

**NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION
DIRECTORATE
CTAG CLINICAL AUDIT GROUP MS TEAMS VIRTUAL MEETING
THURSDAY 10TH DECEMBER 2020 14:00 – 15:30
[Join Microsoft Teams Meeting +44 20 3321 5246](#)
Conference ID: 467 476 287#**

MINUTES

PRESENT

Jayan Parameshwar (JP)	CT CAG Chair; CTAG Chair
Mo Al-Aloul (MAA)	Lung Transplantation Representative
Matthew Fenton (MF)	Paediatrics Representative
Gill Hardman (GH)	Cardiothoracic Clinical Audit Fellow
Margaret Harrison (MH)	CTAG Lay Member Representative
Steve Pettit (SP)	Heart Transplantation Representative
Vipin Mehta (VM)	Donor Management & Organ Retrieval Representative
Sally Rushton (SR)	Senior Statistician, NHSBT

IN ATTENDANCE

Trudy Monday (TM)	Secretary
-------------------	-----------

APOLOGIES

Steve Shaw (SS)	MCS Representative
Ruth Sutcliffe (RS)	Allied Health Professional

Actions

1 CTCAG(20)09 – Declarations of Interest

There were no declarations of interest in relation to the meeting today.

2 CTCAG(M)(20)02 – Minutes of the last meeting held on Thursday 27th August 2020 Accuracy

2.1 The minutes were agreed as an accurate record of the last meeting.

SP expressed apologies for not being able to attend the last two meetings – adequate notice is essential, and it was requested if these meetings can be arranged more in advance so that commitments can be met.

C Robinson has been emailed to ask who is going to provide admin support to CTAG going forward.

2.2 Matters arising

There were no matters arising reported.

3 Membership and Structure of the Clinical Audit Group

3.1 CTCAG(20)10 – Attendance and Memberships of CTCAG (For Information)

The following were highlighted:

- Welcome back to Sally Rushton, who will be working Monday to Thursday from February 2021.
- Marius Berman has just ended his tenure.
- Steve Shaw will be a member for another year.
- Margaret Harrison had finished her tenure but was asked to continue. JP explained that CTAG are keen to have her involvement.

3.2 New Members: Donor Management and Organ Retrieval Representative

Welcome to Vipin Mehta for his first meeting as Donor Management and Organ Retrieval Representative; the tenure is for 3 years.

4 Cardiothoracic Fellow Projects

GH gave an update on the progress with these projects which will be submitted for presentation at the ISHLT 2021 and the BTS 2021.

4.1 The Impact of the SARS-CoV-2 Pandemic on UK Cardiothoracic Transplantation

A summary was given as follows:

- Data analysis and manuscript write-up is now complete;
- COVID lung paper has been submitted to *Clinical Transplantation*;
- COVID Heart paper is currently with the authors for final review.

4.2 Development of the UK Lung Risk Index

A summary was given as follows:

- Methods have been outlined, with the agreement for the inclusion of PGD data collection (it was decided not to include paediatric lung patients, only age 16 plus);
- PGD data collection will commence from January 2021 (retrospective data collection in each centre);
- Agreement has been obtained from all centre directors;
- A team of co-ordinators has been established in each centre to begin data collection;
- GH will attend each centre (starting from mid-January, travel restrictions pending) for data checking and completion of the dataset;
- Aim for completion of this work by March 2021 to proceed with LRI modelling from the spring 2021.

4.3 The potential for uDCD lung transplantation in the UK

At the last CTAG Lungs meeting there was some interest in moving forward with un-controlled DCD lungs, which would be a long-term sub-project within the donation work. Centres who have fully formed MDT groups have been asked if they are keen to take this forward as a single centre pilot – there has been interest from one centre (Newcastle) who are currently forming a working group to potentially take this forward. If there are any other centres interested they are asked to contact GH; particularly important in case there are logistical concerns with the single centre that is involved.

4.4 Cardiothoracic Organ Offering, acceptance behaviours and utilisation

This 3-4 month project is due to commence in January 2021 looking at current behaviours in terms of lung utilisation, looking at patterns in decision making (what is being accepted, and not), human factors, surgeon psychology. This work links quite importantly with the Clinical Lead for Utilisation work – a recently introduced role.

The first part will be analysing current data that is collected through the transplant registry to gauge current practice. The second part may be re-instituting the lung audit (monthly identification of donor offers declined by centres, meeting ideal donor criteria, reported to centres). The final part is a qualitative (approximately 1 hour long) interview study of CT surgeons and co-ordinators to identify behaviours and values surrounding decision making for organ offer decline and acceptance, and conducting a thematic analysis from the information.

MF highlighted that there is a group in Boston studying this within paediatric heart surgery, called the Action Group who look at decision making, including decisions on the night. The time of day/night, and also sleep, can affect decision making, and the physicians at GOSH are really interested in this area – GH will email MF for contact details of these groups.

GH

A survey has already been conducted outside of this group looking at specific clinical case scenarios – this is currently being written up by the wider UK ODT research network – there was no consensus of opinion from this survey. The aim of the interview part of this new project is to look at the last donor offer, and asking the surgeon what they were thinking about when considering it, where value is added, what is considered important in the clinical history etc.

Clinicians are asked to please encourage team members to be enthusiastic about participating in this project.

4.5 **UK Lung Transplantation and Utilisation in Donation after Circulatory Death (DCD)**

A summary was given as follows:

- Presented (virtual) at ISHLT 2020 (abstract published);
- Data will be analysed, with the inclusion of UK lung PGD data (as above), with risk adjustment and will be submitted for publication (summer 2021).

4.6 **Evaluation and quality improvement of UK Donor Management**

A summary was given as follows:

- National survey was developed back in March to evaluate the donor care bundle, but many people on the donation side were suddenly very busy with intensive care and other areas, so the project is currently on hold.
- A meeting is scheduled with Dale Gardiner for the beginning of next year to discuss appropriate re-start data and how it can progress.

5 **Active and Planned Projects**

JP has emailed the group asking for details of any on-going projects, and any planned projects.

Impact of size mismatching on outcomes after heart transplantation in the UK:

SP reported that approximately 2.5 years ago the data was kindly given by NHSBT to enable the calculation of predicted heart mass and look at the impact of size mismatching on outcomes after heart transplantation in the UK. That data was presented at the European Society of Heart Failure meeting last year in 2019 and it has just been accepted for publication in clinical transplantation. The project is close to coming to an end, and the proofs of the manuscript will be circulated when received. The research demonstrated the same relationship between predicted heart mass mismatching and survival in the UK as has been shown in larger US datasets.

Paediatric re-transplantation audit:

MF is interested in an audit of paediatric re-transplantation, however the details have yet to be agreed.

5.1 **Outcome after Urgent Transplantation for LVAD related complications**

At the last CTAG, Sern Lim proposed a project looking at outcomes after transplanting LVAD patients who are on the urgent list after Adjudication Panel approval. There is a virtual meeting scheduled for 17th December to discuss this.

5.2 **Ongoing Lung Allocation Policy Work and S/ULAS Audit Work (MAA)**

MAA reported that the first 20-month review has been completed to assess the impact of the new lung allocation score retrospectively with an equivalent period of time prior to its implementation in May 2017. SR has carried out the analysis, it has been sent to co-authors for approval, and submitted to Thorax – a response is now awaited.

The plan is to use this as a platform to support the desire to carry out a critical review – there have been some expressions of concern both positive and negative; the group which has expressed the most anxiety is the lung fibrosis group. Areas of concern were: some clinical criteria being too strict, and by the time some patients are qualified for lung listing they are very unwell. The main beneficiaries appear to be the cystic fibrosis group, and to a much lesser extent the PH group.

The findings reinforce the desire within the main CTAG committee to conduct a critical review of the allocation system. The Lung Allocation Working Group has been reconvened (as requested) and from the member representatives there was a unanimous view that no revision would be accepted without scientific evidence to support it.

Following liaison with the CF community a critical review of the European model of prognostication in CF was conducted to see if it applies well to the UK. Consent from the CF Trust was obtained to allow full access to their database, and it was concluded that the model which was developed in France and then validated in Canada did not perform well enough in predicting mortality within three years, or the need for transplant within three years of the data inputting. MAA has submitted this manuscript to the European Journal of Respiratory Medicine and a decision is awaited.

A collaboration has been set up with Ruth Keogh – Professor of Epidemiology and Advance Statistics; she is going to cross reference the CF database with the transplant database to identify a new prognostic model that is bespoke for CF patients within the UK. On the IPF front, agreement has been gained from the Patient Group and from the British Thoracic Society (which holds the national database for lung fibrosis) to make available the data on record for the Lung Allocation Working Group to use to identify predictive models and prognostic markers which may or may not outperform the clinical criteria which has been chosen to date. There have been delays with progress over the last six months due to COVID, but the work is still ongoing. SR confirmed that the NHSBT data should be sent to the Lung Allocation Working Group by Christmas.

SP asked how well data from the pre-disease modifying drug (Kaftrio) era will predict the outlook now. This is unknown at present but MAA confirmed that there are fewer CF patients listed due to the use of Kaftrio; some patients are being referred for transplant too late, whereas others improve and come off the transplant list.

5.3 Age related outcomes in heart and lung transplantation

JP reported an update from M Berman: the data was received from SR last month, and the abstract/analysis is hoped to be finished fairly soon which will be shared with CTCAG.

6 Any Other Business

Process for requesting information:

There is an application form which the third party needs to complete, including the exact title of the project; the rationale behind it; the sort of data that is required; and the timescale within which it is needed. The CT Audit Group would then meet and discuss its merits; however, this part of the process has now been removed because it was causing unnecessary delay before this group would meet. The current process involves a decision via exchange of emails (within a two-week timeframe) to avoid delays, although if the data request is more complex it will take longer (eg. for CF data and GDPR) because of governance and sensitive data. It was noted that data being requested which is already a sub-set of the standard transplant data set is easier to collate due to the automated process. There is a page on the NHSBT website under 'Statistics and Reports' called 'Access Data' which includes everything that would be needed. The policy can be viewed, forms can be accessed, and there is also a list of projects completed already, projects which have been applied for and those undergoing. Link to the page:

<https://www.odt.nhs.uk/statistics-and-reports/access-data/>

It is not always communicated as to when the findings of a completed project have been published, therefore it is challenging to keep this resource up to date. It was recognised that this web page could be improved in terms of navigation – VM agreed to liaise with SR on ideas for this.

VM / SR

Mechanical Circulatory Support:

A national meeting to discuss Mechanical Circulatory support took place at Skipton House in September 2019. One of the actions was to look at measuring the quality of life objectively in patients with mechanical circulatory support, and for this information to be reported as an outcome measure within the annual national report. SR reported that NHSBT IT have employed a developer to implement the changes within the VAD database as discussed over the last 3 years; the first meeting is scheduled for January. There will be a lot of communications to centres when this database goes live, and training will be provided. SP to liaise with SS re. contacting centres in terms of preparing for the collection of quality of life data to feed into this database.

SP / SS

Sherpa Pak ice box:

The proposal for a project to examine the use of the Sherpa Pak box instead of the standard icebox was raised by VM. It was noted that Papworth and Newcastle are already using the Sherpa Pak ice box and Harefield are starting too. The data is not currently captured for organs transported using the Sherpa Pak ice box and so will need to be collected separately outside of the main database. It is important to show what the outcomes will be because of the expense of this box (approximately £5K per box). VM was asked to liaise with other interested groups to obtain this data. GH highlighted that PGD data is not routinely collected as an

VM

outcome measure for hearts and lungs and would be required to show any benefit of SherpaPak.

Impact of VADs on Paediatric Transplantation:

MF has submitted a data request to support a study looking at the impact of the increasing waiting list for paediatric heart patients.

Quality of Life in Lung Transplantation:

MAA reported that several members of the ALTP (who are also CTAG members) have expressed a strong desire to look at the quality of life in lung transplantation and the impact of surgery on gains or losses, offset against quality of life. This was agreed at CTAG and supported by NHS England. JP will email Sarah Watson, to find out where this discussion has reached.

JP

Discussion took place around the possibility of using a REDCap database, which are free, easy to write, store data and manipulate through web pages. It was agreed that this approach could be considered for smaller short-term projects. It was highlighted that new databases take a long time to be implemented within NHSBT and are expensive to progress, due to the priority given to the operational needs. MF agreed to take the REDCap idea forward.

MF

Annual VAD Report:

SR reported that there has been a slight delay in producing the annual VAD report because it needed to be re-written due to an issue in Newcastle having a big backlog of data to be included; in addition, there were some delays in submission of data from Papworth. SP expressed apologies for the delay with data from Papworth, and assured the group that there is now a more robust system in place. It is recognised that the database is not the most user friendly, and SR confirmed that NHSBT are improving it.

Communication of Risk: Collaboration with The Winton Centre (Cambridge):

SR reported that the Winton Centre has worked on the model for lungs and the kidney; they will be moving to heart at some point.

Date of next CT CAG meeting:

Late February/early March (minimum of 8 weeks' notice).

Post-meeting note: A calendar invitation has been sent for the next meeting to be held on Thursday 4th March 2021 via Microsoft Teams, 2-4pm.

Dates of next meetings – Spring 2021

CTPG Patient Group – 04/02/2021, 14:00 – 16:00, via MS Teams
 CTAGH Hearts - 22/03/2021, 11:00 – 16:00, MS Teams
 CTAGL Lungs – 31/03/2021, 11:00 – 16:00, MS Teams