

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

**MINUTES OF THE TWENTY- SECOND MEETING OF THE  
LIVER ADVISORY GROUP  
HELD ON WEDNESDAY 14<sup>TH</sup> NOVEMBER 2012  
AT ODT, BRISTOL**

**PRESENT:**

<b>Dr Alexander Gimson</b>	<b>Chair</b>
<b>Mr Murat Akyol</b>	<b>Chair, Liver Selection and Allocation Working Party</b>
<b>Dr Varuna Aluvihare</b>	<b>Kings College Hospital, London</b>
<b>Prof Dave Collett</b>	<b>Associate Director of Statistics &amp; Clinical Audit, NHSBT</b>
<b>Mrs Claire Counter</b>	<b>Statistics &amp; Clinical Audit, NHSBT</b>
<b>Miss Sue Falvey</b>	<b>Head of Clinical &amp; Nursing Governance, NHSBT</b>
<b>Dr James Ferguson</b>	<b>Queen Elizabeth Hospital, Birmingham</b>
<b>Mrs Samantha Fletcher</b>	<b>Assistant Director, External Affairs, NHSBT</b>
<b>Mr Paul Gibbs</b>	<b>Deputy for N Jamieson, Addenbrooke's Hospital, Cambridge</b>
<b>Ms Vicky Griffin</b>	<b>Stakeholder Relations Manager, NHSBT</b>
<b>Dr Bill Griffiths</b>	<b>Addenbrooke's Hospital, Cambridge</b>
<b>Mr Ernest Hidalgo</b>	<b>St James's University Hospital, Leeds</b>
<b>Dr Mark Hudson</b>	<b>Freeman Hospital, Newcastle</b>
<b>Dr Edmund Jessop</b>	<b>National Specialist Commissioning Team</b>
<b>Dr Alastair MacGilchrist</b>	<b>Royal Infirmary, Edinburgh</b>
<b>Prof Derek Manas</b>	<b>Freeman Hospital, Newcastle</b>
<b>Mr David Mayer</b>	<b>National Clinical Lead, NHSBT</b>
<b>Dr Patricia McClean</b>	<b>General Infirmary, Leeds</b>
<b>Mr Paolo Muesan</b>	<b>Birmingham, Queen Elizabeth Hospital</b>
<b>Prof James Neuberger</b>	<b>Associate Medical Director, NHSBT</b>
<b>Mr James Powell</b>	<b>Royal Infirmary, Edinburgh</b>
<b>Mr Dinesh Sharma</b>	<b>Royal Free Hospital, London</b>
<b>Mr Parthi Srinivasan</b>	<b>Kings College Hospital, London</b>
<b>Ms Helen Tincknell</b>	<b>Lead Nurse – Recipient Co-ordination</b>
<b>Prof Jan Van Der Meulen</b>	<b>Royal College of Surgeons, London</b>
<b>Mrs Ann Yates</b>	<b>Duty Office Manager, ODT</b>

**IN ATTENDANCE:**

Mrs Kamann Huang Clinical & Support Services, ODT

## ACTION

## APOLOGIES & WELCOME

Apologies were received from Dr Alistair Baker, Prof Andrew Burroughs, Dr Mervyn Davies, Dr Susan Fuggle, Ms Sally Johnson, Mr Neville Jamieson, Prof Aiden McCormick, Dr Patrick McKiernan, Mr Darius Mirza, Mr Rutger Ploeg, Ms Susan Richards, Mr Douglas Thorburn and Prof Oscar Traynor.

## 1 DECLARATIONS OF INTEREST IN RELATION TO THE AGENDA

– LAG(12)25

1.1 There were no declarations of interest.

**2 MINUTES OF THE MEETING HELD ON 23 MAY 2012 – LAG(M)(12)1**

## 2.1 Accuracy

The minutes of the previous meeting were agreed as a correct record.

2.2 **Action points – LAG (AP)(12)2**

All action points completed with the exception of those below:

**AP1** – Draft protocol for benchwork and preparation of pancreases at retrieval. Refer to agenda item 8.

**AP2 – Developments in NHSBT:** Bribery Act 2010 compliance. Refer to AOB.

**AP4 – Liver splitting activity report:** Circulate revised policy and identify liver splitting surgeons. Refer to agenda item 3.2.1.1.

Examine CIT for imported / exported right lobes. Refer to agenda item 3.2.1.1.

**AP5 – LSAWP:** Changes for representation on appeals panel to be incorporated into the Selection and Allocation Policy is in progress.

**AP6 – Review of outcomes after super-urgent transplant:** Assist in data collection on outcomes of patients removed from the super-urgent transplant list. Refer to agenda item 5.3.4.

**AP7 – Transplantation for neuroendocrine tumours:** Ongoing review through LSAWP.

**AP8 – Combined liver/cardiothoracic transplantation:** Refer to agenda at item 5.3.5.

**AP9 – Liver transplantation for Sickle Cell Hepatopathy:** To be included on Elective Liver Registration Form.

**AP10 – Simultaneous liver and kidney transplantation for patients with atypical HUS:** Refer to agenda item 5.3.6.

**AP11 – Update on SAAH:** On agenda at item 5.3.7.

**AP12 – Proposed renal sparing study in liver transplant recipients:** Ongoing.

**AP13 – Declined liver offer from deceased donors:** Deferred to Spring 2013.

**AP14 – Fast track offering process:** Refer to agenda item 3.7.

**AP18 - AOB: Prepare funnel plots on organ damage:** A paper from D Mayer was circulated to members.

2.2.1 **Matters arising, not separately identified**

There were no other matters arising.

**3 ASSOCIATE MEDICAL DIRECTOR'S REPORT**3.1 **Developments in NHSBT – J Neuberger**

- 3.1.1 - D Mayer is retiring from the Clinical Retrieval Group. Interviews are being held next week for his replacement. It is anticipated that the NHSBT

Microsite will be operational by the end of the year. This will provide a resource for clinicians and others about the policies, documents and information on organ donation and transplantation.

- J Neuberger will be visiting the Northern Ireland Health Department in December to discuss issues relating to donation and transplantation. Members were asked to email him any issues they wish to be raised on their behalf.

**All centre  
Reps**

### 3.1.2 **Update on NHSBT Strategy –**

The Organ Donation Task Force work-plan ends April 2013. Discussions are taking place on the strategy for the next seven years, to which LAG has submitted some views. The draft Strategy will be circulated in the Jan 2013. Feedback from Advisory Groups will be obtained before the implementation date of April 2013.

**C Williment/  
NHSBT**

### 3.1.3 **Update on ACCORD study –**

The EU joint study started in May this year and NHSBT is leading the work to identify variation in end of life care across the sixteen member states and how this impacts on donor rates. The key aim of the Work Package is to strengthen working partnerships between ICU and SNODs.

## 3.2 **Governance Issues**

### 3.2.1 **Non – compliance with liver splitting**

#### 3.2.1.1 **Liver splitting activity report – LAG(12)26**

Members were asked to remind their centres of the need to fill in the NHSBT 'Split Liver Information' form at the time the liver is split to facilitate accurate record keeping.

A Gimson to write to Clinical Leads of the transplant centres concerned for their feedback regarding the reported cases of livers not being split for recipient reasons, as this reason is outside the split liver criteria.

**A Gimson**

A Gimson will re-circulate to transplant centres the criteria for liver splitting as some centres are not adhering to the protocol.

**A Gimson**

C Counter to include both paediatric and adult transplant list mortality with each Liver Splitting Report to LAG.

**C Counter**

#### **Post Meeting note:**

Reasons to why two liver donors from Birmingham were turned down for splitting.

Donor 1: Liver not split due to downtime and Liver function test.

Donor 2: Donor was too fat - 90kg donor with BMI of 31.5

### 3.2.2 **Non-compliance with allocation – A Yates**

There were no instances of non-compliance with allocation.

### 3.2.3 **Incidents for review**

There were no reported incidents.

### 3.2.4 **Summary of CUSUM monitoring of outcomes following liver transplantation – J Neuberger**

There were no triggers being reported.

### 3.3 **Summary of potential and actual organ donation activity – LAG(12)27**

The paper presented current and historical data on organs donated and utilised for the period 1 October 2009 to 30 June 2012.

### 3.4 **Potential for organ donation and transplantation – LAG(12)28**

A paper was circulated describing the points at which a potential donor may be turned down for transplantation. This is being used to inform decisions concerning where investment or changes in donation practice may be most fruitful.

### 3.5 **NHSBT Research**

#### 3.5.1 **Research Governance Policy for Supporting Research Proposals – LAG(12)29**

HTA regulations state that any organs removed from the deceased in England and Wales specifically for research purposes has to be undertaken on licenced premises.

In cases where an organ has been removed and then deemed unfit for transplant, and where consent has been given, the organ can be used for research purposes.

A policy will need to be developed to outline the process and the priority with which the organ not required for transplantation is allocated to specific research projects. Units will need to supply single points of contact for collection and supply.

J Neuberger will draw up guidelines to describe the process and circulate this to transplant centres.

**J Neuberger**

#### 3.5.2 **Allocation of organs for research projects – LAG(12)30**

3.5.2.1 Refer to 3.5.1 above.

#### 3.5.3 **QUOD – J Neuberger**

R Ploeg is developing a facility to collect donor and recipient material as a resource for future research.

### 3.6 **Update on review of Advisory Groups – J Neuberger**

A copy of the formal report from Gillian Schiller and the three independent reviewers has now been received by NHSBT. G Schiller will present her recommendations to a Board Meeting in November to which the Chairs of the Advisory Groups have been invited to attend. J Neuberger will set up an Implementation Group. It is likely that the recommendations will include a wider advisory group meeting twice yearly for each organ and a core group meeting more frequently, both chaired by the Chair of the Advisory Group. The report also recommends a process for patient, carer and lay involvement. Different solutions may be required for each Advisory Group.

**3.7 IT priorities progress report – LAG(12)31**

IT issues will be discussed at the Advisory Group Chairs meeting on 15<sup>th</sup> November.

A revised version of EOS enabling information to be viewed on smart phones and tablets will be rolled out in 2013, and the microsite mentioned in 3.1.1. above.

Once those are completed the prioritisation of the next set of IT projects will need to be decided after advice from the Advisory Group Chair's Meeting.

Whether priority should go to updating different Organ Advisory Group's allocations schemes or to updating the whole of the National Transplant Database will need to be the first decision

A Gimson highlighted his concern regarding the delay in changes being made to the allocation scheme owing to IT issues.

**3.8 EU Organ Directive – S Falvey**

The electronic system for reporting clinical incidents will go live on Monday 19<sup>th</sup> November accessed by a link on the website but will not be password protected owing to the volume of users.

Implementation of the new regulations require all clinical incidents, notifiable under the regulations to be reported within 24 hours. HTA will be monitoring the system.

A Gimson asked for a comprehensive summary of the process managed by NHSBT to be circulated to LAG members detailing the definition of a "clinical incident".

**S Falvey**

There is an Organ Box workshop on 28 November where the decision will be taken to select the most suitable box for transporting organs, attended by the four remaining suppliers. Members were requested to send a representative from their centre to attend.

**Transplant Centres**

**4 Associate Director of Statistics and Clinical Audit's report – D Collett****4.1 Conference presentations, current and future work – LAG(12)32**

The work of the S&CA department was detailed. D Collett reported that much of the work had been focused on the adult elective liver allocation scheme (LTAS). The use of HES data was also highlighted enabling outcome to be looked at from hospitals other than transplant centres; a benefit for audit purposes.

**4.2 Advisory Group workplan – LAG(12)33**

A paper was presented to members for information outlining the schedule of fixed term and annual projects.

**5 Liver Selection & Allocation****5.1 Blood group waiting times and deaths on the transplant list – LAG(12)34**

Data for median waiting times by Blood Group and by Transplant Centre was presented with comparison over previous two years

**5.2 Donor allocation – zone realignment – LAG(12)35**

It was reported that there was a statistically significant difference between the transplant centres in their percentage share of registrations and their percentage share of donors from their liver allocation zones. A change to realign the zone will be circulated to LAG members for approval before implementation.

**C Counter/  
A Gimson**

**5.3 Liver Selection & Allocation Working Party****5.3.1 Minutes of LSAWP meeting held on 7 September 2012 – LAG(12)36**

The minutes of the LSAWP held on 7 September 2012 was presented to members.

**5.3.2 Outcome of appeals (1 May 2012 – 31 October 2012) – LAG(12)37**

Members were informed of two patients referred for super urgent listing; one for liver only and one for bowel and liver. The super urgent criteria for multi-visceral transplant has been agreed by BAG members.

D Manas requested that it would be beneficial to receive feedback on the outcome of transplanted patients following appeals. This information will be included for the next LAG meeting

**C Counter/  
A Gimson**

**5.3.3 Update on interim allocation scheme – M Akyol**

It was agreed at 7<sup>th</sup> September and 31 October 2012 LSAWP meetings that “need/risk of dying on the transplant list” should be the primary consideration in the allocation of organs, as there remained some concern about the validity of transplant benefit scores. At the LSAWP on 31 October 2012 analysis on five scores were presented to predict early mortality on the waiting list. Further work is being undertaken on these scores. It was emphasised that the score would describe an offering sequence and Transplant Teams would make their own decision as to whether to accept the organ for the ranked patients. If they did not wish to use that organ in a specific case they would need to give written justification of that decision.

An interim policy would be circulated before the New Year. Considerable IT support would be necessary to help Units rank their cases by whatever formulae was finally selected

**(i) Reason for Patient Mortality**

As recommended by the LSAWP, all centres will start to collect data on the reason for death of those dying on the transplant waiting list.

**Transplant  
Centres**

**(ii) Sequential Data Collection**

It was agreed that in order to continue the analysis into the optimum adult elective allocation scheme sequential data collection will be undertaken on all patients on the waiting list at monthly intervals.

A Gimson will send a letter to Clinical Leads.

**A Gimson**

C Counter and H Tincknell will send out a letter with the data collection form to recipient co-ordinators.

**C Counter/  
H Tincknell**

**(iii) Minimising variations in score calculations**

Variations in laboratory testing methodologies may impact on allocation scores. This work is ongoing and led by Professor A Burroughs.

- 5.3.4 **Update on review of outcomes after super-urgent transplantation – A Gimson**  
Analysis of this work is still ongoing. The current criteria for super urgent transplantation will not change.
- 5.3.5 **Combined cardiothoracic / liver transplantation update – B Griffiths**  
The protocol for combined liver and cardiothoracic transplantation had been reviewed and accepted at CTAG.  
  
It was recommended that for organ allocation the liver will follow the lung and that this will come below super-urgent/hepatoblastoma/multivisceral allocation but above splitting the liver. This was agreed.  
  
It was recommended that initially cases with cystic fibrosis would be considered and those with very severe disease not included initially. B Griffiths is to amend the proposal for circulation to LAG members for approval. **B Griffiths**  
  
The change will subsequently be incorporated into the Allocation Policy to be effective from 1<sup>st</sup> April 2013.
- 5.3.6 **Update on simultaneous liver and kidney transplantation for patients with atypical HUS – E Jessop**  
No national decision has yet been made on the recommendation for a simultaneous liver and kidney transplantation for patients with atypical HUS. This will be carried over to the next LAG meeting. **CSS**
- 5.3.7 **Update on liver transplantation in the SAAH – LAG(12)38a, b and c**  
A communications policy around the introduction of liver transplantation in SAAH patients for a limited period is in progress. Implementation of this will not occur before the next LAG meeting.  
  
It has been noted that two centres, Edinburgh and Birmingham were not supportive of the proposal,
- 5.3.8 **Sequential data collection – LAG(12)39**  
Refer to minute 5.3.5.
- 5.3.9 **RCS/NHSBT joint audit contract – A Gimson**  
The RCS/NHSBT joint audit comes to an end next year. A Gimson reported that the audit has been highly successful, of excellent data quality and had produced a number of important publications. This view was shared by LAG members. E Jessop stated that further funding would be for the new Commissioning Board and recognised its importance.  
  
D Collett highlighted that in the event of the audit terminating this will have no impact on the collection of NHSBT data.
- 5.4 **Minimal information for exceptional listing requests – LAG(12)40**  
A proposal outlining the minimum information required when submitting a request for exceptional listing to the Appeals Panel was approved by members. A Gimson will circulate the protocol to Clinical Leads for implementation. **A Gimson**

- 6 Review of ABO incompatible liver transplantation – impact of new technology – LAG(12)41a, b and c**
- The LSAWP will take this proposal up looking at new technology in terms of cadaveric donation which would be helpful in cases when an AB liver cannot be placed. LSAWP to feed back to the next LAG meeting.
- M Akyol**
- 7 Review of adult to adult living donor programme in England – LAG(12)42**
- The uptake of adult to adult liver transplantation, since its introduction, had been variable between transplant centres. Edmund Jessup asked for LAG to produce a review of past activity and make recommendations for the future. All centres expressed a wish to be involved in that strategy paper. Edinburgh will only participate in an observer capacity given the review covers centres in England only.
- A Gimson will set up a meeting of all centres to agree a document for presentation the SCB prior to LAG May 2013.
- This topic will be carried forward to the next LAG meeting.
- A Gimson**
- CSS**
- 8 Draft protocol for bench-work and preparation of pancreas at retrieval – LAG(12)43**
- A Gimson will write to PAG regarding this protocol.
- A Gimson**
- 9 Bowel Advisory Group**
- 9.1 Minutes of the Bowel Advisory Group meeting: 21 March 2012 – LAG(12)44**
- Concern was expressed about the selection of cholangiocarcinoma and neuroendocrine tumours as indications for multivisceral transplantations when these were not indications for liver only transplantation.
- A Gimson will write BAG asking for an explanation of their inclusion.
- A Gimson**
- 9.2 Report from the Bowel Advisory Group meeting: 24<sup>th</sup> October 2012 – D Mirza**
- The main issues discussed at the last Bowel Advisory Group meeting were:
- There is a need for referral guidelines and for referral to be done in a timely manner.
  - A proposal to arrangements for the transfer of teenage paediatric intestinal transplant recipients to adults transplant centres was agreed.
  - A proposal for standardisation of protocol for testing, reporting and cross-matching for HLA specific antibodies in bowel transplantation in the UK.
- 10 ANY OTHER BUSINESS**
- 10.1** Three hospitals in Europe have been accused of falsifying blood samples from potential liver transplant recipients in exchange for money. J Neuberger stated that it is the responsibility of the person registering the patient for transplant to ensure the data is accurate and honest. Therefore any malpractice will be the responsibility of the centre and not down to NHSBT. An amendment will be



made on the registration form to include the name of the clinician filling in the form.

## 10.2 **Super Urgent Liver registrations – LAG(12)51**

Members discussed the option for a liver to be offered to a transplant centre with a patient listed as a super urgent liver registration, in exchange for a liver to be returned at a later stage. The decision was made not to adopt the proposal.

## 11 **DATE OF NEXT MEETINGS**

Wednesday 15 May 2013 at ODT, Bristol

Wednesday 13 November 2013 at Society of Chemical Industry, London

## 12 **FOR INFORMATION ONLY**

### 12.1 **Publication of a transplant dataset – LAG(12)45**

Members received a paper outlining how NHSBT handles external requests for national data in support of studies and research.

### 12.2 **Group 2 transplants – LAG(12)46**

A paper reporting on liver transplants performed for Group 2 patients and liver transplants performed for Group 1 non-UK resident EU patients between 1 October 2011 and 30 September 2012 was given.

### 12.3 **Transplant Activity report: October 2012 - LAG(12)47**

A paper outlining the activity of all organ transplants up to October 2012 was given.

### 12.4 **Liver super-urgent and cardiothoracic urgent offering – LAG(12)48**

Members received a list of the changes to the liver super-urgent and cardiothoracic urgent offering.

### 12.5 **NHSBT Contra-indications to organ donation – LAG(12)49**

An updated list was given to members on the absolute contraindications to donation and organ specific contraindications.

### 12.6 **Minutes from the Clinical Retrieval Group: 22 June 2012 – LAG(12)50**

Members received a copy of the minutes of the Clinical Retrieval Group meeting held on 22 June 2012.