

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

**THE EIGHTEENTH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE  
ADVISORY GROUP MEETING**

**AT 11:30 AM ON WEDNESDAY 24 OCTOBER 2018,  
ROOM 5, RADISSON BLU EDWARDIAN HAMPSHIRE HOTEL,  
31-36 LEICESTER SQUARE, LONDON, WC2H 7LH**

**PRESENT:**

Prof Peter Friend	<b>Chairman</b> (and Rep for National Retrieval and Liver)
Dr Philip Allan	Oxford Intestinal Transplant Centre
Ms Carly Bambridge	Recipient Co-ordinator Representative
Dr Martin Barnardo	BSHI Rep
Prof John Forsythe	Associate Medical Director, NHSBT
Ms Monica Hackett	Deputy for Ms Susan Richards – Organ Donation Representative
Dr Jane Hartley	Deputy for Dr Girish Gupte, Birmingham Intestinal Transplant Centre
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Ms Rachel Hogg	Statistics & Clinical Studies, NHSBT
Mr Craig Jones	Lay Member
Prof Elizabeth Murphy	Lay Member
Ms Sally Rushton	Statistics & Clinical Studies, NHSBT
Dr Lisa Sharkey	Deputy for Mr Andrew Butler, Cambridge Intestinal Transplant Centre
Mr Hector Vilca-Melendez	King's Intestinal Transplant Centre
Dr Georgios Vrakas	Deputy for Mr Srikanth Reddy, Oxford Transplant
Ms Sarah Watson	NHS England

**IN ATTENDANCE:**

Mrs Kamann Huang Secretary, ODT

**ACTION**

**Apologies were received from:**

Mr Andrew Butler, Ms Samantha Duncan, Prof Sue Fuggle, Dr Simon Gabe, Mr Henk Giele, Dr Girish Gupte, Mr Michael Gumn, Dr Jonathan Hind, Ms Heather Howe, Prof Simon Kay, Ms Jacqueline Newby, Ms Susan Richards, Mr Khalid Sharif, Mr Mick Stokes and Ms Jacki Newby.

**1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA  
- MCTAG(18)16**

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

## 2 MINUTES OF THE MCTAG MEETING ON 21 MARCH 2018 - MCTAG(M)(18)1

### 2.1 Accuracy

2.1.1 The minutes of the meeting held on 21 March 2018 were agreed as an accurate record.

### 2.2 Action Points – MCTAG(AP)(18)2

2.2.1 **AP1** Analysis not required on intestinal policy and the impact on liver  
L Sharkey reported on behalf of A Butler that Addenbrooke's still have a highly sensitised patient with a small donor cavity on their waiting list after 3 years. The numbers involved in these cases are very small. MCTAG agreed that in future similar cases will be dealt with on a case by case basis rather than make a special request to LAG to change the rules.

**AP2** The issue of approaching France and Euro-Transplant to look at how suitable donors might be referred is still outstanding.

**AP7** Working Group on NHSBT data and post-operative data collection

The proposal for common ways of reporting rejection and classification to represent paediatrics as well in the process for monitoring liver patients at 3 months and 1 year post transplant has been circulated by G Vrakas.

**AP9** Update on dates for NASIT Paediatric Group

No update was available in the absence of S Gabe and J Hind.

### 2.3 Matters arising, not separately identified

2.3.1 Dr Douglas Thorburn has been appointed the new Chair of the Liver Advisory Group effective 1<sup>st</sup> December 2018.

## 3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

### 3.1 Developments in NHSBT

J Forsythe gave an update on Organ Donation Opt Out. It will be a private Members Bill with the amalgam of two forms. The second reading is going through on Friday 26<sup>th</sup> October 2018, which will move forward quickly in the absence of any significant amendments. In Scotland the Bill is going through a financial review. The Isle of Man and Guernsey will be having their own Bill. If it passes, it is anticipated the Bill in England will be adopted in 2020. The Bill proposes a 'soft' opt-out, for which the approval of the family will still be sought.

NHSBT predict that the legislation will increase donors by between - 20 and 230 donors per year, leading to 700 transplants per year quoted by the media. This will require additional resources and infrastructure.

The question of whether the new legislation will change the current lack of diverse organs from ethnic communities was raised.

NHSBT is working with various faith communities on this issue and a toolkit for BAME communities is being launched.

The Organ Donation Register on-line will in future list 'Ethnic/Faith Organ Donation' which when clicked will link to another page to choose from the different religions and to download a card which is faith specific.

Organ retrieval teams are looking at increasing retrieval capacity by improving the way they are mobilised to reduce time spent traversing the country. ODT has written to part-time Organ Retrieval teams asking if their capacity could be increased.

A meeting on 'Patient Consent and Risk' was held in September 2018 working with the Winton Centre in Cambridge. This looked at areas such as relaying complex issues to the public and communicating consistent core transplant information to all patients regardless of where they are treated.

Two other meetings, one on 'Preservation and Perfusion' will be held on 31 October 2018 and the second is a 'Sustainability Project' meeting following the Sustainability Summit held in June earlier in the year.

Following work undertaken with the involvement of Commissioners, a Kidney and Pancreas Regional Review will be held in London. Should this prove successful further regional meetings will be held e.g. NW England and Liverpool.

NHS England will be holding a review of liver transplant services in November 2018.

## 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(18)17

3.2.2.1 A report submitted by J Dark noted one incident where there was confusion as to whether the forearm sentinel skin flap taken from a multi-organ donor was to support transplantation or research. Investigation found that the sentinel skin flap is retrieved as a matter of routine to support transplantation and is not for research.

P Friend to write to Olive McGowan to inform Donation teams that sentinel skin and abdominal wall/fascia may be requested for intestinal transplants and this should be stated at the time of donation.

**P Friend**

H Vilca-Melendez to 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.

**H Vilca-Melendez**

## 4 ODT HUB UPDATE – HTA DIGITAL FORMS

### 4.1

J Newby was unavailable to attend but submitted a paper. The HTA A & B forms will be replaced with a digital version. There has been a delay to the HTA A form but the plan is to make it form part of the

SNOD data collection process; co-operation is needed of SNODs, OPP and surgeons entering data onto the form.

The HTA B form will be available to kidney and pancreas transplant centres from December 2018.

## 5 TRANSFER OF UK INTESTINAL DATA TO THE INTERNATIONAL INTESTINAL TRANSPLANT REGISTRY (ITR)

5.1 S Rushton reported that there has been little progress. The logistics of transferring data safely and securely needs to be discussed with NHSBT Information Governance. The view is that our data should go centrally to a secure location and then be transferred. The data sent out will be anonymised.

S Rushton to move this forward with Information Governance. UCLA is now managing the ITR. It was agreed that an update is required. G Vrakas and J Hind have agreed to assist the process.

**S Rushton/  
G Vrakas/  
J Hind**

## 6 STATISTICS & CLINICAL STUDIES REPORT

### 6.1 Summary from Statistics and Clinical Studies – MCTAG(18)18

A summary update from the report is given below:

- The 'Organ Donation and Transplantation Annual Activity Report for 2017/18 is now available on the ODT Clinical Website: [www.odt.nhs.uk](http://www.odt.nhs.uk)
- E Allen will be returning from maternity leave next Spring.
- There is an IT project within ODT to facilitate formal recording of novel grafts onto the UK Transplant Registry (will include hand, arm and uterus) which is currently undertaken on an ad hoc basis.
- Two clinical fellows have been employed to work with NHSBT on organ utilisation and malignancy in transplantation. Recruitment will also begin for a new CTAG clinical fellow based in Newcastle.

L Sharkey requested two changes in the Annual Report:

- Improved recording of patients on the waiting list i.e. to record patients joining the list within a year, and
- in Table 5.1 to change the word 'malignancy' to 'tumours'.

**S Rushton**

**S Rushton**

## 7 NATIONAL BOWEL ALLOCATION

### 7.1 Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(18)19

A paper giving an update on the NBAS was presented.

Table 1 – Amend heading to include the words 23 patients - 'Details of the 24 intestinal transplant registrations for 23 patients which were active on the elective intestinal transplant list at any time between 1 January 2018 and 30 June 2018'.

**R Hogg**

R Hogg to look at whether there was a significant difference between the numbers of deaths on the list between the two periods.

**8 GROUP 2 BOWEL TRANSPLANTS**

8.1 There were no new cases of Group 2 bowel transplants undertaken.

**9 POTENTIAL BOWEL DONORS AND LOCATION – MCTAG(18)20**

9.1 Key points from the paper presented by S Rushton are:

- Potential DBD donors for bowel donation < 56 years and < 80 kg increased by 11% meeting from 2015/16 to 2017/18. The conversion from offered to transplanted was higher in 2017/18 than in previous years, though the consent rate was highest during 2016/17.
- Of the 152 bowels offered and declined, only 9 were from donors weighing < 50 kg. Of the 281 donors meeting bowel donor criteria, 9 weighed < 30 kg. Six of these had consent for donation resulting in 5 transplants.
- The most common reason for bowel donors meeting criteria during 2017/18 but not offered was 'no suitable recipient'.
- The highest bowel utilisation rate is in patients under 16 years.
- There were 7 overseas bowel offers to the UK in 2017/18 with one leading to transplant. Three declined owing to recipients requiring additional organs; two were declined on logistics; one had no response to a fast track offer.

Members asked if all donors in Table 2 met criteria then why were several donors not offered due to age or size? S Rushton to report back.

**S Rushton**

The question was raised of whether the family decline rate for intestines was higher than for other organs. M Hackett to find out how consent was sought for the 8 donors. S Rushton to provide M Hackett with the donor numbers.

**M Hackett/  
S Rushton**

S Rushton to look at the ratio of bowel to liver offers in relation to SNOD regions.

**S Rushton**

**10 UPDATE FROM THE WORKING GROUPS****10.1 Quality of Life Working Group: data collection****10.1.1 Adults – MCTAG(18)21**

P Allan reported that work with D Massey on key metrics to be collected through NHSBT has started. Progress has been hampered by the absence of junior staff to help data collection.

P Friend acknowledged that taking a generic development tool and turning it into a specific metric for intestinal transplant was a major task. It was commented that there was a team in Oxford looking to undertake this as a 3 year research project with the aim of using questionnaires to establish how this translates into a robust metric. It is unclear if NHSBT will support funding for this.

10.1.2 **Paediatrics - MCTAG(18)22**

C Bambridge reported that the FTWU data collection using the PEDs QL will be a big project requiring expertise. The aim of the FTWU is not to come up with a solution but to start making initial exploration of metrics. The plan is to meet in the next couple of weeks for a report to be given in January.

P Friend proposed that the next step is to take the work forward as a proper national project requiring funding and to include expertise for data collection for both adults and paediatrics. This will require engagement with QoL experts.

10.2 **Update from the Working Group on NHSBT data and post-operative data collection – MCTAG(18)23**

10.2.1 G Vrakas presented a paper on NHSBT data and post-operative data collection.

Feedback to be incorporated from members are:

- Look at immunology data;
- Differentiate between diagnosis and indications for transplantation.

H Vilca-Melendez will write to G Vrakas regarding additional information and follow up data required and copy C Bambridge. G Vrakas to continue the work with A Butler, H Vilca-Melendez and Jane Hartley from Birmingham.

H Vilca-Melendez

S Rushton was asked if it was feasible for NHSBT to collect the detail of data required centrally by NHSBT. This was possible provided the data is filled in by the transplant co-ordinators, which will require unified reporting.

10.3 **Update from the Working Group on a patient information and consent document for intestinal transplantation – MCTAG(18)24**

10.3.1 In the absence of A Butler, L Sharkey was asked to feed back to A Butler for a report to be given in six months' time.

C Bambridge is the paediatric representative.

11 **UPDATE ON ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION**

11.1 In the absence of S Watson, the following feedback was given from centres:

- Birmingham Centre: There was a backlog with transitioning of adolescents. The average age being seen are 16-18 years of age. J Hartley reported good pathways have been set up and most of the patients have gone over to Oxford.
- Cambridge Centre: L Sharkey reported their formal pathway has now been approved by their Trust.
- King's College: C Bambridge reported there were 4 or 5 patients registered for pre-transition to Birmingham. Another joint clinic is being planned with focus on pre-transition patients in preparation for Cambridge. It was highlighted that the key is knowing the patient and family well and it was acknowledged that a young

patient can change their mind regarding transition at the last minute.

## 12 APPEALS/PRIORITY

- 12.1 There were no appeals reported regarding bowel intestinal transplantation.

## 13 FEEDBACK ON ADOLESCENT AND PAEDIATRIC SERVICE SPECIFICATION

- 13.1 In the absence of S Watson, P Friend reported that MCTAG are happy with the final specification and thanked members' input to it.

## 14 UPDATE ON NASIT

### 14.1 Adults

- 14.1.1 L Sharkey reported that the main current issue is to establish the format (e.g. teleconference or face to face meetings) and available resource for minute taking. P Friend noted that although teleconferences do not provide as much clarity as a face to face meeting, the logistical advantages are substantial. Possible central venues for face-to-face meetings could be NHSBT offices in London or Birmingham. Minute taking is unlikely to be provided by NHSBT as it is not an NHSBT issue.

Following discussion, it was agreed to set up monthly teleconferences (or video conferencing) with face to face meetings held less frequently. K Huang to liaise with P Allan regarding date and venue for the next NASIT meeting.

Regarding the need for more frequent meetings, the issue of the 18-week pathway (time form referral to listing) may become an issue. This has been addressed in the context of pancreas transplantation.

### 14.2 Paediatrics

- 14.2.1 In the absence of J Hind, there was no further progress to report from the Paediatrics Group.

## 15 CONSENT FOR THE USE OF PATIENT INFORMATION AND GENERAL DATA PROTECTION REGULATIONS (GDPR)

– MCTAG(18)25

- 15.1 In the absence of M Gumn, a summary of his paper is given below.

ODT carried out a review of the existing consent scheme and it was felt that it could not satisfy the new higher standard for consent around GDPR.

The decision has been taken to process patient data under section 6(1)e of the GDPR.

The information has been published in a booklet in several formats and languages

The consent scheme should have very little impact on transplant centre teams or local processes. However, if there are any questions or queries to use the contact numbers and email address given.

K Huang/  
P Allan

**16 SIMULATION FOR ADULT PATIENTS WEIGHING MORE THAN 35 KG WITH RESTRICTED ABDOMINAL CAVITY – RECTUS SHEAF OR SPLITTING COMPOSITE GRAFT**

15.1 As minuted under 2.2 Action Points - AP1, this will be reviewed on a case by case basis.

**17 ANY OTHER BUSINESS**

17.1 Viability of future meetings to be held in Birmingham.  
Following discussion, the consensus was for future MCTAG meetings to be held in London as this is more accessible to the majority of attendees.

17.2 HIFNET Consultation

P Allan reported that this was at public consultation until Monday 29<sup>th</sup> October 2018. This is a delay of three months. A contract should be in place in January.

The importance of resolving the HIFNET consultation was agreed, as the need for access to IF services equitably across the country is fundamental to the establishment of an effective national intestinal transplant service. Members agreed for P Friend to write on behalf of MCTAG, with support from P Allan.

**P Friend/  
P Allan**

17.3 CIRTA – 3<sup>rd</sup> – 6<sup>th</sup> July 2019, Paris

H Vilca-Melendez asked what the status was regarding the UK presentation at this event and asked S Rushton if NHSBT can assist in putting together a presentation on intestinal transplantation based on 5 years data.

**S Rushton/  
H Vilca-Melendez**

17.4 S Hill proposed showing the agenda and meeting papers on a screen at future meetings. She will undertake the operation of it at the meetings.

**S Hill**

**18 DATE OF NEXT MEETINGS:**

- Wednesday 13 March 2019 – London.
- Wednesday 16 October 2019 – London.

It was reported that 13 March 2019 is the date of the next NASIT meeting. L Sharkey will look to change the date for NASIT rather than changing the date for MCTAG.

**L Sharkey**

Post Meeting Note:

G Vrakas confirmed the date for NASIT will be Wednesday 20<sup>th</sup> March 2019.

**19 FOR INFORMATION ONLY:**

Papers attached for information were:

19.1 Transplant activity report for September 2018 – **MCTAG(18)26**

19.2 Minutes of LAG meeting: 2 May 2018 – **MCTAG(18)27**



19.3 New Appointments

- Sally Johnson, Director of Organ Donation and Transplantation (ODT), will become interim Chief Executive when Ian Trenholm leaves at the end of July.
- Anthony Clarkson, Assistant Director for Organ Donation and Nursing, will become interim Director of ODT.
- Ms Caroline Robinson replaces Kathy Zalewska (1 year secondment as Board Secretary) effective 13 August 2018.

**Organ Donation and Transplantation Directorate**

**October 2018**

**Administrative Lead: Kamann Huang**

To be ratified