

NHS BLOOD AND TRANSPLANT

**NOTES OF THE ADVISORY GROUP CHAIRS COMMITTEE MEETING
HELD AT 10.00 AM ON THURSDAY, 10TH OCTOBER 2013
AT THE AEONIAN CONFERENCE CENTRE, LONDON**

PRESENT: Prof James Neuberger, Associate Medical Director, ODT (**Chair**)
Dr Nick Banner, Cardiothoracic Advisory Group Deputy Chair (Heart)
Mr Roberto Cacciola, Associate Clinical Lead for Retrieval
Mr Chris Callaghan, Deputy for Prof Anthony Warrens, BTS
Prof Peter Friend, Pancreas Advisory Group Chair
Mrs Rachel Johnson, Head of Organ Donation & Transplantation Studies, NHSBT

Ms Sally Johnson, ODT Director, NHSBT
Mr James McNeill, Business Transformation Services, NHSBT
Prof John O'Grady, Liver Advisory Group Chair
Prof Rutger Ploeg, Clinical Retrieval Group Chair
Ms Helen Tincknell, Lead Nurse: Recipient Co-ordination
Mr Steven Tsui, Cardiothoracic Advisory Group Chair
Prof Chris Watson, Kidney Advisory Group Chair
Mrs Claire Williment, Head of Transplant Development, ODT

IN ATTENDANCE:

Mr Mike McManamon, Gatenby Sanderson (part meeting)
Mr Jeremy Monroe, Non-Executive Director NHSBT
Ms Melanie Shearer, Gatenby Sanderson (part meeting)
Ms Helene Usherwood, Gatenby Sanderson (part meeting)
Mrs Kathy Zalewska, ODT (Secretary)

Prof Neuberger introduced Mr Jeremy Monroe, the incoming Chair of the Transplant Policy Review Committee to the meeting. Also welcomed to their first meeting, as Advisory Group Chairs, were Prof John O'Grady and Prof Chris Watson; and Dr Nick Banner as CTAG Deputy Chair.

Apologies were received from Mr Steve Clark, Prof John Dark, Prof Stephen Kaye, Prof Derek Manas, Dr Gerlinde Mandersloot, Ms Lorna Marson, Prof Darius Mirza, Dr Paul Murphy, Mr Mike Potter, Mr Aaron Powell, Mr John Richardson, Prof Anthony Warrens, and Dr Lorna Williamson.

There were no declarations of interest.

ACTION

- 1 MINUTES OF PREVIOUS MEETING: 2ND JULY 2013 – AGChC(M)(13)3**
 - 1.1 The minutes were agreed as a correct record.
- 2 ACTION POINTS: AGChC(AP)(13)4**
 - 2.1 **AP1** - Completed
AP2 – Offering & retrieval pathway – H & I project: A Warrens and S Fuggle, working on behalf of the BTS and BSHI, and with the support of NHSBT will produce a proposal to deliver effective H & I services to England, Wales and N Ireland.

ACTION

AP3 - NHSBT CMV testing: Not all recipient centres undertake CMV testing therefore NHSBT should continue to test donors for CMV, EBV and Toxo.

AP4 - A workshop is being arranged by NHSBT Communications for January 2014 on managing public attitude towards donation, with participation from Chairs, the Health Administrations and the BTS.

AP5 – Completed.

AP6 - Completed.

3 NHSBT ISSUES

3.1 Organ Donation & Transplantation Congress - Sept 2013 – AGChC(13)30

The Congress took place on 3rd & 4th September and positive feedback was received. This will become a bi-annual event.

3.2 Update on TOT2020 Strategy – AGChC(13)30

C Williment reported on the NHSBT TOT2020 strategy, many of the actions from which will fall to NHSBT to lead. Implementation of the strategy will be a phased process. Two oversight groups have been established. The Implementation Oversight Group will be responsible for bringing together all those with a role in implementing the new strategy, and will be chaired by Elisabeth Buggins. The Stakeholder Group has responsibility for overseeing the role of the voluntary and faith third sectors in plans to change society's attitudes and behaviours towards donation. It is likely that the Stakeholder Group will seek advice and steer from both this Group and the individual Advisory Groups.

3.3 Support for Advisory Groups

3.3.1 Admin Support – AGChC(13)1

A paper was received for information detailing the administrative and statistical support for the individual Advisory Groups and Clinical Committees and the ODT Medical Team. The individuals responsible for supporting these Groups would be liaising with Chairs and the Medical Team to discuss support requirements.

4 HISTOPATHOLOGY AUDIT – AGChC(13)32

4.1 R Cacciola reported on progress with the national histopathology audit which started on 1st October and which will focus on the potential impact of provision of an out of hours histopathology service on the number of organs for transplantation. Data are being collected by retrieval teams and at transplant centres. The audit is planned to run initially for 3 months. Interim data will be available after 1 month.

5 RELATIONS WITH REPUBLIC OF IRELAND (ROI)

5.1 J Neuberger reported on discussions taking place to clarify formal arrangements for organ donation and transplantation with other countries, particularly ROI. It is important that the UK continues to provide a transparent service where appropriate and the Department of Health has been approached to provide greater clarity and reassurance in this area.

ACTION

6 SOLID ORGAN ADVISORY GROUP REVIEW**6.1 Draft ToR for Solid Organ Advisory Groups – Chairs’ reports**

J Neuberger reminded Chairs of the need to provide new terms of reference for their individual Advisory Groups, based on the generic terms of reference arising from the SOAG review. He emphasised the need for the Advisory Groups to tailor the ToR to the needs of their particular group.

6.2 Recruitment and involvement of lay members

J Neuberger welcomed to the meeting Mr Mike McManamon, Ms Melanie Shearer and Ms Helene Usherwood from Gatenby Sanderson, the company responsible for recruiting lay members. A presentation on the recruitment campaign and assessment techniques was received. Chairs were encouraged to participate in both the assessment process for lay members and a half day induction.

By the end of 2013 a working group will have taken place for Chairs to receive guidance on best practice in terms of working with lay members.

An annual meeting of lay members will also take place to provide feedback and will be independently chaired.

6.3 Organ decline rates

Item carried forward in the absence of Prof. Dark.

7 UPDATE FROM BUSINESS TRANSFORMATION SERVICES**7.1 Change project update**

J McNeill gave a presentation on the change project; the National Referral Service Vision; and portfolio change initiatives.

Change project update - Key projects are:

- Opt out system and register (new ODR) - Implementation targeted for Q1 2015
- Donor registration transformation - Implementation targeted for Q1 2014
- IFALD - Waiting time functionality to be implemented by early November 2013
- ODT infrastructure refresh - More planning to do but the aim is to complete in Q3 2014
- DCD Kidney - Implementation of allocation scheme elements remains at Q2 2014

National Referral Service Vision:

J McNeill outlined the vision and processes involved in the service. Work on this is still in the early stages. It was noted that no changes would be implemented without full discussion and the support of clinicians. Part of this work will be consideration of a centralised control for retrieval teams and members commented that this aspect needs to be implemented as soon as possible as a ‘quick win’.

S Johnson agreed to liaise with A Powell on the need to fast track this element of the work.

S Johnson

ACTION

Portfolio Change Initiative:

There are 35 initiatives to be scoped, planned and governed, all of which will be competing for funding, scarce resources and stakeholder input. Members reviewed the initiatives under consideration, some of which are current, some are 'need to do' and some are implied as part of the strategy. Output from the discussion would be circulated by J McNeill together with background information on the projects for comment within two weeks.

J McNeill

7.2 Transplantation Support Services (TSS) changes

New appointments within TSS were noted:

Aaron Powell, Assistant Director – Transplantation Support Services

Claire Williment, Head of Transplant Development

Olive McGowan, Assistant Director – Education and Excellence

Following a review of TSS some management roles have been disestablished and new roles for Head of Referral and Offering and Head of Information Services created. A new Performance and Business Manager will also be appointed, reporting to S Johnson.

8 IMMINENT AUDIT OF QUALITY DOCUMENTATION OF DONOR ORGANS (HTA A & B FORMS) – AGChC(13)33

R Ploeg reported on an audit of HTA A & B forms which it is hoped can be carried out on the back of an existing audit programme.

9 UPDATE ON THE USE OF DECEASED DONOR ORGANS FOR NON-NHS ENTITLED PATIENTS

NHSBT has written to the Department of Health to provide greater clarity and reassurance on the issue of private patients and non-NHS entitled patients. Although this is a small cohort of patients and doesn't adversely impact on the work of NHSBT this does have potential impact in terms of generating adverse publicity that may affect donation.

10 MEDIUM TERM WORK PLAN FOR CRG AND ADVISORY GROUP PRIORITIES – AGChC(13)34

R Ploeg advised on proposals for a workplan for the Clinical Retrieval Group looking at quality and sustainability. Advisory Group Chairs would be asked to put forward three organ specific retrieval related priorities to be included within the CRG workplan.

11 HORIZON SCANNING WORKSHOP UPDATE

11.1 This workshop, scheduled to take place on 25th October in Newcastle, will bring together surgeons, commissioners, NHSBT, and industry representatives to help understand the state of current technologies, future needs and the requirements for a business case, potential costs, logistical issues and benefits to recipients.

11.2 Peer review

C Williment reported on behalf of J Dark on plans for peer reviews to be carried out in conjunction with visits from Commissioners. These reviews, undertaken to share best practice and raise quality, currently take place on an ad hoc basis.

ACTION

12 REPRESENTATION OF ORGAN ADVISORY GROUPS ON THE QUOD CONSORTIUM – AGChC(13)35

At the last QUOD Consortium meeting in September there was discussion on the infrastructure; progress with the licensing in England and Wales; transparency of the consortium; and the access policy. R Ploeg advised that he would be asking for Advisory Group representation on the Consortium.

13 BTS REPRESENTATION ON ADVISORY GROUPS

At a recent meeting with the President of the British Transplantation Society it was requested that there should be BTS representation on Solid Organ Advisory Groups. J Neuberger will write to Chairs to ask them to liaise with the BTS President to decide on the representative for their Advisory Group. As there is duplication of interest and representation on the Groups it was suggested that an existing member should represent the BTS where appropriate. This would be acceptable to the BTS. It was emphasised that this should not be a token exercise but used as an opportunity for the views of the BTS to be aired with Advisory Groups and vice versa, perhaps via a regular agenda item. Representation from other professional bodies is also encouraged, where appropriate.

J Neuberger

14 JPAC RED BOOK AND ORGAN DONOR ASSESSMENT GUIDELINES

J Neuberger reported on a suggestion that NHSBT organ donor assessment guidelines be included under the umbrella of JPAC which manages the Donor Selection Guidelines for blood, tissues, stem cells and cord blood. Following discussion it was agreed that although there may be some benefit in learning from JPAC's knowledge there were three key issues to consider:

- The balance of risks for organs and for tissues/blood is very different
- This is a real risk of either duplication and/or confusion. SaBTO and the Council of Europe also provide advice.
- The management of the blood/tissue service lies entirely within NHSBT whereas for organs, the decision is made by transplant clinicians who are not accountable to nor managed by NHSBT.

It was therefore agreed not to change the arrangements at this time.

15 DRAFT TERMS OF REFERENCE OF PATIENT SUPPORT GROUP MEETINGS v3 – AGChC(13)36

Members noted for information the draft terms of reference of the patient support groups. It is the decision of the SOAG Chair to decide the most appropriate links with patient support groups. This should be supplemented by a formal meeting of patient advisory groups once a year. Chairs were asked to submit any further comments to K Zalewska, following which meetings for 2014 would be scheduled.

AG Chairs

16 REVISION OF CORE DONOR DATA FORM

A paper detailing feedback received on the extended consultation on suggested changes to the Core Donor Data set was received for information. Members were asked to ratify the recommended changes.

ACTION

It was agreed that any further comments should be received within the next week following which the changes would be deemed to be ratified.

17 REPORT ON CORONER AND SCOUT PILOT PROJECTS

These projects report to the Clinical Retrieval Group and the National Organ Donation Committee so it was deemed unnecessary for these reports to be duplicated at this Committee.

18 HEART AND LUNG ALLOCATION UPDATE

Work is ongoing on the policies for heart and lung allocation. Both documents are due to be finalised by April 2014.

19 ANY OTHER BUSINESS

- J Neuberger advised of his intention to produce the 'ODT Associate Medical Director's Bulletin' on a monthly basis. This would also be placed on the ODT Clinical Website. Members were asked to ensure this communication is disseminated widely and to feedback comments.
- J Neuberger reported on an issue raised by an MP on the transfer of patients between transplant centres particularly those paediatric patients reaching the age and development where follow-up at an adult centre is more appropriate. NHSBT/BTS would produce broad generic guidelines on the transfer of care and outline the roles and responsibilities of those involved.
- Details of changes to responsibilities within NHSBT Statistics and Clinical Studies are available on the ODT Clinical Website.
- Comments for improvements to the ODT Clinical Website would be welcomed.
- On behalf of the Committee, J Neuberger thanked Prof Andrew Bradley, Dr Alex Gimson, and Prof Stephen Kaye who had all recently completed their second and final terms as Chairs of KAG, LAG and OTAG respectively. It was noted that Mr Derek Tole would be taking over as Chair of OTAG from November 2013.
- C Watson reported on problems with EOS crashing and the Core Donor Data Form being inaccessible. Details to be sent to J McNeill to follow up with the NHSBT Service Desk.
- J McNeill agreed to follow up with John Richardson on a query as to whether there is a process in place to advise surgeons of any changes that are made by the SNOD after the organ has been accepted.

J Neuberger

**C Watson/
J McNeill**

**J McNeill/
J Richardson**

20 PROVISIONAL DATES FOR 2014

Possible dates for meetings in 2014 would be issued to members in due course.

October 2013