

NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE
BOWEL ADVISORY GROUP

SUMMARY FROM STATISTICS AND CLINICAL STUDIES

INTRODUCTION

- 1 This paper provides an update from NHSBT Statistics and Clinical Studies and summarises recent presentations, publications, current and future work.

UPDATE FROM STATISTICS AND CLINICAL STUDIES

- 2 There have been some recent changes to the Statistics group at NHSBT as detailed below. We are currently going through a period of transition as some staff take over new roles but hope this will not affect the service we provide.

Changes to roles within Statistics and Clinical Studies

Statistics and Clinical Studies is the new name for Statistics and Clinical Audit to reflect the recent addition of the NHSBT Clinical Trials Unit to the group and the move of the Clinical Audit team to the Governance and Clinical Effectiveness Directorate. Prof Dave Collett is the Associate Director for Statistics and Clinical Studies.

Following recent appointments to vacant posts, some changes of responsibilities have been made within the Statistics team. Individual lead roles within the group are now as follows:

ORGAN DONATION AND TRANSPLANTATION

Support for all ODT activities is overseen by Rachel Johnson, Head of Organ Donation and Transplantation Studies.

Organ donation and retrieval

Organ donation – Joanne Allen (supporting NODC)

Organ retrieval – Cara Murphy (supporting the Clinical Retrieval Group)

Transplantation - Advisory Groups

Bowel Advisory Group – Elisa Allen

Cardiothoracic Advisory Group – Jenny Lannon

Kidney Advisory Group and Paediatric Sub-Group – Alex Hudson

Liver Advisory Group – Elisa Allen

Pancreas Advisory Group and Islet Task Force – Lisa Bradbury (née Mumford)

Ocular Tissue Advisory Group – Mark Jones

Chairs of Advisory Groups – Rachel Johnson

Other ODT

Performance monitoring of transplant centres – Sue Madden
 ODT Services* – Claire Counter

OTHER SPECIALIST ROLES

Transfusion Medicine, Tissue Donation and Blood Donation – Frances Seeney
 Clinical Trials – Helen Thomas
 Enquiries – Mark Jones – statistical.enquiries@nhsbt.nhs.uk
 Clinical Business Analyst – Iain Harrison

** this new role encompasses projects relevant to all Advisory Groups and coordination, support and development for external facing communications, data provision and publications including enhancements to the statistics content on the ODT clinical (www.odt.nhs.uk) and general (www.organdonation.nhs.uk) websites*

- 3 Statistics and Clinical Studies now incorporates the **Clinical Studies Unit** of NHSBT. The Unit was established over ten years ago and has successfully managed a large number of clinical trials in transfusion medicine. The statistical input was provided by the MRC Clinical Trials Unit, but this contract ended in March 2013 and the statistical support is now provided by statisticians within NHSBT. The new unit is known as the NHSBT Clinical Trials Unit (CTU). The remit of the CTU has expanded to include trials in organ donation and transplantation, tissue and stem cell transplantation, and aims to become the 'provider of choice' in facilitating clinical studies in these areas. A key advantage of the CTU in conducting trials in organ donation and transplantation will be the ability to link trial data to data held on the UK Transplant Registry database and Potential Donor Audit.
- 4 **The 2012/13 Organ Donation and Transplantation Activity Report** is available on the ODT website www.odt.nhs.uk. The report includes new content this year and is accompanied by a slide set for general use.
- 5 **The ODT clinical website** www.odt.nhs.uk launched in January 2013 includes much more information that is useful and relevant to clinical colleagues than does the alternative site (www.organdonation.nhs.uk), which is more of a public facing website. The new site includes Advisory Group agendas, minutes and papers, NHSBT policies including patient selection and organ allocation policies, conference presentations and many other reports and information. There is a quick link to conference presentations on the bottom left of the home page. The content is being developed and any comments or suggestions for additional material are welcome (rachel.johnson@nhsbt.nhs.uk or claire.counter@nhsbt.nhs.uk).

CONFERENCE PRESENTATIONS, CURRENT AND FUTURE WORK

CONFERENCE PRESENTATIONS

- 6 An oral presentation on 'Outcomes after intestinal transplantation in the UK' was given at the ISBTS in June in Oxford.

CURRENT AND FUTURE WORK

- 7 The project to incorporate registrations and transplants of intestinal failure patients and the new allocation scheme went live on 22nd July 2013. An issue with waiting time calculations was identified a month later and the manual allocation scheme was reintroduced. However, a solution to the problem has been identified and thoroughly tested and is expected to be released imminently.
- 8 Centres are currently being asked to provide additional information on the use of the pancreas for historic transplants to ensure the data on the UK Transplant Registry accurately reflect the organs transplanted.

Rachel Johnson
Head of Organ Donation and Transplantation Studies
Statistics and Clinical Studies

October 2013