# NHS BLOOD AND TRANSPLANT
# ORGAN AND TISSUE DONATION AND TRANSPLANTATION

## THE TWENTY-THIRD MEETING OF THE NHSBT CTAG(L) LUNGS ADVISORY GROUP ON THURSDAY 12 JUNE 2025 AT WESLEY HOTEL, LONDON
## MINUTES

**Attendees:**

| | |
|---|---|
| Jasvir Parmar | **CTAG Lungs Chair**, Royal Papworth Hospital |
| Amit Adlakha | Cons. Intensivist/Lung Transplant Physician, Royal Free Hospital |
| Eleanor Blann | NHSE Transformation; Recipient Co-ordinator, Birmingham |
| Rossa Brugha | Paediatric Respiratory Consultant, GOSH |
| Robert Burns | Co-Chair, CTAG Patient Group |
| Heather Chapman | Pharmacist, Royal Papworth Hospital |
| Kavita Dave | Consultant, Respiratory & Transplant Medicine, Royal Brompton and Harefield Hospitals |
| Andrew Fisher | Deputy Director BTRU, Freeman Hospital, Newcastle |
| Rosie Fitzgerald | CTAG Patient Group |
| John Forsythe | DHSC, ISOU |
| Corinna Freeman | H&I rep, British Society for Histocompatibility and Immunogenetics (BSHI) |
| Dale Gardiner | Associate Medical Director – Deceased Organ Donation, NHSBT |
| Vicky Gerovasili | Centre Director, Royal Brompton and Harefield Hospitals / Interim CLU Lead |
| Shamik Ghosh | CTAG Lay Member Representative |
| Margaret Harrison | CTAG Lay Member Representative |
| Jessica Jones | DHSC, ISOU Patient Representative |
| Pradeep Kaul | **Deputy Chair, CTAG Lungs**; Cons Surgeon, Royal Papworth Hospital |
| Maggie Kemmner | NHS England |
| Jim Lordan | Lung Transplant Physician, Newcastle |
| Helen McDaniel | DHSC |
| Gerard Meachery | Consultant, Respiratory Medicine & Lung Transplantation, Newcastle |
| Maria Monteagudo-Vela | Surgical Lead, Royal Brompton and Harefield Hospitals |
| Aaron Ranasinghe | **CTAG Hearts Chair**; Queen Elizabeth Hospital, Birmingham |
| Anna Reed | NHSE Transformation; Royal Brompton and Harefield Hospitals |
| Carla Rosser | Consultant Clinical Scientist, NHSBT / OTDT H&I Lead |
| Rachel Rowson | Regional Manager, London Organ Donation Team |
| Sally Rushton | Statistics and Clinical Research, NHSBT |
| Karthik Santhanakrishnan | Centre Director, Wythenshawe Hospital Manchester |
| Philip Seeley | Transplant Co-ordinator, Freeman Hospital, Newcastle |
| Debra Thomas | Physician Centre Representative, Royal Papworth Hospital |
| Matt Thomas | Paediatric Lung Physician, Freeman Hospital, Newcastle |
| Richard Thompson | Physician Centre Representative, QEH, Birmingham |
| Brian Tierney | Lead Nurse, South-West Team |
| Sophie Walters | Recipient Nurse, QEH, Birmingham |
| Daniel White | Transplant Co-ordinator, Royal Papworth Hospital |
| Julie Whitney | Head of Service Delivery, OTDT Hub, NHSBT |

**In attendance:**

| | |
|---|---|
| Caroline Robinson | Advisory Group Support, NHSBT (Minutes) |
| Sam Tomkings | Medical Director and Group Support, NHSBT |

| Item | APOLOGIES AND WELCOME | Action |
|---|---|---|
| | • J Parmar welcomed everyone to the meeting.<br>• Apologies were received from Liz Armstrong, Richard Baker, Martin Carby, Ian Currie, Debbie Macklam, Derek Manas, Michelle Murray<br>• M Harrison (lay member for many years for CTAG Hearts and Lungs) was thanked for her enthusiasm and participation in the CTAG meetings over many years. | |
| | | |
| **1** | **DECLARATIONS OF INTEREST** | |
| | There were no declarations of interest raised at the meeting.<br>• ***It is the policy of NHSBT to publish all papers on the website unless the papers include patient identifiable information, preliminary or unconfirmed*** | |

| | | |
|---|---|---|
| | ***data, confidential and commercial information or will preclude publication in a peer-reviewed professional journal.***<br>• ***Authors of such papers should indicate whether their paper falls into these categories.*** | |
| | | |
| **2** | **MINUTES AND ACTION POINTS OF THE CTAG LUNGS MEETING HELD ON 12 DECEMBER 2024 – CTAGL(M)(24)02 and CTAGL(AP)(24)02** | |
| 2.1 | The Minutes of the previous CTAG Lungs meeting held on 12 December 2024 were accepted as a true record. | |
| 2.2 | The Action Points from the previous CTAG Lungs meeting on 12 December 2024 were discussed as follows: | |
| 2.2.1 | Survival from Listing – At the last meeting R Thompson agreed to contact S Rushton about one patient who appeared to contradict the data shown. | **COMPLETE** |
| 2.2.2 | Combined lung-liver priority – Meetings are ongoing regarding patients who may need a heart, lung or small bowel transplant in conjunction with or without a liver and whether patients can be saved if the liver fails. | **ONGOING** |
| 2.2.3 | ERAS and Collaboratives – An OUG recommendation is for centres to learn from COVID and to look at options for mutual aid. G Jones came to speak to CT Centre Directors in May 2025 to talk about the potential benefits of collaboration. *See Item 10*<br>ERAS – *See Item 10* | **ONGOING** |
| 2.2.4 | CTAG Hearts CLU / Deputy CTAG Lungs Chair – Andrew Morley-Smith has been appointed as the new CTAG Hearts CLU lead (following A Ranasinghe's recruitment as CTAG Hearts Chair). *See also Item 3.2 below* | **COMPLETE** |
| 2.2.5 | H&I Rep at CTAG meetings – *See Item 3.2 below* | **COMPLETE** |
| 2.2.6 | Lung Activity - At the last meeting, Harefield stated that they were trialling a transplant referral checklist for patients who were on the waiting list. M Carby agreed to share this with checklist with S Watson.<br>**ACTION: V Gerovasili to circulate the form Harefield is using**. | **V Gerovasili**<br>**ONGOING** |
| 2.2.7 | Lung Allocation Working Group – It was previously agreed that the word 'massive' would be dropped for CF patients and replaced with 'life threatening Haemoptysis'. It was also agreed to replace the word 'embolization' with 'intervention'. These changes are in the workstream for update. However, it was noted at CTAG Lungs that this is not timely although it was noted that this will not make a material difference to who is prioritised which is why it has not been raised for earlier more urgent action.<br>**ACTION: Dale Gardiner will establish timelines for this change to be initiated.** | **D Gardiner**<br>**ONGOING** |
| 2.2.8 | Lung Allocation Modelling Update - *See Item 7.1* | **ONGOING** |
| 2.2.9 | Matching and Offering Business Case for IT – L Ellis Morgan is now invited to CTAG Lungs meetings to report on progress with plans. I Harrison (IT at NHSBT) is now invited to Lung Allocation Working Group meetings. | **ONGOING** |
| 2.2.10 | Offer Decline Scheme – *See Item 8.2* | |
| 2.2.11 | CTAG Patient Group – Infectious Diseases Update - Shingles/Chickenpox – To be discussed at CT Centre Directors' meeting in July. | **ONGOING** |
| 2.2.12 | CTAG Patient Group - Respiratory syncytial virus (RSV) Vaccine – CTAG Lungs members were previously asked for expressions of interest to act as clinical representatives to help speed up decision making for medication licences and to improve developments and vaccines. To date none have been received. | **ONGOING** |
| 2.2.13 | CTAG Patient Group – Flu – Due to the spread of flu at the time of the last CTAG Lungs meeting, it was agreed that Tamiflu should be used in the community subject to primary care approval. G Meachery confirmed that Newcastle has updated its own guidelines to meet Department of Health guidelines (to take 10-day Tamiflu course for immunosuppressed individuals). Other trusts need to confirm they are taking similar action. | **COMPLETE** |
| 2.2.14 | Environmental Sustainability in Transplantation (ESIT) Project – A Lung representative is still required to join this voluntary group that is now a formal part of the OTDT workload. Team members at trusts to let J Parmar know if interested. | **ONGOING** |
| 2.2.15 | National Proforma Update – *See Item 12.2* | |
| 2.2.16 | Update on 10 Degree Fridge (hypothermic preservation) – A Ranasinghe has copied J Parmar into an incident report from Birmingham. An incident from Harefield has been sent on for audit. | **COMPLETE** |
| 2.2.17 | COVID 19 Update – *See Item 12.4*. I Ushiro-Lumb will be invited to attend the autumn CTAG Lungs meeting. | **ONGOING** |
| | | |
| **3.** | **MEDICAL DIRECTOR'S REPORT** | |
| 3.1 | Developments in NHSBT – D Gardiner reported the following: | |

| | | |
|---|---|---|
| | • R Burns (CTAG Hearts Patients Co-Chair) and M Harrison (Lay Member) were thanked for their participation in these meetings as they leave their roles at the end of their terms.<br>• Margaret stated that she had very much enjoyed her role. It had been a privilege to be a lay member and she is full of admiration for the work that is done to make organ transplant for hearts and lungs patients successful.<br>• Finances – these remain tight with a 2% cost improvement needed. DCD Hearts, A-NRP and CLU funding is now included in baseline funding.<br>• Histopathology – this remains a challenging issue. It is noted that organs are being lost as it has not been possible to source pathologists on all occasions when they are needed. The Business Case for this work is now with NHSE for consideration. It is hoped that greater use of 10-degree fridges will mean this will become a less pressing issue until it is resolved.<br>• Collaboratives – The Kidney Collaborative is now well-established, and it is hoped that the same will be possible for CT in the coming months.<br>• Donor numbers in the UK fell by 7% last year and this coincides with a period when there is more dissatisfaction with the NHS overall. However, weekly numbers are now ahead of pre-COVID figures. As a result of falling numbers a meeting was held in London which included 7 international experts from Australia, Canada, USA, the Netherlands and Spain. Actions from this relate to processes and a need to be more proactive with marketing. It was also emphasised that the public are currently confused by the new opt out laws in the UK. It was noted that Spain does not refer to the legislation when talking to donor families. | |
| 3.2 | New Appointments – These were highlighted as follows:<br>• John Casey and Rommel Ravanan have been appointed to be joint Deputy Medical Directors for OTDT to support D Manas. The exact nature of the role is still in development.<br>• Carla Rosser (who attended CTAG Lungs) has been appointed as the new H&I rep. She will be invited to all the Advisory Group meetings. Post meeting it is also noted that Corinna Freeman is H&I rep, British Society for Histocompatibility and Immunogenetics (BSHI).<br>• Diana Garcia Saez has stepped down as National CLU Lead. V Gerovasili has been appointed as the interim lead while a permanent lead is appointed.<br>• Pradeep Kaul has been appointed as Deputy Chair for CTAG Lungs. He was welcomed to the meeting. | |
| | | |
| 4. | **NATIONAL OVERVIEW** | |
| 4.1 | Lung Activity – **CTAGL(25)19** - This presentation from D Gardiner was circulated prior to the meeting.<br>• Waiting list - The lung transplant waiting list has dropped possibly due to CF medication. However, it is still low compared with international numbers.<br>• Birmingham has exceeded previous number of transplants and hard work has resulted in more positive numbers overall.<br>• The number of Paediatric transplants remain low. It was queried why 2 paediatric centres are needed if there was only 1 paediatric lung transplant in the last year. The need for easy geographical access was emphasised and one centre's activity declined due to the change of modulators for CF. The dependency on a few experienced surgeons was noted. Unmet need is also an important consideration and there is significant evidence that patients who would benefit from transplant are not being accessed.<br>• Utilisation – Improvements in utilisation were discussed and the hope that recovery continues.<br>• Waiting list numbers – These have dropped and substantial differences in waiting times is noted. Waiting list deaths are monitored and variability between centres is to needs be resolved. | |
| 4.2 | Transplant Oversight Group (TOG) update – There was no update at the meeting<br>**ACTION: D Gardiner to follow up with D Manas** | **D Gardiner** |
| 4.3 | NHSE CT Transformation – Update and Progress Report – **CTAGL(25)25** - M Kemmner reported that a full team has been in place since December with R Burns and R FitzGerald joining to represent patients and E Johnson (Blann), A Reed, M Berman and A Mistry becoming specialty advisors. Visits to all centres have been completed.<br>• A decision to include paediatrics in the transformation work was confirmed last year. | |

| | | |
|---|---|---|
| | • The workload will consider the results of the CT ICE survey and collaboration with the evidence from international experts. Benchmarking against international guidelines is also taking place.<br>• NHSBT and NHSE have now agreed data sharing and workstreams will proceed over the summer.<br>• Input will be needed from all centres and the specialty advisors to look at the ambitions for the CT service. The hope is for significant improvements in outcomes, access to transplant, and patient experience and a reduction in inequalities across the national service. Resilience in the service is also an important consideration given workforce challenges currently and the 'collaboration' agenda is considered key here.<br>The presentation at the meeting is circulated with these Minutes. For further information on the Transformation Programme contact maggie.kemmner@nhs.net or england.heartandlungtransplants@nhs.net | |
| 4.4 | CT ICE Survey – **CTAGL(25)23** - J Forsythe re-stated the background of the CT review coming from Recommendation 5 of the Organ Utilisation Report and suggested that NHSE should "*undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient and are able to provide the best possible outcomes for patients".*<br>• The survey was co-produced with patients and completed by patients and clinicians (including international experts) in March 2024 with the analyses published in Oct 2024. There was a good response with 660 patients completing the survey. In response to patient requests, further analysis of survey findings was also published, including at Transplant Centre level and with gender and ethnicity breakdowns in February 2025.<br>• There was significant variability in lung transplant services between centres, with respect to patient numbers, ethnicity and gender.<br>• There is awareness of the huge overlap in hearts and lungs for personnel.<br>• There were 604 valid responses (57% male, 89% white, 62% heart, 33% lung, 5% heart and lung). 80% had received a transplant.<br>• The topics covered were a) referral to assessment waiting times, b) information provided at assessment, c) transplant admission, d) lifelong care, e) psychosocial care and f) raising concerns.<br>• It was noted that psychosocial care is a priority concern. Females also report lower levels of experience across patient support, support for family carers and social care. Black patients and those who did not declare their ethnicity reported much lower levels of experience. Around 27% of patients were not comfortable to raise concerns at all stages.<br>Full details are shown in the presentation circulated with these Minutes and Reports are published at Cardiothoracic transplant information collation exercise: survey analysis - GOV.UK Data and analysis have been shared with NHSE to consider as part of the Transformation Programme and specific centre level concerns have been raised by senior DHSC officials with executive leaders in relevant trusts. Centre Directors were thanked for their co-operation, and it was agreed that more granular information is needed per centre along with reasons patients are not raising concerns in their transplant centres. It was also noted that it would be useful to know what percentage of people included in the survey results are on the waiting list. The link to the ISOU Patient Engagement sub-group report can be found here: https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/implementation-steering-group-for-organ-utilisation/<br>**ACTION: R Burns agreed to circulate the report shown at CTAG Hearts** | **R Burns** |
| | | |
| **5**. | **PATIENT SAFETY** | |
| 5.1 | Patient Safety Report – **CTAGL(25)01** –In the absence of R Baker, there was no representation from the Patient Safety team at the meeting.<br>• One incident is highlighted in the report that was circulated and concerns DCD lungs retrieved for transplantation. Details are included in the report.<br>• Several cases have also been reported where direct communication between retrieval and implanting surgeons would have been beneficial. Although there was clear communication and documentation with other members of the team, it was felt direct surgeon to surgeon communication would have helped. An example is one where lungs deflated repeatedly before packing, but the implanting surgeon was not fully aware of the complexities.<br>• All transplant teams are also asked to take note of the following link for new guidance on HHV8 and to report any cases to the Patient Safety Team: | |

| | | |
|---|---|---|
| | https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/ | |
| 5.2 | CUSUM Monitoring of 90-day outcomes post lung transplantation – **CTAGL(25)02** – This report, summarising analysis of short-term outcomes following transplantation, indicates that there have been no CUSUM signals for lung transplantation in the 6 months since the last CTAG Lungs meeting. | |
| 5.3 | CUSUM Baseline update – **CTAGL(25)03** - This report presents the 90-day post-lung transplant mortality rates for the updated baseline period, 1 January 2020 – 31 December 2023. Due to the low number of paediatric lung transplants in this period, this was extended to 1 January 2016 – 31 December 2023 for paediatric transplants. Full details are in the report circulated.<br>• It is proposed to move the expected baseline to 1 January 2020 to 31 December 2023 for adults and 1 January 2016 – 31 December 2023 for the paediatric charts and to move the monitoring period forward to 1 January 2024. These changes will be implemented as soon as possible.<br>• It was suggested that as paediatric activity is so low it may not be appropriate to continue paediatric charts at this time.<br>• A query was raised regarding inclusion of percentage of failure rate during the pandemic as this could affect outcomes. It was felt that this makes very little difference to triggers for CUSUM as it is within the confidence level.<br>• It was noted that CUSUM only includes 1st time transplants since numbers for re-transplant are very low.<br>**ACTION: S Rushton to find out the numbers of re-transplants.** | **S Rushton** |
| 5.4 | Group 2 Transplants – There are no Group 2 transplants to report. It was agreed that it was important to keep this item on the agenda as any case that arises needs to be discussed. | |
| | | |
| **6.** | **OTDT HUB UPDATE** | |
| 6.1 | Sustainability and Certainty in Organ Retrieval (SCORE) update – **CTAGL(25)24** - This presentation is circulated with these Minutes. Following visits to centres the following issues have been raised:<br>• Access to daytime theatre is a frequent concern<br>• Multi-organ centres will have greater challenges adapting to changes<br>• Logistics for morning activity and bottlenecks concerns many<br>• Reassurances are needed around transport provision.<br>Regarding TransplantPath, Digital Accept and Decline is complete, and work is starting on the delivery phase. Shadow modelling 'as if in the Pathway Arrival Window (PAW) will also take place to identify any issues. The Go Live date is planned for April 2026 providing: digital solutions are established, transplant centres are ready, NORS teams are equipped, and the donation community is prepared.<br>Concerns were raised that the timings are not realistic, and that trust engagement is key in ensuring success. | |
| | | |
| **7.** | **LUNG ALLOCATION** | |
| 7.1 | Lung Allocation Working Group update (May 2025) and Lung allocation modelling update – **CTAGL(25)21** - J Parmar stated that the Allocation Working Group and the Core Group have now had several meetings and most of the modelling is now completed. The work of the Newcastle team started by Sam Kennedy and continued by Leo Freitas has been central to the development of the new allocation system. The group will now continue to meet to discuss how this will be implemented. The group's work has been:<br>• To look at new modelling to inform the non-urgent allocation score<br>• To understand factors that affect outcomes, relative importance of these factors and any relationships between them.<br>• To look at the post-transplant survival model<br>• To use available registry data<br>• To ensure the model used can be generalised for future listed patients<br>Currently standard statistical regression modelling (Cox proportional hazards model) is used. Now multiple imputation for missing values is being incorporated. The preliminary results were presented at the Lung Allocation Working Group meeting on 15 May 2025. Conclusions to date are:<br>• The waiting list performs reasonably well, but the post-transplant model performs less well.<br>• The functional form of linear terms needs checking<br>• Possible interaction terms are to be explored. | **S Rushton** |

| | | |
|---|---|---|
| | • Censoring removals and escalations in the waiting list model need censoring rather than treating them as events<br>• Conditional survival is to be investigated.<br>• All observations to be retained and bootstrap technique for model validation to be used instead of splitting data set into 70:30 for validation<br>Full details are in the presentation circulated. It was noted that survival post-transplant has perceived ideas only and these do not show up in the modelling and there is no good predictive model of survival available in other parts of the world. There is a limited data set currently. Age is also a factor. It will be important to be able to explain to patients how the score for transplant has been determined. It is hoped that there will be an outline policy by the end of this year. | |
| 7.2 | Lung zone review – **CTAGL(25)04** - The lung allocation zones were last adjusted in July 2024. The report circulated provides up to date figures on each centre's percentage share of registrations onto the national lung transplant list and the percentage share of lung donors that arose in their zone. The time periods are 1 February 2023 to 31 January 2025 for registrations, and 1 February 2022 to 31 January 2025 for donors. Full results are shown in the report circulated. There were no significant differences observed in the percentage share of lung registrations and donors across centres/zones, therefore no changes will be made to the lung zonal boundaries at present.<br>Reasons why the zonal centre might decline the lungs were discussed, including highly sensitised patients. It was noted that while processing of samples is standardised, acceptance by centres is different and this can create inequity of access to a transplant. This will be investigated further. There are also differences in sensitisation between centres and the way it is processed in the lab. BTS will lead further investigations across all organs.<br>**ACTION: It is suggested that A Reed to join the working group and others are invited to contact C Rosser if they are interested in participating.** | **A Reed / C Rosser** |
| | | |
| **8.** | **LUNG UTILISATION** | |
| 8.1 | CLU Update - **CTAGL(25)22** – This paper covering the CLU update and the Offer Decline Scheme is circulated with these Minutes. V Gerovasili reported that funding for local CLUs continues uninterrupted and there have been 4 engagement calls since Sept 2024. The following local CLU projects are:<br>• A Adlakha – Lungs – Drowning (Birmingham)<br>• A Adlakha – Lungs – NRP – on hold (Birmingham) – M Berman will join the CLU Engagement call taking place shortly re data on NRP<br>• V Gerovasili – Lungs – Vaping – (Lead CLU) – There is very little literature on vaping currently.<br>In addition, the following initiatives are noted:<br>• There will be an updated version of the CLU handbook to support all CLUS in their roles<br>• A CLU role description will be updated<br>• Annual 121s to take place<br>• CLU Focus groups<br>• Education (focussing on stats at the next engagement call)<br>• CLU biannual newsletter. | |
| 8.2 | Offer Decline Scheme – V Gerovasili reported that more higher quality organs are being utilised and from February 2025 onwards zero higher quality organs were declined for named patients.<br>Upcoming events include:<br>• NOUC - 13 November - Birmingham – 100 places<br>• CT webinar – from Sept onwards<br>• The 2nd CTUC course will take place in June 2026.<br>It was noted that more work needs to be done on waiting list risk and lungs going for research that could have been utilised for transplant. Could these be used for paediatric patients; half of those utilised by GOSH have undergone lung reduction surgery. The issue of patients on the waiting list with CF is also an issue, eg the lack of availability for the correct size lungs could lead to patient disadvantage. Overall, more awareness of why some people wait longer than others is needed. | |
| | | |
| **9.** | **CTAG PATIENT GROUP –** | |
| 9.1 | Update to Patient Engagement Structure – D Gardiner gave an update in D Manas' absence. | |

| | | |
|---|---|---|
| | • A new Patient Engagement Group is proposed to be a platform for all solid organ groups. This will include 2 patient representatives from each solid organ group plus lay member involvement and other groups will feed into this.<br>• Adverts to recruit membership are coming out currently and there has been some good response to this. It is anticipated that those participating will be reimbursed for their involvement.<br>• There will be an annual engagement meeting. There is a similar process in Australia and there should be synergy with other groups, eg blood test access.<br>• An AMD will also be appointed to work with this group, and it is hoped this will help with communication with hospital trusts. | |
| 9.2 | CTPG Patient Chair Report – **CTAGL(25)05 / CTAGL(25)06 / CTAGL(25)07 / CTAGL(25)18 –** This report from R Burns was circulated with 3 appendices. R Burns was thanked for his enthusiasm and input in the role of CTAG Patient Co-Chair which is now coming to an end. | |
| 9.2.1 | Post Transplant CF Care – **CTAGL(25)08 / CTAGL(25)09** – These papers were circulated prior to the meeting. R Fitzgerald (a CF patient who received a double lung transplant 19 years ago) reported that the CT Patient Group and partner support groups receive accounts from multiple CF patients who receive reduced or no specialist CF care following lung transplantation. Similar concerns have been received from transplant clinical staff and the Cystic Fibrosis Trust. The outcome of work undertaken to improve the situation and from a Freedom of Information request are shown in the paper circulated. In summary it is noted:<br>• There is a commitment to ensure all patient with CF who have undergone lung transplantation receive CF care in line with nationally commissioned standards.<br>• A patient's geography/CF centre should not be a factor in the level of care received.<br>• Transplant centres are asked to check figures in the paper circulated to ensure these are in line with those recorded in local databases.<br>• NHSE representatives at CTAG Lungs are asked to remind Dr Fuld and Ms Blacker that there is response outstanding to a letter to them dated 29 March 2025 (see appendix **CTAGL(25)09**.<br>• There has been good progress with services in Manchester and Harefield/Brompton<br>• Patient representatives are happy to contact CF, lung transplant and senior management teams at Papworth if needed.<br>Those who came forward to talk about their concerns were thanked as this is having a positive impact on CF care. Patient representatives are also happy to contact CF, lung transplant and senior management teams at Papworth if needed. | |
| 9.2.2 | Renal Complications and Requirement following Transplant – **CTAGL(25)10** – R Burns reported that lung and/or heart transplantation is known to place a risk upon kidney function and many patients need renal support in the immediate post-operative phase. Many commonly used immunosuppressants are also known to be nephrotoxic and very often patients with previously normal kidney function develop CKD. This can lead to end stage kidney failure and a need for renal replacement therapy or kidney transplantation. Key points highlighted are:<br>• Patient experience is variable and renal and transplant teams often do not communicate well. Patients therefore become conduits for information, and this can lead to health inequalities due to mixed abilities to communicate and engage in services.<br>• There is lack of renal input for transplantation. Examples of renal support at each centre is shown in the paper circulated.<br>• The transplant database records creatinine levels at transplant and each 12 months after this which is being used to estimate prevalence of CKD over time. This information was obtained via a Freedom of Information request.<br>The CT Patient Group recommends the following:<br>• The NHSE Transformation Programme looks at kidney requirements for CT patients (peri-operative care, lifelong care and holistic care)<br>• The CT transplant service specifications should specify the need for sufficient on-site integrated renal services to meet patient need in acute and long-term periods<br>• Nationally, CT transplant teams work with nephrology colleagues to understand variations in kidney function and develop national care pathways to support long-term kidney function. | **M Kemmner** |

| | | |
|---|---|---|
| | • More robust collection of data to record the CKD stage for patients is needed. Some caution is needed to ensure patients do not become worried about renal care.<br>**ACTION: NHSE/M Kemmner to consider these issues in CT Transformation Programme**. | |
| 9.2.3 | Donor Decisions – **CTAGL(25)11** - S Walters reported that patients and families are often asked to make decisions on whether they would accept an organ from a donor who has or may have risk factors associated with poorer long-term outcomes. The following points were highlighted:<br>• This process is either undertaken as an upfront decision at the time of listing or at a time when an organ becomes available, and the potential donor is known (in real time). A decision is often needed at short notice and can cause stress and anxiety as a result when patients are already in a stressful situation. It was noted that timing can be difficult, but it should be covered in the consent process.<br>• Patients are asked to make different decisions depending on which centre they attend and could be given different information as a result.<br>• DCD organs and the use of 10-degree fridges should be incorporated into any conversation so their use can be fully understood. It is suggested that the SaBTO aide memoire, an online tool to look at cancer risk and infection risk is considered by clinicians.<br>• While it is noted that there is a lot of information already on the OTDT website a lot of patients appear unaware of this, and details passed onto them can be ad hoc at present. Literacy can make it harder for some patients to understand the information so this needs to be more accessible.<br>• It is acknowledged paediatric services do not have sufficient data to inform parents to make decisions on their child's behalf<br>• Despite continued challenges, patient information and decision making should be re-visited each time there is a clinic interaction.<br>It is believed that the references being used are outdated so decisions may not be clinically relevant. It is recommended that updated information and standardised process across all centres would be beneficial and this is back up by national OUG recommendations, the CTAG Hearts Chair and CT Patient Group Co-chair. It is noted that prescribing a specific process for centres to follow may be challenging. It was agreed that more thought and structure need to be considered before a decision is made about a specific process for all centres to follow. | |
| | | |
| **10.** | **ERAS (ENHANCED RECOVERY AFTER SURGERY) UPDATE** | |
| | A Adlakha highlighted this multi-modal programme that enables patients to have some control in their recovery post-surgery. This started with kidney transplantation and there is now an active adult liver transplant recipient workstream and developing pancreas transplant recipient workstreams. The steering group meets quarterly.<br>• Creation of a SOP is the aim. Although this will not be a mandatory means to enhance patient care, it is hoped this work will go some way to address patient health inequalities.<br>• Representation from an intensivist and a transplant co-ordinator from each centre is requested, as well as a dietician/surgeon from any centre<br>• There is purposely less representation from lung transplant physicians or pharmacists as both have national groups to which a rep can feedback, though any interested individuals are welcome<br>• The project aims to start this summer and produce guidance in 12-18 months<br>**ACTION: A Adlakha to update CTAG Lungs in June 2026** | **A Adlakha** |
| | | |
| **11.** | **STATISTICS AND CLINICAL RESEARCH REPORTS** | |
| 11.1 | Summary from Statistics and Clinical Research – **CTAGL(25)13** – The paper circulated is an update from Statistics and Clinical Research summarising recent presentations, publications, and current and future work for CT transplantation.<br>• Nominations from centres are requested to review a manuscript on heart/lung transplantation in the UK under the Blood and Transplant Research Unit (BTRU) looking at historical and present perspectives<br>**ACTION: All centres to contact team members on this and to contact A Fisher at Newcastle with nominations to review the manuscript.**<br>• The Statistics Team contributed to the MELODY (Mass Evaluation of Lateral Flow Immunoassays for the Detection of SARS-CoV-2 Antibody in Immunosuppressed People) Study which was recently published in *The Lancet*. The research reveals how a simple blood test can predict the severity of COVID-19 infection in | **All** |

| | | |
|---|---|---|
| | immunocompromised patients, paving the way for personalised approaches to vaccination and better protection for those most at risk. It was noted that this refers to the Omicron period of COVID, so some care needs to be taken in reviewing the results in the current climate. Patients are encouraged to follow current vaccination guidelines. | |
| 11.2 | Adjudication Panel activity – **CTAGL(25)14** – The paper circulated reports on Lung Adjudication Panel referrals between 1 January 2022 and 31 December 2024 as well as urgent and super-urgent heart-lung adjudication panel referrals, which must always be referred to the Lung Adjudication Panel due to the priority these patients are given above urgent lung only patients. The panel has a representative from each unit.<br>• It is noted that the heart panel often offer more detailed opinions that inform the decision making.<br>• Terms of reference for adjudication are being written for hearts so there is more clarity. It is suggested the same should be done for lungs to demonstrate that decisions made indicate a good use of organs.<br>• The possibility that patients on centres' lists are being dis-enfranchised as their cases do not go to the wider MDT was discussed. A quick response from the panel is essential (within 2 working days).<br>An Allocation Review paper will come to the autumn meeting examining any change in urgent registrations since the urgent criteria were revised. It was noted that Newcastle have almost double the number of Urgent registrations in comparison to the other centres.<br>**ACTION: K Santhanakrishan agreed to develop guidance for the panel on the consideration of urgent and super urgent requests to bring to CTAG Lungs Autumn meeting.** | **K Santhanakrishnan** |
| 11.3 | Update on PROM/PREM Development – A Fisher reported that this work continues looking at healthcare experiences across all organs.<br>• 90-minute detailed interviews with 40 recipients have taken place and 12 aspects of healthcare have been highlighted. The PREM will be built around this.<br>• Quality of life is being investigated through the PROM and a lot of commonalities have been identified including physical and social, sexual and sleep issues which are common across all organs.<br>• Pilot testing is going ahead with focus groups followed by an implementation package to see how tools can be used going forward. Trends over time are to be explored across different centres.<br>Patients are thanked for their involvement to date. | |
| | | |
| **12.** | **STRATEGIC DEVELOPMENTS** | |
| 12.1 | DBD Optimisation Bundle – **CTAGL(25)20** – This paper was circulated prior to the meeting.<br>ACTION: D Gardiner to share information post meeting. This will be discussed further at the December CTAG Lungs meeting. | |
| 12.2 | National Proforma update – This platform was developed at Harefield to harmonise data input for lung transplant referrals across all centres:<br>• Papworth has bought this and despite a few problems with IT integration, they are continuing to make use of it.<br>• Birmingham and Manchester intend using the platform as well.<br>• Newcastle is using a different option but is using an electronic platform. Newcastle and the North East is also going through an amalgamation of trusts. | |
| 12.3 | EVLP (Ex Vivo Lung Perfusion) centre updates - J Parmar reported that after 12 months there have been 11 EVLP perfusions and 9 transplants. 6 additional lung transplants have taken place that did not use EVLP. Some issues were reported with team availability, quality of organs and donors not meeting the criteria necessary and EVLP does add time and complexity to the procedure. However, the system is robust, and the plan is to collaborate with Birmingham and GOSH to create a remote EVLP model. Papworth also intends joining with the abdominal teams at Addenbrookes. The long-term strategy is to have a perfusion specialist.<br>• At Newcastle NHSBT allocated funding was given to develop pilot data and a business case for ARCs for Lung, Kidney and Liver. Organ specific steering groups have been set up and A Fisher will chair the lungs group in the interim. Membership is set at 2 representatives from each centre. The first meeting will be held at end June. There will be 2 meetings in June and 2 in August and the group will then appoint a chair. The group will look at how to generate pilot data, proof of principle that the organ was perfused in one centre and transported and transplanted in other centres. EVLP was started in 2009, and an attempt was | |

| | | |
|---|---|---|
| | made to re-establish it in 2018/19. Links are also being created with abdominal perfusionists.<br>• At Papworth funding is coming from NHSE as a pilot project.<br>• At Harefield, there has been some initial funding from charities initially in theatre space and then in the Heart Science centre and the intention is to link with abdominal teams across London. An abstract has been submitted for long term outcomes for EVLP.<br>• Manchester has charity funding for an initial 4 EVLP procedures.<br>• Birmingham and GOSH are joining with Papworth and are approaching charities regarding funding.<br>The national ARC's program is being devised and will launch in the next few weeks. | |
| 12.4 | COVID Positive Donors – a re-think – All donors are being tested for COVID, and a re-think is ongoing about use of COVID positive donors' organs. To be circulated. Item deferred until Dec CTAG Lungs meeting. | |
| | | |
| **13.** | **REPORTS FROM RELATED GROUPS** | |
| 13.1 | Retrieval Advisory Group (14/5/25) – There was no update in M Berman's absence. | |
| 13.2 | CT Centre Directors' meetings – J Parmar reported that G Jones (Chair of Kidney Advisory Group) came to the most recent meeting to discuss collaboratives and described how collaboratives were working in Renal and Liver transplant programmes.<br>• It was noted that Birmingham and Papworth are working together with an established heart collaborative.<br>• One model is to have one national collaborative for the whole country. This was not the favoured approach from NHSBT.<br>Further discussion around this will be needed. Birmingham and Papworth are keen to continue their established collaboration.<br>**ACTION: M Kemmner to take this to the TOG meeting** | **M Kemmner** |
| 13.3 | Report from Recipient Co-ordinators – D White reported:<br>• Documentation of vaping and e-cigarettes is being reviewed and revised.<br>• A wider review of PACS and what is available is ongoing<br>• There are ongoing transport issues which have been discussed with IMT. There will be a written report at the next meeting.<br>**ACTION: V Gerovasili to link up with D White on this.** | **V Gerovasili / D White** |
| | | |
| **14.** | **FOR INFORMATION** | |
| 14.1 | QUOD Update – **CTAGL(25)17** – This paper was circulated for information prior to the meeting. | |
| | | |
| **15.** | **ANY OTHER BUSINESS** | |
| 15.1 | Key Points to Cascade for CTAG Lungs members to cascade to their teams:<br>• The results of the information collation exercise can be viewed at Cardiothoracic transplant information collation exercise: survey analysis - GOV.UK<br>• The link to the ISOU Patient Engagement sub-group report can be found here: https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/implementation-steering-group-for-organ-utilisation/<br>• Centre transplant teams are also asked to take note of the following link for new guidance on HHV8 and to report any cases to the Patient Safety Team: https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/<br>• A new Patient Engagement Group is proposed to be a platform for all solid organ groups. This will include 2 patient representatives from each solid organ group plus lay member involvement and other groups will feed into this.<br>• The proposed Go Live date for the SCORE programme is planned for April 2026 providing digital solutions are established, transplant centres are ready, NORS teams are equipped, and the donation community are ready.<br>• The ERAS programme is developing and it is hoped there will be an established proposal by December 2025<br>• The national ARC's program is being devised and will launch in the next few weeks. | |
| 15.2 | National Clinical Director for Transplant – a new director for transport for all solid organ transplants will be recruited. The role description will be available in the next 2 weeks and clinicians in CT are encouraged to apply. James Palmer will be running the recruitment process jamespalmer1@nhs.net | |

| | | |
|---|---|---|
| 15.3 | Future Face to Face Reviews/Meetings – Future advisory group meetings from 2026 will need to be constrained in size and choice of venues. There will be less funding for meetings and internal NHS venues will be used wherever possible for the one face-to-face advisory group meeting per year. Birmingham and Newcastle offered use of their trust facilities for CTAG meetings. | |

**Dates of future CTAG meetings**

**CTAG Hearts** – 18 September 2025 – Mary Ward House, London

**CTAG Lungs** – 4 December 2025 – via Microsoft Teams