

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**BOWEL ADVISORY GROUP**

**SUMMARY OF REGISTRATIONS AND TRANSPLANT ACTIVITY**

**SUMMARY**

**INTRODUCTION**

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

**DATA ANALYSIS**

- 2 Data on 26 registrations for an intestinal failure transplant between 1 October 2012 and 30 September 2013 were analysed. Of these registrations, 17 (65%) resulted in a transplant (9 bowel only and 8 multivisceral) and 7 (27%) remained active as at 14 October 2013.
- 3 Median waiting time to intestinal failure transplant was 6 months for elective registrations between 1 April 2008 and 31 March 2013, calculated as at 14 October 2013. Median waiting time was comparable for patients requiring a bowel only, patients requiring a liver, bowel and pancreas and patients requiring a bowel and pancreas but no liver ( $p=0.8$ ).
- 4 17 patients were awaiting an intestinal failure transplant on 14 October 2013; seven paediatric and 10 adult. Three patients had some degree of sensitisation, as indicated by the reporting of unacceptable HLA specificities. Five patients have been on the transplant list for more than two years, however all but one of these have spent some of this time suspended from the list. There were no patients active or suspended on the super-urgent intestinal failure transplant list as at 14 October 2013.
- 5 21 intestinal failure transplants were performed between 1 October 2012 and 30 September 2013, one more than the number performed in the previous year, 1 October 2011 to 30 September 2012. Only 1 (5%) transplant was performed in a paediatric patient in the recent time period, compared with 8 (40%) in the previous year.

**RECOMMENDATION**

- 6 Members are reminded that the data presented and the new elective and super-urgent intestinal failure allocation schemes rely on registration and transplant forms being completed in full. These forms should be completed electronically using ODT online.

**Sally Rushton  
October 2013**

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### SUMMARY OF REGISTRATIONS AND TRANSPLANT ACTIVITY

#### INTRODUCTION

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

#### DATA AND METHODS

- 8 Data on elective and super-urgent registrations for an intestinal failure transplant between 1 October 2012 and 30 September 2013 are provided as well as a summary of the intestinal failure transplant activity between 1 October 2011 and 30 September 2013.
- 9 The Kaplan-Meier estimation method was used to estimate median waiting time to intestinal failure transplantation for elective registrations between 1 April 2008 and 31 March 2013. Any periods of suspension from the transplant list were included in the calculation of a patient's waiting time.

#### RESULTS

##### REGISTRATION ACTIVITY

- 10 In the period between 1 October 2012 and 30 September 2013, there were 26 registrations for an intestinal failure transplant. The outcome of these registrations for paediatric and adult patients, as at 14 October 2013, broken down by transplant centre, is shown in **Table 1**. Note that none of the patients registered in this time period were suspended from the list at time of analysis. Note also that Cambridge registered four super-urgent intestinal failure transplant patients in the time period, all resulting in transplant.
- 11 Of the 26 registrations for an intestinal failure transplant between 1 October 2012 and 30 September 2013, 17 (65%) resulted in a transplant as at 14 October 2013. A breakdown of these transplants by transplant centre and type is shown in **Table 2** for paediatric and adult recipients. Note that none of the registrations at King's College resulted in a transplant by 14 October 2013.

**Table 1 Outcome of intestinal failure transplant registrations in the UK between 1 October 2012 and 30 September 2013, by patient age group and transplant centre**

Transplant centre	Outcome of registrations as at 14 October 2013								No. regns N
	Transplanted		Died		Removed		Active		
	N	%	N	%	N	%	N	%	
<b>Paediatric recipients</b>									
Birmingham	2	50	0	0	0	0	2	50	4
King's College	0	0	0	0	0	0	2	100	2
<b>Total</b>	<b>2</b>	<b>33</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>4</b>	<b>67</b>	<b>6</b>
<b>Adult recipients</b>									
Cambridge	10 <sup>1</sup>	71	0	0	2	14	2	14	14
Oxford	5	83	0	0	0	0	1	17	6
<b>Total</b>	<b>15</b>	<b>75</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>10</b>	<b>3</b>	<b>15</b>	<b>20</b>
<b>TOTAL</b>	<b>17</b>	<b>65</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>8</b>	<b>7</b>	<b>27</b>	<b>26</b>

<sup>1</sup> Includes four super-urgent intestinal failure registrations

Note: None of the 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.

**Table 2 Intestinal failure transplants in the UK, by recipient age group, transplant centre and type, that resulted from registrations between 1 October 2012 and 30 September 2013**

Transplant centre	Transplant type				Total
	BO	MV	MMV	LBP	
	N	N	N	N	
Paediatric recipients					
Birmingham	1	1	0	0	2
Total	1	1	0	0	2
Adult recipients					
Cambridge	3	7 <sup>1</sup>	0	0	10
Oxford	5	0	0	0	5
Total	8	7	0	0	15
TOTAL	9	8	0	0	17

<sup>1</sup> Includes four super-urgent intestinal failure transplants

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

- 12 **Table 3** shows the median waiting time to intestinal failure transplantation by registration type for elective patients registered between 1 April 2008 and 31 March 2013, calculated as at 14 October 2013. The overall median waiting time was 183 days (95% CI: 125 - 241 days). There was not a statistically significant difference between the median waiting times of the different types of registration ( $p=0.8$ ).
- 13 For comparison, the median waiting time to elective liver only transplantation, as reported in the 2012/13 Organ Donation and Transplantation Activity Report, is 147 days (95% CI: 137 - 157 days) (registrations between 1 April 2008 and 31 March 2011).

**Table 3 Median waiting time to intestinal failure transplant for elective patients registered between 1 April 2008 and 31 March 2013 in the UK, as at 14 October 2013**

Registration type	No. regns	Waiting time (days)	
		Median	95% Confidence interval
Bowel only <sup>1</sup>	40	154	88 - 220
Liver, bowel and pancreas <sup>1</sup>	52	181	51 - 311
Bowel and pancreas <sup>1</sup>	30	209	41 - 377
<b>Total</b>	<b>122</b>	<b>183</b>	<b>125 - 241</b>

<sup>1</sup> May also include any of: stomach, spleen, abdominal wall, colon, kidney

Note: Any periods of suspension are included in the calculation of a patient's waiting time

## TRANSPLANT LIST

- 14 A description of the 17 patients who were active or suspended on the elective intestinal failure transplant list as at 14 October 2013 is presented in **Table 4**, for each transplant centre. Note that unacceptable HLA specificities were reported via the intestinal failure transplant recipient registration form in three cases.
- 15 The waiting times reported include any periods when the patient was suspended from the transplant list as this is taken into account in the calculation of the points used in the new elective intestinal failure allocation scheme. Five of these patients have been on the transplant list for more than two years, however all but one of these have spent some of this time suspended from the list.
- 16 There were no patients active or suspended on the super-urgent intestinal failure transplant list as at 14 October 2013.

**Table 4 Patients on the elective intestinal failure transplant list in the UK as at 14 October 2013**

Organs required	Weight (kg)	BMI (kg/m <sup>2</sup> )	Blood group	CRF (%) at registration	Disease	Waiting times (days)
<b>Birmingham</b>						
Liver, bowel, pancreas, stomach <sup>1</sup>	24	27	B	7	Chronic rejection	675
Liver, bowel, pancreas	9	15	B	0	Volvulus	136
Liver, bowel, pancreas	7	14	A	-	Microvillous inclusion disease	129
<b>King's College</b>						
Liver, bowel, pancreas, colon	18	18	A	0	Hirschprung's disease	217
Liver, bowel, pancreas	10	14	O	0	Gastroschisis	45
Bowel, pancreas	14	14	O	0	Severe intestinal failure, underlying gastrointestinal dysmotility and history of enteropathy and colitis	3
Liver, bowel, pancreas, colon	11	14	A	0	Intestinal failure unknown aetiology	3
<b>Cambridge</b>						
Liver, bowel, pancreas, stomach, colon	71	26	O	0	Budd-Chiari Syndrome	2,204
Bowel, pancreas, kidney, stomach, colon	53	21	B	49	Pancreatitis leading to enterectomy and PN requirement	830
Liver, bowel, pancreas, stomach, abdominal wall <sup>1</sup>	62	21	A	0	Gardner's Syndrome and Desmoid	587
Liver, bowel, pancreas, stomach, abdominal wall, colon	59	18	O	99	Primary vascular disease	507
Liver, bowel, pancreas, kidney, stomach, colon	72	27	O	0	Budd-Chiari syndrome JAK2 positive with myeloproliferative disorder, extensive SMV and splenic vein thrombosis necessitating multivisceral transplant	227
Liver, bowel, pancreas, stomach, colon	54	20	O	0	Visceral neuropathy/myopathy	17
<b>Oxford</b>						
Bowel, kidney <sup>1</sup>	63	22	B	0	Crohn's disease	1,740
Bowel, abdominal wall <sup>1</sup>	51	21	B	0	Ulcerative colitis, injury to small bowel during laparotomy	1,330
Bowel, pancreas, kidney, stomach <sup>1</sup>	75	21	AB	-	Type I diabetes, associated enteropathy and gastropathy requiring TPN on a long-term basis	1,008
Bowel, pancreas, stomach, abdominal wall	71	25	B	0	Pseudomyxoma Peritonei	31

<sup>1</sup> Patient currently suspended

Note: Waiting times are calculated including any periods of suspension.

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 where no HLA data had been provided.

## TRANSPLANT ACTIVITY

- 17 Between 1 October 2012 and 30 September 2013 21 intestinal failure transplants were performed compared with 20 transplants in the previous year, 1 October 2011 to 30 September 2012.
- 18 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. Only 1 (5%) transplant was performed in a paediatric patient between 1 October 2012 and 30 September 2013, compared with 8 (40%) in the previous year.

**Table 5 Intestinal failure transplants in the UK between 1 October 2012 and 30 September 2013 (1 October 2011 and 30 September 2012), by recipient age group, transplant centre and type**

Transplant centre	Transplant type									
	BO		LBP				MV		MMV	
	N	N	N	N	N	N	N	N	N	N
<b>Paediatric recipients</b>										
Birmingham	0	(3)	0	(3)	1	(0)	0	(0)	1	(6)
King's College	0	(1)	0	(1)	0	(0)	0	(0)	0	(2)
<b>Total</b>	<b>0</b>	<b>(4)</b>	<b>0</b>	<b>(4)</b>	<b>1</b>	<b>(0)</b>	<b>0</b>	<b>(0)</b>	<b>1</b>	<b>(8)</b>
<b>Adult recipients</b>										
Cambridge	3	(0)	1	(0)	8	(5)	1	(1)	13	(6)
Oxford	6	(6)	0	(0)	0	(0)	1	(0)	7	(6)
<b>Total</b>	<b>9</b>	<b>(6)</b>	<b>1</b>	<b>(0)</b>	<b>8</b>	<b>(5)</b>	<b>2</b>	<b>(1)</b>	<b>20</b>	<b>(12)</b>
<b>TOTAL</b>	<b>9</b>	<b>(10)</b>	<b>1</b>	<b>(4)</b>	<b>9</b>	<b>(5)</b>	<b>2</b>	<b>(1)</b>	<b>21</b>	<b>(20)</b>

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

- 19 Members are reminded that the data presented and the new elective and super-urgent intestinal failure allocation schemes rely on registration and transplant forms being completed in full. These forms should be completed electronically using ODT online.

**Sally Rushton**  
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**October 2013**