

NHS BLOOD AND TRANSPLANT

BOWEL ADVISORY GROUP

SUMMARY OF REGISTRATIONS AND TRANSPLANT ACTIVITY

SUMMARY

INTRODUCTION

- 1 This paper provides information on recent registrations for an intestinal transplant and a summary of recent transplant activity in the UK. Median waiting time to transplant is also provided.

DATA ANALYSIS

- 2 Data on 21 registrations for an intestinal transplant between 1 February 2012 and 31 January 2013 were analysed. Of these registrations, 12 (57%) resulted in a transplant (6 bowel only and 6 included the bowel, liver and pancreas) and 5 (24%) remained active as at 4 February 2013.
- 3 Median waiting time to intestinal transplant was approximately 5 and a half months for registrations between 1 April 2008 and 30 September 2012, calculated as at 4 February 2013. Median waiting time was comparable for bowel only registrations, registrations including a liver and registrations not including a liver ($p=0.9$).
- 4 13 patients were awaiting an intestinal transplant on 4 February 2013; all except one patient were adults. The calculated reaction frequency at registration was only available for six patients.
- 5 There were fewer intestinal transplants carried out between 1 February 2012 and 31 January 2013 compared with the previous one-year period: 16 compared with 22. This reduction can mainly be attributed to a decline in the number of bowel only transplants performed in paediatric patients.

RECOMMENDATION

- 6 Members are reminded that the data presented relies on registration and transplant forms being completed in full. This will also be essential for the new allocation scheme.

Sally Rushton
February 2013

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DATA AND METHODS

- 8 Data on registrations for an intestinal transplant between 1 February 2012 and 31 January 2013 are provided as well as a summary of the intestinal transplant activity between 1 February 2011 and 31 January 2013.
- 9 The Kaplan-Meier estimation method was used to estimate median waiting time to intestinal transplantation for registrations between 1 April 2008 and 30 September 2012.

RESULTS

REGISTRATION ACTIVITY

- 10 In the period between 1 February 2012 and 31 January 2013, there were 21 registrations for an intestinal transplant. The outcome of these registrations for paediatric and adult patients, as at 4 February 2013, broken down by transplant centre can be found in **Table 1**. Note that no patients registered in this time period had been suspended at time of analysis.

Table 1 Outcome of intestinal transplant registrations in the UK between 1 February 2012 and 31 January 2013, by patient age group and transplant centre

| Transplant centre | Outcome of registrations as at 4 February 2013 | | | | | | | | No. regns |
|-----------------------|--|-----|------|----|---------|----|--------|----|-----------|
| | Transplanted | | Died | | Removed | | Active | | |
| | N | % | N | % | N | % | N | % | N |
| Paediatric recipients | | | | | | | | | |
| Birmingham | 1 | 33 | 2 | 67 | 0 | 0 | 0 | 0 | 3 |
| King's College | 1 | 100 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Total | 2 | 50 | 2 | 50 | 0 | 0 | 0 | 0 | 4 |
| Adult recipients | | | | | | | | | |
| Cambridge | 5 | 50 | 1 | 10 | 1 | 10 | 3 | 30 | 10 |
| Oxford | 5 | 71 | 0 | 0 | 0 | 0 | 2 | 29 | 7 |
| Total | 10 | 59 | 1 | 6 | 1 | 6 | 5 | 29 | 17 |
| TOTAL | 12 | 57 | 3 | 14 | 1 | 5 | 5 | 24 | 21 |

Note: No patients registered in this time period had been suspended at time of analysis.
Percentages have been rounded to the nearest whole number and are based on small numbers.

- 11 Of the 21 registrations for an intestinal transplant between 1 February 2012 and 31 January 2013, 12 (57%) resulted in a transplant, as at 4 February 2013. A breakdown of these transplants by transplant centre and type can be found in **Table 2** for paediatric and adult recipients.

| Table 2 Intestinal transplants in the UK, by recipient age group, transplant centre and type, that resulted from registrations between 1 February 2012 and 31 January 2013 | | | | | |
|--|-----------------|----|-----|-----|-------|
| Transplant centre | Transplant type | | | | Total |
| | BO | MV | MMV | LBP | |
| | N | N | N | N | N |
| Paediatric recipients | | | | | |
| Birmingham | 1 | 0 | 0 | 0 | 1 |
| King's College | 0 | 0 | 0 | 1 | 1 |
| Total | 1 | 0 | 0 | 1 | 2 |
| Adult recipients | | | | | |
| Cambridge | 0 | 4 | 0 | 1 | 5 |
| Oxford | 5 | 0 | 0 | 0 | 5 |
| Total | 5 | 4 | 0 | 1 | 10 |
| TOTAL | 6 | 4 | 0 | 2 | 12 |
| Note: BO=Bowel only, MV=Multivisceral, MMV=Modified multivisceral, LBP=Liver, bowel and pancreas BO comprises all intestinal transplants that did not include a liver or pancreas | | | | | |

- 12 **Table 3** shows the median waiting time to intestinal transplant by registration type for patients registered between 1 April 2008 and 30 September 2012, calculated as at 4 February 2013. Overall median waiting time was 169 days. There was not a statistically significant difference between the different types of registration ($p=0.9$).

| Table 3 Median waiting time to intestinal transplant for patients registered between 1 April 2008 and 30 September 2012 in the UK, as at 4 February 2013 | | | |
|---|------------|---------------------|-------------------------|
| Registration type | No. regns | Waiting time (days) | |
| | | Median | 95% Confidence interval |
| Bowel only | 40 | 153 | 95 - 211 |
| Including a liver | 51 | 168 | 116 - 220 |
| Not including a liver | 26 | 224 | 0 - 512 |
| Total | 117 | 169 | 130 - 208 |
| Note: Waiting times are calculated excluding known suspension periods and for BO registration may be up to a week longer | | | |

TRANSPLANT LIST

- 13 A description of the 13 patients on the active/suspended intestinal transplant list as at 4 February 2013 is presented in **Table 4**, for each transplant centre. The calculated reaction frequency (CRF) (%) at registration has been added into the table, however this was only available for six of the patients.

Table 4 Patients on the intestinal transplant list in the UK as at 4 February 2013

| Organs required | Weight (kg) | BMI (kg/m ²) | Blood group | CRF (%) at registration | Disease | Waiting times (days) |
|--|-------------|--------------------------|-------------|-------------------------|--|----------------------|
| Birmingham | | | | | | |
| Liver, bowel, stomach, colon | 21 | 24 | B | - | Chronic rejection | 423 |
| Cambridge | | | | | | |
| Bowel, pancreas, kidney, stomach | 53 | 21 | B | - | Pancreatitis leading to enterectomy and PN requirement | 579 |
| Liver, bowel, pancreas, stomach, colon ² | 80 | 29 | O | - | Budd-Chiari Syndrome | 447 |
| Bowel, pancreas, stomach, abdominal wall | 28 | 15 | O | 0 | Visceral neuropathy/myopathy | 439 |
| Liver, bowel, pancreas, stomach, abdominal wall, colon | 59 | 18 | O | 0 | Primary vascular disease | 255 |
| Liver, bowel, pancreas, stomach, colon | 60 | 20 | A | 0 | Short Bowel syndrome caused by infarction following Whipples disease | 125 |
| Bowel, kidney, colon | 55 | 21 | O | 0 | Crohn's disease | 115 |
| Oxford | | | | | | |
| Bowel, abdominal wall | 51 | 17 | O | - | Visceral neuropathy/myopathy | 1329 |
| Bowel, abdominal wall ¹ | 51 | 21 | B | - | Ulcerative colitis | 857 |
| Bowel ¹ | 63 | 22 | B | - | Crohn's disease | 794 |
| Bowel, pancreas, kidney, stomach ¹ | 75 | 22 | AB | - | Type I diabetes, associated enteropathy and gastropathy requiring TPN on a long-term basis | 724 |
| Bowel, pancreas, stomach, spleen | 86 | 28 | O | 0 | Cholestatic disease | 174 |
| Bowel, abdominal wall | 57 | 20 | O | 0 | Visceral neuropathy/myopathy | 63 |

¹ Patient currently suspended

² Registered before 1 April 2008

Note: Waiting times are calculated excluding suspension periods and for BO registrations may be up to a week longer

Calculated reaction frequency (CRF) is equal to 0% where HLA data had been entered on the intestinal failure transplant recipient registration form but no unacceptable HLA specificities had been entered. CRF is missing either where HLA data had not been entered for that patient or the patient was registered prior to HLA being recorded on the form.

TRANSPLANT ACTIVITY

- 14 Between 1 February 2012 and 31 January 2013, 16 intestinal transplants were performed. 22 intestinal transplants were performed in the earlier time period of 1 February 2011 to 31 January 2012.
- 15 A summary of these transplants, for paediatric and adult patients, broken down by transplant centre and type can be found in **Table 5**, for each of the two time periods.

Table 5 Intestinal transplants in the UK between 1 February 2012 and 31 January 2013, by recipient age group, transplant centre and type (1 February 2011 and 31 January 2012)

| Transplant centre | Transplant type | | | | | | | | | |
|------------------------------|-----------------|-------------|----------|------------|----------|------------|----------|------------|-----------|-------------|
| | BO | | LBP | | MV | | MMV | | Total | |
| | N | N | N | N | N | N | N | N | N | N |
| Paediatric recipients | | | | | | | | | | |
| Birmingham | 2 | (4) | 1 | (2) | 0 | (0) | 0 | (0) | 3 | (6) |
| King's College | 1 | (3) | 1 | (0) | 0 | (0) | 0 | (0) | 2 | (3) |
| Total | 3 | (7) | 2 | (2) | 0 | (0) | 0 | (0) | 5 | (9) |
| Adult recipients | | | | | | | | | | |
| Cambridge | 0 | (1) | 1 | (1) | 5 | (5) | 0 | (1) | 6 | (8) |
| Oxford | 5 | (5) | 0 | (0) | 0 | (0) | 0 | (0) | 5 | (5) |
| Total | 5 | (6) | 1 | (1) | 5 | (5) | 0 | (1) | 11 | (13) |
| TOTAL | 8 | (13) | 3 | (3) | 5 | (5) | 0 | (1) | 16 | (22) |

Note: BO=Bowel only, LBP=Liver, bowel and pancreas, MV=Multivisceral, MMV=Modified multivisceral, BO comprises all transplants not including a liver or a pancreas

RECOMMENDATION

- 16 Members are reminded that the data presented relies on registration and transplant forms being completed in full. This will also be essential for the new allocation scheme.

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February 2013