

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

**MINUTES FROM THE MEETING OF  
CARDIOTHORACIC PATIENT SUPPORT GROUPS AND ODT  
HELD ON WEDNESDAY, 30<sup>TH</sup> JULY 2014  
AT THE INSTITUTE OF EDUCATION, LONDON**

**PRESENT:**

Mr Steven Tsui	CTAG Chair
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
Miss Barbara Harpham	National Director, Heart Research UK
Mr Keith Jackson	The British Cardiac Patients Association
Mrs Jessica Jones	Policy Advisor - Cystic Fibrosis Trust
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 Graeme Marshall	Patient representative from Golden Jubilee National Hospital
Mrs Jane Nuttall	Cardiothoracic Recipient Transplant Co-ordinator, Wythenshawe Hospital
Ms Cheryl Riotto	Transplant Modern Matron, Papworth Hospital NHS Foundation Trust
Mr Michael Thomson	Patient representative from Golden Jubilee National Hospital

**IN ATTENDANCE:**

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

Apologies were received from Mr Nawwar Al-Attar, Ms Tracey Baker, Mr Steve Clark, Prof Dave Collett, Harefield Hamsters, Dr Jim Lordan, Dame Joan McVittie, Prof James Neuberger, Dr Jas Parmar, The Scottish Association for Children with Heart Disorders (SACHD), Dr John Smith, Dr Richard Thompson, Dr John Townend, Ms Sarah Watson, Prof Nizar Yonan.

**1 Welcome and Introduction**

- 1.1 S Tsui welcomed everyone to the second meeting with representatives from national and local patient support groups and charities around the UK. Although the previous (first) meeting was back in February 2010, the aim going forward is to meet at least once per year. More patient representatives are encouraged to attend these meetings; the aim is to provide information and for patient views to be heard.

**2 Terms of Reference**

- 2.1 The Terms of Reference (ToR) was received by attendees. The Organ Donation and Transplantation (ODT) Directorate oversees the areas of organ donation, transplantation, retrieval, managing the national transplant waiting list/database, the organ donor register, auditing the outcome of transplants, etc. However ODT does not commission organ transplantation. The latter is the remit of NHS England and the National Services Division (NSD) in Scotland.

There are various demands for different organs, and each Solid Organ Advisory Group reflects this in their ToR and Selection and Allocation

**ACTION**

Policies. The Cardiothoracic Advisory Group (CTAG ) has two Lay Member representatives; Department of Health (DoH) officials are also included. There is an annual stakeholder meeting: the National Donation and Transplantation Congress; the next one is scheduled on 24<sup>th</sup> and 25<sup>th</sup> March 2015.

Regarding the ToR for the CTAG Patient Support Group, the following points were highlighted and discussed:

- Size of membership: one representative from each centre, with a maximum number of around 25 members would be agreeable. Other suggestions were to have two representatives from each of the centres (one patient representative, one clinician). S Tsui agreed to liaise with J Neuberger for his view on this.
- Patient members should possibly be a current patient or patient carer which would bring current patient experience to the meetings.
- The Chairs will work together to draft the agenda two months before the meeting, circulate the draft to members four weeks before the meeting, finalise the agenda two weeks before the meeting and ensure that papers are available on the ODT website ([www.odt.nhs.uk](http://www.odt.nhs.uk)).

**S Tsui**

T Monday will send the final ToR to centres and attendees to this meeting for comment by a set date; a final version will then be circulated to members of this group.

**T Monday****3 Election of a representative to act as a Co-Chair (for 3 years)**

3.1 The role of the Co-Chair for this group is to prepare the draft agenda together with the CTAG Chair, and to also lead future meetings. Desirable qualities of the Co-Chair were suggested as follows:

- to be able to lead and challenge the group from a 'lay person' perspective, and be able to 'chair' meetings;
- preferably, not a clinician or DoH official, etc;
- have recent patient experience;
- ability to review policies discussed by the group;
- be a voice for the group and write on behalf of the group;
- have qualities that are complementary to the current CTAG Chair.

An email will be circulated to invitees of this meeting to ask for Co-Chair nominations along with a description of their attributes. Nominations and descriptions will be then sent out to invitees for review prior to the next meeting when a vote can take place. It was agreed that the next meeting should be scheduled for approximately three month's time, and it was agreed that a London venue would be most suitable.

**T Monday****4 Latest statistics relating to Organ Donation and Transplantation**

4.1 The Transplant Activity Report is published every summer and covers activities (graft and patient survival) of all solid organ transplants undertaken within the UK. Survival estimates are also produced within this report. The followings were highlighted:

- There has been a decrease in the number of people registered on the transplant waiting list.
- DCD and DBD transplants have increased generally over the last few years (an increase of 7% for DCD, and 11% for DBD between 2012/13 and 2013/14). (DCD: 'donation after circulatory death'; DBD: 'donation after brain-stem death'). In general, DCD hearts are not used for transplantation as we are uncertain about their function. However, a few DCD heart transplants have been carried out, one in South Africa, a couple in the USA,

and one recently in the UK. There is intense research in this area as this could be a potential additional pool of donor organs if they proved to be safe to transplant.

- 75% of adult heart transplants last year (in 2013/14) were for urgent recipients. Each year there is an increasing percentage of donor hearts being used for urgent transplants.
- Heart allocation depends on factors such as blood group and body size. Blood group 'O' hearts often get allocated to the urgent patients. As a result, non-urgent blood group O patients frequently wait a very long time.
- The median waiting time for non-urgent heart patients is 441 days. There is a shorter waiting time for lung patients with a median waiting time of 265 days.
- In previous years, the proportion of donor hearts offered that were transplanted was low (25-28%). However, there was a significant increase in the percentage of donated hearts that were transplanted during 2013-14. The main change in practice that occurred during this period was the introduction of the 'Scout Pilot Project' (refer to minute 8) which could be attributable for this increase.
- Reasons that many donated organs are not transplanted include the donor's medical history, poor organ function and no suitable recipient.
- When patients are removed from the waiting list, it is usually because they have received a transplant, deteriorated and required a VAD implant, or become too unwell for a transplant.

It was noted that it would be useful when summarising the latest statistics in organ donation and transplantation to include international data to allow members to compare UK figures with other countries.

**J Lannon**

## **5 Cardiothoracic Selection and Allocation Policies**

- 5.1 For many years there has been one single document covering patient selection and organ allocation for both heart and lung transplantation. In the last year, CTAG has worked at separating these into four separate policy documents. The revised policies have been submitted to the Transplant Policy Review Committee (TPRC) for approval, and when they are finalised, they will be circulated to members and updated onto the ODT Clinical website. The policies will be reviewed once per year by CTAG; the next review will take place in July 2015. The aim of these policies is to ensure that patients have an equal chance of being considered for a transplant regardless of which centre they are referred to. They provide guidance on good practice and offers transparency.

**T Monday**

## **6 Urgent Heart and Urgent Lung allocation**

- 6.1 There has been a successful urgent heart allocation scheme which was devised around 15 years ago. The criteria for urgent listing have not changed, and the policy aims to make the best use of organs by prioritising urgent (more sick) patients.

More patients are supported with VADs as a bridging to heart transplant. Bridging to transplant can be carried out for lung recipients as well but this is currently not funded. From a surgical point of view, patients with VADs implanted are more difficult to transplant. More than half of the heart transplant waiting list patients at some centres have an LVAD in place already.

Heart allocation: In 2013/14, 75% of heart transplants were carried out under the urgent category. Some of the sicker patients need to be further

prioritised. Therefore, a super urgent heart allocation scheme had been agreed by CTAG. However, implementation has been delayed because the IT infrastructure at NHSBT is out of date and it is not safe to introduce this change at the moment. It is hoped that this change can be implemented in 2015.

Lung allocation: An urgent lung allocation scheme has been discussed and agreed by CTAG. There is uncertainty around offering the sickest patients the transplant due to the possible lower chance of survival post-transplant, and so should the most important outcome be long-term survival? As above, the IT system at NHSBT cannot safely introduce this change at present. A potential solution would be to use a manual white board system to introduce the scheme. However, there is a risk of human error with the white board system and a wrong organ may get allocated to the wrong patient. An analysis will be run to assess the potential benefit of an urgent lung allocation scheme versus the risk of a white board system.

The draft super urgent heart and urgent lung policies will be circulated to members.

**T Monday**

## **7 Zonal Boundaries**

7.1 Historically the UK was divided into a number of zones so that donor organs within that zone are allocated to the transplant centre within that zone first. Demand for organs at each transplant centre has changed over time but the zone sizes have not. This may be resulting in a discrepancy between the needs of a transplant centre for donor organs and the supply of donor organs from within their zone.

CTAG have considered the merits of a national organ allocation system versus a zonal organ allocation system. Each has their pros and cons. Travel time above 1.5 hours is not good for donor organs. Ischemia time compounds many risk factors including age and condition of donor. On balance, because ischaemic time is a risk factor for early mortality after both heart and lung transplants, a zonal allocation system is favoured as this may provide better outcomes for heart and lung transplants because travel time is kept to a minimum.

To address any potential inequalities of a zonal system, CTAG has agreed to adjust the zonal boundaries each year as required, based on the proportion of patients listed for transplantation at each centre in the preceding two years. This system will be introduced in the autumn of 2014. Initially, the calculation of the allocation zone for hearts and lungs will be coupled. The plan is to separate these zones when NHSBT IT infrastructure has gained the necessary capabilities.

At present, a donor heart would first be offered to urgent patients at the zonal centre, then in rotation to urgent patients at other centres in the country in the order that they were urgently listed for heart transplant. If the heart is not accepted for any of the urgently listed patients, it would be offered to a non-urgent recipient at the zonal centre, and then in rotation to the other non-urgent recipients at the other centres. Any centre that accepts and transplants a heart imported from another zone would go to the bottom of the offering sequence for the next non-urgent donor heart.

The Organ Care System (OCS) is a machine, first trialled in 2006, which allows the heart to be perfused (beating in a machine) whilst it is being transported. This technology is already used widely in Germany and the USA. However, the OCS is not funded by Commissioners in the UK and currently, it has to be paid for by the Trusts themselves. Even though some

UK centres had led the field in the past, we are now falling behind other countries as the technology is not funded.

NHSBT's NTOT group (New Technology in Organ Transplantation) have been looking at how this kind of technology could be introduced into the transplant services in the UK. These technologies may enable gene and cell therapy to be used to improve transplant outcomes in the future. Therefore, it is potentially a very valuable platform.

## **8 Scout Pilot Project**

8.1 The difference between the number of organs offered and the number actually transplanted was significant. In 2010/11, CTAG established a working group to look at how heart and lung transplantation can be increased in the UK.

Some donor organs offered are not accepted because surgeons worry that the organs will not function well enough. If a donor heart or donor lung does not function well enough immediately after transplantation, the recipient would need to go onto a life support machine. This is risky because less than 50% of such patients would ultimately survive. The proposal therefore was for donors to be closely monitored and the organs optimised before they are retrieved; if the treatment is right, some poorly functioning donor organs that are turned down for transplantation could improve sufficiently to be transplanted safely.

The Scout is a member of the cardiothoracic retrieval team who travels to the donor hospital to help assess the potential donor, collects information and helps to implement what is good practice in donor management. This process can take from 10 to 20 hours.

The programme was first suggested 2.5 years ago, and a pilot was eventually initiated in April 2013. The first year of the 'Scout' pilot has been completed. Analyses have unfortunately been inconclusive due to potential biases and complications with the data. However, it is likely that the scout project had some influence over the substantial increase in the number of heart donors in 2013/14 compared with previous years.

A survey of staff including ICU staff, SNODs, CLODs, scouts, retrieval surgeons and recipient transplant co-ordinators showed that an overwhelming majority were keen on scout attendance. The final analysis report will be available on the ODT clinical website within the next couple of weeks.

In the USA the average heart donor age is less than that in the UK. This is mainly because death from trauma in the UK has fallen significantly over the last 20 years. In the UK, there were 1.8 heart transplants per million population per annum in 2011-12 and the UK was ranked 20<sup>th</sup> in Europe; last year that figure was increased to 3.2 heart transplants per million population per annum, a very significant increase.

Scouting is demanding and is resource intensive for the cardiothoracic retrieval teams. This programme will not be sustainable unless it is properly commissioned. Currently cardiothoracic teams are doing this extra work with no extra resource and there is concern over surgeons' health when they are being overworked. Another concern is young surgeons not applying for retrieval team positions making recruitment into the speciality difficult.

At the 2013 Examination of Issues commissioned by the Medical Director of the NHS, there was a recommendation to reduce the number of adult heart transplant centres from six to four as the heart transplant activity in the UK was thought to be too low for all centres to maintain competency. However,

almost every centre has now reached the required level of transplants to maintain competencies.

The number of retrievals performed by each cardiothoracic team is lower than that for abdominal teams. However, the time spent per scout/retrieval by the cardiothoracic team is often double that spent by the abdominal team.

Members were informed that they can communicate their views to the commissioners through their individual groups, and also through this group via the new Co-Chair. Concern has been raised by transplant centres that the increase in transplant activity has also put additional pressure on resources within each centre – K Collins reported that there is currently a significant piece of work in progress looking at resources, including for example, numbers of beds. S Tsui confirmed that infrastructure is a concern amongst clinicians, especially as sometimes organs are turned away because there is a shortage of ICU beds.

**9 Any other business**

9.1 S Tsui thanked everyone for attending today's meeting, and the hope is that this group can work in collaboration with CTAG going forward.

It was proposed that the next meeting be scheduled in three month's time, in London.

**T Monday**