## Apologies and welcome

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<th>Item</th>
<th>Action</th>
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| **1** | **CTAGH(19)01 – Declarations of interest**  
Nawwar Al-Attar, Marius Berman, Pedro Catarino and Sern Lim had group involvement preparing a potential trial of Custodial (HTK)-vs-St Thomas’ Solution for donor heart preservation. Pharmapal Ltd were not involved in the study design and have offered Custodial to centres with no charge. |

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 |

| **2** | Minutes of the CTAGH Meeting on Wednesday 10/10/2018 |
### CTAGH(M)(18)02 – Accuracy
Some clinical titles need adjustment. Minute 10.1 Chris Callaghan is the Abdominal lead and some small changes to the attendee list.

**Action:** LN to correct and circulate Minutes CTAGH(18)02(Am) to members and update papers on the ODT clinical website. Post meeting note: Minutes corrected 30/03/19, amended version to be circulated with the minutes of this meeting.

### CTAGH(AP)(18)02 – Action points
The action points raised at the last meeting will be covered during this meeting.

AP 7 – Centres agreed in CTAGL that they would like to receive the quarterly Harefield report

### CTAGH(19)02 – Terms of Reference (ToR)
JyP reviewed the current version of the CTAG ToR, suggestions from MdM have been incorporated. Members should email LN or JyP with further amendments for the ToR.

### Associate Medical Director’s Report
#### 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 the organs available for donation by up to 700 over the first few years. Scotland plans 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 April 11th. 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, together with NHSBT, won the bid to the Council of Europe to host the next European Organ Donation Day which will take place in the UK on Saturday 12th October 2019 and will focus on organ perfusion, BAME and living donation.

#### 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 (Papworth) and Mr Ian Currie (Edinburgh) have been appointed as joint leads to replace Prof. Rutger Ploeg when he retires.
- These appointments will start on 1st April, following a period of shadowing to facilitate a smooth handover of responsibilities.
- Interviews were held on 19th March to appoint a new CTAGL Lungs Deputy Chair. Dr Martin Carby was the successful applicant and is appointed as CTAG Deputy Chair for Lungs. His first official meeting will be September 26th 2019.

### Governance Issues
#### Non-compliance with Heart Allocation
- INC 3489 involved the late decline of a heart based on size, 12 hours after acceptance and after requesting an extended time to retrieval to enable the retrieval team to use the OCS machine which further impacted on the abdominal teams; and the case highlighted the impact on all involved due to requests for significant delays and late declines.
INC 3562 related to accepted DCD lungs, with a centre also considering the DCD heart. The centre said that they would retrieve the organs and requested the NORS team who were already on route to be stood down. The CT centre was mobilised, but prior to their arrival at hospital, they declined the heart, standing down themselves and requesting the NORS team be re-mobilised. The family were understandably distressed by the delays and withdrew consent to donate. This is a rare situation when the teams would be expected to make a reasonable decision which is under investigation.

INC 3572 was a heart leaving theatre 47 mins after cross clamp which is over the NORS standards, which stipulate that time from cross clamp to heart in a box is a maximum time of 30 mins, however the heart was on ice in the box within 27 minutes of cross clamp which is within the standards. There were some discrepancies in the timings, but it highlighted that there are no agreed KPIs for retrieval timings, but there are quality standards present in NORS contracts which specify timings in box rather than leaving theatre.

INC 3840 involved a delay in the heart being handed over for transport which resulted in increased cold ischemic time in a heart where the timings were already borderline, which was subsequently declined by the transplanting centre. As there have been previous delays reported which have resulted in the loss of organs for transplant, this incident has been identified as a Serious Incident and will be subject to a full root cause analysis (RCA). Once the RCA has been completed, actions will be identified, reviewed and shared with centres.

4.3 CTAGH(19)04 – CUSUM Monitoring of 30-day outcomes following heart transplantation

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

Discussion took place about whether the heart CUSUM monitoring should review a 90-day period (as lung CUSUMs do) or whether the current 30-day reporting is adequate. It was agreed that future versions of the annual cardiothoracic report will include 90-day survival rates but CUSUM will continue to be based on 30-day outcome.

Action: SR to present 90 days survival following heart transplant in Annual Report.

5
5.1 Heart Allocation Sub-Group

5.1.1 Paediatric Super Urgent status

This has been documented as a required change to the policy and is with NHSBT IT for development. How long it will take to implement is still uncertain.

5.1.2 Allocation on height rather than age

Transplant Policy Review Committee (TPRC) asked Steven Tsui and CTAG to review the heart allocation policy, especially in relation to paediatric hearts, which were allocated according to age. The new allocation algorithm uses donor height rather than age. Because of the delay in introducing the new 6 Tier Allocation system (at least 3 years) an interim solution was agreed. The latter includes registering larger paediatric patients on the Adult Urgent List. NHSBT IT teams will schedule the IT work to adjust the offering schemes so that larger paediatric patients can be registered on the adult heart waiting lists. This will be a centre’s choice, not mandated, but the patient cannot be on both the urgent paediatric and urgent adult list. The same applies to super-urgent. It was noted that the mortality on the urgent paediatric waiting list is exceptionally high and so this is an urgent issue to address. It was acknowledged that a large urgent paediatric at Great Ormond Street if registered on the urgent adult list will never appear at the top of the list if there are zonal patients, because they do not have a zone. This is not the case for Newcastle, which leads to a slight inequity, but it is an improvement on the current situation and is a good interim step. There was concern that NHSBT IT was unable to carry out the required changes in a timely manner.

Action: JyP was asked to write to NHSBT to convey this concern.

JyP

5.1.3 Sensitisation

Vaughan Carter raised patient sensitisation on the waiting list at CTAG last year, as patients with higher sensitisation are more likely to wait longer or die on the waiting list. NHSBT don’t collect central sensitisation data so each centre has been asked to review their patient sensitisation data to be discussed in a telecon. All centres apart from Birmingham have provided their information. A further teleconference is required to discuss how to take this forward.

Action: JyP/LN Set up Teleconference

LN/JyP

5.1.4 CTAGH(19)05 – 6 tier allocation system

This has been documented as a required change to the policy and is with NHSBT IT for development. How long it will take to implement is still uncertain.

How long it will take to implement is still uncertain.
5.2 **CTAGH(19)06 – Review of latest heart allocation data**

Data on all patients registered to the waiting list from 26 October 2016 to 25 October 2018 was extracted. The data shows that there is a lower transplant rate and a higher mortality rate in urgent paediatric patients than urgent adult patients. Other findings included increased urgent waiting time for adults since the introduction of the super-urgent heart tier, and comparable survival rates to one year across the NUHAS, UHAS and SUHAS. Questions were raised about reasons for removal as well as whether there is a difference in survival outcomes between ECMO and Short-Term VADs. JyP mentioned that NHS England plan to restart the MCS forum and issues such as these will be addresses there. Average wait on the SUHAS is 9 days; it is good that patients are not waiting too long on short-term support.

5.3 **CTAGH(19)07 – Summary of Adjudication Panel Appeals**

In total the Adult Heart Adjudication Panel received 69 applications for listing to the S/UHAS, 48 (70%) of these were approved. The Adult Heart Adjudication Panel received 5 applications for Total Artificial Heart implantation and 3 (60%) of these applications were approved. The Paediatric Heart Adjudication Panel received 11 applications for listing, all of these were approved.

5.3.1 **Panel membership**

JyP thanked panel members for their participation and commitment. Appeals are often answered in an average of 12-14 hours. JyP asked members if they would like to continue serving on the Panel, there is no tenure terms listed in the ToR for adjudication panel members, centres wishing to change their representative should contact JyP. Members commented that outcomes for the patients who are referred to the adjudication panel should be noted as learning points for future decision making. JyP asked members to circulate the decisions and comments to others in their respective centres.

6 **ODT Hub Update**

6.1 **Electronic HTA Cardiothoracic Donor Information Form**

Opt out legislation has halted work on the electronic HTA-A forms which has caused an unexpected delay in their development and production. The delay was further compounded when SMT made the decision to cut the funding of this piece of work to divert money to other areas of work. MB and Diana Garcia Saez are assisting JNe with the development of the HTA-A forms.

7 **Statistics and Clinical Studies reports**

7.1 **CTAGH(19)08 – Summary from Statistics and Clinical Studies**

There have been two recent staffing developments in the Statistics and Clinical Studies team, Helen Thomas has been appointed as Head of Clinical Trials and Lisa Mumford has been appointed as Head of Organ Donation and Transplantation Studies; Rachel Johns 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.nihs.uk/statistics-and-reports/slides-and-presentations](https://www.odt.nihs.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 scheduled this week.

7.2 **CTAGH(19)09 – Transplant Centre Profiles**

JF requested the development of the Transplant Centre Profiles to provide further information about transplants at each centre, giving patients more information with which to make their decision about where they choose to register while waiting for cardiothoracic transplant. Transplant Centre Profiles would have data updated annually. Each centre would have one profile for heart transplants and one profile for lung transplants. Freeman Hospital would have two of each profile – one for adult patients and one for paediatric patients. Suggestions were made about avoiding technical language and splitting out VAD and non-VAD patients as the waiting time is very different. CL volunteered to work with SR on this.

7.3 **Group 2 Transplants**

There have been no Group 2 transplants since the last meeting.

7.4 **CTAGH(19)10, CTAGH(19)11 – Risk Adjustment and Predicted Risk in Heart Transplantation**
A number of papers were brought to the group by SL regarding the US-derived Index for Mortality Prediction After Cardiac Transplantation (IMPACT) and its potential use in the UK population. SR reported that the risk models used in NHSBT’s Annual Report were developed by Jenny Mehew four years ago in collaboration with the CTAG Audit Group. Four out of the 12 factors used in the IMPACT score are included in the UK risk model (creatinine, aetiology, temporary circulatory support, and VAD use), some are not included but are collected on the registry and some are not collected. There was agreement to revisit the risk models and explore whether the IMPACT score could be useful in the UK setting.

**Action:** NAA/SR/SL to take this work forward with the CTAG Audit Group

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<th>8</th>
<th>Reports and Discussion Points from the Chair</th>
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<td>8.1</td>
<td>CTAGH(19)12 – CT Centre Directors Telecon key discussion points</td>
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<td>The minutes from the most recent Centre Directors Telecon are attached, the telecon was well attended. Items discussed included the Lung Allocation Sub Group, Sherpa Pak, Hep C Positive Donors and the Heart Utilisation Sub Group. The next Centre Directors Telecon will be scheduled in approx. two months.</td>
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<td><strong>Action:</strong> LN/JyP to arrange next teleconference in early June</td>
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<td>8.1.1</td>
<td>CTAGH(19)13 – Reasons for declining donor organs – Final Report</td>
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<td>SR has been collecting data on the reasons for declining cardiothoracic donor organs for the past year which are reported direct from centres and not via Hub Operations. Between December 2017 and December 2018, a total of 3324 declined heart offers were recorded. Members asked what is being done with this data and there was a suggestion for someone to write it up into a publication. The reasons for declining donor organs will be built into the new offering system used by the Hub, allowing better recording of reasons. The new system will also mean Hub Operations will be able to record whether a centre wishes to continue to receive further offers after an organ has been turned down earlier in the sequence.</td>
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<td>8.1.2</td>
<td>CTAGH(19)14 – Grading retrieved Cardiothoracic Organs</td>
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<td>Return rates for the grading forms for retrieved cardiothoracic organs have improved since the last meeting, but there are still forms missing from some centres. Surgeons retrieving organs and those receiving organs for transplantation are asked to complete the forms to return to NHSBT. When the new HTA-A forms are introduced, they will negate the requirement for grading retrieved cardiothoracic organs forms with feedback from the retrieving and the receiving surgeons stored electronically in real-time. A comparison was made between the responses of the retrieval and recipient surgeon; there were 22 cases where there was a discrepancy recorded between the heart structure grading.</td>
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<td>8.2</td>
<td>CTAGH(19)15 – Issues with completing Registry Data – Update</td>
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<td>Issues with completing registry data are ongoing, often due to administrative provision. Centres are all working on local solutions and trying to get assistance to get the registry forms completed and returned. The content of some of the forms can also be poor.</td>
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<td><strong>Action:</strong> Centre Directors to follow up in centres to ensure forms are completed and returned. A Champion is required at each centre for each category, i.e. Heart, Lung, MCS</td>
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<td>8.3</td>
<td>Scout Update (Workforce Transformation Working Group Sub Group)</td>
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<td>It was agreed by ODT SMT that cardiothoracic Scouting would receive no funding at present.</td>
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<td>8.4</td>
<td>NRG Update</td>
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<td>There was no NRG update available; MB is a member of NRG and will update CTAGH Meetings on NRG work in future.</td>
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<td>8.5</td>
<td>Hep C in Donor Organs</td>
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<td>Offering cardiothoracic organs from Hepatitis C infected donors will go live on March 27th. Wales and Scotland have already had funding agreements made for post-transplant treatment of Hep C in organ recipients. England has yet to be awarded funding for the treatment of potential post-transplant Hep C in recipients. Some surgeons are willing to accept and transplant these organs but there has been concern expressed in some centres. Some members expressed dis-satisfaction that funding was available for this initiative but not for technologies, such as the OCS. JyP pointed out that the two are not comparable or mutually exclusive.</td>
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<td>8.6</td>
<td>Communicating Risk and Consent</td>
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<td>8.7</td>
<td>Work continues with the Winton Centre to improve on how to improve the communication of risk and consent, and this was also the theme of the second day of the BTS Conference this year. This is starting with lungs and when completed, the work for other organs will begin.</td>
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<td><strong>CTAGH(19)16 – CTAG Workplan (standing item)</strong></td>
<td>Members are requested to write to JyP/SR with any new items to be considered for the CTAG Workplan. The Cardiothoracic Sustainability meeting on April 11th may inform some new items to be added to the workplan, JyP will update the group in due course.</td>
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<td>8.8</td>
<td>Perfusion and Transportation – Sherpa Pak Sherpa Pak is a new method for the transportation of donor hearts for transplantation which may reduce incidence of PGD. The group agreed Sherpa Pak would be used only under specific circumstances. Centres will discuss exact criteria. Papworth and Manchester both have some of the Sherpa Paks to trial, Glasgow is keen to be involved and Sherpa Pak is currently being reviewed by the Clinical Governance Team at Glasgow for approval.</td>
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<td>8.8.1</td>
<td><strong>CTAGH(19)17 – Donor Heart Preservation for Heart Transplantation</strong> CTAGH(19)28, CTAGH(19)29, CTAGH(19)30 – Myocardial Preservation Fluid CTAGH Members discussed the preservation and perfusion fluids currently in use for the preservation of donor hearts following retrieval. NAA, MB, PC and SL have all been involved with the development of a trial of Custodial HTK versus St Thomas’ solution for donor heart preservation. The UK protocol has used the same preservation solution for decades, and as current PGD rates are high alternatives should be explored. Most centres (Harefield use OCS for all DBD retrievals and cannot participate) are keen to participate in the trial. <strong>Action: MB will host a telecon with Centre directors to discuss the trial in more detail.</strong></td>
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<td>8.8.2</td>
<td><strong>CTAGH(19)18, CTAGH(19)19, CTAGH(19)20 – Total Artificial Heart</strong> The adjudication panel approves the use of Total Artificial Hearts on behalf of NHSE. TAH can be used to bridge a patient to transplant as an alternative to a BiVAD, but it is ideal to transplant patients in the first year of support. When the Heart Allocation Sub Group revisited the Heart Allocation Policy, arrangement was made for TAH patients to be listed in Tier 4. Harefield felt that their TAH programme should be allowed to continue without scrutiny from the Adjudication Panel; if other centres don’t want to use the TAH as a bridge to transplant patients could be referred to Harefield. NHSBT made it clear that the current position will not change at present and Harefield have accepted this. There was robust discussion around the outcome after TAH; it was felt that post implant and post-transplant outcomes would have to improve for this technology to be supported. The group agreed that patients supported with a TAH could be placed on the Urgent list 6 months post implant if they were fit for transplant. This should improve post-transplant outcome.</td>
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<td>8.9</td>
<td><strong>CTAGH(19)21 – RINTAG DCD Hearts Working Group Update</strong> The introduction of the DCD Hearts programme has increased the number of hearts available for transplant, but there have been a number of governance issues. A review into all aspects of TA-NRP is being chaired by Dr Alex Manara. A recent incident involving Direct procurement of donor heart and lungs along with abdominal NRP is being investigated by NHSBT. At present no thoracic organs can be retrieved by direct procurement while abdominal NRP is being used; this is likely to have an impact on the number of hearts and lungs transplanted. Once the investigation is completed, it is hoped the position will change. <strong>Action: JyP will share formal communication from JF with Centre Directors relating to direct procurement of organs for donation.</strong></td>
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<td>8.10</td>
<td><strong>DCD Hearts OCS</strong> The case for funding for the use of OCS for DCD Hearts in Cardiothoracic Transplantation continues, NHSBT and NHSE continue to work closely together to investigate and identify possible funding streams. It is hoped that there will be news about funding in the next month or two. <strong>Action: SW to report back to CTAG after May.</strong></td>
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<td>9</td>
<td>Reports from sub-groups</td>
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| 9.1 | **CTAGH(19)22 – CTAG Clinical Audit Group (CAG) Chairs Report** The CTCAG Chairs report has been received from NAA and is attached detailing developments and project progress within the group, as well as responses to cardiothoracic data requests. There have been two staffing changes since CTAG last met, MAA has been appointed as Lung Transplantation Representative, replacing RT as his tenure comes to an end. NAA would like to thank RT for his commitment and contributions to CTCAG during his tenure.
| 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. Applications will be open to Recipient Nurses and Coordinators, Healthcare Scientists, Perfusionists, H & I Members etc…  
**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 Hardman (GH) (ST7 Cardiac Surgeon) has been appointed as the new Cardiothoracic Clinical Audit Fellow. GH will be working closely with the Stats and Clinical Studies Team in Bristol and will be an active member of the CTCAG 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 led by Dale Gardiner to investigate the use of protective lung ventilation and its outcomes to patients.  
**Action:** GH to be invited to attend CTAG as an Observer in Autumn 2019 – LN to invite. |
| 9.3 | **CTAGH(19)23 – CTAG Patient Group**  
The CTAG Patient Group is well attended with proactive members participating actively in meetings and offering valuable patient feedback. The CTAG Patient Group minutes are attached for your information. |

| 10 | **Heart Utilisation**  
**Heart Utilisation Sub-group**  
Aaron Ranasinghe agreed to lead the Heart Utilisation Sub Group to review Ideal Donor heart Utilisation rates. The first telecon will be in the next couple of months.  
**Action:** AR/LN to confirm dates |
| 11 | **For Information**  
**CTAGH(19)26 – Transplant Activity Report**  
No comments received in respect of the Transplant Activity Report. |
| 11.3 | **CTAGH(19)27 – NHSBT ICT Update for Advisory Groups**  
No comments were received in respect of the ICT Update. |
| 12 | **Any other business**  
Will an allocation policy for DCD hearts be developed? SNODs would like to feel better equipped to talk to patients about DCD hearts and understand the offering process. JyP pointed out that till DCD transplantation is funded allocation of organs will continue as present. |

**Date of next meetings**  
**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)