PRESENT:
Jayan Parameshwar (JyP) CTAG Chair, Royal Papworth Hospital
Martin Carby (MC) CTAGL Deputy Chair, Harefield Hospital
Ayesha Ali (AA) Highly Specialised Services, NHS England
Lyn Ayton (LA) Transplant Managers’ Forum Representative
Marius Berman (MB) Cardiothoracic Surgeon, Royal Papworth Hospital
Pedro Catarino (PC) BTS Representative, Centre Director, Royal Papworth Hospital
Melissa d’Mello (MdM) CTAG Lay Member Representative
John Dark (JD) National Lead for Clinical Governance (JF Deputy)
Ioannis Dimarakis (ID) Cardiothoracic Surgeon, Wythenshawe Hospital
Diana Garcia Saez (DGS) Cardiothoracic Surgeon, Harefield Hospital
Lesley Logan (LL) Regional Manager, Organ Donation
Jim Lordan (JL) Respiratory Physician, Freeman Hospital
Jorge Mascaro (JM) Centre Director, Queen Elizabeth Hospital
Jackie Newby (JNe) Head of Offering, NHSBT
Jane Nuttall (JNu) Recipient Co-ordinator, Wythenshawe Hospital
Nick Ramsey (NR) Recipient Co-ordinator, Harefield Hospital
Sally Rushton (SR) Senior Statistician, NHSBT
Helen Spencer (HS) Lung Physician, Great Ormond Street Hospital
Richard Thompson (RT) Respiratory Physician, Queen Elizabeth Hospital
Sarah Watson (SW) Highly Specialised Services Division, NHS England
Craig Wheelans (CW) National Services Division, NHS Scotland (MW Deputy)

IN ATTENDANCE:
Lisa Mumford (LM) Head of Organ Donation and Transplantation Studies, NHSBT (Observer)
Lucy Newman (LN) Secretary, NHSBT
Sophie Walters (SoW) Recipient Nurse, Queen Elizabeth Hospital (Observer)

APOLOGIES RECEIVED FROM:
Mo Al-Aloul, Gareth Brown, Vaughan Carter, Catherine Coyle, John Forsythe, Paul Flynn, Margaret Harrison, Laura Stamp, Mick Stokes, Rutger Ploeg, Debbie Macklam, Karen Redmond, Anthony Snape, Ben Hume, Iain Harrison, Katie Morley, Karen Redmond, Sue Fuggle

<table>
<thead>
<tr>
<th>Item</th>
<th>Action</th>
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<tr>
<td>Apologies and welcome</td>
<td>JyP thanked SR and LN for their support and preparation for the CTAG meetings. This will be the last meeting for LL – the group wish her good luck in her new role. This will also be the last official meeting for JD. JD is involved with projects being run by the new Cardiothoracic Audit Fellow.</td>
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1 | Declarations of interest | There were no declarations of interest recorded at the meeting. |

Please note that 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. Authors of such papers should indicate whether their paper falls into these categories.
### Minutes of the CTAGL Meeting held on Thursday 25/10/2018

#### 2.1 Accuracy

An error was noted in section 8.1.2 regarding the new Chair of the Lung Utilisation Group. **Action:** LN to correct and circulate Minutes CTAGL(18)02(Am) to members and update papers on the ODT clinical website. Post meeting note: Minutes corrected 21/03/19, amended version to be circulated with the minutes of this meeting.

#### 2.2 Action points

The action points raised at the last meeting will be covered during this meeting. RT noted that the error in the Cardiothoracic Annual Report is still causing issues, as the report was circulated widely before the error was identified.

#### 2.3 CTAGL(19)02 – Terms of Reference

JyP has been working on a review of the ToR which is attached. MdM has emailed LN with suggestions for amendment to the TOR. An amended version of the ToR will be circulated in due course. **Action:** LN to forward to JyP. Post meeting note: JyP amended for inclusion in CTAGH(19)02, which will also be circulated with the minutes of this meeting.

### 3 Associate Medical Director’s Report

#### 3.1 Developments in NHSBT

**Opt Out Legislation – Max and Kiera’s Opt Out Law** has reached Royal Assent and will be introduced in England in spring 2020. It may increase available organs for donation by up to 700 over the first few years. Scotland plan to introduce Opt Out six months after England. Northern Ireland will not be introducing an Opt Out Law. The Welsh experience has proven that legislation change can increase consent rates.

JF is running a Cardiothoracic Retrieval Sustainability Evaluation Meeting on 11th April. Members of the cardiothoracic community have been invited.

Work continues on communicating risk to patients, led on the cardiothoracic side by JyP for hearts and Jas Parmar for Lungs.

JF with NHSBT, won the bid to the Council of Europe to host the next European Organ Donation Day in the UK which will be taking place on Saturday October 12th 2019 and will focus particularly on organ perfusion, BAME and Living Donation.

#### 3.2 New Appointments

The new NHSBT Chief Executive Officer Betsy Bassis will be joining the organisation this month. Anthony Clarkson (interim Director of ODT) has been appointed as Director of ODT, replacing Sally Johnson who retires next month.

National Leads for Clinical Governance
Joint leads Prof. Derek Manas (Newcastle) and Mr Richard Baker (Leeds) have been appointed to replace Prof John Dark when he retires.

National Clinical Leads for Organ Retrieval
Mr Marius Berman (Royal Papworth) and Mr Ian Currie (Edinburgh) have been appointed as joint leads to replace Prof. Rutger Ploeg when he retires. These new appointments will start on 1st April, following a period of shadowing to facilitate a smooth handover of responsibilities.

Interviews were held yesterday (19/03) to appoint a new CTAGL Lungs Deputy Chair. Dr Martin Carby was the successful applicant and is appointed as CTAG Deputy Chair for Lungs.

### 4 Governance Issues

#### 4.1 Non-compliance with Lung Allocation

The clinical governance report had two main themes. These were the late decline of lungs, and lungs not suitable for transplant not being retrieved for research.

INC 3502 involved a NORS Team not staying long enough in theatre to retrieve lungs for research after they were declined for transplant at all centres. ODT Commissioning confirmed
that the organs should be retrieved for research if the appropriate consent is in place, but this may not be possible if the NORS Team is required elsewhere. NORS Teams are advised to make the appropriate decision at the time on a case by case basis. NORS Teams are reminded of the need to bring bronchoscopes for QUOD samples and Perfadex which will be reimbursed to the centre.

INC 3671, 3730, 3766 and 3798 all relate to the late decline of lungs which were initially accepted then later declined, for reasons unrelated to deteriorating lung function. This may have impacted retrieval timings, donor hospitals and donor families. These incidents are under investigation and the findings will be reported at CTAGL in Autumn 2019.

JD presented findings on Lung Ischaemic Time; increased ischaemic time has minimal effect on lungs. Centres with longer ischaemic times have comparable outcomes to those with shorter ischaemic times. His slide-set will be circulated and Centre Directors will receive a copy of his manuscript when it is ready for review and comments.

### 4.3 CTAGL(19)04 – CUSUM Monitoring of 90-day outcomes following lung transplantation

There are no CUSUM signals to report since the last CTAG meeting.

Birmingham had an external review following the identification of a CUSUM signal in 2018. NHSE and NHSBT were involved with this review, learning points were identified resulting in changes to protocols. The report of the Review has not been published yet. It is expected that linking of QEH and Heartlands Hospitals in Birmingham will further improve lung transplantation because of the thoracic surgical expertise at Heartlands.

### 5 Lung Allocation

#### 5.1 Lung Allocation Sub Group

**CTAGL(19)05 – Latest Lung Allocation Data (Dates covering 18/05/17 – 31/12/18)**

Data was analysed from May 2017 to January 2019 on patient registrations to the SULAS, ULAS and NULAS and this is presented in tables 1-3 whilst disease group data is presented in tables 4-6. Thirty percent of NULAS registrations ended in transplant compared with 76% and 63% for ULAS and SULAS respectively, which are mainly made up of CF and PF patients. When considering outcome after transplantation, QOL data (which is not collected at present) appears that there has been a decline in transplant rates in certain disease groups, this is also due to surgeons becoming less keen to transplant single lungs and perhaps a reluctance to transplant higher risk recipients.

Work on the Lung Allocation Scheme and additional access to ILD and CF data registries will facilitate discussion and reviews of lung transplant listing criteria. MAA is leading the Lung Allocation Sub Group in their work and will report to CTAG in Autumn. In the long term it would be ideal to create a lung donor scoring system with offering for named patients. There was discussion about the low rate of lung utilisation in some centres and the need to justify to the patients and referrers when suitable organs are not accepted for patients on the waiting list.

**Paediatric prioritisation**

It was previously agreed by CTAGL that paediatric lungs should be offered to all paediatric patients before being offered to adults. The changes to the lung allocation scheme have been documented and agreed. These essential changes have a high priority rating due to the potential impact on patients, and once a start date is announced, work should be completed within three months. The team who will make the changes are currently involved with the kidney and pancreas offering schemes which has a go live date in June or July. NHSBT are also caught up by DoH Opt Out legislation and preparation for this has had to take priority to ensure systems are fully operational for April 2020.

*Action: JyP to write on behalf of CTAG to the IT department about unacceptable delays. JyP to write to Anthony Clarkson/Nick Breeds and request that they consider these and other CTAG projects with some urgency.*

*Action: SR to report back to CTAGL on any times when a paediatric donor has been transplanted in an adult recipient before this allocation change can be implemented*  

**CTAGL(19)06 – Removal of Small Adult tier**

The effect of introducing a small adult tier for patients on the NULAS has been reviewed; there was no significant evidence of any improvement in the transplant rate for non-urgent small adults. The group agreed to revert back to the non-urgent offering scheme in place pre-May 2017 which consisted of 6 steps rather than 12, and centres would prioritise paediatrics and
5.1.4

small adults internally. With the removal of the routine small adult tier it is hoped that Group Offering will stop which was only introduced as a temporary measure. Group offering is very disruptive for centres.

5.2

**CTAGL(19)07 – Review of urgent criteria**
Criteria for listing patient on the ULAS is under review within the Lung Allocation Sub Group, work is ongoing. A further report is expected at CTAGL Lungs in September 2019.

5.2.1

**Panel Membership**
JyP thanked panel members, acknowledging the extra work and swift responses of panel members. JyP asked members whether they are happy to remain on the adjudication panel or whether they would like to change, there is no tenure listed in the ToR for members of the adjudication panel. If any centre wants to change its representative on the Panel JyP should be contacted.

6

**ODT Hub Update**
Hub Operations are introducing a new digital offering system called interactive matching run which will stop organ decisions being written on multiple paper matching runs, and it will allow Hub Ops staff to reduce the number of organ offers made. If a centre states they would accept no organs from the donor this will record on every organ offer, and the system will stop organs that have previously been declined by the centre being offered back to them. The system is far simpler and safer for staff to use and will allow Hub Operations staff to share more logistical information and improve communication at the time of organ offering.

6.1 **Electronic HTA-A Cardiothoracic Donor Information Form**
Opt Out has halted work on the electronic HTA-A forms which will replace the current paper forms. The HTA-A and HTA-B forms will replace the current Organ Grading forms, they will help identify disparity between comments from retrieving and transplanting surgeons and record more detailed information relating to perfusion and retrieval damage. Before the Cardiothoracic forms are introduced testing must be completed on the abdominal HTA-A forms to provide a smoother transition for the cardiothoracic forms. SMT are reviewing the business case for the retrieval teams to have iPads to enable them to complete the HTA-A forms electronically, the forms will be linked to Donor Path which SNODs have access to and this will reduce the time spent gathering information to complete the HTA-A.

**Action: JNe will send a draft of the HTA-A to MB and DGS for comment.** JNe

7

**Statistics and Clinical Studies reports**

7.1 **CTAGL(19)09 – Summary from Statistics and Clinical Studies**
The Statistics and Clinical Studies Team have had two recent staffing developments, Helen Thomas has been appointed as Head of Clinical Trials and Lisa Mumford has been appointed as Head of Organ Donation and Transplantation Studies while Rachel Johnson continues in post as Assistant Director of Statistics and Clinical Studies.

SR presented in the opening plenary session at this year’s BTS and slides are available: [https://www.odt.nhs.uk/statistics-and-reports/slides-and-presentations](https://www.odt.nhs.uk/statistics-and-reports/slides-and-presentations). Within the department, work continues to support all solid organ advisory groups. Re-development of the VAD database continues with telecons planned in the next two weeks to move the project along.

**Action: The quarterly Harefield report was discussed, and centre representatives agreed that this is data that should be provided to all centres** SR

7.2 **CTAGL(19)10 – Transplant Centre Profiles**
Transplant Centre Profiles were requested by JF, with templates initially introduced to CTAG and the CTAG Patient Group for feedback last year. Members are asked to consider the information provided in the infographics and email SR if they have any suggestions for different data to be included or alterations to wording. Suggestions were made about including average transplant activity over last 3 years. Also, the word “median” needs better explanation. Height makes a different for waiting time to lung transplant and this should be represented in the infographic. The latest iteration should be reviewed by the lung transplant physicians group as well as the CTAG Patient Group.
7.3 Group 2 Transplants
There have been no Group 2 transplants since the last meeting. There has been one lung transplant carried out privately on a patient from Qatar using DBD lungs imported from Qatar. This was not of concern to NHSBT.

7.4 CTAGL(19)12 – Analysis of Older Lung Donor Offers (>65 years of age)
In January 2018 CTAGL agreed to extend the age criteria for DBD and DCD lungs to 74 years where the donor was a lifetime non-smoker or had not smoked for the past 10 years. Between January and December 2018 lungs from 92 donors were offered; 31 potential DBD donors and 61 potential DCD donors. Three pairs of the DBD lungs were transplanted while none of the DCD lungs were transplanted. The most common reasons for decline were poor function, age and history. The group agreed that these offers should continue, although some of the lungs would be in marginal condition, some will be accepted and transplanted, and it will take time to change the mindset of clinical teams when it comes to accepting older donor lungs.

8 Reports and Discussion Points from the Chair
8.1 CTAGL(19)13 – CT Centre Directors Telecon key discussion points
The Centre Directors Telecon was well attended. The group discussed small adult lung allocation which has had no measurable benefit for routine small adults. It was agreed that adult lungs would be offered zonally, then to GOSH, then to the remaining adult centres in rotation. Other items included the use of the Sherpa Pak, Scouting, Hep C positive Donors, and the role of the Lung Utilisation Lead (held by JD).

8.1.1 CTAGL(19)14 – Reasons for declining donor organs – Final Report
SR thanked centres for the provision of data from December 2017 to December 2018 which was provided for audit and included a total of 4670 declined donor lung offers. 457 were related to lungs that were eventually transplanted. Reasons for declining donor lungs which were later transplanted were spread evenly across “reason groups”, highlighting that some centres may be declining good lungs for inadequate reasons.

The most common reason for declining donor lungs that were accepted but not retrieved was “organ unsuitable”. The most common reasons for declining donor lungs which were retrieved and not transplanted was poor function; the most common reasons for declining donor lungs not accepted at any centre were past medical history of donor, poor function, or no suitable recipient.

The free-text boxes on the data returns indicated that some further reasons need to be added to the forms, including gender and size mis-match as well as “unable to delay donation”. This data collection has now ceased but centres can continue recording declines for their own purposes.

8.1.2 CTAGL(19)15 – Grading of retrieved Cardiothoracic Organs
Return rates of grading forms for retrieved cardiothoracic organs has improved, but numbers must still increase to produce worthwhile data for analysis. Where retrieving and receiving surgeons have completed forms comparisons were made between the grading of organs which highlighted a small number of times when there was a discrepancy between organ grading forms. It was highlighted that there were 4 incidents where the retrieval surgeon reported no lung injury, but the recipient surgeon reported that the lungs were un-transplantable.

Action: SR to investigate if any clinical incidents have been raised for these donors

The Organ Grading forms are not mandatory which is partly why they are not returned as requested. When the new HTA-A forms go live, they will supersede the Organ Grading forms and will be mandatory. It is hoped that video and photographs of organs can be shared easily, and a platform for sharing heart and lung images is being developed. MB is involved with the project and will update CTAG on developments in due course.

8.2 CTAGL(19)16 – Issues with completing Registry Data – Update
Outstanding registry data from Glasgow, Birmingham and Great Ormond Street is required to be completed at the earliest opportunity. Overall completion of data and the quality and number of these forms returned without issues is poor. Missing data affects survival rate reporting, it is therefore crucial that this data is returned to NHSBT.

Action: Each centre needs to have a form filling champion to ensure that data is completed and returned to NHSBT in a timely manner.

8.3 Scout Update
8.4 
**NRG Update**
There was no NRG update available; MB is a member of NRG and will update CTAGL Meetings on NRG work in future.

8.5 
**Hep C in Donor Organs**
Wales and Scotland will go live with the offering of Hepatitis C infected donor organs on 27th March. As yet England does not have the funding required to treat potential Hepatitis C organ recipients, so whilst surgeons are willing to adopt this process, it is not a viable option at present.

8.6  
**Action:** JyP to forward JF letter to SW and AA

8.7  
**Communicating Risk and Consent**
This was the theme of the second day of BTS this year, the Winton Centre will start working on communicating risk and consent in lung transplantation once current work on the abdominal process has been completed. Maria Ibrahim is working closely with Jas Parmar on a web-based pilot study which should be ready towards the end of the year.

8.8  
**Quality of Life (QoL)**
Quality of Life is a measure of transplant outcome and should be quantified. It was suggested that this should be a project to capture data within the CTAG Clinical Audit Group, but the project should not be started unless there is adequate resource to complete the project. SW and Edmund Jessop met with JF and Rachel Johnson to discuss whether NHSE could work in collaboration with NHSBT to collect QoL data, but this was not supported by NHBST. The group agreed that data on QoL should be collected centrally. MC will invite Jo Rae (JR) (colleague of HS) to attend the next Association of Lung Transplant Physicians meeting to discuss further as JR has been collecting data of this nature for the past 30 years.

**Action:** SR will investigate with RJ and report back to CTAGL whether EQ5D forms could be trialled with cardiothoracic transplant patients

8.9  
**CTAGL(19)17 – CTAG Workplan (standing item)**
Members are requested to write to JyP/SR with any new items to be considered for the CTAG Workplan. The sustainability meeting on 11th April may inform some new items to be added to the workplan, JyP will update the group in due course.

8.10  
**VV-ECMO for Super Urgent Lung Patients**
A proposal is being considered by NHSE and the overall impact of VV-ECMO on different disease groups, CF and PF is being considered. AA was working on this while MC was on leave and has drafted a letter which is under review.

**Action:** Once comments have been received AA will forward to MC.

9.1  
**Reports from sub-groups**

9.1.1  
**CTCAG Allied Health Professional Vacancy**
Katie Morley was recently appointed to CTCAG as an Allied Health Professional but has decided to step down from the role to focus on a secondment opportunity as Lead Nurse Recipient Coordinator.

**Action:** LN will send details of the application and election process to relevant members for dissemination in centres before the end of April.

9.2  
**Appointment of New CTAG Audit Fellow**
Gill Hardiman (GH) (ST7 Cardiac Surgeon) has been appointed as the new Cardiothoracic Clinical Audit Fellow. GH will be working on a project to create a lung donor score and modelling this to include recipient data which should provide more robust data for Audit. GH will
also be working on a project with Dale Gardiner to investigate the use of protective lung ventilation and effect on outcomes. GH will be invited to attend CTAG in Autumn and will become an active member of CTCAG when she officially starts in post in August 2019.

9.3 CTAGL(19)20 – CTAG Patient Group
The CTAG Patient Group is well attended with proactive members who are participate actively in meetings and offer valuable patient centred feedback. The CTAG Patient Group minutes are attached for information.

10 Lung Utilisation
10.1 CTAGL(19)21 – Centre-Specific Lung Utilisation (April 2016 – March 2019)
Cardiothoracic organ utilisation rates are published in the annual Cardiothoracic Transplant Report, these figures only include transplanted organs but counts all organ offers. The data show that the national utilisation rate for donor hearts and lungs offered (DBD only) has dropped to 25.7% for hearts and 20.4% for lungs. Centres identified potential reasons for the decline in the use of donor organs which are mainly lack of resources such as staffing, logistics, less common use of single lungs in transplants, not having the right recipient etc. A lack of experienced surgeons in some centres may also be contributing.

Cardiothoracic scouting had increased cardiothoracic organs available for transplant, the second phase of the pilot scout project ended in 2016 which would have further added to the decline. If just one centre has a marked decline in transplant activity, this would impact on figures and show a decline across all organs used for cardiothoracic transplantation. Centres should be regularly reviewing offers and organ acceptance/decline rates in the light of high waiting list mortality.

10.2 Lung Utilisation – Continuation
The Lung Utilisation Project was led by JD to highlight examples of best practice and identify areas for improvements in lung utilisation rates across centres by identifying ideal donor lungs which were declined for transplantation. Despite the effort made by JD, SR and other members of the lung transplant community, organ utilisation rates have not improved.

Discussion took place within CTAGL about development of the lung donor score as a more robust way to determine the quality of the lungs being offered, which is one of the projects that the Clinical Fellow will be working with. The group felt that it is important to drive an increase in numbers of lungs transplanted, the organ decline spreadsheets at each centre should be completed for review and members with an interest in improving donor lung utilisation rates should email MC. MC has agreed to move this work forward and will be working with PC to find a way to develop patient specific organ offering.

The group thanked JD for initiating this project.

11 For Information
11.1 CTAGL(19)22 – Transplant Activity Report
No comments received in respect of the Transplant Activity Report

11.2 CTAGL(19)23 – NHSBT ICT Update for Advisory Groups
No comments received in respect of the ICT Update

12 Any other business
- JyP asked to consider CTAG being on two adjacent days rather than one week apart for travel implications. Potential problem is that some people will find it hard to be away from the centre for two successive days.

Date of next meetings
CTAGH Hearts – Thursday 28th March 2019 - 1100-1600 @ Coram
CTAG Patient Group – Monday 13th May 2019 – 1230-1600 @ Coram (Sandwich Lunch 1200-1230)
CTAGH Hearts – Wednesday 11th September 2019 – 1100-1600 @ Venue TBC
CTAGL Lungs – Thursday 26th September 2019 – 1100-1600 @ Venue TBC
CTAG Patient Group – Monday 11th November 2019 – 1230-1600 @ Venue TBC (Sandwich Lunch 1200-1230)