

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE**

**MINUTES FROM THE MEETING OF
CARDIOTHORACIC PATIENT SUPPORT GROUPS AND ODT
HELD ON WEDNESDAY, 12TH NOVEMBER 2014
AT BIRKBECK, UNIVERSITY OF LONDON**

PRESENT:

Mr Steven Tsui	CTAG Chair
Mr Derek Airey	Chairman, Freeman Heart & Lung Transplant Association
Mr Nawwar Al-Attar	Surgeon, Golden Jubilee National Hospital, Glasgow
Dr Nick Banner	CTAG Heart Deputy Chair
Dr Martin Carby	Chest Physician, Harefield Hospital, Middlesex
Ms Kathy Collins	Nursing and Quality Adviser, NHS National Services Scotland
Mrs Kathryn Graham	Chair of Transplant Patient Support Group, Papworth Hospital
Mr Rob Graham	Patient representative from Papworth Hospital
Miss Barbara Harpham	National Director, Heart Research UK
Mr Keith Jackson	The British Cardiac Patients Association
Mr Matthew Knight	CTAG Lay Member
Dr Jenny Lannon	Statistics & Clinical Studies, NHSBT
Mrs Debbie Lovett	Deputy Policy Lead for Organ Donation and Tissue Transplantation, Department of Health
Mr Nick Medhurst	Policy Manager, Cystic Fibrosis Trust
Mrs Jane Nuttall	Cardiothoracic Recipient Transplant Co-ordinator, Wythenshawe Hospital
Ms Cheryl Riotto	Transplant Modern Matron, Papworth Hospital NHS Foundation Trust
Ms Amy Smullen	Policy Lead for Organ Donation, British Heart Foundation
Mr Michael Thomson	Patient representative from Golden Jubilee National Hospital
Mrs Joan Whitney	Treasurer, Freeman Heart & Lung Transplant Association
Mr Jon Williams	Patient Representative from Wythenshawe Hospital
Miss Katie Wilson	User Involvement Network Manager, British Heart Foundation
Ms Jan Withington	Heart Transplant Social Worker, Wythenshawe Hospital

IN ATTENDANCE:

Miss Trudy Monday	Clinical & Support Services, ODT (NHSBT)
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ACTION**Apologies**

Apologies were received from Mr Ged Higgins, Mrs Jessica Jones, Ms Lesley Logan, Mr Graeme Marshall, Dame Joan McVittie, Mrs Katherine Murphy, Prof James Neuberger.

1 Welcome and Introduction

- 1.1 S Tsui welcomed everyone to the third meeting with representatives from national and local patient support groups and charities around the UK. Although attendance is good today, more patient representatives are encouraged to attend these meetings; the aim is to provide information and for patient views to be heard. All Cardiothoracic Transplant Unit Directors have been asked to forward information to their patients and local patient support group members.

2 Minutes of the meeting held on 30th July 2014

- 2.1 The minutes of the meeting held on 30th July 2014 were agreed as an accurate record.

ACTION

The date of the National Donation and Transplantation Congress which is 24th and 25th March 2015, clashes with a UK cardiothoracic surgery meeting. As a result, the CTAG stakeholder event will be deferred and not form as part of the congress; the new date will be circulated to all of you.

- 3 **Action points**
- **Size of membership:** The size of the membership of this group was discussed at the last meeting. J Neuberger indicated that NHSBT is keen to engage as many people as possible at these meetings so there will be no limit to the membership. It is important to engage with patients pre- and post-transplant, patient relatives and patient representatives.
 - **Terms of Reference:** S Tsui thanked members for sending their helpful suggestions and comments – the ToR were amended, circulated and are agreed.
 - **Election of a representative to act as a Co-Chair:** Due to limited attendance at the last meeting and a lot of people not previously aware of the existence of this group, voting will be deferred. Two candidates have already come forward to date – these nominations will remain, and the opportunity is open to those present and those who have sent apologies for today's meeting to nominate themselves as well – T Monday will send out an email. CTAG members, NHSBT staff and staff from government departments present at the meeting all felt that they should not nominate themselves to be a candidate for the co-chair nor would they vote. Nominees should understand what the group's remit is, and send their personal manifesto (no more than one side of A4) to T Monday by a set deadline. Manifestos received will be circulated to members and votes will be collated. T Monday
 - **Inclusion of international data when summarising the latest statistics in organ donation and transplantation:** J Lannon will include relevant international data when presenting UK figures in the future.
 - **Cardiothoracic Selection and Allocation Policies:** These have been circulated to members.
 - **Draft super urgent heart and urgent lung policies:** These will be circulated to members when they are available. T Monday
- 4 **Updates on Urgent Heart and Urgent Lung allocation schemes**
- Urgent Heart Allocation Scheme**
- Urgent heart allocation has been in place in the UK since 2001 with the initial plan of having only 25% of heart transplants as urgent. This has been a very successful program and as a result, demands on the scheme has grown with over 70% of patients being transplanted as urgent in 2013-14. Unless patients are listed urgently, they are now unlikely to get a transplant, and there is no means of prioritisation within the large group of urgently listed patients, therefore further criteria is required leading to a revision of the urgent heart allocation scheme. This will take the form of a super-urgent scheme.
- Following lengthy discussions, CTAG have now devised a set of criteria to establish a super-urgent heart allocation scheme. This caters for patients who are on mechanical circulatory support, such as VAD or ECMO, and these will have priority over other urgent patients. This was accepted by transplant clinicians in 2013 and signed off by CTAG.
- Currently the Duty Office at ODT in Bristol manages the offering of donor hearts manually with a physical whiteboard. An algorithm (computer software) needs to be devised to automate this task and to include the super-

urgent scheme, requiring IT support. Costings are now being finalised, and although there is no date set for implementation, this is one of NHSBT's IT priorities. The allocation process for super-urgent hearts will be detailed in the Heart Selection and Allocation Policies.

Urgent Lung Allocation Scheme

Regarding lung allocation, at present the unit decides which patient donor lung(s) goes to. There had been no urgent allocation scheme for lungs – CTAG have been aware of the need for criteria to be devised in a similar manner to the urgent heart allocation scheme. With lungs it is more complex because of the various diagnostic groups and it is difficult to compare groups of patients in terms risks of dying on the waiting list. CTAG is mindful that the involvement of experts of a particular diagnostic group could potentially result in a bias towards patients of that diagnostic group.

The clinicians have agreed to implement an urgent and super-urgent lung allocation scheme. The scheme has been finalised and NHSBT are working with IT to investigate a new, more efficient, system of implementation.

Questions:

Heart-lung transplants: It was questioned as to whether there would be any system for prioritising heart-lung transplant patients. This is something which is being debated as there are so many tiers and categories to consider. A discussion point with heart-lung transplantation is that three donor organs are being utilised for one patient potentially resulting in two other patients not receiving an organ. As the average survival of a heart-lung recipient is inferior to that of a heart recipient, the net benefit of the transplanted organ will be reduced.

At the last meeting of the Heart Allocation Working Group (sub-group of CTAG), it was agreed that there are sometimes alternative methods of dealing with some heart patient's health issues (as opposed to transplantation), and clinicians are trying to identify those patients who inherently need both a heart and lung transplant. Some heart-lung patients can be prioritised however they will not be listed in the super-urgent category. If those patients show an urgent need for both organs they are then listed in the urgent heart category. If a patient has heart failure or heart disease and a secondary problem in the lung, it then makes them difficult to transplant and there is risk of chronic rejection, and therefore overall reduced long-term survival; the patient may benefit from having a VAD and then just a heart transplant, instead of a heart-lung transplant.

There is an on going ethical debate with regards to donor organ use – how this limited resource is best used and how to maximise the benefit is up to society. There are also some patients who would benefit from a combined heart-lungliver transplant, so it is difficult to define what is best. It is important for this group to have input on the guidelines going forward and express concerns.

Age: Age is not used in prioritising any allocation scheme; once a patient is accepted for transplant, age is not a contributing factor in organ allocation.

Allocation processes in relation to disease groups, and changes in patient situations: It was questioned as to how the lung allocation scheme will accommodate for particular disease groups, e.g. is there a tier which caters for patients where their situations can change very rapidly (e.g. CF patients). The CTAG Lung Allocation Working Group have engaged with every centre to devise criteria for each disease group, however this is largely based on the opinions of physicians and surgeons. Survival statistics will

need to be monitored to ensure that the system is working.

ODT website: Members are encouraged to look at the following link to the ODT website for patient information, meeting minutes, selection and allocation policies, and to feedback on whether the information is adequate and if anything else which could be included which would be of benefit.

<http://www.odt.nhs.uk/>

5

Allocation Zone Boundaries

The UK is divided geographically into six allocation zones and there is one cardiothoracic zone per adult transplant unit. Over time, some units have become busier than others in terms of number of patients listed for transplant, and some units are carrying out more lung transplants than heart transplants or vice versa, so it was felt that the current zones were no longer appropriate.

At the recent CTAG meeting, a system matching zonal size to centre activity was agreed, by considering the number of patients listed each year at each unit. There is also a plan to separate heart allocation zones and lung allocation zones across the country to achieve equitable allocation for both transplant types. To confirm, zonal allocation is related to where the donor is located as opposed to the recipient. Donor organ ischemia time has a major impact on outcome so prioritising local units helps to keep ischemia time down whilst trying to be fair on a national basis. Currently, adjustment of the combined heart and lung zones is being confirmed and then implementation will take place. Any subsequent necessary adjustments required will be submitted to CTAG on an annual basis at the autumn meeting. Separate heart and lung zones will be implemented at a later date.

6

Scout Project

It was recognised that since 2001, heart transplant numbers had plummeted and the rate per population per million per annum for the UK fell to 1.8 about five years ago. Compared with other European countries, the rates were around 12 for Slovenia and 10 for Croatia, 6 for Spain and Austria, and 5 for Italy and Germany, so this gave cause for concern. This is combined with a relatively high rate of decline in organ donation – 40% of next of kin say 'no' to consent. The donor demographics are however different amongst countries. UK road safety is very good which partly explains the low numbers of donor hearts. Only about 25% of donor hearts are used for transplantation, compared with around 85% for abdominal donor organs.

G Mandersloot produced a national guiding document re. how to manage potential donors, which was agreed amongst the intensive care society in the UK in 2013. Most donors come from Intensive Care Units (ICUs) and ICU staff do not necessarily have all the expertise in how to manage potential donors, whereas cardiothoracic retrieval teams perform this task regularly. Following extensive discussion a national "Scout Pilot" was agreed for implementation whereby a cardiothoracic retrieval team member (a Scout) travels to the donor hospital as soon as consent had been obtained to help manage the donor.

This Scout Pilot was introduced in April 2013 with the plan of running for one year. As the year progressed, ICUs and staff were increasingly keen to have scouts attending. A survey was carried out which showed that approximately 82% of people were in favour of the scout program. Scouts attended 60% of all potential eligible cardiac donors. Several parameters were analysed and it was found that scouted donors were statistically more likely to be taller and less likely to have diabetes than the non-scouted donors – this introduces the possibility of some unintentional selection carried out by the teams. The

conversion rate (potential donors into actual donors) for hearts as well as for some other organs was higher in the scouted group of donors compared to the non- scouted group. There was a 42% increase in the number of donor hearts in the UK during this 12 month period, which was unheard of anywhere else in the world. However, it is difficult to say whether the main reason for this increase was the national donor management guideline, the scout, or a combination, and there has been a lot of discussion re. the next steps.

Although some centres are continuing with scouting this is additional work for the existing retrieval teams; more resource is required to run this as a sustainable national programme and at this stage further money is not available. There are also more patients being put onto ECMO before transplantation, but this uses more surgeons and resources, etc. NHSBT SMT have recently agreed to support the phase 2 of the scout project and to cover travel costs. CTAG is engaging all cardiothoracic retrieval teams in a discussion about taking part in this. Phase 2 will be designed to obtain more robust data and conclusions in order to see whether there is a strong case to request further funding for a sustainable national programme. A further meeting on 19th November 2014 is taking place with all teams to ask them to continue to support the scout program. It was queried how the UK compare with other 'opt in' countries, and S Tsui agreed to circulate the figures (even though the figures will be around two years out of date).

S Tsui

Phase 2 of the scout project will not be a randomised control trial so as to avoid delays in initiating and carrying out. NHS England will be funding a full-time research fellow post to support the project.

7

NHSBT Annual Cardiothoracic report 2013/14

Historically transplant activity has been monitored in collaboration with the Royal College of Surgeons who produced an annual report, but now this responsibility has been passed solely to NHSBT. The revised format is slightly different to previous reports and is consistent in layout with the NHSBT activity report. It provides lots of information regarding transplant activity and survival analysis after first heart and/or lung transplantation, both on a national and centre-specific basis. Members are encouraged to communicate anything they wish to see in this report in the future.

Quality metrics have been monitored for some time, and NHSBT and CTAG have monitored 30-day survival after heart or lung transplantation as a benchmark, and compared with the national average. If a unit is significantly better than the national average the centre is then compared to their results historically to monitor any change.

CUSUM monitoring is carried out as a continuous process. If there is a signal (a cluster of early deaths following transplantation), the unit is informed as well as the commissioner and CTAG Chair. There are different reasons why centres may perform higher risk transplants. Survival is the primary outcome which is monitored. All units can compare their own position against other centres; if they are an outlier the unit then knows that they need to examine their own process, which is seen as a positive development. All units now work together and review data together for shared learning so that this treatment is consistent around the country across all units.

The pressure on bed use in ICUs is very different in the US compared to the UK. For example, in the UK, following the diagnosis of death, ICUs want to move the cadaver along to make room for admitting the next patient. One of the pressures cardiothoracic retrieval surgeons are working against is retrieving heart and lungs quickly whilst the donor may be in a very bad condition before the donor organs had a chance to recover. In the US, the

ICU is happy to keep the potential donor longer and carry out tests, etc, to maximise organ function and organ use.

In 2007 a report from the Organ Donation Taskforce recommended expanding the number of donor co-ordinators to engage with families in ICU to support them in arriving at a decision about organ donation, which NHSBT embraced, resulting in the role of the 'Senior Nurse in Organ Donation' (SN-OD). The aim was to increase organ donation in the UK by 50% within 5 years, which was achieved in April 2013. Each acute hospital was to identify a donation champion, who are now called 'Clinical Lead for Organ Donation' (CL-OD), funded by NHSBT, to promote organ donation in their units. The Trust Board is held accountable for the organ donation rate within individual hospitals.

8 Any other business

Membership: Members were informed that the compilation of the group has evolved from knowledge of previous contacts, people approaching others, Cardiothoracic Centre Directors, and CTAG members; as many people as possible have been contacted. This group is not exclusive, and members are asked to engage with others who may be interested to be involved.

Characteristics of organ donors: It was highlighted that it would be of benefit to Trusts and recipients for NHSBT to deliver information on how differences in characteristics of organ donors influence recipient outcomes. S Tsui described the recent 'risk' meeting which explored what recipients want to know; when the minutes from this meeting are available they will be circulated to members.

T Monday

Format of meetings: Members agreed that it would be of benefit to know in advance of future meetings the key areas for discussion so that questions can be prepared beforehand. J Neuberger very much would like feedback from members regarding the format of these meetings, and the aim is to have easily accessible information available on the ODT website. Members are encouraged to explore the website.

Expenses claim forms: T Monday will email this form to all attendees.

T Monday

9 Date and venue of next meeting

Members felt that it would be of benefit to hold future meetings from mid-morning to mid-afternoon to allow plenty of time for attendees to travel from a distance.

Following discussion, members agreed that it would be sensible for the next CTAG Patient Support Group meeting to take place half-way between the spring and autumn 2015 CTAG Wider Group meetings, and again half-way between the CTAG autumn and spring meetings. The dates will be discussed with the new Co-Chair, and then emailed out to members to gauge availability.