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 13TH OCTOBER 2021, VIA MS TEAMS VIDEO CONFERENCING

PRESENT:

Mr Andrew Butler	Chair
Dr Philip Allan	Oxford Intestinal Transplant Centre
Dr Elisa Allen	Statistics and Clinical Research, NHSBT
Ms Carly Bambridge	Recipient Co-Ordinator Rep
Ms Chloe Brown	Statistics and Clinical Research, NHSBT
Ms Kim Corbey	Recipient Co-Ordinator Rep
Mr Ian Currie	Clinical Lead for Organ Retrieval, NHSBT
Ms Samantha Duncan	Recipient Co-Ordinator Rep
Prof Peter Friend	Oxford Intestinal Transplant Centre
Dr Simon Gabe	Adult Small Bowel and BAPEN Representative
Dr Girish Gupte	Consultant Paediatric Hepatologist, Birmingham
Ms Monica Hackett	Organ Donation Representative
Dr Susan Hill	Paediatric Gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's College Hospital
Ms Rachel Hogg	Statistics and Clinical Research, NHSBT
Mr Craig Jones	Lay Member
Prof Elizabeth Murphy	Lay Member
Dr Matthew Ridley	Postdoctoral Research Associate on AboutFace, University of York
Mr Neil Russell	Cambridge Intestinal Transplant Centre
Dr Lisa Sharkey	Cambridge Intestinal Transplant Centre
Ms Sarah Watson	NHS England
Ms Julie Whitney	OTDT Hub Representative, NHSBT

IN ATTENDANCE:

Miss Trudy Monday	Secretary, OTDT, NHSBT

ACTION

Welcome

Apologies were received from:
Prof Fay Bound Alberti, Dr Richard Baker, Mr Marius Berman, Mr Chris Callaghan, Prof John Forsythe, Prof Simon Kay, Prof Derek Manas, Ms Sarah Peacock, Dr Tracey Rees, Mr Khalid Sharif, Mr Hector Vilca-Melendez, and Ms Sadie Von Joel.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA - MCTAG(21)11

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

ACTION

2 MINUTES OF THE MCTAG MEETING ON 17 MARCH 2021 - MCTAG(M)(21)1

2.1 Accuracy

2.1.1 The minutes of the meeting held on 17 March 2021 were agreed as an accurate record, subject to the following amendment:

Minute 16 to read:
The question was raised regarding assessment and transplantation for potential patients from Scotland and Wales following a recent case of a patient referred from Wales to Birmingham, and then from Birmingham to Cambridge, 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. **T Monday**

In response to this, S Watson confirmed that both commissioners in Scotland and Wales were approached and noted the sense of delay was around the process in Wales. Reassurance has been received from both devolved countries that there should be no delay in the system going forward.

Members were informed that if in future there is a hint of concern about patients from Wales or Scotland coming into the system, the advice is to contact S Watson in future to escalate through the countries.

Minute 2.2: NBAS – Prolonged waiting time for paediatrics:
G Gupte reported that he would take this forward through the Birmingham representative at the next LAG. **G Gupte**

2.2 Action Points – MCTAG(AP)(21)1

2.2.1 **AP1: (From AP2 October minutes) Detailed analysis of incidents for review (24.10.18):**
Liaise with HTA regarding the classification of abdominal fascia in the context of intestinal transplantation:
James Richards (Registrar at Addenbrooke's) is working closely with both Tissues Services and also the SNODs. At the end of November/beginning of December Hub Operations will have added abdominal fascia to the research component of the SOP, and so therefore abdominal fascia can then be retrieved and sent for processing. It is envisaged that the surgical process is straight forward with no problems anticipated for implementing this. There is no HTA conflict with retrieving fascia for the same recipient. The issue in the past was for obtaining fascia for third party transplantation and use in hernia repairs and abdominal wall reconstructions. The HTA are content to allow preservation around 48 hours which is incredibly limiting and is not helpful in terms of semi-elective procedures. This work has been classified as 'research' instead of 'service development'; retrieval of a pilot source of samples will be starting soon.

ACTION

AP1: (From AP2 October minutes) Detailed analysis of incidents for review (24.10.18):
NBAS – Prolonged waiting time for paediatrics:
J Whitney will send the Comms link to J Hind today to raise the visibility of paediatric bowel donation through public campaigns — **J Whitney**

AP2: Performance report of the National Bowel Allocation Scheme (NBAS): Refer to minute 6.1.2.

AP3: Patient survival after intestinal transplantation: Conditional survival to one year will be included in this report from spring 2022. — **C Brown**

AP4: Quality of Life Working Group: data collection: Details around paediatric and adult data collection, and discussions re. a multi-centre approach – a meeting has taken place, refer to minute 11.1.1 and 11.1.2.

AP5: Update from the Working Group on NHSBT data and post-operative data collection: Initial discussions have taken place.
J Whitney explained that there are some significant resource issues around staffing and making changes to policies; IT will take some time to put these changes into place and in the meantime a workaround is required in terms of data collection. Refer to minute 11.2.

AP6: M&F Proposal: Intestinal failure transplantation: An update is awaited from D Manas re. possibility of funding being made available from NHSBT to make a film. — **D Manas**
S Watson reported that M&F are the company (which previously worked with BAPN) who were looking at the possibility of broadening knowledge and enthusiasm about referrals into this service, and looking at the strategy and overall progression. S Watson will email S Gabe and J Hind for a first stage discussion, who will further invite those who have previously put their names forward for involvement. — **S Watson / S Gabe / J Hind**

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**
A Butler commented that it has been quite remarkable how organ donation and transplantation has carried on throughout the pandemic despite all of the disruption. Although it is recognised that there has been a big decline in 2021, going forward the situation is improving and similar figures prior to the pandemic are being observed. I Currie commented that transplants of organs which are vital for day-to-day survival have been affected in a modest way, and this is a testament to everyone's initiative, creative thought and commitment to have been maintained to the level it has; the transplant community have done a fantastic job.

3.2 **Governance**

3.2.1 **Non-compliance with allocation**
There were no non-compliance issues reported with respect to allocation.

3.2.2 **Detailed analysis of incidents for review – MCTAG(21)12**
There were no reported incidences for review regarding intestinal transplants.

4 OTDT Hub Update

4.1 **Review of HTA B return rates - MCTAG(21)13**
Members received a paper illustrating findings of a review of HTA B form return rates. There is an issue with the return of these forms and Members are reminded that there is a statutory obligation to provide information for all organs accepted for the intention of transplantation irrespective of whether that organ was transplanted, sent for research or disposed of. The HTA are now using form return rates as indicators to identify which centres to audit initially at the end of this year/early next year.

As a result of this finding, the HTA chase process will change:

- if a form is not submitted within 5 working days of the transplant, all users of HTA forms in the organ group at the centre will be notified;
- a chase will follow 10 days after;
- a letter to the Clinical Director will follow 14 days after;
- an email to the license holder and Centre Director will then follow at day 26;
- finally, an email from the NHSBT Medical Director.

If an escalation takes place in NHSBT and within a Trust, the chase reports will be forwarded to the license holder (which could be the Chief Executive). Centres are asked to return the forms in good time.

The HTA B forms are now administered electronically. In terms of the categories listed it was highlighted that clarification is needed to avoid ambiguity. J Whitney explained that this feedback is common, therefore a stakeholder group of people who use the forms is going to be convened to review, amend and improve these for end users. It was noted that the IT change required will take some time to implement.

5 Summary from Statistics and Clinical Research - MCTAG(21)14

E Allen highlighted the following to Members:

- The department changed its name in March to ‘Statistics and Clinical Research’.
- The 2020/21 Annual Report on Intestine Transplantation has been published on the organ-specific report page of the OTDT Clinical website: https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/ Centres were thanked for implementing and reviewing it.

ACTION

- R Hogg and E Allen are moving into other areas within the team, and C Brown will be the new statistical lead for MCTAG.
- Patient information on the risks and benefits of organ transplantation is now available online https://www.nhsbt.nhs.uk/organ-transplantation/ together with the Risk Communication Tool (RCT) https://www.odt.nhs.uk/ This tool is available for lung and kidney transplantation only at the moment, and is currently being developed for other organs except intestinal transplantation – this is because of the very low numbers and lack of risk adjusted models for patients, particularly paediatric patients. It was noted that data on around at least 10 deaths would be required but this depends on what the breakdown is, so it could be possible for adult patients in the near future, but not for paediatric. Further discussions around this can be had in the future.
- The extended bowel donor criteria will be reflected in POL193 - Intestinal Transplantation: Organ Allocation; POL196 – Deceased Donor Liver Distribution and Allocation; and POL188 – Clinical Contraindications to Approaching Families for Possible Organ Donation, all available at: https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/ and will go live on 1st November.

5.1 **Addition of graft survival rates to the annual report**

Discussion took place around the definitions used to describe the details of graft failure, and potential inconsistencies re. the date that the actual graft failed. It was agreed that C Brown will work with Members of MCTAG to agree definitions to be used, publish them in the policy, and communicate these to the transplant community. **C Brown**

5.2 **Colon-containing grafts; numbers and impact on patient outcomes - MCTAG(21)15**

E Allen highlighted the following:

- Adult patient data only was used in this analysis.
- Total of 150 adult small bowel transplants analysed, of these, 97 (65%) contained the colon; including the colon has been more common since 2013.
- Overall, the 5-year survival rate is 58.4%, and there is no significant difference between the colon-included and no-colon-included groups at any time.
- There is a significant difference at one year survival post transplantation between the four subgroups.

Thanks were expressed to R Hogg for preparing this information. Following discussion, it was agreed that this colon containing graft activity and outcomes analysis (to include the stomach) would be useful on occasions as there are not large enough numbers to repeat this analysis on a yearly basis to give meaningful data. Patient functionality would be worthwhile including in the future as well.

ACTION

6 NATIONAL BOWEL ALLOCATION

6.1 Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(21)16

Members received this regular report for information, and E Allen noted that there was nothing new to report in terms of trends. Members are reminded to notify OTDT online with any data amendments, for example deaths on the waiting list or removals.

Some patients have been removed from the list due to their condition deteriorating. Unless the patient is relisted the outcomes are unknown. It was noted that it would be interesting to know what the patient outcomes are for those who come off the list. **C Brown**

6.1.2 Disproportionate waiting time for liver and bowel patients compared to a liver patient only

H Vilca-Melendez was unable to attend this meeting to report on this.

7 GROUP 2 BOWEL TRANSPLANTS

E Allen reported that between February 2021 and August 2021 there were no patients in Group 2 or Group 1.

Discussion took place around the effects of Brexit on the sharing of organs, however it seems that currently nothing has changed re. rules around eligibility, and the pathway of retrieved and transplanted organs in the UK and Europe. J Whitney reported that D Manas and O McGowan have been working on a guidance document around this which will be uploaded to the website.

8 Potential bowel donors and location – MCTAG(21)17

Members received this regular paper for information, review and comment. The following were noted:

- Both the offered and transplanted rate dipped slightly in 2020/21, however the consent rate increased from 83% in 2018/19 to 86% in 2020/21.
- Sometimes consent is obtained and then further medical assessment and other issues/contraindications/virology which arise post consent leads to no formal offering. M Hackett and C Brown will review donor data relating to past history during this period to identify if any conclusions can be drawn. **M Hackett / C Brown**
- It would be helpful to have the virology information at the earliest opportunity.
- It would be useful to have the weights of the donors which have been offered from overseas in the next report, as rejection rates will help inform decisions re. the transplanting of small recipients. **C Brown**
- It is hoped that the access to beds, theatres, staffing will improve in time.
- The geographical distribution of potential bowel donors during 2020/21 shows a spread across the whole of the UK.

ACTION

9 Conflict in using smaller donor organs in MV recipients and for paediatric hepatoblastoma patients

Following previous discussions within this group regarding the long waiting times for the very small paediatric patients, there has been an agreement at the LAG to allow placing of small multivisceral recipients into the same category as the hepatoblastoma patients, which would then give them access to every potential liver donor within the UK, other than those allocated to super urgent patients. However, there does not appear to be a mechanism within the system which discriminates against weight and age which means that co-ordinators would receive a lot of offers which would not be of an apporpirate size.

G Gupte noted that it is important to be clear around the definition of 'small', and suggested that if the weight of paediatric patients are listed at a minimum of 20kg, and maximum of 30 kg, it would possibly restrict the number of offers in that category. G Gupte and J Hind agreed to discuss these issues with transplant surgeons and transplant co-ordinators in their centres without delay, and report a recommendation to A Butler who will then take it to D Thorburn (LAG Chair) for consideration and approval. **G Gupte / J Hind / A Butler**

S Hill highlighted that the extreme pyschological stress for children on the waiting list (and after) needs to be emphasised and understood, and looking to reduce the waiting time for these patients is very reassuring.

10 Transfer of UK intestinal data to the International Transplant Registry (ITR)

J Hind reported that the transfer of data was delayed due to problems with the International Transplant Registry (ITR) changing from where it was hosted. Work is in progress although the IT is going to take some time to complete, but going forward the new system will be very useful.

In the meantime, data will be collected on the new Excel spreadsheet in the usual way and asked to be submitted to NHSBT. The launch date for the new dataset is hoped to be early next year; data will be submitted twice a year and can be uploaded onto the new ITR platform. Any data which has been previously stored in the current Excel system will be able to be loaded into the new platform within the ITR.

Discussion took place around the possible use of REDCap for collating the data. J Hind agreed to arrange a meeting with J Whitney, L Sharkey and the TTS Registry contact about whether the REDCap tool would be the best web application to use. **J Hind / J Whitney / L Sharkey**

11 Update from Working Groups

11.1 **Quality of Life Working Group: data collection**

11.1.1 **Adults**

P Allan gave the following update:

- A meeting is being held soon with the co-ordinators and nurses in Cambridge who are often administering the Quality of Life (QoL) questionnaire, to discuss the questions to be included on

a generic questionnaire, and a disease specific questionnaire, to encompass the whole patient journey from intestinal failure through to transplant and beyond.

- A paper has been written re. the data to be collected and will be circulated for the next meeting. **P Allan**
- There is a new disease specific PNIQ patient related outcome measure for intestinal failure, consisting of 20 (generic) questions designed by patients who are on PNIQ.
- Considering capturing data for patients who do not continue their transplant journey.

11.1.2 **Paediatrics**

C Bambridge reported that work on this data collection has not started yet but there are plans to discuss this further soon. An update will be reported at the next meeting. **C Bambridge**

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

Refer to minute 10.

11.3 **Update from the Working Group on a patient information and consent document for intestinal transplantation**

N Russell has been working on a cross unit document relating to consent for intestinal transplantation. The text for the website has been prepared and will be live soon.

11.3.1 **Generic Adult document**

In addition, there was question as to whether a national unified generic consent form should be in place for all organs. Fairly standard questions across all organ groups could exist, however it is felt that multiple questions associated with different transplant types could not easily be encompassed within a single form, however, there needs to be consistency amongst centres re. information collected.

It was noted that the addition of a video describing potential complications/risk with organ transplantation at different levels of detail which patients have to know, for use amongst all units, would be helpful.

12 Appeals/Priority

A Butler reported of one appeal from King's relating to a 4-year-old girl who has been listed for 825 days for consideration of a combined liver and small bowel. She was eventually removed from the liver bowel listing and transferred to the Hepatoblastoma Group and was then able to be transplanted with a liver only organ.

A second appeal was outlined whereby a request was made to increase donor weight for an individual from Addenbrookes. This would require increased interaction at the OTDT Hub level and could potentially cause problems if the donor weight is increased. It is hoped that the amendment to age criteria will contribute to reducing the need to increase donor weight in future.

A third appeal was an urgent request relating to a patient with acute liver failure in the context of IFALD. The patient has been transplanted and while still on HDU is currently recovering.

13 M&F Proposal: Intestinal failure transplantation

Refer to minute 2.2.1, AP6.

14 Impact of IF commissioning on Intestinal Transplant services

Previous discussions have taken place around equity of access to transplant services across the country, there is concern however re. the recent redesigning of specialist IF services and how this might affect referrals for transplantation. The situation would need to be kept under review.

It was noted that MCTAG has an adult and paediatric IF centre representative, and it may be beneficial to have a representative from a HPN centre which rotates to ensure equity of access across the country, or another consideration is to perhaps have a national formal organisational structure to represent views from all centres.

A Butler agreed to discuss this further with S Gabe and provide an update at the next meeting. **A Butler / S Gabe**

15 National paediatric intestinal failure rehabilitation and transplant meeting

S Hill reported that work is in progress with the establishment of the UK Joint Intestinal Failure and Rehabilitation Forum, providing a national network for adult and paediatric patients.

Another meeting is planned for 19th October involving 68 participants who have registered, representing all intestinal failure centres (subsequent meetings will be held every 6 months). Two cases will be presented and discussed at the meeting. Members noted that this forum is yet to be endorsed by BSPGHAN.

16 Update on NASIT

L Sharkey reported that this forum, which is run monthly (virtually), continues to be successful given that there are a substantial number of patients to present on a monthly basis. Some of these patients are immensely complex, so good management of time is needed in highlighting the key areas, with data shared prior to meetings to help support that.

17 Addition of chimerism testing to service specification

L Sharkey reported of a problem in Cambridge with the turnaround time for chimerism testing which has changed from one week (or less) to sometimes 4 or 5 weeks later. One of the problems with this is that the test is not on the test directory of the new genomics lab hubs under solid organ transplantation. Members agreed that this is a clinically critical part of managing these patients to keep them safe, and that the

ACTION

labs be encouraged to add this to the test directory as a rapid test. It was noted that this is also a problem from a paediatric perspective.
A Butler agreed to write on behalf of MCTAG to S Watson to be able to apply some pressure. **A Butler**

18 Feedback from Liver Advisory Group Meeting on 19 May 2021

A Butler announced that there was nothing further to update with regards to MCTAG. The discussions relating to allocating small paediatric multi visceral and liver small bowel recipients into the hepatoblastoma group were addressed in minute 12.

19 ANY OTHER BUSINESS

19.1 **Update on face transplantation**

M Ridley, Research Psychologist, from the University of York presented some slides on a 7-year research project (NIHR study and NHS ethically approved) looking at investigating the effective and cultural histories of face transplants, and some of the blocks and problems relating to this within the UK. Key points are summarised below:

- Face transplantation within the UK has not taken off; could be the same for hand transplantation, and to an extent probably abdominal wall transplantation also.
- To date, there has been 48 face transplants, including two re-transplants. These have taken place at 21 hospitals worldwide in 11 countries.
- Currently working with NHSBT around the permissions of donor families and specialist surgeons.
- There are ethical concerns, the sample pool is getting smaller, shortage of funding. This could be replaced in the future by innovative treatments such as tissue regeneration.

1600 participants responded to a survey conducted during the pandemic which indicated the following key views: (published research in the British Journal of Surgery)

- a face transplantation would be worthwhile as long as it would improve quality of life.
- many respondents raised concerns about the risks and potential rejection and failure which would negatively impact on identity in psychology, and trauma of facial loss for donors and for families.
- Worry about the impact on donor families, especially if ‘recipients resemble their donors’ – (public perception, although clinically incorrect).
- Face deemed too personal compared to other organs donated as it is visible, the idea could be upsetting unbearable or uncomfortable.

There is interest not only in patients and donor families in terms of how they are faring, but also in staff. In terms of outcome analysis, the objective is to explore the holistic context about how it has happened and where it might progress from here. The writing of a narrative

review is currently under preparation, focussing on patient psychology, patient experience, protocol, patient selection and follow-up.

Another part of the project includes looking at the international perspective, and collaborations amongst the nine countries currently represented; the objective essentially is to create a blueprint for face transplant policy and practice.

It was noted that there have been many discussions over the last 10 years on this subject, with a lot of interest coupled with mixed feelings from authorities. There are all sorts of challenges relating to patient selection and donor families. Although not yet funded by the NHS does not mean that the cause is lost, and it falls into the remit of this group. M Ridley would be happy to receive any feedback from centres and be involved in this group when appropriate. A Butler encouraged M Ridley to ask for anything which MCTAG may be able to help with in future. **Centre Reps**

19.2 **Use of COVID positive donors for multi-visceral and intestinal transplantation**

A Butler asked MCTAG Members their views on considerations around decisions in relation to utilisation of donor organs from donors who have had and potentially cleared COVID, but remain RNA positive.

In terms of lungs, the position currently remains that a donation may not proceed if the donor has tested positive for COVID. As there are mixed feelings within the group, no guidelines and a lack of information/evidence, the conservative approach suggests that it is the decision of the individual unit based all of the risk factors as to which organs should and should not be used, but to not use those with a positive viral DNA. In terms of informing the recipient (and relatives) re. considering receiving donor organs from a patient who has been COVID positive, it is important to say that the potential risks are unknown.

19.3 **Review of CMV and EBV infections in Intestinal transplantation UK wide experience – incidence, outcome and strategies**

L Sharkey reported of a concern with receiving EBV results in good time at the time of organs being offered. Looking at PTLD data it transpires that the vast majority of PTLD cases arise when there is an AB mismatch between donor and recipient; there may be EBV naïve bowels transplanted into an EBV positive recipient for then the PTLD to develop within the transplant, but there is not enough detail on this yet.

There is an issue with some of the laboratories not reporting EBV donor status, so there is a degree of inconsistency across the UK re. routine testing prior to organ offering. It was agreed that A Clarkson be contacted to ask for an adjustment to the system within national donor testing to get some change across the UK in clinical practice to address this. L Sharkey reported that the unmatched figure is over 20%, and having a mismatch could double the risk of a patient **A Butler**

contracting PTLD. The overall decision is a case of balancing the risk on an individual basis.

19.4 **Use of CMV positive donors in CMV negative patients**
G Gupte raised a question of how many units use CMV IGG in prophylaxis in post-transplant period, and whether or not some teams use CMV mismatched donors (if the CMV recipient is negative, and the donor was positive, would that donor be accepted). A Butler confirmed that the aim is to try to avoid a CMV mismatch if possible, but if there was a small sensitised patient and there was a CMV mismatch, the risk would have to be accepted and donation proceed, and be aware of trying to avoid situations where CMV prophylaxis is interrupted. It was highlighted that when a positive donor is transplanted into a negative recipient the figure is 90% reactive CMV infection, with minimal benefit. It was agreed that a joint review of CMV and EBV usage in prophylaxis in post-transplant period be carried out across the four units; G Gupte will write to all four centre representatives to conduct this. **G Gupte**

20 DATE OF NEXT MEETINGS:

To be advised.

21 FOR INFORMATION ONLY:

Papers attached for information were:

21.1 ICT Progress Report - **MCTAG(21)18**

21.2 Transplant activity report for August 2021 - **MCTAG(21)19**

21.3 Minutes of LAG meeting: 18 November 2020 - **MCTAG(21)20**

October 2021