NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE ELEVENTH MEETING OF NHSBT CTAG HEART ADVISORY GROUP ON WEDNESDAY 25TH APRIL 2018, 15:00 – 17:00, THE TRAINING ROOM, CORAM CAMPUS, 41 BRUNSWICK SQUARE, LONDON, WC1N 1AZ

PRESENT

Steven Tsui (ST)	CTAG Chair
Jayan Parameshwar (JyP)	In-coming CTAG Chair
Rajamiyer Venkateswaran (RV)	Incoming Deputy CTAG Chair (Heart), Heart Surgeon, Wythenshawe Hospital
Nawwar Al Attar (NAA)	Heart Surgeon, Golden Jubilee National Hospital
Lyn Ayton (LA)	Transplant Managers Forum Representative
Mike Burch (MBu)	Heart Physician, Great Ormond Street Hospital
Vaughan Carter (VC)	British Society of Histocompatibility and Immunogenetics
Steve Clarke (SC)	Lung Physician, Freeman Hospital
Owais Dar (OD)	Heart Physician, Harefield Hospital (Deputising for Andre Simon)
John Dark (JD)	Clinical Governance Representative
John Forsythe (JF)	Associate Medical Director - NHSBT
Margaret Harrison (MH)	CTAG Lay Member
Rachel Hogg (RH)	Statistician, Statistics and Clinical Studies, NHSBT
Clive Lewis (CL)	Heart Surgeon, Royal Papworth Hospital
Lesley Logan (LL)	Specialist Nurse in Organ Donation, NHSBT
Jorge Mascaro (JM)	Heart Physician, Queen Elizabeth Hospital
Jackie Newby (JNe)	Head of Referral and Offering, HUB Operations, NHSBT
Jane Nuttall (JNu)	Recipient Transplant Co-ordinator, Wythenshawe Hospital
Laura Ramsay (LR)	Lead Nurse Recipient Co-ordinator, NHSBT
Sally Rushton (SR)	Senior Statistician, Statistics and Clinical Studies, NHSBT
Sarah Watson (SW)	Programme Director, Highly Specialised Services, NHS England
Mike Winter (MW)	Medical Director, NHS National Services Division Scotland

IN ATTENDANCE

Lucy Newman (LN)	Secretary, NHSBT
Zdenka Reinhardt (ZR)	Paediatric Observer, Freeman Hospital

APOLOGIES

Gareth Brown (GB)	Consultant in Public Health, DOH Scotland
Catherine Coyle (CC)	Public Heath NI
Nicky Crouchen (NC)	Recipient Transplant Coordinator, Harefield
Melissa D'Mello (MDM)	CTAG Lay Member
Sue Fuggle (SF)	Scientific Advisor, NHSBT
Anushka Govias Smith (AGS)	National Services Division, NHS Scotland
Ben Hume (BH)	Assistant Director TSS, NHSBT
Rutger Ploeg (RP)	National Clinical Lead for Organ Retrieval
Andre Simon (AS)	(Deputy Owais Dar) Heart Surgeon, Harefield Hospital

to be ratified

Item		Action
1	**Apologies and welcome** ST welcomed the group and thanked members for attending the meeting. Apologies were given and are listed above. ST introduced JyP as the in-coming Chair for the Cardiothoracic Advisory Group	
2	**Declarations of Interest:** Nawwar Al Attar declared two external interests via email • Member of advisory board to Medtronic and Ethicon biosurgery • Recipient of travel grant from Edwards for TAVI training	
2	**Minutes of the meeting held on: Wednesday 13th September 2017**	

2.1	**Accuracy** The minutes were approved as a correct record of the last meeting	
2.2 AP1	**Action Points** **Accuracy** The minutes of the April 2017 meeting were amended and recirculated	
AP2	**UK VAD Data to IMACS** Completed	
AP3	**Clinical Governance Newsletter** **JD will produce a Clinical Governance Summary for a Newsletter.**	**JD**
AP4	**SU and UHAS** Completed	
AP5	**Prolonged heart registrations** No changes have been reported to SR to date. The correct route is to make corrections to patient registrations	
AP6	**Cleaning Schedule for Ice Machines used by NORS Teams** Completed	
AP7	**Monthly Declined Ideal Hearts Telecon** See Hearts minutes item 8	
AP8	**CUSUM Baseline Data** See Hearts minutes item 3.3.1	
AP9	**Intra Aortic balloon Pumps (IABP)** Completed	
AP10	**Pro-forma for SUHAS Application** Completed	
AP11	**Removal of unregistered SUHAS Patients** Completed	
AP12	**Other Statistical Reports** See Hearts minutes item 5	
AP13	**Convene a new CTAG Heart Allocation Sub Group (HASG)** Completed	
AP14	**DCD Heart Transplants** Completed	
AP15	**DCD Heart offers** Completed	
AP16	**OCS Machines** Completed	
3 3.1	**Governance issues** **Non-compliance with heart allocation** Incidents relating to non-compliance with heart allocation are voluntarily reported. The non-compliance report is standard on the agenda, and events reported in this section are rare. Nothing further to report on non-compliance	
3.2	**Heart incidents for review**	

to be ratified

	Reporting Heart incidents is voluntary, the volume of incidents reported has remained similar to previous periods with no significant increase of decrease in the numbers this period compared to the last period.	
3.2.1	**Clinical Governance report** Heart incidents were overall similar to lung incidents. Cardiothoracic teams have accepted then declined hearts, prospective cross matches have required delays, protracted offering sequences have caused delays, NORS retrieval teams have not had the correct equipment with them. Often it can be difficult for the NORS teams to access patient records as these are largely electronically stored – visiting teams do not have access to electronic records and systems vary nationally so it is not possible for visiting staff to log in to interrogate and recall data relating to individual patients. One incident involved an incorrect listing of a patient who went on to receive a super-urgent heart and lung transplant ahead of other patients who had been listed earlier. The request to list the patient for Super Urgent Heart Lung transplant was sent to the Adjudication Panel on Christmas Eve 2017 and the Adjudication Panel decision to reject this request was sent on Boxing Day. The Bank Holiday timing likely caused a delay in the Adjudication Panel responding to the requestor. Even though there was no approval by the Adjudication Panel, the Hub made an incorrect decision to add the patient to the Super Urgent Heart list. There was no guidance on what process to follow should there be an unavoidable delay in the Adjudication Panel responding with their majority decision. The Adjudication Panel should respond to the requestor within 24 hours, and if this does not happen, then the requestor should not list the patient as approval to do so has not been granted. The response from the Panel will be returned to the requestor, and if it is agreed that the patient may be listed, this response is required to be emailed to the HUB with the application to list the patient. The Hub must insist on seeing evidence of approval where required.	
3.3	**Summary of CUSUMs** There were no heart CUSUM signals in the past six months	
3.3.1	**Updating CUSUM mortality rates** NHSBT monitor 30 day outcomes of recipients post-transplant and use baseline data from 2008-2011 to measure performance against. Resulting from discussion and changes within other SOAGs, SR requested approval to update the baseline data to more recent years; 2013-2016. Implementing this change would decrease the average mortality rate at 30 days following heart transplant from 14.3% to 8.9% among the adult population. In paediatric patients, the average mortality rate at 90 days would increase from 4% to 6% following heart transplantation. Centres would continue to receive centre specific CUSUM reports where they raise a trigger against their own average when this is below the national average. Only those CUSUMs reported higher against the national rate would be investigated formally. **SR will discuss with CUSUM colleagues in the Stats and Clinical Studies Team and report to centres whether they will start with a zero rate**	**SR**
	Within LAG, an agreement has been reached to lower the threshold for Liver CUSUMs due to having very few triggers for several years. Whilst there has only been one Heart signal raised in the past 7 years, lowering the Hearts trigger from 2.5 to 2 would detect earlier divergence and false alarms, but would only have increased CUSUM signals by two further signals in the last 7 years. CUSUM signals should not be perceived as pejorative, they present opportunities for MDT as well as internal/external reviews and peer reviews. The group decided that the trigger would remain at 2.5, since lowering the average 30-day mortality rate would already make monitoring more stringent. There was discussion about measuring 90 day mortality for hearts as per lungs, as it is sometimes possible to keep a very sick patient alive for 30 days. There was no major	

to be ratified

3.4	impetus to change the status quo at this point. Therefore, 30-day mortality post-transplant will continue to be used for CUSUM monitoring for hearts. **CUSUM Monitoring for heart transplantation** Inclusion of both DBD and DCD hearts would decrease the national mortality rate from 8.9% to 8.3%. Results are more favourable when DCD heart transplantation is included in CUSUM monitoring, however there may need to be leeway when including centres who have only just started DCD heart transplantation as it is a new procedure. Discussion surrounding risk data and newly included centres took place. It was agreed that it is reasonable to include DCD heart transplants in the CUSUM monitoring but to exclude them from the average mortality calculation, since DBD results are the benchmark to measure against	
4 4.1	**Heart Allocation** **Review of SUHAS** SR provided a report reviewing the first 12 months of the SUHAS. 15% of adult registrations were made on the SUHAS, 38% onto the UHAS and 48% onto the NUHAS. For paediatrics the split was 69% on the UHAS and 30% on the NUHAS. The median waiting time for heart transplant is 52 days on the UHAS and 9 days on the SUHAS, for adults, and 111 days on the UHAS for paediatric patients. On average there are 5 patients registered on the SUHAS at any given time which has remained fairly static since 2016, however there has been a large increase in patients registered on the UHAS from 16 at the end of 2016 to 42 a year later. 29% of all adult donor hearts offered and 71% of all paediatric hearts offered were transplanted, however this has still resulted in an overall decrease in heart transplant activity of 10% during the review period. The 30 day post-transplant outcomes for patients were comparable, with 94.6% survival on the SUHAS, 92.1% on the UHAS and 93.9% on the NUHAS. The need to remove age as a criterion for donor heart allocation and the deficiencies of the 2016 Heart Allocation Scheme with a diverse group of patients listed in the UHAS have prompted the development of the Heart Allocation Sub Group (HASG) to stratify patients equitably.	
4.2	**Report from Heart Allocation Sub Group (HASG)** HASG members have had two meetings so far and propose improved stratification of patients on the heart transplant waiting list, and to decide whether zonal priority should be given to any of the newly created Tiers. The 2018 Heart Allocation Scheme will have six tiers, with the current super urgent patients in Tier 1, the current UHAS patients divided among Tiers 2-5, and non-urgent patients in Tier 6. Tiers 1 and 2 will not have zonal priority but the other Tier will maintain zonal priority. The new scheme would make heart transplantation more equitable among all potential recipients. It was also agreed that age would be removed as criteria for listing in heart transplantation, size will instead be used to determine whether a small or standard sized donor heart would be required for each patient. **JNe will meet with JyP to discuss the implementation of these alterations in more detail.** The level of care required by patients will also have an impact on the Tier that a patient is listed under, it was agreed that in Tier 2 'Level 3 Care' should be changed for 'Level 2 or Level 3 care'. Under Tier 2 section a) 'acute' will be changed to 'temporary' (endovascular circulatory support devices). Tier 4e patients awaiting combined heart/kidney transplants will be reviewed again by HASG to establish the appropriate Tier they should be listed in.	**JNeJyP**

to be ratified

	SR will write a paper based on these criteria, and will finalise paper in time for submission to TPRC in July **SR will speak to IT to find out whereabouts in the workplan this adjustment might fit** **ST will raise with HASG the question about combined heart/kidney patients**	**SR** **SR** **ST**
5 5.1	**Statistics and clinical Studies Reports** **Prolonged Heart Registrations** There are currently 65 patients listed for heart transplant who have been waiting for two years or longer. **Centres are required to check these numbers and arrange for amendments to be made through ODT online**	 **Centre reps**
6 6.1 6.1.1 6.1.2 6.1.3 6.1.4 6.2 6.3	**Update on DCD Hearts** **Centre Updates** **DCD Harefield** Harefield have completed 10 DCD heart retrievals **DCD Manchester** Manchester have completed seven DCD heart retrievals **DCD Papworth** Papworth have transplanted 43 DCD hearts **DCD Others** Newcastle is in the process of applying to RINTAG and NRG for permission to carry out DCD heart retrieval and transplants. However, Newcastle has implanted one paediatric DCD heart and the patient is doing well so far. Great Ormond Street has no funding for DCD heart retrieval at present. There was discussion about what sign-off would be required for Great Ormond Street since they would only perform the implant, not the retrieval. This and other issues will be discussed at a new DCD Heart Working Group. Glasgow have used the OCS machine in three DBD heart retrievals, one was not transplanted. **Review of activity and outcomes** This paper was not discussed due to time constraints. ST suggested that it be presented at the RINTAG DCD Hearts Working Group meeting in June. **RINTAG DCD Hearts Working Group** Approval to carry out DCD heart transplantation is granted via RINTAG and NRG, and a new DCD Hearts Working Group has been set up as a sub group of RINTAG. Centres seeking approval will need to apply to the RINTAG DCD Working Group. MBu asked about DCD heart funding in other units and ST explained that DCD retrieval is not currently funded by NHS England, and NORS Teams retrieve DCD hearts on goodwill rather than as a commissioned service. Cardiothoracic organ retrieval in smaller patients is only done by the Newcastle and Papworth NORS Teams, and as GOS has no retrieval zone, it has no allocation zone for DCD Hearts. The priming volume requirement of the OCS is too big for small donors and this further limits the process. **MBu will attend the RINTAG DCD steering group meeting on 20th June to discuss options with the other units** The meeting will be chaired by JyP, with one representative from each centre in attendance, and SW will also be attending, giving opportunities to talk about future plans, share information and discuss funding (which is unlikely to be increased).	**MBu**

to be ratified

	RH will report on DCD Heart activity again at the June DCD Hearts Working Group meeting	**RH**
7 7.1	**VAD Update** **UK VAD Database restructure** The update from the Cardiothoracic Clinical Advisory Group reports on VADs, see Shared minutes item 7.1 and paper CTAGS(18)13 section 7 NHS England do not currently fund Destination LVAD Therapy. However, NIHR are looking at the cost effectiveness of using VADs as Destination Therapy and will update NHS England in due course	
8	**Heart Utilisation** Other solid organ advisory groups have identified their ideal organ donors whose organs are not used in transplantation and hold monthly meetings to review these, looking at reasons for declining the organs and reporting if the organs were utilised at another unit with the outcome for the patient. Work to define the criteria for a standard donor heart is underway within the Heart Allocation Sub Group. See Hearts paper CTAGH(18)05 and CTAGH(18)05a for definition. Using these criteria should flag about 8-12 unused standard donor hearts for investigation each month. A similar process to the lung utilisation telecons would be adopted and feedback will go back to centres. **Criteria to be used will be taken from CTAGH(18)05a and SR will circulate the first set of data after this meeting.** **Volunteers will be requested from each centre to represent the centre in the teleconference and a volunteer to lead the process.**	**SR** **Centre Leads**
9	**NORS Echocardiogram** Some centres insist on seeing Transoesophageal Echocardiogram (ToE) data before deciding on whether to accept an organ. However, ToE is not part of the NORS standard and the group agreed that ToE will remain an optional extra for NORS teams and not a mandatory requirement. Transplant centres accepting a heart cannot demand a ToE but NORS team can carried out this investigation on a voluntary basis if they have the capability to do so.	
10	**Any Other Business** Regarding SCTS/SAC Workforce Update CTAGS(18)15 MH asked whether there is any plan in place for CTAG and NHSBT to look at how future staffing issues can be resolved. JF responded that the Department of Health is aware that transplantation and retrieval teams rely heavily on overseas professionals; less than a week ago JF received two representations from Kidney units unable to employ staff that had been appointed as they were unable to secure Visas to land and work in the UK. The current lack of movement on Visas is causing a delay and this needs to be addressed. **Any concrete examples of new staff being unable to obtain visas should be highlighted to JF, NHS England will also make DoH aware of any visa related issues that they are made aware of**	**Centre Leads**
11	**Dates of next meetings:** **CTAG Patient Group Meeting**: Tuesday 5th June 2018, 13:00 – 17:00 (Sandwich Lunch 13:00-13:30) The Board Room, West End Donor Centre, 26 Margaret Street, Marylebone, London W1W 8NB **Autumn CTAG Wider Group (Hearts) Meeting**: **RESCHEDULED** Wednesday 10th October 2018, 10:00-12:00 Coram Campus, 41 Brunswick Square, London, WC1N 1AZ	

to be ratified