NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE FORTY EIGHTH MEETING OF THE LIVER ADVISORY GROUP AT 11:00am on WEDNESDAY 21st MAY 2025 at Friends House, 173-177 Euston Road, London, NW1 2BJ

ATTENDEES

Varuna Aluvihare LAG Chair, Kings College Hospital

Anya Adair Surgical lead for LAG/Liver Lead CLU/Royal Infirmary of

Edinburgh

Mike Allison

Matt Armstrong

David Bartlett

Joan Bedlington

Will Bernal

Cambridge University Hospitals

University Hospitals Birmingham

University Hospitals Birmingham

Patient Representative, LIVErNORTH

Kings College Hospital, London

Lisa Burnapp AMD - Living Donation and Transplantation, NHSBT

Lee Claridge St James's University Hospital, Leeds
Becky Clarke Regional Head of Nursing, NHSBT
Miriam Cortes-Cerisuelo Kings College Hospital, London

Matthew Cramp University Hospitals Plymouth/BLTG Representative

Tim Court Lay Member

Vijay Dhakshina St James's University Hospital, Leeds

Omar El-Sherif St Vincent's Hospital, Dublin Ewan Forrest Glasgow Royal Infirmary

Paul Gibbs Cambridge University Hospitals

Vanessa Hebditch British Liver Trust

Brian Hogan Royal Free Hospital, London

Jade King Statistics and Clinical Research, NHSBT

Andrew Madden Lav Member

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

Steven Masson LAG Deputy Chair/The Freeman Hospital, Newcastle

Marumbo Mtegha Birmingham Children's Hospital Joerg Pollock Royal Free Hospital, London

Peter Robinson-Smith Transplant Coordinator, The Freeman Hospital, Newcastle Ian Rowe Chair of the National Liver Offering Scheme Monitoring

Committee/ St James's University Hospital, Leeds

Rhiannon Taylor Statistics and Clinical Research, NHSBT

Doug Thorburn Royal Free Hospital, London Gwilym Webb Cambridge University Hospitals

Julie Whitney Head of Service Delivery - ODT Hub, NHSBT

Mike Williams Royal Infirmary of Edinburgh
Colin Wilson The Freeman Hospital, Newcastle

IN ATTENDANCE

Abby Horne Clinical Support Services, NHSBT Alicia Jakeman Clinical Support Services, NHSBT

APOLOGIES

Richard Baker, Ian Currie, Audrey Dillon, Pam Healy, Michael Heneghan, Andrew Holt, Gareth Jones, Preya Patel, Chris Watson, Sarah Watson, Steve White

| ITEM | | ACTION |
|------|--|--------|
| 1. | Welcome | |
| | Declarations of interest in relation to the agenda | |

| T | T., | |
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| | V Aluvihare welcomed members with introductions. There were no | |
| | declarations of interest. | |
| 2. | Minutes of the last Meeting, held on 13 th November 2024 - | |
| 2.1 | LAG(M)(24)02 The minutes were approved as an accurate record. | |
| 2.2 | Action Points - LAG(AP)(24)02 | |
| L. L | Action Points - LAG(AI)(24)02 Action Points outstanding are included on the agenda. | |
| | AP8 - Replacement for Ayesha Ali will be advertised next week, with | |
| | more engagement with 2 PAs per week by a Transplant Clinician. | |
| 2.3 | Matters Arising, not separately identified | |
| | There were no matters arising. | |
| 3. | Medical Director's Report | |
| | Appointments: | |
| | Carla Rosser H&I Deputy Lead for NHSBT. | |
| | National Lead CLU role - This role is not funded and has been | |
| | decreased to one person and combined for Cardio-Thoracic and | |
| | Abdominal. D Manas' Medical Director Deputy vacancy has been interviewed for. | |
| | | |
| | Finance: | |
| | The spending review was favourable; £3.6 million which will cover DCD | |
| | Hearts, ARCs and ANRP. A Programme Board has sub-groups for each | |
| | organ. Piloting the new process will start in August 2025. | |
| | A Liver ARC implementation Group Chair vacancy will be advertised. | |
| | A Workforce meeting was held; recognition for all staff roles was | |
| | highlighted, under Trust Engagement work to support transplantation, | |
| | engage more students, also reimbursement needs to change. | |
| 3.1 | Organ Utilisation Group recommendations | |
| | The OUG made 14 recommendations including a proposal for an AMD | |
| | in Patient Engagement, to engage with patients and stakeholders. The AMD Team are doing a lot of this work, collaboratives and a | |
| | sustainability group for ESIT are progressing. ISOU work is with the | |
| | Health Minister to improve H&I, to finish this year. From 2 nd to 5 th June | |
| | 2025 a summit will be held with International Colleagues to discuss the | |
| | consent rate, currently DBD is 59%, DCD is lower than 50%. | |
| 3.2 | NRP funding | |
| 2.2 | This was discussed under item 3. SCORE | |
| 3.3 | J Whitney confirmed that engagement is complete, funding has been | |
| | received, full development will start June 2025. Visits have been made | |
| | to all liver centres. Slides were shared with members prior to the | |
| | meeting. 5 Operational Consideration scenario-based | |
| | recommendations, previously discussed with Core Group members | |
| | were discussed with the group. 4 were agreed, scenario 5 will be | |
| | discussed under the ARC Pilot first. 2 additional considerations of | |
| | whether to retain the current Fast Track Triggers and number of offers to be considered under the new SCORE model were agreed. | |
| | A caveat for re-allocation was requested, with a uniform discussion by a | |
| | trained person at each centre with the original patient. A cut-off time | |
| | was also suggested. L Barton will be asked to ensure consistent | |
| | information is detailed on NHSBT webpages. | |
| 3.4 | Regional collaboratives | |
| <u> </u> | G Jones was not present at the meeting. | |
| 3.5 | HHV-8 | |
| | D Manas provided an update, with a request for pre-transplant HHV-8 | |
| | testing. The numerous antibody tests are inaccurate, pre-transplant PCR is also inaccurate. A working group has made SaBTO | |
| | recommendations. Current serology testing will continue with a PCR | |
| | post-transplant. A machine to process the pre-transplant testing quickly | |
| | in the state of th | i |

| | is required for deceased and living donors, this will require funding from | |
|-----|---|-------------------------|
| | the Department of Health. | |
| 3.6 | NOUC update | |
| 3.7 | D Manas updated the group that under the arm-length body government spending review, face-to-face meetings have come under scrutiny. External venues are being cancelled and meetings are being held via Teams with NHSBT/NHS/Government Venues being utilised. Liver Utilisation Report for noting - LAG(25)01 | |
| | The paper created by R Taylor was shared with the group prior to the meeting. There were no questions from members. | |
| 4. | LDLT Project | |
| | L Burnapp provided an update on the project, which has been running for three years. There are two workstreams for this year on data and piloting the donor reported outcome and experience measures that have been developed post-transplant. This registry information and reported outcomes will be shared at the Network meeting. The service specification has been discussed with NHSE, S Watson continues to work on this service specification. There is an NHS.net Proctor email. There have been 16 referrals across five centres, the Proctor Team Core Group meet monthly. Two transplants have been undertaken, with one ongoing today. Funding will continue for another two years. A Hakeem has completed a huge amount of work updating the living donation guidelines, these will be sent to the group and BTS. The Living Donation Network meeting is in York, registration will open next month, with two US speakers and donor advocacy. L Burnapp will ask Temi Adams/Sam Tomkings to send the invitation to LAG members. | L Burnapp/ A Jakeman |
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| | R Taylor reported on the elective liver SDC form return rates as at 27 | |
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| | April 2025 and advised that reports are sent to all centres monthly | |
| | indicating the time from last SDC form received by NHSBT. She | |
| | thanked centres for completing the forms. | |
| 6.3 | National Liver Offering Scheme (84 month data) and Summary Feedback of key points from NLOS - LAG(25)03 | |
| | I Rowe provided an update from the monitoring committee, 7 years on | |
| | from the introduction of the National Liver Offering Scheme. | |
| | He provided the headlines on the overall outcomes with the proportion removed from the waiting list remaining lower than before the scheme, | |
| | due to earlier transplantation for those at greatest need, showing | |
| | increased benefit. | |
| | Offering has changed since 2018/19, with 803 DBD transplants on | |
| | patients on the adult elective tier, 491 (79.1%) were from named patient | |
| | offers. In 2024/25 there have been 315 DCD transplants. The DCD | |
| | offers have implications after increased offers made to Super Urgent | |
| | and variant syndrome patients. | |
| | The Committee have observed that new registrations has stopped rising and fallen over last year possibly due to change in practice at centres. | |
| | Variant syndrome registrations have increased, currently with an | |
| | unclear implication. | |
| | The changes made to the scheme in October 2022 were to address | |
| | concerns in increased waiting list time for HCC patients. This impact is | |
| | not clear. In parallel other groups are now impacted with those with | |
| | 'other' indication who have not had a single offer since 11th September 2024. | |
| | Members agreed that the number of DBD offers have declined since | |
| | COVID-19, impacting the scheme. I Rowe confirmed that change is | |
| | more urgent now and the outcome of the formal review will help by | |
| | implementing those changes. | |
| | M Armstrong asked for television adverts for solid organ donation to | |
| | engage the public. UHBNHSFT are completing work with NHSE to undertake a 24/7 machine perfusion programme. NHSE have identified | |
| | disparity in the waiting list and will be writing to patients and centres | |
| | further. D Manas confirmed that under the OUG, patients have asked to | |
| | choose which tertiary centre to go to and then to be moved to a different | |
| | centre for their transplant. | |
| | Nationalising the waiting list and identifying geographically where | |
| C 4 | patients are most disadvantaged is required. | |
| 6.4 | Flight costs and blue light paper - LAG(25)04 R Taylor presented the paper detailing that there were 14 flights where | |
| | the estimated road journey was less than 5 hours with a total flight cost | |
| | of £173,933.10. Six of the 14 flights had an estimated road journey of | |
| | less than 4 hours with a total flight cost of £74,068.77. R Taylor will ask | R Taylor |
| | centres to review their flight requests. | |
| 6.5 | New service evaluations and HPS patients - LAG(25)05 | |
| | R Taylor reported that since 1 st August 2022, 2 intrahepatic cholangiocarcinoma patients have been registered and transplanted at | |
| | Cambridge having received NRP DCD livers within 92 days of | |
| | registration. Of 5 Colorectal Metastases (CRC Mets) patients, 4 have | |
| | been transplanted, one within 10 days of registration. A further patient | |
| | with Hilar Cholangiocarcinoma has gone through the appeals process | |
| | but has not transplanted. Additional outcome data was discussed by | |
| | members as there is no database currently. A Adair advised of a | |
| 6.5.1 | universal approach to collect this data. New indications - update and review - LAG(25)28 | |
| J.J. I | A Adair thanked the members who fed back to the group, with sufficient | |
| | stakeholder engagement. They ask is offering working and if not what | |
| | has to change. Inclusion/exclusion criteria for intrahepatic | |
| | cholangiocarcinoma and colorectal patients will come under review. | |

| | The Colorectal liver Mets. group has needed more work than others | |
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| 6.5.2 | with a monthly MDT for sharing and learning. The recommendations of the group were shared, the increase to the criteria from 2cm to 3cm for intrahepatic cholangiocarcinoma patients was agreed. There are plans for stakeholder events with other communities and colleagues who don't work in transplantation. Standardising waiting list and mutual aid - LAG(25)07 B Hogan provided an update to members highlighting important points on relooking at standardising the minimum dataset criteria and thoughts on reducing variation in assessments and to make recommendation on mutual aid provision. The group considered two mutual aid scenarios; | |
| | short-term and a medium term if unable to deliver transplant services. They created a National Liver Transplant (LT) Assessment Template and discussed how this data can be shared across centres. The FTWG also discussed consent and follow-up. D Manas advised that mutual-aid is discussed with the Collaboratives, with templates created during the pandemic and SLAs required. J Whitney asked for an amendment to point 8.4.2; NHSBT to be amended to 'NHSE should develop plans to fund this requirement' for the additional funding for relatives' travel/accommodation. V Aluvihare will continue this discussion with the new BTS president. B Hogan will move this forward with BLTG and Collaboratives. Members advised that they do not have the level of trust between their anaesthetic colleagues as with each other. It was agreed that this was a suitable minimum standard dataset and will be progressed within BTS and BLTG anaesthetic colleagues. | V Aluvihare/ B Hogan |
| 7. | Lessons learned from Synnovis outage - LAG(25)08 | |
| | V Aluvihare advised members that only 21% of offers made during the outage were named DBD offers through the National Liver Offering Scheme, the offers were unpredictable making mutual aid decisions difficult. | |
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| 8. | Paediatric Subgroup | |
| 8.1 | Paediatric offering data - LAG(25)09 R Taylor shared the report findings with metabolic liver disease patients not receiving any offers. Members were reminded that IT changes on splitting criteria and changes to zonal criteria will be required to make improvements. The group agreed that living donation is the best option for transplantation for paediatric patients. | |
| 8.2 | Paediatric prioritisation/non zonal offering - LAG(25)10 V Aluvihare advised that work on paediatric prioritisation is being standardised using the ACLF referral form. This is working well with patients being transplanted appropriately. The low number of offers for paediatric patients is a concern and may be as a consequence of NLOS. | |
| 8.3 | Paediatric offering sequence/multi-visceral transplant T Grammatikopoulos and A Butler were not present at the meeting. | |
| 0 | | |
| 9. | New indications | |
| 9.1 | W Bernal confirmed that the ACLF pilot programme was completed successfully. Each case no longer needs to be scrutinised prior to be elevated to the Tier. The group concluded that a further 23 transplants saved patients lives. There were concerns originally however the number of registrations is approxiamately 2 per month. On removal of the panel there was no impact on patients' survival time, this has | |

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| | Pro-active assessment as a service evaluation on Quality of Life of | |
| | patients who have had a profound illness was agreed by the Group. | |
| | J Whitney confirmed that this will be a 9am-5pm 7 day a week service | |
| | from June 2025. | |
| 9.2 | Hilar Cholangiocarcinoma | |
| | D Thorburn updated members that this is being run as a Clinical Trial, | |
| | they have Ethics approval from November 2024, Transplant centres are | |
| | being set-up as PIC sites. One patient has been registered outside of | |
| | the pilot for PBT under an appeal. If patients meet criteria, centres can | |
| | request an IFR to fund their treatment outside of the pilot. | |
| 9.3 | UKTR data collection | |
| | I Rowe previously presented a paper in November 2024 LAG, this is a | |
| | work in progress. | |
| 9.4 | Early liver transplantation for severe alcohol-related hepatitis - | |
| | LAG(25)13 | |
| | E Forrest and M Allison chaired a FTWG with various stakeholders. The | |
| | families advised that they trusted the medical decision made. The | |
| | criteria for the original service evaluation was not perceived to be quite | |
| | right. They have identified two groups of patients for a new service | |
| | evaluation; ACLF Grade 3 and Failure to recover, MELD >35. E Forrest | |
| | detailed the process, this will be monitored with national oversight of | |
| | patient selection. There is no plan to introduce an additional tier for | |
| | these patients currently. The opinion of donor families was agreed as | |
| | · · · · · · · · · · · · · · · · · · · | |
| 9.5 | important. LAG members gave their approval. Sickle cell liver disease | |
| 9.5 | | |
| | A Suddle was not present at the meeting. | |
| 10. | Liver CLU Scheme and Liver Utilisation | |
| 10.1 | Ideal liver report and late declines - LAG(25)14 | |
| | A Adair advised of the results of the local CLUs survey results, 77% of | |
| | respondents feel the CLU scheme is working effectively, 41% don't | |
| | have this recognised in their job plan. | |
| | They wish to address logistics causing late declines, letters are | |
| | reducing in numbers. The group want to look into this, starting with DBD | |
| | organs. Approval from LAG was given. | |
| | Agreement was made to increase number of offers under consideration | |
| | to 4, although the impact of this on increased discard numbers needs to | |
| | be monitored. | |
| | R Taylor will send the draft paper will be sent to members, to include | |
| | NHSBT data. | R Taylor |
| | | |
| | National appeal for acute liver failure | |
| 11. | | |
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| | R Taylor detailed the summary of CUSUM monitoring of outcomes | |
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| | following liver transplantation. All triggers are reviewed by V Aluvihare | |
| | and D Manas. A review of re-graft outcomes will be undertaken. | |
| 12.3.2 | Report on recent triggers (shared learning) | |
| | S Sinha was not present at the meeting. | |
| 13. | OrQA | |
| | C Wilson advised members of the OrQA app, to be run as a national | |
| | trial. A severe steatosis score will be measured by the app and attached | |
| | to the photograph. Over 1000 photos have now been taken in UK, USA | |
| | and Europe. NIHR randomised controlled trial, is due to go-live from | |
| | September 2025 to September 2027. LAG members gave their | |
| | approval for the Trial. | |
| 14. | National Clinical Trials - LAG(25)18 | |
| | R Taylor shared a paper providing an update on the clinical trials in | |
| | organ donation and transplantation that NHSBT Clinical Trials Unit | |
| | (CTU) are currently managing. There are currently 11 ongoing trials. | |
| 15. | Statistics and Clinical Research Report | |
| 15.1 | Summary from Statistics and Clinical Research - LAG(25)19 | |
| | R Taylor provided a summary with Risk Communication Tools updated | |
| | recently. | |
| 15.2 | Follow-up form return rates - LAG(25)20 | |
| | R Taylor advised that for adult transplants, the overall form return rate | |
| | for the one-year follow-up form was 98%. For paediatric transplants, the overall form return rate for the one-year form was 75%. She confirmed | |
| | that this data will be included in the Annual Report. | |
| | | |
| 16. | Multi-visceral and Composite Tissue Advisory Group (MCTAG) update | |
| | A Butler was not present at the meeting. P Gibbs advised that MCTAG | |
| | are moving from liver and small bowel to small bowel only transplants. | |
| | The liver offering pathway for patients who require a liver after a small | |
| | bowel transplant has been reviewed by the liver after intestinal or | |
| | cardiothoracic transplantation FTWU who will report the findings at the | |
| | next LAG. D Manas confirmed that its been agreed that patients could | |
| | be registered on the ACLF tier. | |
| 17. | AOB | |
| | V Hebditch advised members that NICE are undertaking an evaluation | |
| | on NRP: Early Value Assessment – HTE10066 Ex-situ machine perfusion devices for liver transplants. | |
| | Date of next meeting - Tuesday 25 th November 2025, via MS Teams | |
| | | |
| 18. | FOR INFORMATION | |
| 18.1 | Outcome of appeals - LAG(25)21 | |
| 18.2 18.3 | Activity and organ utilisation monitoring (dashboard) - LAG(25)22 Machine Perfusion working group - LAG(25)23 | |
| 18.4 | Minutes of MCTAG meeting - LAG(25)24 | |
| 18.5 | Minutes of the Retrieval Advisory Group - LAG(25)25 | |
| 18.6 | QUOD Statistical Report - LAG(25)26 | |
| 18.7 | IT Changes and Update - LAG(25)27 | |
| 18.8 | Clotbust-L trial - LAG(25)06 | |
| | | |