**BAG(M)(13)1(Am)** **LAG(13)43**

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

**THE SEVENTH MEETING OF THE BOWEL ADVISORY GROUP MEETING AT 11:30 AM ON WEDNESDAY, 6 MARCH 2013 AT ODT, BRISTOL**

**PRESENT:**

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| Mr Darius Mirza | **Chair** |
| Dr David Briggs | BSHI Representative |
| Mr Andrew Butler | Deputy for Mr Neville Jamieson, Addenbrooke's Hospital, Cambridge |
| Mrs Claire Counter | Statistics & Clinical Audit, NHSBT |
| Miss Sue Falvey | Head of Nursing Development, ODT |
| Dr Girish Gupte | Birmingham Children's Hospital |
| Dr Jonathan Hind | King's College Hospital |
| Mr David Mayer | National Clinical Lead of Organ Retrieval, ODT |
| Dr Steve Middleton | Addenbrooke's Hospital, Cambridge |
| Ms Ella Poppit | Organ Donation, S Central and S East |
| Mr Aaron Powell | Business Manager, NHSBT |
| Ms Sally Rushton | Statistics & Clinical Audit, NHSBT |
| Mr Anil Vaidya | Deputy for Prof Peter Friend, Oxford Transplant Centre |
| Mr Hector Vilca-Melendez | King's College Hospital |

**IN ATTENDANCE:**

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| Mrs Kaman Huang | Secretary, NHSBT |

**ACTION**

**Apologies were received from**: Dr Joe Brierley, Prof. Dave Collett, Dr Mark Dalzell, Dr Simon Gabe, Prof. Peter Friend, Dr Susan Fuggle, Ms Lydia Holdaway, Mr Neville Jamieson, Prof James Neuberger, Mr Khalid Sharif, Dr Simon Travis and Mrs Ann Yates.

## 1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA – BAG(13)2

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

## 2 MINUTES OF THE BAG MEETING ON 24 OCTOBER 2012 – BAG(M)(12)2

2.1 **Accuracy**

The minutes of the meeting held on the 24 October 2012 were agreed as a correct record.

2.2 **Action Points – BAG(AP)(13)1**

**AP1**: (Ref: AP 14.1 – AOB meeting on 21 March 2012:
14.1 – AOB: Suggest some agreed guidelines for a common retrieval protocol for multi-abdominal organs across the four transplant centres in terms of utilising new technology in writing to D Mayer. This was completed by D Mirza.

**ACTION**

Write to K Quinn copying J Neuberger and A Butler regarding the costs of sending a team to retrieve bowels, which is outside of NORS, so that it may be raised with the Commissioners. Communication was sent out by D Mirza to this effect in November 2012.

A Butler highlighted that the issue was the cost borne by retrieval teams going to retrieve and retrieval not taking place e.g. if organ retrieval was required in Newcastle the cost of this would be borne by the Cambridge retrieval team. The issue of reimbursements are to be discussed at the next NCT meeting.

Discussion took place around organ retrieval in Europe and for Europe. Members agreed to retrieve bowels for Europe. At present there is a list of UK surgeons available though the list of surgeons from the continent is incomplete. It was suggested that the closest available NORS team would undertake the retrieval for bowels. In the event of a centre not being comfortable retrieving paediatric bowels then this would be undertaken by the Birmingham and King's retrieval team.

With regards to the retrieval of grafts in Europe, King's College, Birmingham and Addenbrooke's Hospital representatives stated they would prefer to retrieve themselves. It was reported that if a retrieval team is sent to Europe most centres would struggle to find a second retrieval team if required. Non retrieval also incurs a fine. D Mirza will write to K Quinn asking for clarification and will ask K Zalewska about amending the Standards to accommodate a request from the European team via the D.O. for the closest NORS team to retrieve. **D Mirza**

**AP2: Potential for organ donation and transplantation:** Communication was sent to A Clarkson by J Neuberger in October 2012 regarding consent for abdominal organs not including bowels.

**AP3: Research Governance Policy for supporting Research Proposals:** Draw up guidelines for circulation to transplant centres to address where an organ has been removed and then deemed unfit for transplant, where consent has been given, for the organ to be used for research purposes. This action is still ongoing by J Neuberger.

**AP4: Advisory Group workplan:** Draw up broad guidelines to provide uniformity for non transplant clinicians to refer paediatric and adult patients on to the UK national transplant list within an appropriate timeframe and be held accountable. The document is yet to be finalised and is still ongoing. **G Gupte/ S Gabe**

**AP5: Intestinal transplant record form returns:** A Butler has been informed of the name of the contact for Intestinal transplant record form returns from Cambridge.

**AP6: Summary of registrations and transplant activity: 1 October 2011 to 30 September 2012:** G Gupte presented a paper on paediatric mortality in relation to IFALD.

**AP7: Transition in small bowel transplant patients:** Feedback on proposal to provide arrangements for the transfer of paediatric intestinal transplant to adults. It was agreed for the Cambridge team to work on preparing a business case to take on the small numbers of patients transitioning every year from paediatric to adult services. **A Butler/ S Middleton**

**ACTION**

Raise at Advisory Group Chairs' meeting the proposal of setting up a group to examine the principles across the transplant community for the creation of a co-ordinated approach with standards and resourcing, including aspects of graft survival and quality of life, to strengthen the case for funding for a transplant wide policy rather than just for bowels. This has been undertaken.

Email a copy of the amended proposal to provide arrangements for the transfer of paediatric intestinal transplant to adults to J Neuberger, D Mirza and K Zalewska. This is still outstanding. **G Gupte**

**AP8: Report from meeting on risk stratification of highly sensitised small bowel recipients:** Amend the proposal for standardisation of protocol for testing, reporting and cross-matching for HLA specific antibodies in bowel transplantation in the UK and re-circulate to members of BAG for approval. Refer to agenda item 18.1.

**AP9: Update on overseas donor offers: co-operation with Eurotransplant:** A conference call involving D Mirza, J Neuberger, A Butler and A Yates to resolve the logistical issues regarding overseas donor offers and co-operation with Euro-transplant was set up on 14 November 2012.

**AP10: Any other Business:** S Fuggle discussed with A Hudson the possibility of using all unacceptable specificities to calculate the points score, but taking a limited number of acceptable specificities into account when offering organs through the allocation algorithm. Following discussion members agreed that if donor HLA was available patients with unacceptable specificities would be excluded from the matching run.

**AP11:** Draw up some guidelines for inclusion into the Pancreas and Intestinal Allocation Policy regarding the issue of pancreases being discarded following small bowel transplants. This is still in progress by P Friend. **P Friend**

2.3 **Matters arising, not separately identified**

There were no matters arising.

## 3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

### 3.1 Developments in NHSBT

3.1.2 **New appointments:**

3.1.2.2 ODT will be recruiting three new part-time clinicians next month. Finalisation of all three job descriptions are still in progress but D Mayer's role will be filled by R Ploeg responsible for the training of retrieval teams and NORS whilst R Cacciola will be working with K Quinn on commissioning.

The third position will be filled by J Dark looking at clinical governance around retrieval to alleviate disparities between centres for the acceptance of organs.

**ACTION**

3.2 **Governance**

3.2.1 The on-line SAER system launched in November seems to be working well with no negative feedback. Reports are now being developed to look at trends with the aim of publishing them every six months.

Members were reminded that legislation requires the reporting of all SAER to the HTA within 24 hours.

3.3 **NHSBT Strategy update**

3.3.1 The NHSBT Strategy will be presented at the Board Meeting for approval at the end of this month.

3.4 **Update on SOAG review**

3.4.1 Members were informed that all centres should have received a letter sent out on the 5 March regarding the implementation plan.

3.5 **IT priorities progress report**

3.5.1 **EOS Mobile**

A Powell gave a presentation and updated members on EOS Mobile. User feedback regarding the length of time to login and difficulty in getting onto some sites is being addressed.

The aim is for the D.O. to maintain a single list of contacts for each transplant centre for the appropriate organ offering, excluding fast track at this stage. This is to reduce the current lengthy process and time spent by the D.O. ringing around each of the transplant centres.

**Centre Reps**

Members were requested to provide their centre's primary and secondary method of communication for offers of organs out of the current six methods. It was agreed that communication via the automated voice system would be dropped altogether. A Powell stated that IT will be streamlining the communication process by eliminating those methods of communication not used by transplant centres.

The Offering Protocol is to be approved at the Advisory Group Chairs meeting in April.

Members stated that it would be preferential to have a mechanism to indicate whether an organ has been accepted or declined.

3.5.2 **Micro-site**

3.5.2.1 S Falvey reported that the Micro-site went live a few weeks ago but unfortunately cannot be accessed by website search engines. The website address is: www.odt.nhs.uk.

ACTION

**4 STATISTICS & CLINICAL AUDIT REPORT:**

4.1 **Conference presentations, current and future work - BAG(13)2**

4.1.2 A presentation entitled 'Intestinal transplantation: Can mortality on the transplant list be avoided?' will be presented at BTS in March.

Work on the migration of data on registration and transplantation for 'Intestinal failure and liver disease (IFALD)' to the UK Transplant Registry has commenced.

4.2 **Advisory Group workplan - BAG(13)3**

4.2.1 Work around IFALD is the main project currently being undertaken by Stats.

**5 CURRENT ACTIVITY:**

5.1 **Summary of registrations and transplant activity: 1 February 2012 to 31 January 2013 - BAG(13)4**

5.1.2 Although it was reported that the reduction in intestinal transplants for 1 February 2012 to 31 January 2013 compared with the previous one year period was attributed to a decline in the number of paediatric bowel only transplants, J Hind started that the real reason could be due to a decline in liver/bowel transplants and better management of patients.

Regarding the column for 'Removed' in Table 1 of the paper presented, members requested the reasons be looked into. If patients are removed due to condition deteriorating they should be classed as deaths. **C Counter**

**6 BOWEL DONATION**

6.1 **Potential bowel donors and location: 1 February 2012 to 31 January 2013 - BAG(13)5**

6.1.1 Following discussion members agreed that the current donor age limit of 65 years be dropped to 55 years of age and the weight limit from 100 to 80 kilos. E Poppit will inform SNODs of the change. **E Poppit/**
S Falvey will inform the Duty Office. **S Falvey**

It was also reported that it would be beneficial to see how many organs are offered to Europe. **C Counter**

**7 POST TRANSPLANT SURVIVAL AFTER INTESTINAL TRANSPLANTATION - BAG(13)6**

7.1. A paper was presented to members showing results suggesting that paediatric patient survival to 90 days and one year has improved. However, owing to the small number of transplants available for analysis the data needs to be treated with caution.

**8 UPDATE ON TRANSITION IN SMALL BOWEL TRANSPLANT PATIENTS - BAG(13)7**

8.1 G Gupte presented a proposal at the last meeting in October to provide arrangements for the transfer of paediatric intestinal transplant to adults but stated that current infrastructure would not support this.

ACTION

G Gupte is to amend the document to include the effects of graft survival, quality of life and the transition to local care and circulate to members for feedback. J Neuberger stated at the previous meeting that this would strengthen the case for funding for a transplant wide policy rather than just for bowels. **G Gupte**

NCG funding may be available for the proposal involving the two paediatric transplant centres.

## 9 THE FUTURE OF NASIT – NATIONAL AUDIT SMALL INTESTINAL TRANSPLANTATION

9.1 A Vaidya stated that an update would be provided at the next meeting. **A Vaidya**

CSS to raise as an agenda item. **K Huang**

## 10 UPDATING THE INTESTINAL TRANSPLANT FORM

10.1 In the absence of K Sharif at the last two meetings with no information being provided for updating the form, D Mirza will remove the item from the agenda.

## 11 PAEDIATRIC MORTALITY – BAG(13)8

11.1 There is limited information available on the British Intestinal Failure Registry database as it relies on centres registering patients. National paediatric mortality statistics could be used to work backwards to obtain data on mortality of children with IFALD. J Hind will help in obtaining additional information on paediatric mortality. **J Hind**

## 12 UPDATE ON OVERSEAS DONOR OFFERS: CO-OPERATION WITH EUROTRANSPLANT

12.1 This is also covered under point 14.1 under Action Points.

D Mirza asked members what would be the size and quality of bowels that would be accepted from Europe. Following discussion it was agreed that donors over 50 kilos would not be accepted. Four centres (King's College, Queen Elizabeth, Addenbrooke's and Oxford) would only accept donors up to the age of 55. S Falvey will update A Yates. **S Falvey**

## 13 NATIONAL PROTOCOLS – USE OF PARVOLEX

13.1 D Mirza reported that parvolex is not used in bowel transplantation and is therefore not relevant.

The suggestion was made that all centres should be using the same guidelines for the preparation of bowels for transplant. Four centre reps to email their protocols to E Poppit. Queen Elizabeth Hospital and King's College will represent the paediatric community and Addenbrooke's and Oxford will represent the adult units. **D Mirza/ H Vilca- Melendez/ A Butler/ A Vaidya**

ACTION

## 14 UPDATE ON OXFORD ISBTS MEETING

14.1 D Mirza reported that the deadline of 4th March 2013 for the submission of abstracts has been extended to the 12th March 2013.

## 15 TRAINEE CONSULTANT TO ATTEND BAG AS OBSERVERS

15.1 D Mirza informed members that he was happy to support a trainee consultant to attend the Bowel Advisory Group meetings as an observer.

CSS to send a letter to Transplant Centres via the Centre Reps requesting the name of any nominees. This will be restricted to one nominee per centre. **K Huang**

## 16 ANY OTHER BUSINESS

### 16.1 NHSBT Communications Team

Post meeting note:
It was agreed to invite Leonie Austin, Director of Communications, to the next meeting to seek members' views on how to effectively deliver the new Strategy for increasing organ transplantation. **K Huang**

16.2 D Mayer informed members that he is retiring at the end of March. D Mirza and members thanked D Mayer for his contributions to date.

16.3 A Vaidya asked for clarification on bowel transplants for foreign non UK patients. These overseas patients can only be considered if there is no suitable UK/EU entitled patient for the available donor graft offer. Current UK intestinal transplant activity is modest, there are a few potential spare grafts available, and many EU and foreign countries do not have intestinal transplantation programmes, which would provide the UK an opportunity to strengthen international co-operation. It would be up to the individual transplant centres to appropriately list these recipients as a Group 2 patient.

16.4 Concern was raised at LAG that patients with cholangiocarcinoma and neuorendocrine tumours could be transplanted under the Intestinal Selection Policy but are not undertaken under the Liver Selection Policy. Following discussion it was agreed that C Counter would remove the wording "occasionally cholangiocarcinoma" and specify bowel only transplantation for localised neuroendocrine tumours under section 1.2, item 2 on page 2 of the Policy. **C Counter**

## 17 DATE OF NEXT MEETING:

Wednesday, 30th October 2013 at The Royal College of Anaesthetists, London.

**18 FOR INFORMATION ONLY:**

18.1 **Report from meeting on risk stratification of highly sensitised Small bowel recipients – BAG(13)9**

The revised report was submitted to members.

18.2 **Transplant activity report - BAG(13)10**

A paper outlining the activity of all organ transplants up to January 2013 was given.

18.3 **Minutes of LAG meeting : 14 November 2012 - BAG(13)11**

Members noted the minutes of the Liver Advisory Group meeting for information.