TO BE RATIFIED **CTAG S(M)(17)02**

NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

MINUTES OF THE NINTH MEETING OF THE NHSBT CTAG SHARED ISSUES MEETING ON WEDNESDAY 13th SEPTEMBER 2017, 12:30 – 14:45 IN THE INTAVENT SUITE, ASSOCIATION OF ANAESTHETISTS, 21 PORTLAND PLACE, MARYLEBONE, LONDON W1B 1PY

PRESENT:

Mr S Tsui	**Chair**
Dr M Al Aloul	Respiratory Physician, Wythenshawe Hospital, Manchester
Prof N Al Attar	Surgeon, Golden Jubilee National Hospital, Glasgow
Dr N Banner	Cardiologist, Harefield Hospital, Middlesex
Dr M Carby	Chest Physician, Harefield Hospital, Middlesex
Dr V Carter	BSHI Representative, Newcastle
Mr P Catarino	BTS Representative, Surgeon, Papworth Hospital, Cambridge
Mr C Chalk	CTAG Lay Member Representative
Ms N Crouchen	Recipient Transplant Co-ordinator, Harefield Hospital, Middlesex
Prof J Dark	National Clinical Lead for Governance, ODT
Ms J Foley	Head of Clinical Governance, NHSBT
Mr P Flynn	Welsh Health Specialised Services Committee
Prof S Fuggle	Scientific Advisor, ODT
Mrs M Harrison	CTAG Lay Member Representative
Mr A Hasan	Surgeon, Freeman Hospital, Newcastle
Mr J Mascaro	Surgeon, Queen Elizabeth Hospital, Birmingham
Ms J Newby	Head of Referral and Offering, NHSBT
Dr C Lewis	Cardiologist, Papworth Hospital, Cambridge
Ms L Logan	Regional Manager, Organ Donation Services, ODT
Dr J Parmar	Chest Physician, Papworth Hospital, Cambridge
Miss S Rushton	Statistician, Statistics and Clinical Studies, NHSBT
Mr O Senbaklavici	Deputy for Mr J Lordan, ULAS Representative
Dr J Simmonds	Deputy for Dr M Burch, Great Ormond Street Hospital, London
Dr H Spencer	Physician, Great Ormond Street Hospital, London
Mr R Venkateswaran	Surgeon, Wythenshawe Hospital, Manchester
Ms S Watson	Commissioner, NHS England
Miss E Wong	Statistician, Statistics and Clinical Studies, NHSBT

IN ATTENDANCE:

Mr J Asher	Medical Health Informatics, ODT
Mr A Kourliouros	Observer, Clinical Fellow, Papworth Hospital, Cambridge
Mr J McGuinness	Surgeon, Mater Misericordiae University Hospital, Dublin
Prof R Ploeg	National Clinical Lead for Organ Retrieval, NHSBT
Ms S Rendel	QUOD Bio-bank, Oxford
Dr Z Reinhardt	Paediatric Observer, Freeman Hospital, Newcastle
Ms D Russell	Observer, General Manager, Harefield Hospital, Middlesex

APOLOGIES:

Ms T Baker	Transplant and Divisional Manager, Harefield Hospital
Dr M Burch	Cardiologist, Great Ormond Street Hospital, London
Prof J Forsythe	Associate Medical Director, ODT
Dr E Jessop	Medical Advisor, NHS England
Ms S Johnson	Director of Organ Donation and Transplantation, NHSBT
Mrs J Nuttall	Recipient Co-ordinator Lead, Wythenshawe Hospital, Manchester
Prof S Schueler	Cardiologist, Freeman Hospital, Newcastle
Mr M Stokes	Head of Hub Operations, NHSBT
Dr R Thompson	Lung Physician, Queen Elizabeth Hospital, Birmingham
Dr M Winter	National Services Division, Scotland

1 **Declarations of interest in relation to the agenda**
There were no declarations of interest in relation to the agenda.

2 **Minutes of the meeting held on:**
Wednesday 26th April 2017

2.1 Accuracy
The minutes of the last meeting are a correct record for publication.

2.2 Action Points

1 – Reconvene scout sub-group
The Scout sub-group has been reconvened and the first meeting takes place on 21/09/17.

2 – NHSBT ODT Website
The redesigned website is now live. Thanks to C Lewis, J Parmar, M Carby and M Harrison all of whom have offered assistance with developing the website. C Williment is now leading on this project and will be in contact in due course when further content alterations are required.

3 – Association between survival and decline rates
Refer to minute 5.3 of the shared minutes.

4 – Transplant Centre dashboard/profiles
The transplant centre dashboard/profile is a template for patients' use which displays the metrics of each centre. The group felt that it should be called a Transplant Centre Profile rather than a dashboard so as not to be confused with the NHS England dashboards; paediatric information should be removed for adult centres as not relevant. S Rushton will be creating a first draft to be ready by Spring 2018 CTAG. **S Rushton**

5 – Defibrillator for retrievals
All NORS teams now have a defibrillator to take on retrievals. Harefield had minor issues regarding the cleansing and sterilising of the equipment, but this will be resolved in the next few weeks. N Banner to confirm when completed. **N Banner**

6 – Perfadex protocol
All teams have been reminded about the Perfadex protocol regarding retrieval and storage of retrieved lungs.

7 – Grading of retrieved cardiothoracic organs
Refer to item 6.1.3 of the shared minutes

8 – CTAG Patient Group Update
Refer to minute 7.2 below.

9 – Encourage recipients to write to donor families

Only 12% of organ recipients write to thank their donor families. Harefield actively encourage recipients to write to their donor families and proactively mention this at the time of listing and in information leaflets. L Logan would provide some examples of good practice, but this needs to be addressed. Suggestions include a poster suggesting words, or a card, or postcard. When the new Lead Nurse Recipient Coordinator starts in post in October, this will be one of the priorities of the role. **L Logan**

3 **Associate Medical Director's Report**

3.1 Developments in NHSBT

A prototype File Transfer Protocol (FTP) file sharing website is being developed to enable the effective sharing of clinical governance and other learnings, as well as a full database of cardiothoracic contacts. NHSBT would have access to this website to enable a more effective cascade of information to centres. The database of contacts is a project for 2018. Access to the FTP site would be password protected.

3.1.1New appointments

There have been no new relevant appointments since the last meeting.

4 **ODT Hub Update**

The Hub has so far transformed the liver waiting list by using an algorithm to allocate organs to named patients for offering.

4.1 Duty Office Cardiothoracic Offering

From 25/09/17, cardiothoracic offering will be within the remit of the Duty Office, beginning with 4 regions then expanding to the whole of the UK within 3 months. This will enable the Duty Office to track offers more efficiently and record whether they were accepted or declined and the reasoning behind the decisions made. Over time, offering will move to patient specific offers, starting with liver later in the year. Taking the non-urgent cardiothoracic offering in house to the Duty Office has enabled a reduction of around 5 hours due to group offering but it is acknowledged that group offering is not perfect and there will be a workshop on 09/10/17 to try to iron out issues.

4.2 Back Up Offers

Clarity regarding back up offers for heart-lung block and bilateral lung acceptances is still required as there is inconsistent practice nationally. The group decided that back up offers should be made where there is a risk that one of the lungs may not be usable. When heart-lung blocks or bilateral lung offers are accepted, the accepting centre should decide whether the Duty Office should also make back-up offers to other centres. There will be no indication as to which lung, left or right, requires a back-up. The accepting centre should initiate the back-up offering, via the Duty Office if they do not have a suitable backup recipient at their own centre. Back-up offering should be done via a Group Offer and should follow the agreed allocation sequence. This should reduce the overall number of unused organs, and increase the number of transplants carried out. J Newby to make this operational practice. **J Newby**

5 **Statistics and Clinical Studies Report**

5.1 Summary from Statistics and Clinical Studies

The Annual Activity Report on Organ Donation and Transplantation has been published on the ODT website. The organ specific Cardiothoracic report will be published shortly and downloadable from the ODT website in the next few weeks.

Within the Statistics and Clinical Studies Department, Prof Dave Collett has now retired and Rachel Johnson has been appointed as the Assistant Director of Statistics and Clinical Studies; Jenny Mehew (nee Lannon) has now returned from maternity leave to her new role working with organ utilisation, perfusion and ischemia time. S Rushton will remain in her role

supporting CTAG, helping with ISHLT submissions, and working on the VAD database. **All centres**
S Rushton and others have also been working hard to support the Hub, new Duty Office processes and also with the Paediatric Organ Allocation Working Group. Regarding the VAD database, members were asked to update the database if the numbers in Table 1 of the report are incorrect.

5.2 Summary of heart/lung transplants

Over more than 6 years, since the start of the CUSUM monitoring period, 25 heart-lung transplants have been carried out resulting in 5 deaths within the first 90 days (i.e. 20% mortality). The median waiting time for heart-lung transplant is two years which is less than the median time for patients on the non-urgent heart list, which is three years. The two recent urgent heart-lung patients were approved by the adjudication panel. Last year only two heart lung blocks were transplanted and this year there have been three so far.

5.3 Association between survival and decline

The analysis present at the last meeting has been re-run so that the time periods match and the survival outcome is shorter-term. This shows no association between survival rates at one year post-listing and centres with higher decline rates.

Discussion that followed agreed that medium term outcome is probably more relevant for assessing differences in clinical practice and behaviour since most patients listed for transplants have not yet had their transplants by 1 year. It might be interesting to see how many transplants there would be if all centres had the lowest decline rate. However the rates are calculated from organs that were eventually transplanted. If an organ is accepted earlier in **S Rushton**
the offering sequence, it would probably have no effect on the national organ utilisation rate. CTAG would need a steer from J Forsythe who initiated the original analysis. S Rushton to liaise with J Forsythe.

5.4 Allocation zonal boundary changes

Following the last meeting, a paper was presented on the second part of the phased changes to the heart and lung allocation zonal boundaries. The zone sizes are based on the proportion of patients registered on the waiting list and the proportion of donors in each geographical **S Rushton**
area. It was noted that the time period had been moved forward since the last analysis but could be even more up to date to account for the most recent activity. S Rushton to update the numbers up to the end of September and bring a new proposal to the November CTAG Core Group meeting for agreement.

6 **Report from Chair**

6.1 CTAG Core Group Telecons: Key Discussion Points

6.1.1 Reasons for declining donor organs

The CTAG Core Group revised the long list of reasons for declining cardiothoracic organs and reduced the list from 70-80 reasons to four categories with 10-12 reasons for decline in each. This list can now be distributed to centres so that both the centres and the Duty Office have the same reasons and there will be less room for misreporting. This process can be implemented immediately and before the Duty Office IT systems are changed to receive this information.
J Asher noted that he had an amendment to make to the reasons to be in-line with the plan for **J Asher**
other organs. J Asher to send the list to S Tsui and S Rushton to circulate. **S Rushton**

6.1.2 Removal of age as a cut off for donor heart allocation

TPRC challenged whether there is a clinical justification for using age as a cut off for heart allocation. Paediatric centres agreed that there is no clinical justification for doing so. A new Cardiothoracic Heart Allocation Sub-Group (CTAG HASG) will be convened to revise donor **CTAGHASG**
heart allocation and eliminate the age cut-off. The CTAG HASG will report back to CTAG and TPRC.

6.1.3 Grading of retrieved cardiothoracic organs

The grading of cardiothoracic organ forms were introduced on 18th January 2017. Since then, the overall return rate for the forms stands at around 37%-40% from retrieval surgeons and 17%-27% from recipient surgeons. An improvement to 60% form return rates is required before any analysis will be carried out. Development of a fully electronic system is in place and it was felt that once this is introduced, it will be easier to request and return this important information.

6.2 Scout Update (WorkForce Transformation Working Group and Scout Sub Group)
Centre representatives have been invited to a meeting on 21/09/17 regarding the future of the Scout function and its place in the donation/retrieval pathway. CTAG will be updated on developments.

7 **Reports from sub-groups:**

7.1 CTAG Clinical Audit Group Chair's Report
S Tsui thanked N Banner for the sterling work that he and the CAG have carried out over the years. The CTAG CAG Chairman's report has been circulated which provides an update on the activity of the group, associated project groups and clinical fellows. Within the group, elections will be taking place for the position of Organ Retrieval Representative. R Venkateswaran currently holds this post and would be welcome to stand for re-election. Paperwork will be circulated to voting members of CTAG for nomination. It was also decided that a position would be made available for professionals allied to medicine; nominations of individuals should be forwarded to N Banner.

7.1.1 UK VAD Database restructure
The UK VAD database was built to serve a specific purpose and has become cumbersome over time. The NHSBT IT change programme is not scheduled to cover any alterations to the VAD database. The cardiothoracic community use the data contained in the database, and informal discussions suggest that contributions from NHSBT and each of the cardiothoracic centres could fund the necessary revamp at a cost of approximately £7k each. All centres are supportive of the revamp at this stage and further discussion will be had at the meeting with Euromacs on 21st September 2017. S Watson indicated funding possibility from NHS England and N Al Attar reported that M Winter would also support this from Scotland.

7.2 CTAG Patient Group Update
The CTAG Patient Group members are passionate and proactive. R Graham has been reappointed as co-chair of the group alongside S Tsui. At the last meeting the group decided to write to MPs to discuss funding for DCD heart transplantation. The results will be brought to the next CTAG Patient Group Meeting on 16th October 2017. Members who would like to attend should contact L Newman to register their attendance.

7.3 CTAG Paediatric Organ Allocation Working Group
The CTAG POAWG met in January to review age being used as a cut off for cardiothoracic organ allocation. It was agreed that there is no clinical justification for this approach for heart transplants although it is justifiable in lung transplants.

7.3.1 Paediatric Allocation Zones
Paediatric organs are currently offered between GOSH and Newcastle on rotation for non-urgent paediatric patients. Super urgent and urgent paediatric lungs are served by the urgent schemes. To ensure fairness, allocation of donor organs needs to match the demand at each centre. The proposal is to use allocation zones for paediatric organ offering. These would be calculated using similar methodology to the adult allocation zones, based on the number of registrations per centre. This proposal has been agreed by the CTAG POAWG and will go to Transplant Policy Review Committee for approval. **S Rushton S Tsui**

8 **QUOD Update**
Following capital investment in bio-banking, an application has been completed for inclusion of heart, lungs and pancreas specimens to be collected for QUOD research. Although a number

of hearts are not used for heart transplant, taking biopsies is a crucial part of research. Heart biopsies from hearts which will be transplanted should be taken from the left ventricular apex using a trucut biopsy. Hearts which are not being used for transplant may have a punch biopsy taken. A research BAL should be taken from all donor lungs by the CT NORS team, irrespective of whether transplant goes ahead, as this is valuable research. A BAL will not be possible where only an abdominal team attends the retrieval.

Harefield and Glasgow declined for hearts that they have accepted for their recipients to be biopsied. It was noted that recipient co-ordinators would be able to specify whether a recipient is happy to have a biopsied organ and would be able to decline biopsy of an organ accepted for patients who specified that they do not wish to have a biopsied organ.

GOSH would not be offered hearts or lungs which have had biopsies taken; heart and lung biopsies will not be taken from donors who are less than 140cm in height and under 18 years of age. RINTAG and SMT will receive this update and NORS Teams must accommodate these requests. An SOP with photographs for standardisation will be developed for NORS teams. If necessary, a review will be carried out with CTAG to decide on whether to include paediatric hearts and lungs in the biopsy process for QUOD.

9 **For Information only**

9.1 Transplant activity report: August 2017

Papers in this section of the meeting are included for information only

9.2 Update on Patient Consent Scheme

Papers in this section of the meeting are included for information only

10 **Any other business**

No other business was raised for discussion

The CTAG Patient Group Meeting will take place in central London on Monday 16th October 2017 from 12.00-16.00. Members to contact L Newman to register their attendance.

11 **Date of next meeting:**

2018 CTAG Wider Group (Shared) Meetings:
Wednesday 25th April 2018, 12:30 – 14:45 – venue TBC
Wednesday 26th September 2018 12:30 – 14:45 – venue TBC