

NHS BLOOD AND TRANSPLANT

ORGAN DONATION & TRANSPLANTATION DIRECTORATE

**THE NINTH MEETING OF THE BOWEL ADVISORY GROUP MEETING
AT 11:30 AM ON WEDNESDAY, 9 APRIL 2014 AT ODT, BRISTOL**

PRESENT:

Prof Darius Mirza
Dr Elisa Allen
Dr David Briggs
Mr Neil Russell

Chairman

Statistics & Clinical Studies, NHSBT
BSHI Representative
Deputy for Mr Andrew Butler,
Addenbrooke's Hospital, Cambridge

Ms Melissa D'Mello
Prof Peter Friend
Dr Susan Fuggle
Dr Jonathan Hind
Ms Lydia Holdaway
Mrs Rachel Johnson
Dr Steve Middleton
Prof Elizabeth Murphy
Prof James Neuberger
Ms Susan Richards
Ms Sally Rushton

Lay Member
Oxford Transplant Centre
Scientific Advisor, NHSBT
King's College Hospital
Recipient Co-ordinator representative
Statistics & Clinical Audit, NHSBT
Addenbrooke's Hospital, Cambridge
Lay Member
Associate Medical Director, NHSBT
Organ Donation, S Central and S East
Statistics & Clinical Studies, NHSBT

IN ATTENDANCE:

Mrs Kamann Huang

Secretary, NHSBT

Apologies were received from: Ms Carly Bambridge, Dr Joe Brierley, Mr Andrew Butler, Prof Dave Collett, Prof John Dark, Ms Sam Duncan, Dr Simon Gabe, Dr Girish Gupte, Dr Edmund Jessop, Mr Khalid Sharif, Dr Simon Travis, Mr Hector Vilca-Melendez and Mrs Ann Yates.

Dr Mark Dalzell has stepped down as a member and a replacement is being sought.

WELCOME TO LAY MEMBERS

D Mirza welcomed Prof Elizabeth Murphy and Ms Melissa D'Mello to the Bowel Advisory Group meeting as Lay Members.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA – BAG(14)1

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

2 MINUTES OF THE BAG MEETING ON 30 OCTOBER 2013 – BAG(M)(13)2

2.1 Accuracy

2.1.1 The minutes of the meeting held on the 30 October 2013 were agreed as a correct record.

2.2 Action Points – BAG(AP)(14)1

2.2.1 All action points have been completed or are in progress. Actions with an oral update are listed below.

AP1: Terms of Reference: Refer to agenda item 3.1.

AP5: Update on NHS England: Refer to agenda item 4.4.

AP6: Reporting of registration data: Centre representatives confirmed that data items agreed at BAG as part of the new data collection and allocation procedures were being reported.

2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

3 BOWEL ADVISORY GROUP

3.1 Terms of Reference – BAG(14)2

3.1.1 Darius informed members that the Bowel Advisory Group is different from the other Advisory Groups in being smaller. Rather than create further working subgroups to deal with issues arising, the suggestion was made to look at smaller task groups.

Following discussion it was agreed that the current turn-round of six/twelve months to deliver projects, either involving statistical input or not, is acceptable.

3.2 Workplan – BAG(14)3

3.2.1 Members were presented with a Workplan outlining ongoing and recently completed projects and reports produced on a regular basis.

Discussion took place on one of the ongoing issues of the lack of small bowels being donated along with long patient waiting times and the refusal rate for organs that are offered.

It was commented that J Dark has asked for a prospective audit to be undertaken for every donor and this would provide useful information.

S Richards will liaise with Dale Gardiner, Deputy National Clinical Lead for Organ Donation, to initiate short lectures to SNODs and CLODs for example, to increase awareness of the lack of paediatric bowels offered for donation. The two issues that need to be addressed are:

- Are the organs being used effectively?
- Are the organs of the required quality?

It was recommended that time should be given to attending a Transplant Focus Day. One route could be a representative from each of the four transplant centres attending the twice-yearly Regional Collaborative Meetings for their region. The Forum could also be used to address the issue raised by J Hind that for neo-natal deaths there are no nationally agreed criteria for brain stem death.

S Richards, J Hind, J Brierley and M D'Mello are to present a report at the next BAG meeting in October looking at a strategy to increase awareness for bowel donation for Neonates and for children under the age of two years. This will include looking at adult bowel donation and examining the current methodology for both paediatrics and adults.

J Hind highlighted that when patients change addresses and move to a new GP, the GP registration forms GMS1 do not give an option for bowel donation. J Hind to email a copy of the registration form to J Neuberger.

Post meeting note:

ODR at ODT are communicating with the AD of Transplant Support Services to drive forward organ donation which will cover the current GMS1 form not including the option for bowel donation. Dates have been requested of when the forms will be reviewed and updated but none have been given.

If a registrant has ticked the 'Any organs and Tissue box' then we would accept this as being consent for small bowel donation.

3.3 Postcode analysis of registered patients – BAG(14)4

- 3.3.1 A paper was presented listing the residency of patients newly registered to the bowel transplant list and residency of patients who received a bowel transplant over the last five years.

S Middleton commented that a better analysis would incorporate e-HPN (Home Parenteral Nutrition) data and plot it according to population density by strategic health authority. This would give a clearer indication of access to intestinal transplantation. It is expected that there would be hot spots around the centres that provide HPN (e.g. Salford and Harrow). P Friend, S Middleton, J Hind and E Murphy are to liaise with Dr Tim Bowling at BAPEN (British Association for Parenteral and Enteral Nutrition) to look at collating data to investigate the issue of geographical inequity of access to transplantation. It was, however, acknowledged that the numbers alone may be too small to get a true reflection.

It was also raised by N Russell that teams around the country will not be aware that super-urgent intestinal transplantation is an option for patients who present these set of problems – Cambridge have transplanted four such patients in the last year successfully. These patients would have died otherwise.

4 ASSOCIATE MEDICAL DIRECTOR'S REPORT**4.1 Developments in NHSBT**

- 4.1.1 J Neuberger informed members that the Cardiothoracic Advisory Group have set up a Scout Pilot Scheme since April 2013 to send a scout in advance of the CT retrieval team to assess the quality of a heart for transplant. The number of hearts transplanted has increased but there is debate as to whether the scouts' interventions led to an increase in the number of hearts retrieved.

There is a forthcoming review on Organ Retrieval Services and this will be chaired by a Lay member.

4.1.1 New appointments:

- 4.1.1.1 - A Hudson – Head of Information Services - 1 April 2014
- Ian Trenholm replaces Lynda Hamlyn as the new Chief Executive - 1 July 2014

4.2 Governance**4.2.1 Non-compliance with allocation**

- 4.2.1.1 No non compliances with allocation were noted

4.2.2 Incidents for review

- 4.2.2.1 No incidents for bowels were brought up for review.

4.3 Transplantation of Jehovah Witnesses – BAG(14)5

- 4.3.1 Transplant centre representatives reported that the acceptance of transplantation of solid organs for Jehovah Witnesses who will not accept blood or blood products will be considered on a case by case basis.

4.4 Update on NHS England

- 4.4.1 Transplant surgeons raised the concern that the body commissioning NHS activities has become fractured. Many of the Clinical Reference Groups (CRG) include transplantation as part of their remit (such as liver, intestine) but they may not have priority. The group would welcome an overarching Solid Organ Transplant CRG, with representatives from Scotland, N Ireland and Wales as well as professional bodies. This would enable transplant surgeons to speak with a single voice and to provide a formal link into NHS England.

P Friend highlighted that issues around the liver tend to get obscured by issues around the dominant organs such as the heart and kidney at current CRG meetings. P Friend will lead a delegation under BTS, with representatives from Scotland and Wales, to speak to Mr James Palmer.

4.5 IT progress report – BAG(14)6

A report was presented to members outlining the progress made since September 2013 on information technology projects.

4.5.1 Performance report of the National Bowel Allocation Scheme (NBAS) – BAG(14)7

- 4.5.1.1 An electronic scheme was introduced on 22 July 2013 for allocating donor bowels to patients requiring an intestinal transplant in the UK. It was recognised that the period of time during which the NBAS has been consistently applied has been short and numbers of transplants are small, making it difficult to produce meaningful results but the operational details of the scheme were of interest to members.

D Mirza requested that a NBAS report continues to be produced on an annual basis and that reasons for decline by centre are included as part of the report. Members are happy for results presented to be centre identifiable.

5 STATISTICS & CLINICAL STUDIES REPORT**5.1 Summary from Statistics and Clinical Studies - BAG(14)8**

- 5.1.1 R Johnson presented a paper giving an update on the current and future work undertaken by the Statistics and Clinical Studies Department at NHSBT. One change will be in addition to the Annual Activity Report, reports for Transplant Centres will be consolidated to an annual report with shorter interim reports produced every six months after each full report. Data in the consolidated annual report will be validated with centres first and will meet the requirement for reporting to NHS England. This will enable transplant centres to obtain all the required information in one format as opposed to various individual reports. This initiative is at its infancy and will start with the Heart and Liver organs. Communication is taking place with surgeons to look at what topics need to be reported. R Johnson will present a draft report at October's meeting.

6 CURRENT ACTIVITY:**6.1 Summary of registrations and transplant activity:****1 February 2013 to 31 January 2014 - BAG(14)9**

- 6.1.1 It was reported that some liver and pancreas transplants have been classed as including a bowel at Addenbrookes Hospital.

D Mirza stated that where an organ transplant entails a small part of the bowel being transplanted and the recipient doesn't have intestinal failure, e.g. pancreas transplants, this should not be classed as a bowel transplant. M D'Mello asked if there was a protocol for how the various organ transplants are recorded so that organs are not double counted in multi-organ transplants. D Mirza confirmed that there is one and explained the process.

E Allen will discuss with C Watson the issue of misclassification of some liver and pancreas transplants at Addenbrookes Hospital.

P Friend requested that the word 'failure' should be removed from the wording 'intestinal failure transplant' in all future stats papers.

BAG members agreed that in future NHSBT reports liver-only transplants of patients with intestinal failure shouldn't be reported as part of intestinal transplant activity.

7 BOWEL DONATION**7.1 Supplement to potential bowel donors and location:****1 October 2012 to 30 September 2013 - BAG(14)10**

- 7.1.1 Data were presented indicating that the main reasons why bowel offers from potential bowel donors weighing less than 50 kg between

1 October 2012 and 30 September 2013 were declined by transplant centres were due to either size, history or poor function.

It was requested that this supplement should be kept as part of the regular 'Potential bowel donors and location' report that is presented at BAG in the Autumn.

8 SMALL BOWEL TRANSPLANTS**8.1 Policy for islet transplants for non UK recipients**

- 8.1.1 It was agreed that if a donor was accepted for an intestinal transplant then the pancreas from the same donor could be allocated for a pancreas islet transplant rather than a whole pancreas organ transplant for non UK recipients.

9 EURO-TRANSPLANT**9.1 Outcome of pancreases accepted by Euro-transplant and not used**

- 9.1.1 In the event of a bowel/pancreas transplant outlined in the situation above being allocated to a possible Group 1 recipient, receiving either of the grafts would take precedence.

10 POST TRANSPLANT SURVIVAL AFTER INTESTINAL TRANSPLANTATION - BAG(14)11

- 10.1 The 82% follow-up return rate was commented to be quite low. Members requested that follow-up form return rates by centre be reported in future. S Rushton to liaise with Information Services regarding this. Members also mentioned that it would be interesting

to present a summary of causes of death and whether death with a functioning graft occurs rarely/frequently.

J Neuberger requested that a proposal for a centre specific survival model post-intestinal transplantation is presented at the next BAG Meeting. The survival analysis will be run by transplant centre, be anonymised and kept as confidential by BAG members. Members noted that the small number of intestinal transplants can produce misleading outcome figures if analysis is done by transplant centre.

11 ANY OTHER BUSINESS

- 11.1 M D'Mello commented that some of the information on the website did not seem to include 'bowel/intestine' as a separate category - as for the other advisory groups. The suggestion was made that if we are to raise awareness of the work of the BAG, then this should also be reflected as a separate heading in information/stats sheets.

E Allen will look into making BAG information more visible on the ODT website.

- 11.2 D Briggs asked if ODT get involved with holding HLA information for donor organs received outside of the UK. ODT do not hold this type of information.

12 DATE OF NEXT MEETING:

Wednesday, 8th October 2014 at ODT, Bristol.

13 FOR INFORMATION ONLY:

13.1 Transplant activity report - BAG(14)12

- 13.1.1 A paper outlining the activity of all organ transplants up to March 2013 was given.

13.2 Minutes of LAG meeting : 13 November 2013 - BAG(14)13

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

13.3 IFALD Consent - BAG(14)14

- 13.2.1 Data presented showed that of the 144 patients registered on the national list for an IFALD transplant, 100% had given consent for the use of their personal data.