

NHS BLOOD AND TRANSPLANT

BOWEL ADVISORY GROUP

SUMMARY FROM STATISTICS AND CLINICAL STUDIES

INTRODUCTION

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

UPDATE FROM STATISTICS AND CLINICAL STUDIES

- 2 The Centre Specific Reports referred to in the paper for the previous (Spring 2014) meeting are now being finalised.
- 3 A national allocation scheme for DCD kidneys has been developed and went live on 3 September 2014.
- 4 Following staff changes, Lisa Bradbury has taken over responsibility for coordinating our work in kidney donation and transplantation.
- 5 Rachel Johnson has been seconded to the position of Assistant Director, Governance and Clinical Effectiveness for a six month period from August 2014. During this period Prof Dave Collett will attend the Advisory Group Chairs meetings. Joanne Allen has also been seconded to the position of Organ Donation and Transplantation Performance and Business Manager for a six month period.

CURRENT AND FUTURE WORK

- 6 The issue of the classification of some liver and pancreas transplants including a short length of bowel and performed at Addenbrooke's Hospital, has been followed up. These transplants used a short length of bowel for anatomical reasons and not because of intestinal disease. The transplant type of three patients has been identified to disagree between Addenbrooke's and UK Transplant Registry (UKTR) records. The UKTR will be updated in line with Addenbrooke's classification.
- 7 A series of recommendations have been produced to ensure that liver and pancreas transplants that require a short length of bowel for anatomical reasons and not because of intestinal disease are registered, offered and recorded in the UKTR as multi-organ and not multi-visceral transplants. The recommendations will be presented to BAG (agenda item 6.2), PAG and LAG members in due course.

- 8 The word 'failure' has been removed from the Intestinal Selection ([POL194](#)) and Intestinal Allocation ([POL193](#)) Policies when it refers to 'intestinal failure' and if appropriate. This term will also be removed from all future statistical reports. A request has been submitted to the IT team to remove the word 'failure' from relevant registration, transplant and follow-up forms.
- 9 The ODT (<http://odt.nhs.uk>) and organ donation (<http://www.organdonation.nhs.uk>) websites have been updated to make data on intestinal transplantation more visible. In particular, a standard dataset including all intestinal transplant data until 31 December 2012 has been created; the data are available on request (<http://odt.nhs.uk/uk-transplant-registry/data>).
- 10 The 2013/14 Organ Donation and Transplantation Activity Report was published last July. It reports on intestinal registration and transplant activity, and survival rates following transplantation. Available from <http://odt.nhs.uk/uk-transplant-registry/annual-activity-report/>
- 11 Work is being carried out on modelling the survival of patients after intestinal transplantation while adjusting for factors known to influence survival and it will be discussed in agenda item 9.2.
- 12 A Centre Specific Report on intestinal transplantation will shortly be prepared. The report will use transplant data between 2004 and 2014 and will be available on the website as well as being sent to all transplant centres for validation before publication (agenda item 5.2).

ACTION

- 13 Liver-only transplants of patients with intestinal failure will be excluded from future reports. Members are asked to carefully consider and decide if the option to register a patient for a liver-only transplant because of intestinal failure via the intestinal registration form should be removed. If so, a number of forms, validation rules, database fields and operational processes would have to be modified, meaning that this would be a significant and time consuming change.

Elisa Allen
Statistics and Clinical Studies

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