

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

**THE NINETEENTH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE
ADVISORY GROUP MEETING
AT 11:30 AM ON WEDNESDAY 13 MARCH 2019,
THE HALLAM CONFERENCE CENTRE, 44 HALLAM STREET, LONDON, W1W 6JJ**

PRESENT:

Prof Peter Friend	Chairman (and Rep for National Retrieval and Liver)
Dr Girish Gupte	Deputy Chair & Birmingham Intestinal Transplant Centre Rep
Dr Ayesha Ali	NHS England
Dr Philip Allan	Oxford Intestinal Transplant Centre
Ms Carly Bambridge	Recipient Co-ordinator Rep
Mr Andrew Butler	Cambridge Intestinal Transplant Centre
Prof John Dark	National Clinical Governance Lead, ODT
Ms Samantha Duncan	Recipient Co-Ordinator Rep
Prof Sue Fuggle	Scientific Advisory, ODT
Ms Monica Hackett	Organ Donation Rep
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Mr Craig Jones	Lay Member
Mr Mark Jones	Statistics & Clinical Studies, NHSBT
Prof Simon Kay	Composite Tissue Rep
Prof Elizabeth Murphy	Lay Member
Ms Jacki Newby	Referral & Offering Rep, NHSBT
Ms Sarah Peacock	BShI Rep
Ms Sally Rushton	Statistics & Clinical Studies, NHSBT
Mr Khalid Sharif	Birmingham Intestinal Transplant Centre
Dr Lisa Sharkey	Cambridge Intestinal Transplant Centre

IN ATTENDANCE:

Mrs Kamann Huang	Secretary, ODT
Ms Hannah Westoby	Observer

ACTION

Welcome

- Ms Sarah Peacock replaces Dr Martin Barnardo as the BShI representative.
- Dr Ayesha Ali replaces Dr Edmund Jessop, NHS England
- Mark Jones is to take over from Sally Rushton as the Statistics and Clinical Studies representative.

Members thanked J Dark, who is retiring from NHSBT at the end of March, and S Rushton for their hard work and support to the Group.

Apologies were received from:

Prof John Forsythe, Dr Simon Gabe, Mr Henk Giele, Ms Heather Howe, Mr Mick Stokes, Mr Hector Vilca-Melendez, Dr Georgios Vrakas and Ms Sarah Watson.

**1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA
- MCTAG(19)1**

1.1 There were no declarations of interest in relation to the agenda.

**2 MINUTES OF THE MCTAG MEETING ON 24 OCTOBER 2018
- MCTAG(M)(18)2**

2.1 Accuracy

2.1.1 The minutes of the meeting held on 24 October 2018 were agreed as an accurate record following inclusion of the following amendments:

- Add Dr Susan Hill to the Attendance list.
- Page 6, Minute 11 Update on adolescent transition in small bowel transplantation. 11.1, third bullet point, second line. Remove the words 'to Birmingham'.

2.2 Action Points – MCTAG(AP)(18)2

2.2.1 AP2 Liaise with HTA regarding the classification of abdominal fascia in the context of intestinal transplantation and inform J Forsythe to confirm if further action is required

A concern was raised regarding abdominal fascia being requested by non-intestinal transplant centres (e.g. the Royal Free to aid abdominal wall closure in an isolated liver transplant). Retrieval of tissue (as opposed to organs) is not covered under the HTA licence for NORS teams and must be performed by an intestinal transplant team with appropriate HTA credentials. There is an additional issue regarding allocation, and the point was made that tissues do not have the same contraindications as organs. A Butler and H Vilca-Melendez to email a proposal to P Friend to raise this at NRG (National Retrieval Group) regarding the NORS issue and to LAG regarding the allocation issue. Olive McGowan and Vicky Gauden would be good contacts at NHSBT to assist with the drawing up of the proposal, in particular regarding the licensing.

**A Butler/
H Vilca-Melendez/
P Friend**

Currently Addenbrooke's have an agreement with the HTA to continue with their retrieval process for abdominal fascia, but the Royal Free need to resolve this with J Newby in the interim.

AP6 Potential bowel donors and location

Refer to Minute 9.

AP9 – 17.3 CIRTA – 3rd to 6th July 2019, Paris

An abstract on intestinal transplantation has been submitted and we are awaiting a response.

Post meeting note:

The abstract has been accepted for poster presentation.

2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

3.1 Developments in NHSBT

A number of changes are happening within NHSBT:

- Sally Johnson (CEO) is retiring at the end of March and will be replaced by Betsy Bassis who previously worked at Defra.
- Anthony Clarkson has been appointed Director of Organ Donation and Transplantation.
- Dr Richard Baker and Prof Derek Manas have been appointed as the two new Clinical Governance Leads starting from 1st April 2019, replacing Prof John Dark.
- Mr Ian Currie, University of Edinburgh, and Mr Marius Berman, Papworth Hospital, have been appointed as National Retrieval Leads, replacing Prof Rutger Ploeg.
- The Bill for the Organ Donation Opt-out legislation has been passed in the House of Lords, is due to gain Royal Assent imminently and will come into effect in 2020. A letter to this effect has been sent out by J Forsythe. There was a query as to why people under 18 years of age are excluded from the legislation.
- J Dark explained that although deemed consent under the Opt-out does not include the under 18 age group, every family will still be approached for consent to organ donation. It is believed that, following the new legislation, support for adult donation will move across to children as part of changing the general culture. Paediatrics will be reconsidered within 'making the most of the change in legislation' category in the new 2020 strategy.
- The European Day for Organ Donation and Transplantation (EODD) is on 12th October 2019 and will be held in the UK. A key topic will be organ perfusion.

3.2 Governance

3.2.1 Non-compliance with allocation

3.2.1.1 There were no non-compliances reported with respect to allocation.

3.2.2 Detailed analysis of incidents for review – MCTAG(19)2

3.2.2.1 Two issues were reported.

There is a problem recording the precise details of which organs are transplanted in multi-visceral transplants: this is often not determined until during the implantation. NHSBT requires feedback regarding these details after the operation, both for accurate record-keeping and in order to update the donor family

It was commented that the list for a multi visceral block comes up as a default. When Addenbrooke's asked for a pancreas this proved to be difficult. A Butler to email details to J Casey, Chair of PAG.

A Butler

The second issue was raised regarding recipients who have a latex allergy. In these cases, the retrieval team must be required to use latex free gloves. Life-threatening allergies e.g. penicillin and food allergies need to be considered as potentially transferrable with the

organ. It was noted that King's is already checking for these allergies before transplant.

4 ODT HUB UPDATE – HTA A & B FORMS

- 4.1 The digital HTA B forms have gone live and are working well. The first prototype for the digital HTA A form has been finalised and is linked with donor path and the SNOD data collection app. There are two forms, cardiothoracic and abdominal, and within each form are organ specific data fields, giving the bowel surgeons data fields specific to their retrieval. It is planned that the abdominal form will move from design to development in the new financial year with a go live date at some point in 2020.

5 UPDATE ON TRANSFER OF UK INTESTINAL DATA TO THE INTERNATIONAL INTESTINAL TRANSPLANT REGISTRY (ITR) – MCTAG(19)3

- 5.1 Work on this is being undertaken with the Terasaki Institute, a private organisation. The ITR template from the Institute has been circulated to members for feedback. This will cover both data collections needs of adult and paediatric cases. The paper on NHSBT data and post-operative data collection (minute 15.2 MCTAG(9)10) is the data proposed to be collected by the Working Group. It is intended to align what is collected by NHSBT with what the ITR requires as far as possible.

It will not be possible for NHSBT to transfer the data in time for the ITR submission deadline of 31st March 2019. It was agreed on this occasion for the four transplant centres to send in their own information to ITR.

It was agreed that there should be one surgeon and one medical representative from each centre to review what information should be collected. The representatives will be:

Addenbrooke's: A Butler and L Sharkey,
Oxford: G Vrakas and P Allan,
Birmingham: K Sharif and G Gupte and
King's: H Vilca-Melendez and J Hind.

Post-meeting note:

The deadline has now been moved to April.

Concern was raised regarding UK data if other countries can access the whole database. M Jones will attend the relevant meetings to consider this and other data governance issues.

The recommendation is for the data collection to be established prospectively in the first instance, and then on a retrospective basis.

6 STATISTICS & CLINICAL STUDIES REPORT

- 6.1 **Summary from Statistics and Clinical Studies – MCTAG(19)4**

A summary update from the report is given below:

**A Butler &
L Sharkey,
G Vrakas &
P Allan,
K Sharif &
G Gupte,
H Vilca-Melendez
& J Hind**

M Jones

- Helen Thomas has been appointed to the new role of Head of Clinical Trials Statistics and Lisa Mumford has been appointed to Head of ODT Studies.
- Two clinical fellows are currently working with Statistics and Clinical Studies; one on organ utilisation and the other on malignancy in transplantation.
- Work is underway to facilitate the transfer of intestinal transplant data to the Intestinal Transplant Registry.
- HLA DSA post-intestinal transplantation data will continue to be collected.
- The abstract submitted on behalf of the UK intestinal transplant centres to CIRTA can be seen in the appendix.

7 NATIONAL BOWEL ALLOCATION – MCTAG(19)5

7.1 Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(19)5

The performance report on the National Bowel Allocation Scheme from July – December 2018 was presented.

It was reported that no statistically significant conclusion could be drawn due to small numbers when analysing increasing/decreasing transplant/mortality numbers. The group recommended that removals due to deteriorating condition should be combined with deaths on the list in future and waiting time should be analysed separately for adults and paediatrics.

M Jones

It was noted that patients can currently accrue time whilst suspended on the waiting list without any time limit, whereas in other allocation schemes there is a time limit to this. Centres were in agreement with a one month suspension limit for patients on the NBAS. NHSBT will implement this.

**M Jones/
J Newby**

It is important that patients who die whilst waiting on the list are reported to NHSBT.

**Transplant
Centres**

8 GROUP 2 BOWEL TRANSPLANTS

- 8.1 There were no new cases of Group 2 bowel transplants undertaken. There is currently a patient listed at Kings.

9 POTENTIAL BOWEL DONORS <30KG CONSENT – MCTAG(19)6

- 9.1 Out of the nine potential bowel donors weighing less than 30kg identified in the period 2017/18, consent for multi-visceral/bowel donation was given in six cases, two families declined: one initially wished to consent to heart donation only, and the other was not approached (in the North West region and an exclusion was ticked on the consent form).

In all nine cases, consent for other abdominal organs (liver and kidneys) was given.

It was noted that the design of the new consent form is not conducive to donation. It is current practice to go through the whole list of organs individually, rather than asking if the family wish to consent to all

organs. M Hackett commented that the discussion is tailored to the individual family, but eventually a decision has to be made for each organ.

There was discussion regarding the launch of the paediatric donation strategy with eight outcome measures and action plans. Data from the ODT website (e.g. the number of paediatric donors nationally) was used for the national strategy. It was noted that paediatrics are missing in the referral pathway in the national strategy. S Hill requested that there should be an update at the next meeting in October on paediatric donation initiatives. Contacts to assist in this area are Reinout Mildner (Birmingham) and Angie Scales, NHSBT.

M Hackett

10 REASONS FOR DECLINING SMALL BOWEL OFFERS

- MCTAG(19)7

- 10.1 Commonly recorded reasons for declining a bowel offer have been drawn up, including those recorded in free text. Members were asked to review the list of reasons presented and suggest others that might be included in the drop-down box to be used by ODT Hub Operations. Hub Operations currently record two reasons for decline: it was acknowledged that there is often a combination of reasons for decline, and that these should be recorded, but clarity would be enhanced if the reasons could be specified as closely as possible. It was highlighted that there is currently no record of CIT, and it was agreed that this should be recorded, as should DSA. The timing of donation should also be recorded as a logistical reason. These recommendations will be fed back to IT.

M Jones

11 PATIENT SURVIVAL AFTER INTESTINAL TRANSPLANTATION (5 YEAR DATA BY TRANSPLANT TYPE) - MCTAG(19)8

- 11.1 For the period 1 January 2003 to 31 December 2018, 219 elective intestinal transplants were undertaken in first time recipients. Analysis of data is therefore based on small numbers and is not risk adjusted. There is little difference between survival between adults and paediatrics. There is no evidence that short-term outcomes have improved with time in relation to either paediatric or adult survival.

Bowel only transplants are shown to have better outcomes compared with multi-visceral i.e. liver, bowel and pancreas transplants. Future analysis might consider the optimum timing of transplantation and a re-examination of the criteria. Resolution of the HIFNET proposal and education of referring units will have a role in improving outcomes. It was agreed that BAPEN would be an appropriate forum in which to engage with clinicians caring for patients with intestinal failure. It was highlighted that the criteria for referral are different to the criteria for transplant. P Allan to draw up referral criteria for intestinal transplantation, assisted by G Gupte.

P Allan/
G Gupte

12 REVIEW OF INTESTINAL FAILURE DIAGNOSES COLLECTED BY NHSBT - MCTAG(19)9

- 12.1 It was commented that the term 'pseudo obstruction' occurs commonly, but is not listed within the intestinal failure diagnosis codes. This is covered by the document on UK intestinal data collected for the ITR, under minute (5). It was agreed that L Sharkey would lead on agreeing a list of diagnoses, and that this should marry up with the ITR for adults and paediatrics. Statistics colleagues to send free-text to L Sharkey.

L Sharkey

M Jones

13 SMALL BOWEL TRANSPLANT COMMISSIONING CHANGES

- 13.1 Long term follow-up care is not included under NHSE Highly Specialised Commissioning and the costs of post-12 month delivered by the transplant centres are currently being recovered via other specialist commissioning routes. The current clinical policy holders are not the budget holders. A Ali to confirm if long term follow up care costs can be reimbursed elsewhere in Commissioning.

A Ali

It was confirmed that transplant centres should be reimbursed for the cost of post-12 month care from NHS Clinical Commissioning Groups (CCG), as patients are financially their responsibility at this point. Birmingham stated that this is not happening. K Sharif to give specific details to A Ali.

K Sharif

It was commented that the section on funding for life care has been removed from the 'Adolescent transition in small bowel transplantation' document when it was last reviewed with NHS England in 2016.

14 POST 1 YEAR LOCAL INVOLVEMENT FOLLOWING INTESTINAL TRANSPLANTS

- 14.1 Although transplant centres are retaining long-term responsibility for the overall management of intestinal transplant patients, it was highlighted that there should be involvement by the local centre after one year.

15 UPDATE FROM THE WORKING GROUPS**15.1 Quality of Life Working Group: data collection****15.1.1 Adults**

Owing to the lack of junior support in the work, unfortunately there is no progress to report.

15.1.2 Paediatrics

The amount of work and expertise required for the national project has been discussed and the aim is now to identify someone to work on this full time, rather than an ad hoc basis, to move it forward. S Kay is happy to share their expertise from the area of composite tissue.

15.2 Update from the Working Group on NHSBT data and post-operative data collection – MCTAG(19)10

- 15.2.1 Refer to minute (5).

15.3 Update from the Working Group on a patient information and consent document for intestinal transplantation – (MCTAG(19)11 – amended to verbal report)

15.3.1 The patient information and consent document is part of a national initiative. The Information Sheet has been generated, circulated and changes made. Of all the organ groups, bowel transplant information is the most comprehensive. The objective remains that all four transplant centres will have one uniform consent form to avoid disparity in the information given to patients depending on the centre.

16 UPDATE ON ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION

16.1 Cambridge has started a patient transitional care programme with the Birmingham transplant centre. Patients are given a choice of where they wish their care to be located. To-date Oxford has had seven patients transitioned to them. King's transitional care programme was also confirmed to be in progress.

17 APPEALS/PRIORITY

17.1 There were no appeals reported regarding bowel intestinal transplantation.

18 UPDATE ON NASIT

18.1 Adults

18.1.1 Six meetings have been held within the last year looking at 48 cases with a broad distribution of organs considered. Face-to-face meetings have some advantages compared to conference call meetings, but clearly incur considerable logistic implications. The next step is to decide on the best format for engagement of the different centres on a monthly basis. One solution is to have a face to face meeting at the NHSBT office in Birmingham. P Phil to let K Huang know the date of the next meeting to check if the NHSBT office is free. J Hind and C Bambridge are invited to attend.

**P Allan/
K Huang**

18.2 Paediatrics

18.2.1 It was reported that paediatric intestinal failure surgery is not nationally-commissioned. It would be beneficial to see the outcome of HIFNET for adults first before assessing paediatrics. K Sharif to advise the direct point of contact for MCTAG to write as a body for intestinal failure in children.

K Sharif

Post meeting note - HIFNET Update

A Ali provided the following statement from NHSE about IF procurement.

NHSE Specialised Commissioning Oversight Committee (SCOG) considered the revised IF proposal following Public Consultation and agreed the proposal was approved to move to the Procurement phase. However, because there were some changes to the Lotting Strategy (criteria for selecting a service) it was agreed a further review with each Regional Team would be undertaken to confirm the

detail. This will be completed within March. A revised timeline will be issued once the Invitation for the tender date is confirmed.

19 ANY OTHER BUSINESS

19.1 Case for discussion – if the abdominal wall is deemed un-transplantable by Oxford can it be offered by fast track to other intestinal transplant centres? MCTAG(19)15

19.1.1 MCTAG agreed that as the abdominal wall is an organ it is reasonable for it to be offered by fast track before offering this for research.

19.2 MCTAG representation at LAG on 8th May 2019

19.2.1 A Butler confirmed his attendance at LAG in May, as P Friend's deputy.

19.3 S Kay agreed to give an update on limb transplantation at the next meeting in October. There is evidence of increasing demand for this type of transplant. To-date there have been 10 transplants undertaken on 6 patients and all six patients have survived.

S Kay

Transplantation of the uterus will come under the remit of MCTAG. The first living uterus transplant is planned; the programme involves a collaboration between Oxford and London (Imperial College). The deceased donor uterus transplant programme is also planned and will follow shortly.

19.4 Birmingham will be hosting the next Annual Intestinal Forum. G Gupte requested feedback from the last meeting in order to set the agenda for the next meeting. It was confirmed that a brief report on topics discussed and feedback will be provided at the end of these meetings. The intention is to hold the Forum in the same month annually.

20 DATE OF NEXT MEETING:

- Wednesday 16 October 2019 – Grange White Hall Hotel, London.

21 FOR INFORMATION ONLY:

Papers attached for information were:

21.1 ICT Progress Report – February 2019 – MCTAG(19)12

21.2 Transplant activity report for January 2019 – MCTAG(19)13

21.3 Minutes of LAG meeting: 21 November 2018 – MCTAG(19)14

Organ Donation and Transplantation Directorate

March 2019

Administrative Lead: Kamann Huang