NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

MINUTES OF THE TWELFTH MEETING OF THE NHSBT CTAG LUNGS ADVISORY GROUP
ON THURSDAY 25TH OCTOBER 2018 11:00-16:00
AT CIARB, 12 BLOOMSBURY SQUARE, LONDON WC1A 2LP

PRESENT
Jayan Parameshwar (JyP) Chair of CTAG, Royal Papworth Hospital
Mo Al-Aloul (MAA) Respiratory Physician, Wythenshawe Hospital
Nawwar Al-Attar (NAA) Centre Director, Heart Surgeon, Golden Jubilee National Hospital
Ayesh Ali (AA) Highly Specialised Services, NHS England
Pedro Catarino (PC) Centre Director, BTS Rep, Royal Papworth Hospital
Melissa D’Mello (MD’M) CTAG Lay Member
John Dark (JD) NORS Clinical Governance Lead
John Forsythe (JF) Associate Medical Director, NHSBT
Diana Garcia Saez (DGS) Cardiothoracic Physician, Harefield Hospital
Margaret Harrison (MH) CTAG Lay Member
Jim Lordan (JL) Respiratory Physician, Freeman Hospital
Jackie Newby (JNe) Head of Offering, NHSBT
Jane Nuttall (JNu) Recipient Transplant Co-ordinator, Wythenshawe Hospital
Jasvir Parmar (JsP) Lung Physician, Royal Papworth Hospital
Nicky Ramsey (NR) Specialist Nurse in Organ Donation, Harefield Hospital
Anne Reed (AnR) Respiratory Physician, Harefield Hospital
Rachel Rowson (RR) (Deputising for Lynne Ayton) Transplant Managers Forum
Sally Rushton (SR) Senior Statistician, NHSBT
Karen Redmond (KR) Observer – Cardiothoracic Surgeon, The Mater Hospital, Dublin
Laura Stamp (LS) Lead Nurse Recipient Co-ordinator, NHSBT
Richard Thomspen (RT) Respiratory Physician, Queen Elizabeth Hospital
Craig Wheelans (CW) Deputising for Mike Winter, NHS Scotland

IN ATTENDANCE
Lucy Newman (LN) Secretary, NHSBT
Caroline Robinson (CR) Clinical and Support Services Manager, NHSBT
Nicola Schulz (NS) Information Officer II, NHSBT

APOLOGIES
Lynne Ayton, Vaughan Carter, Catherine Coyle, R Graham, Iain Harrison, Ben Hume, Sally Johnson, Joe MacGee, Rutger Ploeg, Anthony Snape, Mick Stokes, Rajamiyer Venkateswaran, Sarah Watson.

Apologies and welcome
JyP welcomed members and thanked them for their time and attendance today.

1. Declarations of interest
There were no declarations of interest from members in relation to the CTAG Lungs Meeting today.

2. Minutes of the meeting held on Wednesday 25th April 2018

2.1. Accuracy
The Lung minutes are approved as an accurate record of the last meeting in April. The Shared minutes had some minor amendments which were identified at CTAGH, minutes have been amended and circulated. The minutes of both meetings are now approved as an accurate record of the last meeting.

2.2. Action points
LUNGS action points (CTAGL(AP)(18)01 have all been completed aside from those listed below.
AP5 – Monitoring and feeding back on the utilisation of older donor lungs (up to age 75 and non-smoker), will be discussed under item 7.4
AP7 – CTAGL(18)04 – Birmingham Shared Learning Paper – this will be circulated with the minutes and action points of the meeting today
AP8 – Lung Allocation Sub-Group will review aspects of the Lung Allocation Policy will be discussed under item 5.2
AP9 – Arrange for category 93 to be established within SULAS – this is ongoing work
AP11 – Ideal Lung Donor Initiative will be discussed under item 10.1

SHARED action points (CTAGS(AP)(18)01 have all been completed aside from those listed below
AP3 – Cardiothoracic Offering will be discussed under item 6.1
AP4 – The work on Transplant Centre Profiles is on-going
AP9 – Combined organ transplants involving cardiothoracic organs will be discussed and decided by HASG

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3.1 Associate Medical Director’s Report

Developments in NHSBT

Work towards opt out legislation is on target; the Private Members Bill is due for submission on Friday. Opt out legislation has increased momentum with further discussions being held in Scotland, Northern Ireland, Jersey, Guernsey and the Isle of Man. There have been no amendments to the bill which will go before the House of Lords to be passed as statute in early 2019.

The UK leads on Perfusion and Preservation of organs in many aspects, there is a Preservation and Perfusion meeting next week involving key researchers, all manufacturers invited have responded and each will present. The afternoon session will be focussed on strategy building.

Information must be made available to inform patients of the risks associated with transplantation and ensure that they are fully aware of the treatment they are consenting to receive. Information should be provided in a clear and concise manner. NHSBT is working in collaboration with the Winton Centre for Risk and Evidence Communication to ensure that the information produced is of suitable quality and detail. CTAG is initially working on information provided to patients awaiting a lung transplant, once this has been finalised, work will start on the information for those awaiting a heart transplant.

Work is being done to make HCV positive organs available to properly consented HCV negative recipients in a safe and well controlled way.

3.2 New appointments

Sally Johnson has been appointed as Interim Chief Executive of NHSBT, taking over from Ian Trenholm who has resigned. Anthony Clarkson is Interim Chief Executive of ODT, taking over from Sally Johnson pending a permanent appointment in spring.

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4.1 Governance Issues

Non-compliance with Lung Allocation

There have been no incidents of non-compliance with lung allocation since the last meeting.

4.2 Clinical Governance Report

The clinical governance report has been produced in a format which clearly highlights the learnings from incidents.

INC 3216, 3234 and 3345 all relate to the pulmonary artery being cut short and left un-useable, with a hole. Guidance has been updated to state that the suture used in the cannulation site must be left in situ. This is demonstrated at the Organ Retrieval Masterclass and there is also a training video available.

INC 3167 identified that cardiothoracic organs have been offered without necessary HLA information being available. JNe reported that system changes made by HUB Operations means that offers will no longer commence without HLA and Virology Reports. The reviewed process was implemented last week. It should be noted that awaiting HLA and Virology Reports would not reduce the prolonged offering time.
INC 3440 identified that lungs intended for research had been placed in formalin which is not suitable in these circumstances. RINTAG will decide on the solution to be used when cardiothoracic organs are to be used for research.

Further to the details above, two sets of lungs were unused due to extended ischemic time. Centres are reminded to seriously consider lungs where the ischaemic time to reperfusion is up to 12 hours. Queries were noted about the effect of extended ischaemic time in addition to older donor age and smoking history.

**ACTION:** JD will circulate slides to the group which will demonstrate that there is no discernible effect on the lungs following a longer ischaemic time

**ACTION:** Incidents are to be included in minutes and communicated

### 4.3 Lung Transplant Activity

Lung transplant activity has decreased by an average of around 20% when compared to lung transplant activity the previous year. The decrease is across all centres, with the greatest decrease at Newcastle. There was no single explanation for this decrease. PC commented that an analysis of Papworth acceptance rates showed that compared to the US, surgeons in the UK are more aggressive when it comes to accepting organs. Papworth had fewer patients on the waiting list making it more difficult to utilise donor organs. Statistically, 2017/18 was a good year for lung transplantation, with a high number of lung transplants carried out. The current fall may be a reversion to the mean. There was a view that the quality of retrieved donor lungs is poorer than previously; techniques like EVLP may help but is currently not funded.

### 4.4 CUSUM Monitoring of 90-day outcomes following lung transplantation

As agreed at the CTAG Meetings in April, the CUSUM monitoring baseline has been updated to include transplants performed between January 2013 and December 2016 while the outcome monitoring period has been updated to January 2017. There have been no CUSUM signals reported since the last CTAG in April 2018.

**Error in Cardiothoracic Annual Report**

An error was detected in the annual cardiothoracic transplant activity report in October 2018 and involved the calculation of risk-adjusted 5 year post lung transplant centre-specific survival rates. The error has been present in the cardiothoracic lung data since 2013 but had not been detected when internal or external reviews occurred. The error occurred within a line of code which generates the risk adjusted post-lung transplantation survival data. The error was not present in the heart code, the survival from listing code or the routine code used for other reports such as CUSUM. The code has been corrected and three of five centres had <3% difference, Birmingham’s 5 year rate has increased from 29.9% to 54.7% and Manchester’s corrected 5 year rate reduces from 62% to 47.4%. The Cardiothoracic Annual Report is being amended and will be replaced on the website. NHSBT wishes to apologise to all centres, particularly Birmingham, for this error.

**ACTION:** Rachel Johnson will write to centres and NHS England to explain the error in cardiothoracic reporting next week. Post Meeting Note: Completed 26/10/18

### 5 Lung Allocation

#### 5.1 Review of Allocation Zones

In 2017 CTAG decided to review and separate the cardiothoracic donor organ allocation zones into Heart and Lung allocation zones, with the zone for each centre measured proportionately against the number of patients registered on the waiting list at the centre. An annual review of allocation zones was agreed, and any more frequent reviews will be triggered by significant differences between the number of patients on the waiting list and the number of transplants completed at each centre. Three years of lung donor data has been compared with two years of lung patient registration data, with no significant differences found. No alterations will be made to the lung allocation zone at this time.

#### 5.2 Lung Allocation Sub-Group

The Lung Allocation Sub-Group (LASG) will review the lung allocation sequence for adult and paediatric centres and report to CTAGL in Spring 2019. The CTLASG will be chaired by Mo Al-Aloul (Manchester), members from each centre will include Helen Spencer (GOSH), Anna Reed (Harefield), Jim Lordan (Newcastle), Jasvir Parmar (Papworth) and Richard Thompson (Birmingham). The group will review the data and propose changes in light of any findings that are of concern.
5.3 Summary of Adjudication Panel Appeals
The summary of CTAG Adjudication Panel Appeals was reviewed at CTAGL today for the first time, applications had previously been reported in Review of Lung Allocation Schemes paper at CTAG in April 2018. In the 10 months from October 2017 to August 2018, five of ten (50%) of applications to the Adult Lung Adjudication Panel were approved and all four (100%) of the paediatric applications to the Paediatric Adjudication Panel were approved. Of the five rejected applications, two patients died within one month of the application, one was listed as urgent eight months after the application, one received a non-urgent transplant a month after application and one is still active on the list. Appeals make up less than 10% of registrations since most patients fulfil an existing category. MAA reported that he has examined all of the adjudication panel appeals and some cases may require further discussion as part of the LASG.

JyP reported that almost all decisions are made within 24 hours, and thanked members of the Lung Adjudication Panel for their commitment.

5.4 Paediatric Lung Donor Offers
Paediatric donor lungs should always be allocated to paediatric patients in the first instance, but the current sequence offers lungs to super-urgent adult patients before urgent or non-urgent paediatric patients on the list. Concerns were raised about whether any patients are disenfranchised. Age can still be stipulated in the allocation of donor lungs due to lung development in the paediatric population.

CTAGL agreed that lungs from a paediatric donor would be offered to all paediatric patients first, before being offered to adults.

This will require an IT change and will be added to the queue.

6 ODT Hub Update

6.1 HUB Operations Cardiothoracic Offering
Cardiothoracic offering (except for DCD hearts) was redirected to Hub Operations from the Specialist Nurses in Organ Donation (SNOD) in December 2017. This decision was taken to enable Cardiothoracic offering to be managed centrally, because the SNODs didn’t have access to make group or fast track offers. This also ensures that only one group of people are responsible for making organ offers. In future the Hub are looking to introduce case management so that one person is responsible for each donor. Group offering is still causing big issues for centres and there is currently no solution. An exercise was run to look at size restrictions for Small Adults and Paediatrics on the waiting list, but the suspicion is that this will not work due to the wide ranges given by certain centres.

**ACTION:** MAA, SR and the Lung Allocation Sub-Group are tasked with reviewing the current scheme, particularly whether prioritising Small Adults has added real benefit and if there are any clinically appropriate solutions to Group Offering. A solution is needed by the end of the year. It was agreed that if the small adult sequence was removed, Group Offering could cease in the New Year.

6.2 Minimum dataset required for Cardiothoracic Offering
Best practice is to have all necessary information relating to donor organs available to the recipient surgeon at the time of offering; no accurate data is available to record the number of times that further information was requested. SNOD refresher training is taking place in October to reiterate the importance of providing all necessary data using the core donor data form which requests chest x-ray, blood results, blood gases, MRI or CT results, ECG, ECHO, PA catheter or cardiac output monitoring, haemodynamic status and inotropic levels.

CTAGL is asked to agree the following (detailed in CTAGL(18)14):
- Donor HLA and Virology will always be documented on EOS before any cardiothoracic offer is made. Regional Managers must be consulted in the exceptional circumstances listed in CTAGL(18)14.
- Where a SNOD shares the decision with Hub Operations that on screening, a centre states it doesn’t want to receive any organs from a specific donor, Hub Operations will document the decline reason against the centre and not offer to them. This also applies to group offering. This process will be introduced when further changes are made in Hub Operations systems, hopefully in March.
Centres who cannot decide whether to accept an organ offer because there is no ECHO available will be documented as having declined the offer and the Hub will move on.

Centres receiving multiple organ offers will be given additional time to decide whether to accept or decline organs. 80% of organ donors are registered between the hours of 2200 and 0800 – this is unavoidable. However, there is some work going on to look at larger ICUs and delaying donation until the next evening if donation doesn’t proceed before 2am.

Revisiting the contraindications for cardiothoracic donation was discussed. Some of this will be taken forward by the new CTAG Audit Fellow in collaboration with Andrew Broderick, Donor Assessment Programme Lead.

### 7 Statistics and Clinical Studies Reports

#### 7.1 Summary from Statistics and Clinical Studies

The Organ Donation Activity Report was published in July and showed over 5,000 organ transplants last year, of which 8% were cardiothoracic. The Annual Report on Cardiothoracic Transplantation was published last month and is available online but is currently being updated due to the error. The MCS report is in progress and should be published by the end of 2018. There are no Statistics presentations of note.

Work will start on the CTCAG approved standard Cardiothoracic Dataset in line with other solid organ advisory groups which would only be made available when specific criteria are met in the application. The new CTCAG Fellow will be based at Freeman Hospital who proposed the winning projects for the appointment.

While reviewing the (CTAGL(18)15, Table 2) Regular Reports, two centre specific reports were identified, 20 – Harefield Transplant Record Report and 21 – Glasgow Survival Report. NAA confirmed that the Glasgow Survival Report can be cancelled, SR will establish the purpose of the Harefield Transplant Record Report and confirm whether this report could also be stopped.

**ACTION:** SR to investigate two centre specific reports and explore discontinuing

#### 7.2 Summary of heart-lung transplants

The report covers the period January 2017 to April 2018, during this time, 13 patients received an urgent heart-lung transplant, resulting in three deaths within 90 days of transplantation, a 23% mortality rate. Over the same period 18 patients were registered for a heart-lung transplant, of these patients, two died on the waiting list, two were removed, six were transplanted and eight remain on the waiting list. Overall the number of heart-lung transplants have increased as a result of more urgent listings for these patients, but the overall number of registrations has remained relatively stable.

#### 7.3 Group 2 transplants

No Group 2 Cardiothoracic transplants have been performed since the last meeting.

#### 7.4 Analysis of Older Lung Donor Offers (>65 years of age)

In January 2018, the donor age for lung offering was extended up to 74 years for lifetime non-smokers or donors who had not smoked for 10 years or longer. During the first 9 months, 22 DBD lungs were offered from donor age 70 years or older and 48 DCD lungs were offered from donors aged 65 years or older. Three of the DBD and none of the DCD offers were accepted and used. Approximately 8 lungs are offered per month from donors who fit the older category. DGS queried which centres transplanted the older donors (Harefield and Newcastle).

**ACTION:** SR to bring more data to the next meeting, including number of offers for older donors. This will help CTAG make a decision on whether to continue offering such donors.

#### 8 Reports from the Chair

**8.1 CT Core Group Telecon key discussion points**

The Core Group Telecon involves the cardiothoracic Centre Directors, the group name will revert to CTAG Centre Directors Telecon with immediate effect. Most of the discussion points are covered by the agenda here at CTAG Hearts or at CTAG Lungs. The next item to review at the Centre Directors Telecon will be the Cardiothoracic Advisory Group Terms of Reference.
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<th>Section</th>
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<td>8.1.1</td>
<td>Reasons for declining donor organs</td>
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<td>Reasons for declining donor organs was a pilot project set up to identify why cardiothoracic donor organs were declined and establish whether organ utilisation rates could be improved. Data shows that between June and August 2018, there were 1551 cardiothoracic organ declines across six centres, 566 hearts, 843 lungs and 142 heart-lung blocks. Data collected is on declined offers meaning that one donor could have been declined more than once and could have been accepted in the end. It was agreed that data would be collected for one year, with a decision to be made on whether this data is useful. Free-text is added when 98 Other, please specify is listed at the reason for declining the organs. The free-text from the 151 submissions in this category will be reviewed and some of the more common reasons will be added to the pick list of reasons to decline organs. This will be reviewed again once 12 months’ worth of data has been collected. It was acknowledged that these data are useful in light of Group Offering which has led to incomplete reporting of reasons for decline to the Hub.</td>
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<td>8.2</td>
<td>Grading retrieved Cardiothoracic Organs</td>
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<td>Centres had fallen behind in the return of the grading of retrieved Cardiothoracic Organs forms; Organ Grading Form Champions have now been identified at each centre and return rates have increased above 60% as required prior to any analysis being carried out. The Lung Utilisation Group – led by John Dark, analyses and reports to CTAG on unused ideal donor lungs which are declined. JD will step away from the Lung Utilisation Group, the new Chair of the group will be MAA. It was agreed that this data collection should be monitored until the electronic HTA As/Bs are introduced.</td>
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<td>8.3</td>
<td>Centre identified organ grading form champions</td>
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<td>All centres have identified their organ grading champions which should increase numbers of organ grading forms completed and returned to NHSBT.</td>
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<td>8.4</td>
<td>Issues with completing Registry Data</td>
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<td>This was discussed and communication to centre leads at the CTAG Heart meeting. NHSBT form returns are behind for some centres.</td>
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<td>8.5</td>
<td>Scout Update (Workforce Transformation Working Group Sub Group)</td>
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<td>The Scout Pilot was deemed successful by an external review and so a subgroup of the NORS Workforce Transformation Board was established to build a business case for a funded Scouting service in the UK. The first business case was rejected by ODTSMT. It was concluded that the cost of Scouting would need to be reduced but there was no indication by how much. Scouting services at all centres would be too expensive and so the revised business case only includes three teams; it is anticipated that approximately 70% of potential cardiothoracic donors could be scouted with this model. A potential solution is a fixed tariff model where NHSBT pay a fixed amount per scout episode, however this is not financially sustainable for centres. Another solution is to pay a tariff in advance and for teams to Scout on their off duty NORS weeks. Decision pending.</td>
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<td>8.6</td>
<td>NRG Update</td>
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<td>NRG minutes will be published in due course and available on the ODT website.</td>
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<td>8.7</td>
<td>Hep C in Donor Organs</td>
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<td>See Item 3.1 of these minutes.</td>
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<td>8.8</td>
<td>Communicating Risk and Consent</td>
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Organ Donation and Transplantation Directorate

8.7 **QUOD Update**

QUOD requires NORS teams to take a bronchoscope with them to cardiothoracic organ retrievals to carry out the BAL of all lungs retrieved to send to the biobank to develop specimens for research. All surgeons have been briefed in this aspect, SNOD training is to follow. The Medical Research Council will release funding to archive whole hearts and whole lungs from early 2019, and where lungs are unsuitable for implant, the NORS teams will be expected to remain to flush and dispatch organs to QUOD in Newcastle.

9 **Reports from sub-groups**

### 9.1 CTAG Clinical Audit Group (CAG) Chairs Report

CTCAG meets four times per year, twice as telecons and twice face to face. Since NRB retired, NAA has chaired two meetings, one telecom and one face to face. Marius Berman (Organ Retrieval and Transplantation Representative), Stephen Pettit (Heart Transplantation Representative) and Katie Morely (Allied Health Professional) have all been elected as new members to the group.

CTCAG Members have recently published two papers using data from the VAD database, BTC VAD Project and the paper on PGD. Over the coming months Stephen Pettit and Steve Shaw will be working together with SR to determine updates to NHSBT data collection and add to the IT workstream. A draft will be produced for approval by centres prior to final submission.

CTCAG would like to try and increase funding available for research and other projects, NAA will discuss further at CTAG Meetings and with JyP.

Work will start on the CTCAG approved standard Cardiothoracic Dataset in line with other solid organ advisory groups. Data would be available only when application criteria are met. CTCAG would like to see evidence of how the data has been used following its release.

#### 9.1.1 CAG Lung Transplantation Representative

The CTCAG Lung Transplantation Representative position on CTCAG will be open for election following this meeting, NAA thanked RT for his commitment over the last three years, RT is welcome to reapply for the role.

**ACTION:** LN will circulate and oversee the election documentation.

### 9.2 Appointment of New CTAG Audit Fellow

The new CTAG Fellow will be based at Freeman Hospital who proposed the winning projects for the appointment. The projects focus on Cardiothoracic Organ Utilisation and the development of a lung scoring system which takes into consideration recipient and donor variables. Congratulations to the Freeman Hospital (Newcastle) for their submission, the recruitment process is underway.

### 9.3 CTAG Patient Group

JyP outlined the constitution and purpose of the CTPG and updated CTAGL members on activity within the group which is co-chaired by Rob Graham (Governor at Papworth). Past activity within the group, including writing to local MPs about DCD Heart transplantation funding and writing to the House of Commons about ICU funding. Individual Trust Patient Support Groups promote themselves, raise funds, and support patients and their families pre or post-transplant. The group is well attended and includes patients, representatives from each centre, and organisations such as British Heart Foundation and Cystic Fibrosis Trust. On behalf of RG, JyP thanked NAA, JNU, MH, SR and LN for their attendance and support and extended invitation to any CTAGL Members wishing to attend the patient group meeting.

### 10 Lung Utilisation

#### Lung Utilisation Sub Group

The Lung Utilisation Sub-Group (CTLUSG) adapted the French definition of ideal donor lungs (set by the Agence de Biomedicine) to establish how many ideal donor lungs were utilised in the UK (60%), compared to French utilisation rates (90%). Data collected over the past five years shows that utilisation rates are falling. When the group looked at the
data initially, there were minimal numbers of unutilised lungs, so the criteria was extended and increased the number of potential ideal donor lungs. Following discussion, lungs were declined for various reasons such as logistics, no suitable recipient, only one lung available or required at the time, lungs accepted then declined which were not offered on after decline. Kidney and Pancreas Advisory Groups review un-utilised donor organs, centres are advised and requested to justify their reasons for declining potentially ideal donor organs.

Non-utilisation of ideal donor lungs should be reviewed locally on a weekly basis with non-utilisation reasons challenged. Development of a donor and recipient scoring system was suggested and will be considered within the CTLUSG.

### 11 For Information

#### 11.1 Transplant Activity Report

For information, no questions raised

#### 11.2 NHSBT ICT Update for Advisory Groups

For information, no questions raised

### 12 Any other business

JsP will establish whether there has been any progress on the Quality of Life Project and report back at the next CTAGL in the Spring 2019.

The division of CTAG over two days has worked well and members would like to retain the split across the two days.

The Heart Transplantation and Lung Transplantation booklets (identified at the meeting by JNu) are no longer in production. NR has an electronic version of the original booklets. RT also has copies. JNu, RT, NR and MAA will work on modifying text and generating a new and updated version of the booklet.

There was a temporary pause on the recruitment of trainees into the peri-CCT surgical fellowship, the last three trainees all secured posts, but not in the field of cardiothoracic transplantation. Recruitment will commence again soon, as it has been predicted that a further five Consultant cardiothoracic transplant surgeons will be required in the next two years.

### Date of next meetings (venues TBC)

CTAGL Lungs – Wednesday 20th March 2019, CTAGH Hearts – Thursday 28th March 2019

CTAG Patient Group – Monday 13th May 2019

CTAGH Hearts – Wednesday 18th September 2019, CTAGL Lungs – Thursday 26th September 2019

CTAG Patient Group – Monday 11th November 2019