Approved 12.10.16
BAG(M)(16)1 **LAG(16)43**

NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

THE THIRTEENTH MEETING OF THE BOWEL ADVISORY GROUP MEETING AT 11:30 AM ON WEDNESDAY 2 MARCH 2016 IN THE KING FISHER SEMINAR ROOM, GREAT ORMOND STREET HOSPITAL, LONDON

PRESENT:

Prof Peter Friend	**Chairman**
Dr Martin Barnardo	BSHI Rep
Mr Andrew Butler	Cambridge Intestinal Transplant Centre
Ms Melissa D'Mello	Lay Member
Ms Jackie Green	Deputy for Lydia Holdaway, Recipient Co-ordinator Rep
Dr Girish Gupte	Birmingham Intestinal Transplant centre
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Dr Edmund Jessop	Public Health Advisor
Dr Dunecan Massey	Deputy for Steve Middleton, Cambridge Intestinal Transplant Centre
Prof Elizabeth Murphy	Lay Member
Mr Srikanth Reddy	Consultant Transplant Surgeon, Oxford
Ms Susan Richards	Specialist Nurse Organ Donation Rep
Ms Sally Rushton	Statistics & Clinical Studies, NHSBT

IN ATTENDANCE:

Mrs Kamann Huang	Secretary, NHSBT

ACTION

Apologies were received from:
Ms Carly Bambridge, Prof John Dark, Dr Simon Gabe, Prof Sue Fuggle, Ms Lydia Holdaway, Mrs Rachel Johnson, Mr Hector Vilca-Melendez, Dr Steve Middleton, Dr Lisa Sharkey, Mr Khalid Sharif, Ms Anne Sheldon, Mr David Stagg and Prof Simon Travis.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA – BAG(16)1

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

2 MINUTES OF THE BAG MEETING ON 7 OCTOBER 2015 – BAG(M)(15)2

2.1 **Accuracy**

2.1.1 The minutes of the meeting held on 7 October 2015 were agreed as an accurate record of the meeting.

2.2 **Action Points – BAG(AP)(16)1**

2.2.1 All action points have been completed, are in hand or are referred to in the Agenda, apart from the following:

ACTION

AP2 - Update on postcode analysis of registered patients
A letter to the President of BSPGHAN has been sent by J Hind. He reported that centres have to apply to the Clinical Reference Group (CRG) to get Home Parenteral Nutrition (HPN) for patients. Centres listed on the Briefing document submitted at the meeting will get reimbursement. Those who are not will need to apply.

Members agreed that it was difficult to get concrete data on intestinal failure and writing to clinicians is not practical. P Friend to write to BIFA (Trevor Smith in Southampton) regarding HPN for adults. **P Friend**

AP3 – Annual report on intestinal transplantation 2014/2015
A number of system bugs are being resolved to create a robust IT process and a mechanism for chasing transplant follow up forms (going back to 2008) from centres. There has been an improvement in the return rates for the past year as a result of Information Services and recipient coordinators helping to chase them up.

AP6 – Adolescent transition in small bowel transplantation
Refer to agenda item 9.1.

AP8 – AOB
Item 3 - **Review of indications for intestinal transplantation**
A Butler will liaise with N Russell to get an update on the review of indications for intestinal transplantation with input from all centres to submit to a medical journal. **A Butler**

Item 5 - **Request for prospective donor data to a project in Germany**.
Headings for data domains were submitted from L Sharkey for members to consider. The questions raised by P Friend were: Will the information help future patients? What is the value to us? Do we want our data to be exported? Who will own this (e.g. European Registry)? and What are the quality controls for the data? In her absence D Massey to inform L Sharkey to request a formal proposal for submission to the next BAG meeting. **L Sharkey**

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**

3.1.1 - James Neuberger retired on 29 February 2016. Prof John Forsyth will be the new Associate Medical Director starting on 7 April 2016.

New Appointments:
- Anne Sheldon - Head of Offering and Referral. Started 4 January 2016.
- Bill O'Neill - NHSBT's Chief Technology Officer. Started 3 February 2016.

ACTION

3.2 **Governance**

3.2.1 **Non-compliance with allocation**

3.2.1.1 On behalf of J Dark, P Friend reported that there were no non-compliances with allocation.

3.2.2 **Detailed analysis of incidents for review – BAG(16)2**

3.2.2.1 There were no incidents brought up for review.

3.3 **IT Progress Report – BAG(16)3**

3.3.1 A report giving the progress of IT projects was submitted to members.

4 STATISTICS & CLINICAL STUDIES REPORT

4.1 **Summary from Statistics and Clinical Studies and Annual Report – BAG(16)4**

4.1 S Rushton reported on the following:

- The second Annual Report on intestinal transplantation was published last September and is available on the website. Improvements to the report content will be completed by the summer of this year.
- Notification has been sent to centres in December regarding the change to the National Bowel Allocation Scheme increasing the number of points awarded to a paediatric donor to paediatric recipient match from 1000 to 5000 points.
- Data on 20 year trends in UK intestinal transplantation have been presented and will be written into a manuscript by D Mirza and S Rushton to submit to a medical journal for publication. Centres were invited to give their input.
- Internal work is being undertaken to correct errors identified on the intestinal transplant data form. Owing to the small numbers involved this will create a proportionately larger discrepancy in the data.

S Rushton to liaise with colleagues within NHSBT to come up with a solution for the incorrect communication of organs/tissues transplanted to the ODT Duty Office at time of transplantation. **S Rushton**

5 BOWEL DONATION

5.1 **Performance Report of the National Bowel Allocation Scheme – BAG(16)5**

5.1.1 The question was raised as to whether the regular Autumn BAG paper on Potential Bowel Donors offering data and reasons for decline should be omitted as the Spring report on potential bowel donors also includes this information. Members agreed to keep the Autumn report brief as long as the Spring report contained all the relevant information required?

Following the change in the Bowel Allocation Scheme there have been five paediatric donor offers.

A small fixed term Working Group is to be set up chaired by E Murphy to look at the use of age and weight parameters in the scheme. This should include clinical representation from the four centres: Oxford, **E Murphy**

ACTION

Cambridge, King's College and Birmingham and stakeholders to discuss in detail regarding the current allocation disadvantage to a small proportion of people i.e. children and small adults. S Rushton and R Johnson to provide statistical data support. **S Rushton/ R Johnson**

To add to the agenda for review at the next meeting in October. **K Huang**

6 QUALITY OF LIFE PROJECTS (QoL)

6.1 Set up Working Group

6.1.1 It was reported that there is no defined tool for measuring quality of life for intestinal transplant. Tools used have been a visual analogue score, EQ5D data and the FS36. D Massey informed members that a project undertaken showed some cross over between adults and paediatrics. It was acknowledged any tool used needs to be based on robust and validated data with longitudinal controls.

D Massey to Chair a Working Group, with two representatives from each centre (clinician and psychologist) and M D'Mello as a lay member with the aim of publishing a QoL evaluation for both adult and paediatric intestinal transplant recipients. **D Massey**

7 PATIENT SURVIVAL OUTCOMES

7.1 Patient survival after intestinal transplantation – BAG(16)6

7.1.1 Members agreed that this report should continue to be presented alongside the Annual Report as it provides useful additional detail. A new area of reporting is on abdominal wall patient survival combined with other organs.

7.2 Review of published survival data on intestinal transplant patients – BAG(16)7

7.2.1 No major objections to NHSBT publishing risk-adjusted centre specific survival rates if statistically appropriate. Some discussion about suitable risk-factors and comments from members about the relevance of comorbidity indices. Comments that there is a difference between bowel only and modified multivisceral outcomes.

It was acknowledged that the data presented in this report was robust enough to take into account risk adjustment in spite of the small numbers used for adults.

Members agreed that they wished to continue receiving this report as well as the 'Patient survival after intestinal transplantation' report listed in item 7.1 above.

8 REVIEW OF NHSBT TRANSPLANT DATA COLLECTION – BAG(16)8

8.1 Statistics and Clinical Studies typically look at 10 years of data for monitoring looking mainly at causes of organ failure and cause of death.

Members agreed that S Reddy to lead on a small Working Group with representatives from each centre, NHSBT and the recipient coordinators to go through in detail all the data that is collected and to look at post-operative data collection. J Hind to confirm whether H Vilca-Melendez **S Reddy** **J Hind**

ACTION

should be the representative for King's and G Gupte the representative from Birmingham Children's Hospital. The work will require IT involvement.

It was stated that it would be useful to collect QoL data once it has been agreed what these are. **S Reddy**

9 ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION

9.1 E Jessop reported that a couple of meetings have been held but there has been no movement going forward. Following discussion regarding annual reimbursement to transplant centres for local care (currently individual Trusts bill Clinical Commissioning Groups (CCGs)), E Jessop reported that if a Trust provides treatment they will be reimbursed but treatment episodes need to be assigned to an existing contract e.g. specialist gastroenterology.

The Governing document on life-time care is inconsistent with the NHS England specification. E Jessop will confirm if the cut off period is two years for local care for pancreas and small bowel transplant patients. **E Jessop**

10 NEONATAL ORGAN DONORS – MINIMUM GESTATIONAL AGE AND WEIGHT CRITERIA – BAG(16)9

10.1 Discussion took place regarding whether the appropriate criteria to use for neonatal organ donation should be gestational age > 38 weeks or birth weight <3 kg. G Gupte stated that if this criteria is approved the following factors should also be considered before consent:

- Normal antenatal history;
- No family history of neonatal deaths, metabolic liver disease, multiple miscarriages in the past;
- No family history of malignancy in parents and siblings;

G Gupte will email S Tsui and ask if the CT team, and Kings, if they have any agreed criteria for neonatal organ donation. **G Gupte**

11 UPDATE ON POSTCODE ANALYSIS OF REGISTERED PATIENTS – BAG(16)10

11.1 It was agreed that it would be useful to include data in the Annual Report. The question "Is the intestinal failure service available to everyone i.e. is there national coverage?" was raised.
E Jessop to email K Huang the HIFNET report to circulate to members. **E Jessop**

12 APPEALS/PRIORITY – BAG(16)11

12.1 Further work will be undertaken by the small Working Group chaired by E Murphy to look into whether the current Bowel Allocation Scheme disadvantages a small proportion of people i.e. children and small adults. Refer to agenda item 5.1.

ACTION

13 NATIONAL INFORMATION AND CONSENT WORKING GROUP

13.1 It was highlighted that patients are being given different information at different centres and that there would be advantages in providing a nationally consistent view. This issue was discussed at the Pancreas Advisory Group (PAG) a year ago and

A PAG working group is currently in the process of producing a booklet. It was agreed that it would be beneficial to look at this booklet as a starting point. It was agreed that the patient consent booklet should be uploaded on the website at a later stage.

A Butler to Chair a Working Group to write a patient information and consent document for all types of intestinal transplant. A Butler to inform P Friend membership of the group. **A Butler**

14 ADULT AND PAEDIATRIC SERVICE SPECIFICATION – BAG(16)12

14.1 E Jessop reported that the purpose of the Specification is to ensure that costs are assigned to the correct contracts, as well as to describe the service. K Huang to re-circulate the Specification for feedback from Centres by Wednesday 30th March 2016 and for the proposal to include paediatrics. The question was also raised as to whether living donors should be included (although not carried out for several years, this does still remain a potential therapeutic option). NHS England will also be provide input. It was agreed that, in due course, this document should be put in the public domain. **K Huang/ All**

15 ANY OTHER BUSINESS

15.1 Following recent commissioning of limb transplantation NHSBT have been asked to provide a framework. J Neuberger proposed that the Composite Tissue Group should join the Bowel Advisory Group as the Group already involves composite tissue. P Friend to liaise with Simon Kaye and will provide an update. **P Friend**

16 DATE OF NEXT MEETINGS:

- Wednesday 12th October 2016. ODT, Bristol.

17 FOR INFORMATION ONLY:

Papers attached for information were:

- Transplant activity report for January 2016 – BAG(16)13
- Minutes of LAG meeting : 18 November 2015 – BAG(16)14
- Intestinal Patient Consent – BAG(16)15