

**NHS BLOOD AND TRANSPLANT**

**ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**CARDIOTHORACIC 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, including that undertaken by, and in collaboration with, the Clinical Effectiveness Unit, Royal College of Surgeons under the auspices of the UK Cardiothoracic Transplant Audit.

**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 Loza

Cardiothoracic Advisory Group – Jenny Lannon

Kidney Advisory Group and Paediatric Sub-Group – Alex Hudson

Liver Advisory Group – Elisa Loza

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](mailto: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](http://www.odt.nhs.uk)) and general ([www.organdonation.nhs.uk](http://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](http://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](http://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](http://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](mailto:rachel.johnson@nhsbt.nhs.uk) or [claire.counter@nhsbt.nhs.uk](mailto:claire.counter@nhsbt.nhs.uk)).

## CONFERENCE PRESENTATIONS, CURRENT AND FUTURE WORK

### CONFERENCE PRESENTATIONS

- 6 An oral presentation on 'Donation after circulatory death lung activity in the UK – 100 transplants and counting' was given at the ISHLT Congress in April, together with three poster presentations on:
  - Non-transplantation of hearts when there is consent for donation: a UK national study
  - Current status of donor echocardiography in UK
  - Primary graft dysfunction following heart transplantation: validity of a pragmatic self-reporting definition

### RECENT PUBLICATIONS

- 7 Emin A, Rogers CA, Parameshwar J, MacGowan G, Taylor R, Yonan N, Simon A, Tsui S, Schueler S, Banner NR on behalf of the Steering Group of the UK Cardiothoracic Transplant Audit and the UK VAD Forum. Trends in long-term mechanical circulatory support for advanced heart failure in the UK *European Journal of Heart Failure* 2013; doi: 10.1093/eurjhf/hft127

### CURRENT AND FUTURE WORK

- 8 Further analysis and support has been provided to the lung allocation working party. Analyses have focussed on access to organs for paediatric patients and for patients of different blood groups. The next priorities are to agree the data collection requirement for the super-urgent lung allocation scheme, and develop models for survival on the transplant list and survival following lung transplantation.
- 9 Preliminary analysis of the early data from the Scout pilot project has been undertaken and presented at the recent ODT National Donation and Transplantation Congress.
- 10 The analysis to identify factors associated with primary graft dysfunction (PGD) following heart transplantation continues and cases of PGD are now being validated directly with the transplant centres.
- 11 Several fixes and improvements are being made to the VAD database, and the new version will be released to centres soon. Following agreement that the paediatric transplant centres will also submit data via the VAD database, relevant staff have been trained to use the database. We continue to work closely with IMACS to facilitate submission of all UK VAD data to this international VAD registry in the near future.
- 12 Work continues on the validation of the US-derived donor risk score, primary adverse events after heart transplantation and DCD lung transplantation manuscripts. Analysis is underway for the study of quality of life for patients

listed for heart transplantation, patients who have received a transplant and patients who receive a VAD.

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

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