACTION
11	Declarations of interest in relation to the agenda	
	There were no declarations of interest.	
2.	Minutes of the last Meeting, held on 24 May 2023 - LAG(M)(23)01	
2.1	Accuracy	
	The minutes of the last meeting were agreed as an accurate record	
	and ratified.	
2.2	Action Points - LAG(AP)(23)01	
	Action Points that were not marked as complete have been added to the agenda, with verbal updates asked for during the meeting. Those	
	not given will be carried forward to the next meeting.	
2.3	Matters Arising, not separately identified	
	There were no matters arising.	
3.	Medical Director's Report	
J.	D Manas informed members of new appointments with a new Chair	
	(Varuna Aluvihare) and deputy Chair (Steven Masson) of the Liver	
	Advisory Group (LAG) from 1 December 2023 with Anya Adair the new	
	surgical lead. L Armstrong will be supported by Carrie Scuffell.	
	D Manas advised that L Burnapp will retire in March 2024 and return	
	for three days per week. Interviews for the Lead Nurse in Living	
	Donation will be held on Friday 1 December with the appointee	
	working alongside Lisa, to continue with operational aspects of the program.	
	Funding for NRP is being sought from the Department of Health (DoH)	
	and whether this is approved is awaited.	
	CLUs have funding until mid-2024. Histopathology has been funded	
	for the interim.	
	Sub-Groups have been set up to support implementation of the OUG	
	recommendations: an oversight group, a Trust engagement group, a	
	stakeholder sub-group a patient stakeholder sub-group and an innovation sub-group.	
	Workforce issues, with teams lacking resilience, are being supported	
	as much as possible. This is mainly affecting paediatric renal	
	transplants.	
	D Manas confirmed flights should not be used for transporting organs	
	(unless in exceptional circumstance) when a road journey option is	
	available.  The BTS liver machine perfusion meeting was held recently at the	
	Wellcome Trust, a consensus was not reached. D Manas advised that	
	the data will be collated to draw up a summary. K Menon advised that	
	the seven centres that were represented will be presented in the data.	
	It was agreed that DCD livers need some form of perfusion. If data can	
	be presented from all centres, this will support a strong case for a	
	sustainable solution.	
	RINTAG will become an R&D Steering Group and Research Operational Feasibility Group.	
	There were very few CUSUM signals in the last six months.	
	TransplantPath will be released in early 2024.	
	D Manas has met with the MHRA, he confirmed that alternative fluids	
	will be refunded if purchased through Trusts.	
	He advised that one of the OUG recommendations was to further	
	develop learning from COVID on mutual aid. G Jones has been	
	working with renal centres to extend National Collaboratives, these will	
	now be extended to Liver.  D Manas advised that TA-NRP (Cardiothoracic NRP) discussions	
	have been held with a study in development to move this on.	

five years.  3.1 Organ Utilisation Group recommendations This item was covered under Agenda item 3.  3.2 National Liver Offering Scheme review  It was confirmed that a formal review of NLOS will be established in early 2024 with D Thorburn leading the review.  3.3 Sustainability and Certainty in Organ Retrieval (SCORE) This item was discussed under Agenda 10.1  3.4 Regional collaboratives This item was covered under Agenda item 3.  3.5 Liver Utilisation Report for noting - LAG(23)31 D Thorburn advised that this report is presented at the monthly Centre Directors meeting. Transplant activity is down 5%, DCD donors now exceed DBD donors. The waiting list has nearly 700 patients active. C Watson asked for data on machine perfused organs to be incorporated in this report accurately. This data needs a narrative recording with an IT change, which has been requested. R Taylor will scrutinise the forms received by NHSBT listing NRP use. D Manas confirmed that consent has now dropped to 61%.  4. LDLT Project L Burnapp provided an update on the LDLT project, whose aim is to expand the Living Donor Liver Transplant Programme across the UK. She confirmed that the first year of the project focused on developing the operational model and getting the recommendations for indications up and running. The Operational Model has been developed and been signed off. An Engagement Event was held in February 2023 at the Royal Free Hospital.  In the second year, time was devoted to establishing the Proctor Team so that the operational model could be rolled out, the MDT Proctor Team has now produced a detailed operational template. This Team has been funded by NHS England with an additional £10k received from Scottish Commissioners.  The aim now is for this to be embedded by March 2024, to deliver 41 transplants adult to adult LDLT transplants by 2025/26. L Burnapp confirmed that there are constraints currently, including equity. She asked Centres to consider their referrals to the programme, to engage prior to March 2024. Also, she aske	Γaylor
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champions for living donor liver transplantation, wo have an interest in this across all centres, to contact her. The first meeting for these has been scheduled for 21 <sup>st</sup> May 2024, in Leeds.	All /atson
5. Update on the National Liver Offering Scheme	
5.1 Compliance with Sequential Data Submission - LAG(23)32	
needs to be contemporaneous and single sample data.	centres
5.2 National Liver Offering Scheme (66 month data) and Summary Feedback of key points from NLOS - LAG(23)33	
I Rowe, Chair of the NLOS Monitoring Committee thanked R Taylor and D Thorburn for all their hard work. He highlighted that this monitoring is challenging with COVID, changes in donor characteristics and changes in donor numbers. Overall, he confirmed that there hasn't been a change in waiting list mortality over the course of the last twelve months and particularly since the parameter changes on 4 <sup>th</sup> October 2022. Individual patient characteristics have not changed in terms of removal from the waiting list.	

	Since December 2019, the proportion of CLD patients and	
	HCC/HCC downstaging patients registered post NLOS and	
	transplanted within a year of registration has been decreasing.	
	He confirmed that a potential increased mortality within the age	
	group 25-39 will be investigated further.	
	Since NLOS was introduced, there has been a small decrease in	
	utilising DCD organs.	
	Since the parameter changes removal due to condition deteriorated	
	has decreased, there is a small increase in patients with Blood	
	Group A&B, not Blood Group O.	
	Impact of NLOS by aetiology will be examined in further detail. It is	
	difficult to see the relative impact on waiting list outcomes, this will be	
	intensely monitored.	
	The median length of stay remains at two weeks, on average. In	
	Variant Syndrome patients, the decrease DBD offers could be driving	
	the increased use of DCD grafts. It seems that there is variation over	
	centres in registration of severe HPS patients which may affect	
	potential offering.	
	The offer outcome for DBD grafts that are offered and subsequently	
	transplanted is 30% and rising over time. V Aluvihare asked for data	
	on outcomes of second opinions. D Thorburn confirmed that this	
	data is not centrally recorded but may be looked at by the	
	collaboratives.	
	Mortality on the variant list is between 1-2%, they receive a high	
	number of offers although there are high rates of decline. The	
	proportion of patients on the variant remains at 7-8%. There was a	
	statistically significant difference in ninety-day survival for HCC	
	patients and CLD patients, which is impacted due to small numbers	
	of patients. 90-day survival is better for DCD than DBD transplants.	
	Re-graft data and reasons for patient removal due to condition	
	deteriorated remains constant. The outcomes are not a consequence	
	of the offering scheme but are at increased risk of waiting list	
	removal. D Thorburn confirmed that data from King's College	
	Hospital came to the same conclusion.	
	M Armstrong asked if data on increased use of DCD NRP preventing	
	an increase in deaths could be used as a business case for support	
	in centres. I Rowe confirmed this data cannot be easily collected and	
	waiting list mortality remains the same as 2017/18 due to a number	
	of factors. D Thorburn confirmed that NLOS identifies those patients	
	at risk of highest mortality after registration.	
	K Simpson asked if separating the data for M1 and M2 complicates	
	the data. P Healy advised that enabling patients to understand how	
	complicated this is will be useful. British Liver Trust will help to	
	produce better communication for patients, to highlight this process	
	is fair and transparent. D Thorburn confirmed that the NLOS review	
	will contain these themes.	
5.3	DCD zones - LAG(23)34 - for noting	
	D Thorburn advised that this paper included updated analysis from	
	the paper presented at last November's LAG meeting. This will be	
	taken to the next LAG Core Group for discussion and what the	
	implications are from donor zones. C Watson asked for reference to	R Taylor
	the term 'donors' to clarified.	
5.4	Flight costs and blue light paper - LAG(23)35	
	D Thorburn highlighted that £150k was spent on flights arranged and	
	charged to NHSBT, for offers that were not transplanted. Most of the	
	flights are used for named patient offers rather than fast track.	
	Flights have been used for travel times of less than 5 hours, D	
	Thorburn asked for the use of flights to be reflected on by centres.	All centres
5.5	DCD SLK - LAG(23)36	
	D Thorburn confirmed that the scheme has been reviewed following	
	a change in November 2021 that, subject to there not being high	

5.6	priority patients on the National Kidney Waiting List, a kidney from a DCD donor is reserved until the zonal and linked centres had declined the kidney. The paper highlights that three DCD SLK transplants have been performed since 1 November 2021. It was agreed by members to offer a DCD D4 kidney directly to the kidney offering scheme rather than holding a kidney back until the zonal and linked liver transplant centres declined the kidney. This will be raised and discussed at the next Kidney Advisory Group meeting.  New service evaluations and HPS patients - LAG(23)37  D Thorburn updated members on review of the service evaluations for patients with either neuroendocrine tumours (NETs) or	R Taylor/ J Whitney
	unresectable Colorectal liver Metastases (CRC Mets) which were introduced in August 2022 and outcomes after registration for those patients listed under the new indications.  He asked if members were content with the outcomes seen with the current system.  A prospective audit was proposed to analyse the 3 month-blood	
	gases for those these patients who have not received a named offer within three months, to measure the trajectory. It was agreed that this should continue to be looked at closely, with no adjustment required at present This data will be reviewed by LAG Core Group.	
	Description Continue and Other discretization Washington	
6.	Paediatric Subgroup/Standing Working Group  The first meeting has not yet been scheduled, with this due to be held in December. Their recommendations will be bought to LAG.	
6.1	Paediatric offering data - LAG(23)38	
0.1	D Thorburn confirmed that this paper highlights the unequal number of offers received by centres and the unequal distribution of donor organs that fulfil the splitting criteria between the three centres.	
7.	New indications	
7.1	ACLF - LAG(23)39	
	D Thorburn highlighted the success of the ACLF programme, recruiting 50 patients into the pilot. He asked LAG members how they should pursue this moving forward. W Bernal detailed some proposed processes within the paper, advising that there are also a number of ongoing studies. He felt that the outcomes should continue to be monitored. Longer term follow-up data is being collected, he confirmed that it is difficult to assess frailty as there is no matrix. He advised that a third of PSC patients have had a undiagnosed cholangiocarcinoma on the explant.  J Whitney confirmed that there is a risk to Hepatoblastoma patients if this is amended to a 7-day service, for those patients registered over a weekend. S Watson if there will be resource implications, however, D Thorburn confirmed that this is within the current guidance and is within the existing criteria of patients being transplanted. W Bernal confirmed that resource implications are quantified in terms of length of stay, with the exclusion criteria keeping the numbers small. The proposal to operationalise this as an accepted indication, allowing centres to register patients automatically without going through the LAG Chair, with some revisions on a 5-day basis was agreed. This will be moved to a 7-day basis, when it is perceived safe to do so.	
7.2	Hilar Cholangiocarcinoma	
	D Thorburn confirmed that he is working with the FTWG to develop the EMPHATIC Protocol for the Clinical Trial of the neoadjuvant pathway including proton beam therapy. The final changes will be made with a view to submitting to Ethics before Christmas. This is one of four pilot evaluations for commissioning PBT. Governance approval from Christie will be sought following Ethics approval.	

7.3	Liver transplantation for severe alcohol-associated hepatitis - LAG(23)41	
	D Thorburn confirmed that a previous pilot in 2016/17 recruited very low numbers and was closed due to the entry criteria poorly selecting patients with a poor prognosis. E Forrest and M Allison submitted a proposal to establish a new pilot for this indication, circulated prior to the meeting. Members were asked to consider how these patients	
	would be prioritised.  E Forrest advised that he understood the reticence to consider an	
	additional indication at this time. He confirmed that there is far more experience internationally since the original pilot, however it is	
	understood that Communications will need to manage the message due to possible concerns regarding unintended consequences. It was agreed that a FTWG will be set-up, to include representation across all transplant centres and specialties, Lay members and patient groups.	
7.4	Adenoma listing patients - LAG(23)42	
	D Thorburn advised that several appeals had been made for transplants for patients who had not yet developed a life-threatening complication, but these might arise as a consequence of adenoma.  B Desari confirmed that the FTWG aimed to identify patients before they develop a malignancy, to be considered for a transplant without	
	an appeal process. Those patients with high-risk adenomas were recommended surgical resection wherever possible. Two sub-sets of patients have been identified who would not benefit from transplant as a treatment option. D Manas asked for ablation to be included for patients who will go into the HCC pathway. K Menon asked for	
	oversight of decision making of what is and isn't resectable. B Desari advised that these referrals could follow a regional transplant MDT model. D Manas advised that an oversight group should look at the patients referred, for decision making. I Rowe advised that this	
	document is outside of international guidance.  This will be bought back to the next LAG meeting to agree the criteria for listing patients, the appeals process will remain in place for these patients.	
7.5	HCC downstaging - LAG(23)43	
	D Thorburn confirmed that 66 patients have been registered with 55 transplanted. He advised that the proposal is to move this to routine indication, recurrence is less than 10%.  This was agreed by LAG members and the Liver Selection Policy will be updated	R Taylor
7.6	Appeals process for small HCCs	
	D Thorburn reiterated that the group meet monthly to review patients that have been registered without discussion at MDT. This has been open for one month, all centres have been contacted.	
7.8	UKTR data collection - LAG(23)45	
	This was not discussed during the meeting.	
8.	Liver CLU Scheme and Liver Utilisation	
8.1	Ideal liver report - LAG(23)46	
	A Adair advised that centres are written to following high-offer declines, as a consequence positive feedback has been received in terms of education and learning. Trainees are included. There will be a series of Webinars. D Thorburn confirmed that the rate of right lobe utilisation is falling and the Cold Ischaemia Time of those right lobes will be looked at in LAG Core Group.	
9.	Liver Transplant Commissioning	
9.1	NHS England	
	S Watson advised that transplant meetings will be set-up with standing agenda items, including Unit capabilities and asked for	

	agenda items for the adult or paediatric meetings. She confirmed	
	that patient groups also attend these meetings, she will invite D Manas.	S Watson
	S Watson will discuss using NHSBT data with R Taylor out of this	S Watson
	meeting. She will write to Centre Directors to confirm funding for the service.	S Watson
	Several conversations have been held regarding workforce issues,	
	specifically at Birmingham Women's and Children's Hospital. She advised that reassurance has been given that some vacant posts	
	have been filled.	
9.2	National waiting list	
	S Watson previously met with NHSBT IT Colleagues for them to scope the requirements for the system. This document has not yet	D Manas
	been created. D Manas will speak to L Ellis-Morgan and feedback.	Dividias
10.	RAG Update - National NRP development	
	I Currie advised that six centres who deliver NRP continue to do so	
40.4	on an ad-hoc basis.	
10.1	Super-urgent liver pathway update  I Currie updated members on the SCORE programme. There are	
	two contributions with an increase from 3 to 9 hours from the time of	
	family agreement to registering the donor with the Hub and the time	
	of first offering to a NORS team on the road increasing. The plan is	
	at 8am if the donor is registered with the Hub, a guaranteed Retrieval Team will arrive that same night between 10pm and 3am. This will	
	hopefully result in daytime transplant, having looked back at	
	Cardiothoracic Team's data, they were able to reduce travel time and	
	flights by 10%.	
11.	Governance Issues	
11.1	Non-compliance with allocation	
11.2	This item was not discussed during the meeting.  HTA B forms - LAG(23)47	
11.2	This item was not discussed during the meeting.	
11.3	Governance report - LAG(23)48	
44.44	The report was included with papers circulated prior to the meeting.	
11.4.1	Summary of CUSUM monitoring of outcomes following liver transplantation - LAG(23)50	
	Over the last seven months, there were no signals against the	
	national rate for adult elective liver transplants.	
11.4.2	Report on recent triggers (shared learning)	
	This Agenda item was not discussed.	
12.	National Clinical Trials - LAG(23)40  The paper was included with papers circulated prior to the meeting.	
13. 13.1	Statistics and Clinical Research Report Summary from Statistics and Clinical Research - LAG(23)51	
13.1	R Taylor advised that the manuscript on the development of the TBS	
	and the impact of the first two years of the National Liver Offering	
	Scheme has been submitted, with the re-submissions being worked	
	on.	
14.	Multi-visceral and Composite Tissue Advisory Group (MCTAG) update	
	D Thorburn advised that discussions were held in the last MCTAG	
	meeting regarding a liver transplant patient who might then require a	
	small bowel transplant. He confirmed that the level of unfavourable outcomes was not finalised during the meeting. The minutes were	
	circulated to LAG members prior to the meeting.	
15.	AOB	
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	P Healy thanked the Royal Free for hosting the APPG on Liver Health, this meeting included two MPs. She asked that Centres invite MPs to visit, a toolkit has been developed by British Liver Trust. P Healy had asked supporters of Fibre Scans to contact their local MPs, who will then speak with the Department of Health, to ask questions in the House of Commons.  P Healy advised that the Big Give Appeal has a target of £60,000 to raise by Tuesday 5 <sup>th</sup> December 2023, donations can be made online.	
16.	Date of next meeting -	
17.	FOR INFORMATION	
17.1	Group 2 Transplants - LAG(23)52	
17.2	Outcome of appeals - LAG(23)53	
17.3	Prioritised paediatric patient outcomes - LAG(23)54	
17.4	Prolonged registrations - LAG(23)55	
17.5	Activity and organ utilisation monitoring (dashboard) - LAG(23)56	
17.6	Machine Perfusion working group - LAG(23)57a,b,c	
17.7	Neuroendocrine Tumours - for noting - LAG(23)59	
17.8	HCV positive transplants into HCV negative recipients - for noting -	
	LAG(23)44	
17.9	Minutes of MCTAG meeting - LAG(23)60	
17.10	Minutes of the Retrieval Advisory Group - LAG(23)61	
17.11	QUOD Statistical Report - LAG(23)62	
17.12	IT Changes and Update - LAG(23)63	