NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

THE SIXTEENTH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE ADVISORY GROUP (FORMERLY BAG) MEETING AT 11:30 AM ON WEDNESDAY 11 OCTOBER 2017, CONFERENCE ROOM, MEDICAL SOCIETY OF LONDON, LETTSOM HOUSE, 11 CHANDOS STREET, MARYLEBONE, LONDON, W1G 9EB

PRESENT:

Prof Peter Friend	**Chairman** (and Rep for National Retrieval and Liver)
Dr Philip Allan	Deputy for Dr Simon Travis, Oxford Intestinal Transplant Centre
Dr Elisa Allen	Statistics & Clinical Studies, NHSBT
Prof Sue Fuggle	Scientific Advisor, ODT
Dr Simon Gabe	Adult and small bowel and BAPEN Rep
Mr Michael Gumn	Head of Information Services, NHSBT
Dr Girish Gupte	Birmingham Intestinal Transplant Centre
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Prof Simon Kay	HAUL VCA Rep
Prof Elizabeth Murphy	Lay Member
Mr Srikanth Reddy	Oxford Transplant Centre
Dr Lisa Sharkey	Deputy for Dr Steve Middleton, Cambridge Intestinal Transplant Centre
Mr Khalid Sharif	Birmingham Intestinal Transplant Centre
Mr Hector Vilca-Melendez	King's Intestinal Transplant Centre
Ms Sarah Watson	NHS England

IN ATTENDANCE:

Mrs Kamann Huang	Secretary, ODT

ACTION

Welcome:
MCTAG welcomed Prof Simon Kay to his first meeting as the representative for hand/limb transplants.

Apologies were received from:
Ms Carly Bambridge, Dr Martin Barnardo, Mr Andrew Butler, Prof John Dark, Ms Victoria Gauden, Mr Henk Giele, Ms Lydia Holdaway, Ms Melissa D'Mello, Prof John Forsythe, Ms Jacqueline Newby, Ms Susan Richards, Mr Mick Stokes and Prof Simon Travis.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA - MCTAG(17)17

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

ACTION

2 MINUTES OF THE MCTAG MEETING ON 15 MARCH 2017 - MCTAG(M)(17)1

2.1 Accuracy

2.1.1 The minutes of the meeting held on 15 March 2017 were agreed as an accurate record following the amendment below:

Page 7, section 14.1, second paragraph, second line '*for discussing patients following transplantation*' to be amended to '***for discussing patients prior to transplantation'***.

2.2 Action Points – MCTAG(AP)(17)1

2.2.1 All action points have been completed or are listed as agenda items. An update is given below for those with a verbal update or are In Hand.

AP1 - Recipient Co-ordinators for informing ODT Hub Operations (Duty Office) within 72 hours of what organs have been transplanted

- Ann Turner was confirmed to the Birmingham rep.
- Carly Bambridge - King's College
- Jackie Green - Cambridge
- Lydia Holdaway – Oxford

All centres are aware that in the event of absence or annual leave, a second person must be nominated to contact ODT Hub Operations (Duty Office) within 72 hours of transplantation.

Offers outside the acceptance criteria
NHSBT have recoded the National Bowel Allocation Scheme (NBAS) to permit the maximum donor weight, specified for each patient at registration, to be used by the NBAS when selecting the patients to offer to. Centre Reps to communicate this to their centres. **Centre Reps**

AP2 – The first teleconference (J Forsythe, P Friend and R Ploeg) has been held to examine timings to reduce the UK CIT time. Current analysis being undertaken by J Forsythe will start giving more correct time points.

AP3 – The change in Intestinal Policy to allow adult intestinal patients with contracted abdominal cavity and weighing more than 35 kg to be treated as paediatrics for matching run purposes will be raised at the next Liver Advisory Group (LAG) meeting. **E Allen**
Simulations, undertaken by NHSBT Statistics, to examine potential disadvantages on liver patients found that two liver recipients could have potentially been disadvantaged. Historic records of organ offering processes were used to ascertain the impact on liver patients if this type of intestinal recipients were treated as paediatrics at the point of offering. E Allen will provide a report at the next LAG meeting in November. **E Allen**

AP7 – Further analysis of 90-day outcomes will be presented at the next meeting in March.

AP10 – NASIT Forum. Refer to Agenda Item 15.

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 – MCTAG(17)18a & 18b**

J Forsythe submitted a paper in his absence. NHSBT are currently looking in depth at reasons why organs are declined. Offering and waiting times are also being reviewed for improvements to reduce the delay in the donation/retrieval process.

A letter has been sent by J Forsythe to the Transplant Community on 29 September 2017 regarding the commencement of donor testing for Hepatitis E (HEV).

3.2 **Governance**

3.2.1 **Non-compliance with allocation**

3.2.1.1 There were no non-compliances reported with allocation.

3.2.2 **Detailed analysis of incidents for review – MCTAG(17)19**

3.2.2.1 J Dark submitted a paper to members in his absence.

4 STATISTICS & CLINICAL STUDIES REPORT

4.1 **Summary from Statistics and Clinical Studies – MCTAG(17)20**

The latest Organ Donation and Transplantation Annual Activity Report, showing activity for all solid organs for 2016/17, was published in July 2017 and can be accessed on the ODT website. A report outlining specific organs, trends and centre specific activity has also been sent to NHS England.

Nothing significant was found regarding geographical variability in registration and transplant rates in the report on specific organs.

E Allen stated that all transplant centres should have received a letter explaining the schedule for HLA donor antibody data collection. No data have been received by Statistics and Clinical Studies as of 10 October 2017.

5 NATIONAL BOWEL ALLOCATION

5.1 **Performance report of the National Bowel Allocation Scheme – MCTAG(17)21**

Points of discussion raised from the paper presented:

Table 1– patient number 6 with no data provided. King's College performed their first live donor liver and bowel transplant earlier this year. H Vilca-Melendez reported that both patients are doing well though this type of transplant is rare and aother one is not imminently planned.

Patient number 11. E Allen outlined a case at Addenbrooke's regarding a patient registered for a multi-visceral transplant but ultimately receiving a liver only transplant. The question was asked whether this patient should have been removed from the intestinal

ACTION

list and re-registered as a liver patient; a pancreas was not registered and required a fast track pancreas. Only the liver was transplanted into the second patient and the bowel returned to the donor. L Sharkey clarified that this case required a decision on the organs required at the time of transplant and the Group agreed that this was reasonable. The Group also agreed that the patient should be re-registered as a liver patient so that the right follow up forms are issued. E Allen will liaise with ODT Hub Information Services. **E Allen**
L Sharkey will liaise with the Recipient Co-ordinator to feedback to NHSBT if any other organs were transplanted. **L Sharkey**

G Gupte informed members of the death of two children while waiting for an intestinal transplant. There is a need to get as many donors as possible to consent for paediatric transplantation. Ireland do not have consent for intestinal transplant. In England, offers of intestinal organs do occur but on an ad hoc basis.
E Allen to include Dublin in the report and for LAG to show data evidence on small bowel donors from Ireland and circulate it to MCTAG. **E Allen**

6 GROUP 2 TRANSPLANTS – MCTAG(17)22

6.1 Summary of points from the paper presented by E Allen:

- Table 2 – Group 2 recipients who have received bowel only transplants. From the information obtained there is generally no evidence of Group 1 patients missing out on an offer except for patient number 3 (an error that was addressed at the time it was identified).

- Group 1 non UK resident recipients. There were 5 recipients in this category; 3 paediatric and 2 adults.

E Allen to continue including Group 1 non-UK recipients in this report. **E Allen**

7 UPDATE FROM WORKING GROUPS

7.1 Update from the Quality of Life Working Group

7.1.1 Working Group Members: D Massey and P Allan for Adults and C Bambridge for Paediatrics.

P Allan reported that EQ5D has been agreed as a tool to be used by NHSBT nationally.

A UK Transplant Registry – Intestine Transplant Recipient – Quality of Life form, which can be submitted electronically, was presented to members. S Gabe recommended including HIFNET – quality of life data. J Hind stated that a separate form was required for Paediatrics. G Gupte to check with C Bambridge on this. **G Gupte**

Other feedback from members were:

S Kay commented that there is a lot of experience in quality of life measurements in the area of reconstructive surgery and that this

ACTION

might be relevant. P Allan to liaise with S Kay on the data collection for monitoring hand/limb transplants. **P Allan/ S Travis**

7.1.2 **Adult Quality of Life data collection - prototype form – MCTAG(17)23**

At the moment there is no platform to store the data centrally other than on Excel. In the short term the suggestion is for the individual transplant centres to undertake their own data collection. In the long term the recommendation is for Information Services to collect the data and request a modification for the NHSBT system to store the data. P Allan to lead on the communication front with Maggie Bellew (proposed by S Kay) and D Massey regarding the refinements to the data required. **P Allan/ S Travis**

7.1.3 **Paediatric Quality of Life Inventory**

In the absence of C Bambridge, J Hind outlined a paediatric QoL tool for discussion. The proposal was to provide questionnaires for ages 2 – 18 years and measure health related QoL factors to include those with acute or chronic health problems. This is a well validated tool covering all age ranges including parents and can therefore be used throughout the child's life span and provides consistency. There is also a transplant focused version of this tool. C Bambridge is happy to provide details of this at the next meeting in March and it could be something that can be adapted for intestinal transplantation.

The second tools are more age and gender specific e.g. the GCO Girl's Item Booklet. This will need further research before the meeting.

7.2 **Update from the Working Group on NHSBT data and post-operative data collection – MCTAG(17)24**

7.2.1 S Reddy will liaise with E Allen, A Butler/L Sharkey, G Gupte/ K Sharif and H Vilca-Melendez/J Hind within the next six weeks and will send a report to P Friend (copy to K Huang). **S Reddy**

7.3 **Update from the Working Group on a patient information and consent document for intestinal transplantation – MCTAG(17)25**

7.3.1 In the absence of A Butler, P Friend reported that the two draft documents, currently for adults, has been amended with the recommendations (the patient information document and the consent for intestinal transplantation to outline the same key criteria). A Butler to draw up the same two documents for paediatrics. **A Butler**

8 POTENTIAL BOWEL DONORS AND LOCATION – MCTAG(17)26

8.1 E Allen presented a paper on potential donors after brain death (DBD) for bowel donation.

S Hill asked whether there was a problem with consent for donation from teenagers, or find out the reason, as there is

ACTION

currently a long wait for paediatric transplants. E Allen to look at non-consented donors less than 30 kg and present at the next MCTAG meeting in March; their age, weight and reasons why they haven't been consented.. **E Allen**

9 UPDATE ON ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION

9.1 It was reported that as Cambridge do not accept patients for transitional care, Oxford have taken on some of these patients**.** Cambridge confirmed that they are now ready to accept transitional patients.

G Gupte believes there are currently five patients in clinic in Birmingham waiting for transition but he will check and confirm the information to S Watson. **G Gupte**

10 APPEALS/PRIORITY

10.1 There were no appeals reported regarding bowel intestinal transplantation.

11 UPDATE ON ADULT AND PAEDIATRIC SERVICE SPECIFICATION - MCTAG(17)27a & 27b

11.1 S Watson reported that the Adult Service Specification report has now been finalised.

G Gupte and J Hind are to confirm to S Watson that they are happy with the Paediatric Service Specification. As the Paediatric Service lacks the level of expertise, e.g. St Marks and Salford, available within the Adult Service, the Specification needs to detail what is undertaken, the process and provide a forum e.g. NASIT and local MDT to discuss cases prior to transplantation. S Watson requested feedback by Wednesday 25 October 2017. **G Gupte/ J Hind**

S Watson to circulate the QOL indicators for paediatrics to J Hind and G Gupte for comment asap. **S Watson**

It was reported that the Peer Review team queried the anaesthetic support, experience, and the critical care support. J Hind stated that paediatrics require a paediatric intensivist and possibly a paediatric endocrinologist. Clarity also needs to be given for paediatric multi-visceral patients.

12 HAND/ARM TRANSPLANTATION – MCTAG(17)28

12.1 S Kay presented to MCTAG for the first time on hand/arm transplantation. Summary points were:

- All patients are screened for a year. Psychological assessment is a main area where patients are lost for transplantation and managing psychological rejection for hand/arm transplants forms the largest part of the programme. Great emphasis is placed on how limbs look to match the other limb. A great deal of assistance has been provided by NHS England and NHSBT.

- It is not necessary to have lost a limb for undertaking hand transplantation. Above the elbow transplants are very difficult. Protocols are constantly being updated.
- Although hand/arm transplants are not considered life threatening, this type of transplant is life changing. Prosthetics are said to be cheap but some people do not want them.
- A huge demand for hand/arm transplants has started to be seen. The next controversial step is whether to extend this type of transplant to children.
- There is a reluctance amongst SNODS to ask for hand/arm donation.
- One of the challenges in the year ahead is to free up the referral process. There are currently two patients waiting, and we expect there to be 6 patients by next August. Donation is currently limited to the north of England due to ischaemic time.

13 COMBINED INTESTINAL AND PANCREATIC RETRIEVAL

13.1 It was agreed that intestinal retrieval will be permitted to have the full length of the superior mesenteric vessels. This will not prevent the pancreas being referred for islets rather than solid organ if required. The number of pancreas involved in combined intestinal and pancreatic retrieval is small and is considered to be a reasonable compromise.

14 INCONSISTENT USE OF HTA A FORMS IN BOWEL TRANSPLANTS

14.1 In the absence of A Butler, he is yet to update MCTAG on his communication with the HTA. **A Butler**

15 NASIT

15.1 L Sharkey raised an issue that having an MDT (multi-disciplinary team meeting) with no formal governance would pose huge problems for responsibility for outcomes i.e. would responsibility fall under NASIT or the clinician in charge of the patient? The other issue is NASIT currently provides an advisory role for adults only. Should paediatrics be managed in the same way? Members were asked the question if they would be happy to stand by a decision made by NASIT i.e. what is the liability for the Trust for a decision made by NASIT? Should the responsibility be taken to a higher level i.e. NHS England? Following discussion members agreed that NASIT should act in an advisory capacity/make recommendations. Patients should be discussed with recommendations to be documented and formalised under NASIT. As NASIT has no formal secretariat, the proposal is for some form of responsibility for someone on a secretarial level. S Gabe has made changes to the NASIT Terms of Reference and will discuss these issues at the next meeting on 1st November.

ACTION

S Gabe will send out guidelines following the meeting on 1st November. **S Gable**

The Paediatric Group will be represented at NASIT every two months by J Hind. **J Hind**

16 ABDOMINAL WALL TRANSPLANTATION

16.1 H Giele has undertaken 24 abdominal wall transplants with success. He will attend the next meeting in March to present to members.

Stand alone transplants e.g. uterus transplants may be available on the NHS in the future.

17 ANNUAL REPORT ON INTESTINAL TRANSPLANTATION – MCTAG(17)29

17.1 No additional feedback was given by members to include in the report.

18 ANY OTHER BUSINESS

18.1 **Intestinal Transplant Registry**

It was reported there are two issues regarding abdominal wall transplant registration. The first regarding traceability to ensure every composite can be traced between the recipient and donor and secondly, the process not being robust enough. Members would like MCTAG data to be changed to the NTxD system for intestinal transplants.

Following a report from M Gumn on the number of stomach and colon alone transplants. P Friend stated that he believes this to be a classification error owing to the number of separate forms that are required to be completed. M Gumn to trace the stomach and colon alone transplants back to the transplant centres. It was re-iterated that there is a requirement for a Co-Ordinator to let NHSBT Hub Operations know within 72 hours what organ(s) have been transplanted for a multi-visceral bloc transplant. **M Gumn**

M Gumn to raise with J Forsythe how to improve the efficiency of multiple form completion which still requires carbon copies and involve the intestinal transplant community. P Friend will also raise this at the next Chairs Advisory Group meeting on 5th December 2017. **M Gumn** **P Friend/ K Zalewska**

The UK is the second country with the highest number of intestinal transplant registrations. MCTAG agreed to NHSBT Statistics submitting UK intestinal transplant data to the international Intestinal Transplant Registry.

18.2 **Nomination of Deputy Chair**

G Gupte was nominated to be the Deputy Chair for MCTAG.

19 DATE OF NEXT MEETINGS:

- Wednesday 21st March 2018 – Medical Society of London
- Wednesday 17 October 2018 – West End Donor Centre, London

20 FOR INFORMATION ONLY:

Papers attached for information were:

- Transplant activity report for August 2017 – MCTAG(17)30

- Minutes of LAG meeting : 10 May 2017 – MCTAG(17)31

- Intestinal Patient Data Record Consent – MCTAG(17)32

NEW APPOINTMENTS

- Mike Gumn has been appointed permanently to the role of Head of Information Services - July 2017
- Nick Breeds appointed Assistant Director, Solutions Delivery – 24 July 2017.
- Christie Ash appointed Assistant Director, Performance and Business Development - starting early September.
- Mark Davis appointed as the Head of Development and Integration, ICT – starting mid September.

Organ Donation and Transplantation Directorate **October 2017**

Administrative Lead: Kamann Huang