NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE TENTH MEETING OF THE NHSBT CTAG SHARED ISSUES MEETING ON WEDNESDAY 25th APRIL 2018, 12:30 – 14:45, 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 CTAG Deputy (Heart), Heart Surgeon, Wythenshawe Hospital
Mohamed Al Aloul (MAA)	Respiratory Physician, Wythenshawe Hospital
Nawwar Al Attar (NAA)	Heart Surgeon, Golden Jubilee National Hospital
Lyn Ayton (LA)	Transplant Managers Forum Representative
Mike Burch (MBu)	Cardiologist, Great Ormond Street Hospital
Martin Carby (MC)	Lung Physician, Harefield Hospital
Vaughan Carter (VC)	British Society for Histocompatibility and Immunogenetics
Steve Clarke (SC)	Lung Physician, Freeman Hospital
Pedro Catarino (PC)	British Transplant Society Representative
John Dark (JD)	Governance Representative, NHSBT
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)	Cardiologist, Royal Papworth Hospital
Lesley Logan (LL)	SNOD Representative, NHSBT
Jorge Mascaro (JM)	Heart Surgeon, Queen Elizabeth Hospital
Jacki Newby (JNe)	Head of Referral and Offering, HUB Operations, NHSBT
Jane Nuttall (JNu)	Recipient Transplant Coordinator, Wythenshawe Hospital
Jasvir Parmar (JsP)	Respiratory Physician, Royal Papworth Hospital
Laura Ramsay (LR)	Lead Nurse Recipient Co-ordinator, NHSBT
Sally Rushton (SR)	Senior Statistician, Statistics and Clinical Studies, NHSBT
Helen Spencer (HS)	Lung Physician, Great Ormond Street Hospital
Richard Thompson (RT)	Respiratory Physician, Queen Elizabeth Hospital
Sarah Watson (SW)	Programme Director, Highly Specialised Services, NHS England
Mike Winter (MW)	Medical Director, NHS National Services Division for 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

Item		Action
	Apologies and welcome ST welcomed the group and thanked members for attending the meeting. ST introduced JyP as the in-coming Chair for the Cardiothoracic Advisory Group	
	Declarations of Interest Nawwar Al attar declared two external interests via email • Member of the advisory board to Medtronic and Ethicon biosurgery	

	• Recipient of travel grant from Edwards for TAVI Training	
2 **2.1**	**Accuracy** The minutes were approved as a correct record of the last meeting	
2.2 **AP1**	**Action Points** **Transplant Centre Profiles** See Shared minutes item 5.3	
AP2	**Defibrillator for Retrievals** All NORS teams are fully equipped with their own defibrillator to take to retrievals. Action completed	
AP3	**Writing to donor families** LL shared examples with other recipient coordinators who actively encourage recipients to write to their donors family	
AP4	**Back Up Offers** This has been operationalised; see Shared minutes item 4.1	
AP5	**UK VAD Database** UK VAD data has been checked by all centres and the Annual VAD Report has been published	
AP6	**Association between survival and decline** It was decided not to take this any further. However there is interest in comparing centres with low and high decline rates to see whether there is any evidence that patients in the former have worse outcomes	
AP7	**Allocation zonal boundary changes** The latest allocation zone changes were made in January 2018 following sign off from the CTAG Core Group in November 2017. They will be reviewed again in Autumn.	
AP8	**Reasons on agenda** See Shared minutes item 6.1.3	
AP9	**Removal of age as a cut off for donor heart allocation** See Hearts minutes item 4.2	
AP10	**Paediatric allocation zones** The policy changes relating to paediatric allocation zones have been ratified for implementation by TPRC	
3 **3.1**	**Associate Medical Director's Report** **Developments in NHSBT** 2017/18 was another record year. There were 1575 deceased donors, an 11% increase on last year and a 95% increase over the ten years since the Organ Donation Taskforce baseline year (2007/08: 809). 4035 patients received a solid organ transplant from a deceased donor in 2017/18, a 9% increase on last year and a 69% increase over ten years (2007/08: 2384). Electronic versions of the HTA-A and HTA-B forms are being developed which will make life easier for those involved in retrieval. RV mentioned that his centre has experienced difficulty submitting the current paper forms and they are regularly being returned or getting lost. **RV, JNu and JNe will discuss the issue and work to find a solution**	**JNe/RVJNu**
3.2	**New Appointments** • JF thanked ST for his time and dedication to CTAG Wider group • ST thanked his deputy Chairs SC and Nick Banner (NB) for their commitment and assistance in running CTAG	

	• ST further thanked NB for his chairmanship of the CTAG Clinical Audit Group and congratulated him on his retirement • Congratulations to JyP on his appointment to the role of CTAG Chair • Congratulations to RV on his appointment to the role of CTAG Deputy Chair (Hearts) • Congratulations to NAA on his appointment as CTAG Clinical Audit Group Chair (CTCAG) A vacancy has arisen on the CTAG Clinical Audit Group: Heart Representative. Members should contact JyP to express interests in this role. **LN will oversee the process to appoint a new Heart Representative for CTCAG. Post meeting note: expressions of interest deadline – Friday 25th May 2018. Votes will be counted Friday 15th June 2018**	**LN**
4 **4.1**	**ODT Hub Update** **Hub Operations Cardiothoracic Offering** Over the last 6 months Hub Operations have taken over responsibility for offering hearts, lungs and livers; previously these organs would have been offered by the SNOD. Overall the timeframe for the actual offering has reduced. However, the time between acceptance, mobilisation of the NORS Team and retrieval surgery commencing averages eight hours. One of the issues which has come about since the Hub took over Cardiothoracic organ offering into their remit is that centres can accept an organ whilst awaiting further information and once a centre has accepted, the offering process is then halted in line with SOP 5139. In one example, a group offer was made, all centres accepted and once further details had been received, all centres declined – the total time on this occasion was 5 hours and 29 minutes when it should take a maximum of 45 minutes which then allows the organ to be offered to the rest of Europe Around 30% of cardiothoracic offers are group offers and when group offers are made, it seems that some centres won't speak to the transplanting surgeon until after the organ has been accepted, other centres accept organs and then decline them later. When initial offers are made, it could be that the offer is declined by all or most of the centres, where this is the situation, organs are then offered via group offering so the declining centre may be contacted again as part of the process. Using more rigid criteria around the minimum and maximum acceptable height and weight of donor when listing the patient would negate some of this. NCTLs are not clinical and don't have the knowledge or judgement to decide who should receive offers beyond the algorithms built into the system. There will be another meeting on 1st May to iron out some of the operational issues within the Hub. **JNe will review cardiothoracic offering over the next six weeks and will review with JyP to decide how to move this forward** There is also a continuing issue around the number of offers made without HLA data which JNe is trying to move forward	**JNe/JyP**
5 **5.1**	**Statistics and Clinical Studies Report** **Summary from Statistics and Clinical Studies** Lung transplant numbers have increased by 14% and heart transplant numbers have remained the same as they were in 2016/2017. This is a surprise as there has been an increase in DBD donors. The annual report on Cardiothoracic transplantation was published October 2017. The MCS report (which has replaced the VAD report) was published in January 2018 and members have also been sent the interim cardiothoracic transplantation report via email. Members from the statistics and clinical studies teams attended BTS and ISHLT and papers which have resulted from long-term projects have been submitted for publication.	

	Further work within the department has included monitoring the new cardiothoracic organ allocation schemes and updating the VAD database. There is funding for a new CTAG Audit Fellow and recruitment is being discussed.	
5.2	**Summary of heart/lung transplants** Combined heart and lung transplants are not monitored through the CUSUMs, hence this regular report. Looking back over a six year period from 2011 to 2017, only 28 heart lung transplants have been carried out; six recipients died within 90 days post-transplant. 78 patients in total were listed for heart lung transplants between 2011 and 2017, seven were listed urgently and one was listed super urgently. The mortality rate on the waiting list is 28%, the transplant rate is 40% and the remaining 32% of patients listed for heart lung transplant were removed from the list or are still waiting. Heart lung patients wait for an average of 2 years, many die whilst waiting. Since 2015, 12 applications for listing have gone to the adjudication panel to register on the waiting list for urgent heart lung transplants, most of these within the last year. Four were not approved, two of which were registered anyway, both with poor outcomes post-transplant.	
5.3	**Transplant Centre Profiles** A plethora of information is available on the ODT website and a better way to present this to patients would be via a transplant centre profile. Examples are given in CTAGS(18)05. It is important that data is presented in an unambiguous way and is not open to misinterpretation. Appropriate text or caveats will be included. They will be made available on the ODT Clinical Site when finalised. There was feedback that including the average range of outcomes would be helpful rather than just a single percentage. **SR and JF will liaise on this and the Transplant Centre Profiles will be taken to the CTAG Patient Group in June**	**JF/SR**
5.4	**Group 2 Transplants** One group 2 transplant was carried out in January 2018 at Papworth. The patient received a non-urgent heart transplant, the heart had originally been accepted by Manchester for a Super Urgent patient but was then declined based on pressures. Papworth were the NORS team retrieving on this occasion and as the only centre who showed interest, they were allocated the heart. Technically, anorgan declined for Group 1 patients in the UK should be offered to Group 1 patients in Europe before being offered to any Group 2 in the UK. The centre in question stated that they are unsure if this patient was truly Group 2. **JyP to investigate and report the correct Group status to NHSBT** **Post meeting note: this patient had right of residence in the UK at the time of listing for transplant and was therefore a Group 1 patient**	**JyP**
6	**Report from Chair**	
6.1	**CTAG Core Group Telecons Key Discussion Points**	
6.1.1	**Minutes from Telecon 20th Nov 2017** The last Cardiothoracic Core Group Telecon (CTCG) took place in November 2017. The CTCG Telecon takes place bimonthly to make decisions and actions on issues in between the 6-monthly CTAG Wider Group Meetings. The Paediatric Organ Allocation Working Group (POAWG) was set up as a result of the CTCG to revisit the definition and allocation of paediatric cardiothoracic donor organs and the Heart Allocation Sub Group (HASG) to revisit the 2016 Heart Allocation Scheme. As a result, there was no need to convene the second CTCG during the last 6 months.	
6.1.2	**Update on allocation zones** Phase two of the 2017 allocation zone revision was introduced at the start of this year. Allocation zones will be revisited annually in the autumn and will consider the past three	

years of registration data and the last two years of donor data. Agreed zonal revision will be implemented on 1 January in the following year.

6.1.3 **Reasons for declining donor organs**

It was decided at the November CTCG teleconference that centres will record declined offers and the 'reasons for declining donor organs' spreadsheet has been circulated to all centres for completion and return to NHSBT Statistics and Clinical Studies.
Feedback to date as follows:

- Birmingham have recorded reasons for declining donor organs, but not in the right format to be able to import the data without manipulation.
- The return rate for other centres has been poor

RT will feed this back to his centre and will use the correct format moving forward — **RT**

Harefield, Great Ormond Street (GOS) and Papworth have all been using the new codes for reasons for declining donor organs listed in the spreadsheet table for declining donor organs.
In the month of December 2017:

- Harefield recorded 144 offer declines
- GOS recorded 49 offer declines
- Papworth recorded 78 offer declines
- Glasgow has sent data in to NHSBT but it wasn't received early enough to make it into the report, Glasgow uses this report to form the basis of a daily and weekly debrief
- Newcastle have yet to start using the new coding system for the reasons for declining donor organs

Centres also give the reasons for declining donor organs to the Hub when they decline the organs. However, it is unnecessary for every centre to phone and provide reason for decline as it would tie up the Hub telephone line.

Centres required to try and record decline reasons and return the spreadsheet on a monthly basis as previously agreed — **Centre Reps.**

6.1.4 **Grading of retrieved Cardiothoracic Organs**

Forms for grading retrieved donor organs has been running as a pilot since January 2017 with electronic forms for the separate grading of retrieved donor hearts and retrieved donor lungs. The forms should be completed by the lead retrieval surgeon at the time of retrieval; the organs should also be graded by the transplanting surgeon at the time on implant. Completing the two sets of forms enables analysis of these reasons, and comparisons between the condition of donor organs at the point of retrieval and at the point of implant, which would further identify injuries to organs not picked up at retrieval. CTAG has put a lot of effort in generating these forms, but return rates have yet to improve. 60% of forms must be returned before any analysis can carried out on the data.
Return rates for the latest period:

Hearts

- Retrieval surgeons grading of retrieved donor organs form return rate: 45%
- Transplanting surgeons grading of retrieved donor organs form return rate: 39%

Lungs

- Retrieval surgeons grading of retrieved donor organs form return rate: 35%
- Transplanting surgeons grading of retrieved donor organs form return rate: 33%

Centres Leads are requested to identify a Champion in their centre to oversee the return of the forms to NHSBT. — **Centre Reps**

Return rate and subsequent data will be reported at the next CTAG Wider Group Autumn Meeting.

6.3 **Scout Update (Workforce Transformation Board Scout Sub Group WFTBSSG)**

The business case to seek agreement and funding for the Scouting of Cardiothoracic Organ Donors business case has been put to the Senior Management Team (SMT). The SMT agree that the role of the Cardiothoracic Scout is important in principle and particularly with changing donor profile. However, cardiothoracic scouting has yet to be commissioned due to lack of funding.

	NHSBT is keen to support cardiothoracic scouting, but it needs to be affordable. Currently, centres who are using cardiothoracic scouts are doing so voluntarily. ST and Karen Quinn (KQ) will look at the proposal further and establish whether there are other delivery models and whether the costs of cardiothoracic scouting can be minimised. CTAG is keen to try and find a solution and prevent a mass exodus of valuable and highly trained cardiothoracic scouts	
6.4	**CTAG Workplan** No comments have been received to date on the current CTAG Workplan. In principle, the themes that are covered will remain the same: increasing the number of donor organs available, cardiothoracic NORS teams working to specific standards, data collection and reporting etc. Actual workstreams are included in the workplan. Upcoming work includes the need to define how patients waiting for heart lung blocks are defined and further work on heart and lung utilisation. Suggestions for additional workstreams will be welcomed – please email CTAG Chair. It has been noted that within CTAG there is a data deficit with no data collected on the quality of life that a recipient has after they receive a donor organ. To counteract this, further forms could be developed; they would require completion and return in a timely manner. However, with a lack of funding for clinical and clerical support, return rates for currently required forms are poor. Therefore, this is not something which can only be implemented after further discussion. It may be that in some centres this data is collected, but nationwide collection and collaboration is required. ST commented that funding for cardiothoracic transplantation in the UK is based on old statistics and needs to be revisited. The group suggested that the Workplan might be better spilt into a CTAG Lungs Workplan and a CTAG Hearts Workplan. **JyP and ST welcome input from group members into refreshing the CTAG Workplan**	**Centre Reps**
6.5	**Combined cardiothoracic/liver transplants** The past year has seen many changes relating to allocation and offering of cardiothoracic organs and livers; CTAG was keen to engage with the Liver Advisory Group (LAG) to discuss how patients needing a combination of cardiothoracic organs and a liver should be listed on the separate waiting lists whilst maintaining the urgency of listing they require. Historically, patients requiring lungs and liver are very sick and don't have the luxury of time; in the last 10 years only 50% of those patients requiring combined cardiothoracic organs and livers received the transplant they needed. Patients generally wait three to four years for multi organ transplants and this waiting time needs to be reduced to give these patients a better outcome and chance of survival. The cardiothoracic organ allocation seems to be the rate limiting step. Discussion and a vote took place within the group to determine whether the proposal to give these combined patients automatic urgent status would be favourable - four centres agreed, two centres disagreed and one centre abstained from voting. **This is majority support for urgent listing of patients requiring combined heart-liver, lung-liver or heart-lung-liver transplants. This will need to be implemented and monitored.** **SR to revise listing forms**	**JyP** **SR**
6.6 **6.6.1**	**Cardiothoracic NORS** **Cardiothoracic organ retrieval for small donors** An incident regarding retrieval of organs from a small donor by a non-paediatric retrieval team has motivated the need to review the criteria, which is currently <145cm. It was agreed that weight should also be taken into account so that if the donor has a height less than 145cm OR a weight less than 40kg, a Cardiothoracic NORS for small donors should be mobilised. **JNe to implement the new criterion**	**JNe**

6.6.2	**Cardiothoracic perfusion protocol update** The Cariothoracic Perfusion protocol was introduced in 2016 and reviewed in 2017. Centres are reminded that Perfadex Plus has been introduced in 2018 and requires no THAM or Calcium as additives. ST sent revised standards to all centres with changes tracked. The group agreed to sign off the changes highlighted in CTAGS(18)12 with immediate effect. **ST to feedback to NRG**	**ST**
7 **7.1**	**Reports from sub-groups** **CTAG Clinical Audit Group Chairs Report** Dr Nick Banner (NB) retired in April 2018 after 34 years working in cardiothoracic transplantation. Under the leadership of NB, the CTAG Clinical Audit Group has increased in size, with several projects coming to fruition, and new projects planned. The two Clinical Audit Fellows will finish their fellowships this year and CTAG will be looking to appoint a new Audit Fellow. JyP will work closely with NAA, JF, SW and Rachel Johnson (RJ) to facilitate the appointment and ensure good linkage with the NHSBT Statistics and Clinical Studies Team. NAA was selected as the new Chair of the CTAG Clinical Audit Group, and the role of heart representative in CTCAG is now vacant. **NAA/LN to send out email for expression of interested in the heart representation role. See Post Meeting Note under item 3.2** Moving forward, there is a lot of work to be done on the VAD database and SR will arrange a meeting with Steve Shaw (SSh). The group must also start thinking about changes required for the heart and lung transplant database. Datasets were also discussed and JD plans to bring a proposal to CTAG to request that accessible datasets should be available as they are to other advisory groups; whilst the application for data is quick, the extraction of the data takes time and delays the process.	**JyP/LN**
7.2	**CTAG Patient Group Update** The next CTAG Patient Group Meeting (CTPG) will take place in June 2018. Rob Graham (RG) Co-Chair of the CTPG attended CTAG HASG as a Lay Person Observer. ST asked whether the group felt it would be beneficial for RG to be invited to attend or nominate an attendee for the CTAG Wider Group Meeting, to make the link between the CTPG easier. The group agreed that this was a good idea. RG was successfully reappointed as Co-Chair of the CTAG Patient Group in January and was also appointed to work within one of the NHS England Advisory Groups and would therefore be a valuable link for member of CTAG and CTPG. **Post Meeting Note: ST wrote to RG to ask him to nominate an attendee for CTAG Wider Group Meetings, RG will attend future CTAG Wider Group Meetings as a Patient representative**	
8 **8.1**	**QUOD Updates** **Routine of BAL and cardiac biopsies** NORS teams are funded by NHSBT to retrieve BAL samples from donor cardiothoracic organs. Cardiac biopsies will also be taken at the point of retrieval although not all recipients in all centres will accept a biopsied heart. It is not possible to specify the preference for each individual patient, centres can have an overarching policy on whether they will accept biopsied hearts. BALs are straightforward, so a starting point will be to request that all NORS retrieval teams (cardiothoracic and abdominal) carry their own bronchoscopes and do the BAL. Marius Berman (MBe) will train the abdominal retrieval teams in the southern half of the UK and JD will train those in the northern half of the UK	
8.2	**QUOD/MRC Extension**	

	Whole organs and whole lungs are required for biobanking and construction of a QUOD atlas in Newcastle. A limited number of whole hearts and whole lungs declined when the NORS Team attend will be retrieved and sent to Newcastle. Nationwide there is huge demand for heart tissue to use as a control, and currently researchers spend £4000 per time obtaining complete donor hearts from Minneapolis. NORS teams to be reminded to take necessary equipment with them to retrievals to take QUOD samples.	
9	**Workforce Issues**	
9.1	**Peri-CCT Fellowship** Peri CCT Fellowships were developed in 2009 to address issues with the aging workforce in cardiothoracic transplantation surgery. A recent survey revealed 90% of fellows felt well prepared and would recommend following the Peri CCT route. The survey found high levels of satisfaction throughout the programme, and fellows felt well supported and on the whole the scheme provides good outcomes	
9.2	**Transplant Surgeon Survey** In summary the transplant surgeons survey found that 44% of the cardiothoracic workforce is over 50 years of age, only 6% of heart and lung surgeons are under the age of 40 years. Predictions show five potential posts will be available in the next five years, a further six may be required between two and five years across Scotland and England. This is a snapshot which doesn't consider all of the options; surgeons may retire before they reach age 65, and between 2023 and 2026, a further 10 surgeons will be required. Scouting and the inception of DCD Heart transplantation will likely increase the requirement and there is a need to maintain equilibrium without expansion	
9.3	**SCTS/SAC Cardiothoracic surgery workforce UK update** There are issues surrounding the further employment of fellows once they have received certification. Three recent positions didn't lead to consultant positions. Of these, the fellow at Newcastle is staying on as a fellow for now;, the fellow at Papworth has been appointed to work in ECMO at The Royal Brompton, and the fellow at Manchester is going to become a locum Consultant in a non-transplant related post in Liverpool. Furthermore, three transplant centres recently made new appointments, but none of these were from the Peri-CCT cardiothoracic fellows. SC reported that he will no longer be a member of CTAG to report on surgical training and the group felt it was necessary to ensure that someone can cover this in future. **JyP to consider**	**JyP**
10	**For Information Only**	
10.1	**Transplant activity report**	
10.2	**NHSBT ICT Update**	
11	**Any other business** **Hypothermia in DBD Donation** Chris Watson (CW) Chair of the Kidney Advisory Group (KAG) provided a paper which proposes reducing the donor temperature from 36.5-37.5°C to 34-35°C between consent to donate and retrieval in DBD organ donors as this has been shown to improve eGFR after 12 months. Please address any concerns to CW JD requested reconsideration of splitting the day to focus more specifically on the heart and the lungs rather than covering both on the same day which extends the day and the meeting and doesn't necessarily allow time to fully discuss all agenda items. **JF and JyP to liaise and consider this before the next meeting in October 2018**	**JF/JyP**
12	**Date of next meeting** **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 (Shared) Meeting:** Wednesday 10th October 2018, 12:30-14:45 Coram Campus, 41 Brunswick Square, London, WC1N 1AZ	