NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE

THE TWENTY THIRD MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE ADVISORY GROUP MEETING AT 11:30 AM ON WEDNESDAY 17 MARCH 2021, VIA MS TEAMS VIDEO CONFERENCING

PRESENT:

Mr Andrew Butler	Chair
Dr Philip Allan	Oxford Intestinal Transplant Centre
Dr Elisa Allen	Statistics and Clinical Studies
Ms Carly Bambridge	Recipient Co-Ordinator Rep
Ms Kim Corbey	Recipient Co-Ordinator Rep
Ms Samantha Duncan	Recipient Co-Ordinator Rep
Prof Peter Friend	Oxford Intestinal Transplant Centre
Dr Simon Gabe	Adult small bowel and BAPEN Rep
Ms Monica Hackett	Organ Donation Rep
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's College Hospital
Ms Rachel Hogg	Statistics and Clinical Studies
Mr Craig Jones	Lay Member
Prof Derek Manas	National Clinical Lead
Prof Elizabeth Murphy	Lay Member
Ms Sarah Peacock	BSHI Rep
Dr Tracey Rees	Scientific Advisor
Mr Neil Russell	Cambridge Intestinal Transplant Centre
Dr Lisa Sharkey	Cambridge Intestinal Transplant Centre
Mr Hector Vilca-Melendez	King's Intestinal Transplant Centre
Ms Sarah Watson	NHS England
Ms Julie Whitney	ODT Hub Rep
Ms Phillipa Cahill	M&F Health (Guest)

IN ATTENDANCE:

Mrs Kamann Huang	Secretary, ODT

ACTION

Welcome
Ms Kim Corbey, Recipient Co-Ordinator, replacing Heather Howe.

Apologies were received from:
Mr Chris Callaghan, Prof John Forsythe, Dr Girish Gupte, Prof Simon Kay, Mr Khalid Sharif and Sadie Von Joel

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA - MCTAG(21)1

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

ACTION

2 MINUTES OF THE MCTAG MEETING ON 21 OCTOBER 2020 - MCTAG(M)(20)2

2.1 Accuracy

2.1.1 The minutes of the meeting held on 21 October 2020 were agreed as an accurate record.

2.2 Action Points – MCTAG(AP)(20)2

2.2.1 **[1]** 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 (AP2 24.10.18)
A meeting has been held with V Gauden. The protocol has been finalised and for a pilot study in the East of England for fascia to be sent to Tissue Services in Liverpool. A Butler to liaise with the Chair of RINTAG, G Oniscu, for the Group's involvement. Their next meeting is on 25th May. **A Butler**

AP3 – Establish if post-transplant DSA data collection can be simplified
S Peacock reported it is hoped that work on the paediatric data can be undertaken in the next couple of months. Progress has been made on the adult data. The objective will be to import data directly from the system and for other centres to link in.

AP4 **–** Extending the donor criteria for the offering of intestine-containing grafts
This was selected for implementation due to the increase in transplants. The expected release date is around September this year to January next year? Work is underway with SNOD Teams to ensure policies and processes are communicated and in place.

[2] NBAS - Prolonged waiting time for paediatrics
In the absence of G Gupte. King's reported that their key problem and concern was the lack of donors for paediatrics (currently four paediatrics listed over 800 days on the waiting list). On average there are about four to five paediatric transplants per year with one paediatric death. Recommendations made were:

(1) G Gupte to raise this at LAG for the Chair of MCTAG and LAG to come up with a resolution rather than have a policy to cover every eventuality.
(2) raise the visibility of paediatric bowel donation through public campaigns e.g. Children in Need via the NHSBT Comms department as well as from transplant centres. J Whitney to send the Comms link to J Hind. **J Whitney**
(3) raise visibility through patient stories on a national level, this strategy has already proved positive at King's.
(4) speak to SNODS to ascertain parents/family perspective.

[3] Meeting criteria before registering liver for a multi-visceral transplant
G Gupte was not available to report. Criteria for transplant was stated to be met.

[4] Potential bowel donors and location
Refer to agenda item 9.

[5] Referral criteria strategy for intestinal transplant
A Butler has spoken to Trevor Smith regarding allocation and contacts.

Simon Gabe (Representative of IF and BAPEN) stated that there is an IF network holding regular meetings in England to be attended by BAPEN and national reference centres (although it will not be commissioned until September 2022 now due to COVID). The key is to get the right formal representation at these meetings without it being too overloaded. There is a requirement for good interlinking of IF and IF transplant centres to be more developed and it was suggested that Advisory Group representation could be done by e.g. a hepatologist from LAG and a nepthrologist from KAG.

[6] Transfer of UK Intestinal data to the International Intestinal Transplant Registry
Refer to Minute (7) below.

[7] Update from the Working Group on NHSBT data and post-operative data collection
Refer to Minute (10.2) below.

[8] Update on NASIT
Refer to Minute (14) below.

2.3 **Matters arising, not separately identified**

2.3.1 There were no matters arising.

3 MEDICAL DIRECTOR'S REPORT

3.1 **Organ donation and transplantation management during COVID-19 pandemic**

3.1.1 D Manas reported that the impact of COVID has brought liver centres working together on a mutual/partnership basis and a closer liaison with

3.2 NHS England not seen before. ODT Hubs have been very responsive in putting in place interim measures manually which could not be accommodated as quickly on the IT side. Donation has now returned to the pre-pandemic level. The transplant rate, at its lowest at 12-18 transplants across all organs, is improving but has yet to return to its pre-pandemic level.

During the first wave many transplant centres closed down, some to a limited degree, as a 'knee jerk' reaction. On reflection this was not the correct decision. Many guidelines were drawn up to manage and maintain transplantation with the involvement of Advisory Group Chairs and NHS England.

The pandemic has caused a big drop in referrals across the board from March to June last year resulting in a current backlog and long waiting lists. There is now concern regarding a third wave.

All patients active on the liver waiting list have been vaccinated (Kidney are trying to reach agreement for their patients with some problems in the north). Three liver centres have been secured as protected centres to

ACTION

maintain transplantation. It has highlighted that transplantation should not be delayed in the absence of not being vaccinated.

The question has arisen regarding what will happen with transplantation with positive COVID donors. This will depend on the type of test and its sensitivity, though the general feeling is to use these donors. Work is currently being undertaken by a virologist at NHSBT for this type of donor and to look at risk which will be different organ groups.

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(21)2**

3.2.2.1 There were no reported incidences regarding intestinal transplants. However, it was emphasized that pictures need to be taken of grafts retrieved as opposed to relying on verbal communication. There are plans by NHSBT to make imaging a formal process.

4 STATISTICS AND CLINICAL STUDIES REPORT

4.1 Summary from Statistics and Clinical Studies – MCTAG(21)3

4.1.1 Key points from the paper are summarised below:

Collaboration with the Winton Centre is continuing for Risk Communication, to develop a tool to support conversations between patients and clinicians at the time of listing with regards to the risks and benefits of transplantation. The lung and kidney models have been developed first with the other organs to be developed shortly.

A robust process is being worked on for offers to intestinal Group 2 patients to follow agreed policies every time. This will introduce a 'Group 2 combined liver/intestinal' tier towards the bottom of the adult and paediatric DBD donor Liver and Intestinal matching runs, scheduled for release in January 2022.

Discussion took place regarding the categorisation of Group 2 patients from the EU following BREXIT. The Chair believed EU citizens would not get the same access to transplantation as before. It was commented that e.g. a citizen from Denmark requiring a liver and bowel transplant in England will need a visa.

Wider conversation was said to be required as to why a patient from the Republic of Ireland should get preference for a transplant compared to the EU and funding for hospitals for transplantation in Wales, Scotland and Ireland?

Raise at LAG the issue regarding the priority of liver and bowel transplant. **A Butler/ E Allen**

Post meeting note:
The guidance in the link below was circulated to members regarding patients coming into England for a transplant.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/964543/Main_Guidance_post_February_2021_v3.pdf

ACTION

5 NATIONAL BOWEL ALLOCATION

5.1 **Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(21)4**

There is a disproportionate waiting time for patients requiring a liver and bowel transplant compared to a patient just requiring a liver. The question was raised whether a patient waiting over 1000 days should be given special status? H Vica-Melendez to set up a Working Group to include Neil Russell, Julie Whitney and Khalid Sharif to look into the disproportionate waiting time. **H Vilca-Melendez**

6 GROUP 2 BOWEL TRANSPLANTS

6.1 **Group 2 bowel transplants**

There have been no group 2 bowel transplants since the last meeting.

7 TRANSFER OF UK INTESTINAL DATA TO THE INTERNATIONAL TRANSPLANT REGISTRY

7.1 The IRTA will fund the transfer of the registry from the Terasaki Research Institute to TSS. Once this is in place we can look at importing NHSBT data direct to the registry. In the meantime, centres should continue to submit data in the way they always have. The IRTA will inform members once the registry has moved and if there are new ways to submit data. Ongoing funding for the registry will need to be secured. J Hind will seek funding for Stanford University.

8 PATIENT SURVIVAL AFTER INTESTINAL TRANSPLANTATION – MCTAG(21)5

8.1 Data showed that there was a high death rate in the first year for both adults and paediatrics following a liver and bowel/multi-visceral transplant. Isolated bowel transplants continued to have problems later and liver and bowel transplants showed a longer survival rate. R Hogg to include conditional survival for one year**.** **R Hogg**

It was stated that the numbers involved in the ten-year survival rate estimates for paediatric and adult elective intestinal transplants are small and the removal of only one or two patients can produce a relatively bigger change. The recommendation was made to include the risk adjustment to adults and paediatrics for one year for patients transplanted with or without a liver and to include retransplant data for patients in the Annual Report. **E Allen/ R Hogg**

Discussion took place regarding what the risk factors are. This has been looked at in the past by Stats but there was not enough data to draw any real conclusions.

A Butler stated that compared to other organ transplants e.g. lung transplants, intestinal transplantation is doing well. Paediatric survival performed well between 5 and 10 years but not so for adults.

9 REVIEW OF 15 BOWEL DONORS NOT OFFERED – MCTAG(21)6

9.1 A review of the data presented at the Autumn MCTAG for fifteen bowels consented for donation but not offered showed that 3 had consented for

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multi-visceral, 3 families declined consent, 7 families were not approached and 2 cases showing no good reasons for not offering. The suggestion was made to look at how data is pulled from the NxTD. Screening is undertaken but not documented. It was reported that recent consent from families has included multi-visceral donation.

10 UPDATE FROM THE WORKING GROUPS

10.1 Quality of Life Working Group: data collection

10.1.1 Adults

There has been a lot of data collection undertaken in Oxford but there appears to be a big gap between adult and paediatric data requiring further work. C Bambridge will liaise with their psychologist, Tara Parfitt, to establish how the paediatric data collection can be started. P Allan will liaise with Charlotte Rutter from Addenbrookes on the adult data collection. **C Bambridge P Allan**

10.1.2 Paediatrics

A multi-centre approach has been looked at but not much progress has been made since the impact of COVID. C Bambridge will discuss further with H Vilca-Melendez, J Hind and G Gupte. **C Bambridge**

10.2 Update from the Working Group on NHSBT data and post-operative data collection

A meeting will be set up to go through the draft document to come in line with IT at NHSBT. E Allen will lead this to the next stage and J Whitney will liaise with M Stokes for the date of implementation. It was suggested that in the interim, we look at how we collect data until the IT structure is in place and transplant centres to continue data collection in an agreed format so the process will be easy to implement when required. **J Whitney**

J Whitney stated that data can be built into the IT on a retrospective level from an agreed date. L Sharkey will amend and circulate the spreadsheet to the transplant centres to include drop down boxes. **L Sharkey**

10.3 Update from the Working Group on a patient information and Consent document for intestinal transplantation

It was confirmed that this work is already being undertaken under a Consent Working Group led by Neil Russell to unify consent and consent forms for all organ groups and will include the use of videos. A pilot study is taking place with Kidney. Wording for the bowel and 'Why have a transplant' has been drawn up with Liver being looked at next. Work is also being undertaken for a website.

10.3.1 Generic Adult document

As 10.3 above.

11 APPEALS/PRIORITY

11.1. There were no appeals reported regarding bowel intestinal transplantation. Paediatrics will be dealt with separately?

ACTION

12 M&F Proposal: Intestinal failure transplantation – MCTAG(21)7

12.1 Phillipa Cahill from M&F Health attended to present awareness of options for people with intestinal failure – one option being a bowel transplant.

Key points were:

- Public awareness of bowel transplantation is low even though patient groups exist. The strategy is to target patients through traditional media but be sensitive in the information delivery. Communication could be:
  - supported by a virtual workshop with stakeholders and MCTAG and the message amplified by BAPEN, PINNT and other core groups.
  - creating a mission statement would encourage individual groups to start their own communication.
  - using a social media campaign to coincide with Organ Donation week w/c September 7-12th 2021 could be another option.
  - have a radio day to include a local clinician and a local patient?
  - peer to peer execution with 4 or /5 expert people in their specialised fields with discussion with patients to look at issues, why there is low awareness, what are the barriers, timing of referrals.
  - undertake an anonymised survey amongst gastroenterologists to identify the barriers which can be done through the BAPEN Medical.
  - Include BAME
  - put opinion features in targeted journals depending on funding.

D Manas will see if there is funding available from NHSBT to include making a film. **D Manas**

NHS England would not be able to support funding for a social campaign but S Watson can make some enquiries to see what assistance can be given. **S Watson**

P Cahill will incorporate a survey and radio feature in her paper regarding awareness.

Enthusiasm and funding are two key factors affecting success of raising awareness.

13 National paediatric intestinal failure rehabilitation and transplant meeting

13.1 Birmingham and King's going forward will have twice a year meetings and the plan is to try and include the nutrition and IF centres.

14 UPDATE ON NASIT

14.1 Monthly meetings are being held virtually and there are no plans to return to face to face meetings.

ACTION

15 FEEDBACK FROM THE LIVER ADVISORY GROUP MEETING ON 18TH NOVEMBER 2020

15.1 Both of the offerings to multi-organ patients listed below were approved at LAG:

Liver and cardiothoracic patients
It was agreed with the Chairs of CTAG and LAG that named patients would be offered after cardiothoracic organs offered to super-urgent patients but prior to elective offering. The new liver/cardiothoracic tier on cardiothoracic matching runs (agreed at CTAG) will require an IT change and has been implemented manually in the interim.

Liver and intestinal patients
Changes in the bowel donation criteria are to be agreed. Hepatoblastoma liver/intestinal patients offered through liver/intestinal tier will be prioritised above other liver/intestinal patients. The offering pathway for liver/intestinal patients who would also like liver only offers will be to be determined on a case by case basis.

16 ANY OTHER BUSINESS

16.1
- It was stated in cases where there is a potential donor with a transplanted bowel, the bowel would not be considered for retransplant.
- J Hind informed members of early registration for CIRTA with a cheaper rate for members. Members were encouraged to vote for IRTA.
- Thanks was given to J Hind and C Bambridge for the National Intestinal symposium held virtually on 11 March. The format worked well and consideration will be given whether to hold future Symposiums in the same way.
- The question was raised regarding assessment and transplantation for potential patients from Scotland and Wales following a recent case of a patient from Wales in Birmingham requiring a liver and bowel transplant. The patient was declined and is now unsuitable for transplant owing to a neurological decline. S Watson will look into this for Scotland. **S Watson**

17 DATE OF NEXT MEETINGS:

Wednesday 13th October 2021

18 FOR INFORMATION ONLY:

Papers attached for information were:

18.1 ICT Progress Report **– MCTAG(21)8**
18.2 Transplant activity report for January 2021 **– MCTAG(21)9**
18.3 Minutes of LAG meeting: 20 May 2020 **– MCTAG(21)10**