

ANNUAL REPORT ON INTESTINE TRANSPLANTATION

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CONTENTS

CONTENTS

EXECUTIVE SUMMARY	5
INTRODUCTION	7
TRANSPLANT LIST	7
TRANSPLANT ACTIVITY	10
ADULT INTESTINE TRANSPLANTATION	13
TRANSPLANT LIST	13
RESPONSE TO OFFERS	14
TRANSPLANTS	15
TRANSPLANT SURVIVAL – FIRST TRANSPLANT	20
PAEDIATRIC INTESTINE TRANSPLANTATION	24
TRANSPLANT LIST	24
RESPONSE TO OFFERS	25
TRANSPLANTS	26
TRANSPLANT SURVIVAL – FIRST TRANSPLANT	31
FORM RETURN RATES	35
APPENDIX	37
DATA	37
METHODS	38
GLOSSARY OF TERMS	38

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

This report presents key figures about intestine transplantation in the UK. The period covered is 10 years of transplant data, from 1 April 2005 to 31 March 2015. The report presents information on patients on the transplant list, number of transplants, demographic characteristics of donors and transplant recipients, and patient survival after first intestine transplant; both on a national and a centre-specific basis. The results on post-transplant survival should be regarded as guidance only due to the limited number of transplants performed.

Key findings

- On 31 March 2015, there were nine patients on the UK active intestine transplant list, which represents a 50% decrease relative to four years earlier, when the list reached its maximum figure of 18 within the reported time period. Of those patients registered onto the transplant list in a recent one year period (1 April 2012 31 March 2013), 71% had received a transplant two years post-registration, while 18% had died and 12% were still waiting.
- There were 162 intestine transplants performed in the UK in the 10 year period.
 Eighteen of these were re-transplants and 46% were in paediatric recipients while 54% were in adult recipients.
- The number of transplants in adult recipients has generally increased each year over the last 10 years. This has not been the case for paediatric recipients, for which the number was roughly the same at the start of the time period and the end.
- The national rates of survival after first intestine transplantation for elective adult patients were estimated at 87%, 78% and 52% at 90 days, one and five years post-transplant, respectively.
- The national rates of survival after first intestine transplantation for elective paediatric patients were estimated at 93%, 85% and 66% at 90 days, one and five years post-transplant, respectively.

INTRODUCTION

INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2005 and 31 March 2015, for all four designated centres performing intestine transplantation in the UK. Data were obtained from the UK Transplant Registry, at NHS Blood and Transplant, which holds information relating to donors, recipients and outcomes for all intestine transplants performed in the UK.

The report is divided into two main sections; one for adult recipients (aged≥18 years) and one for paediatric recipients (aged<18 years). Unadjusted <u>patient survival rates</u> are calculated for these two groups at 90 days, one year and five years post-transplantation; these should be regarded as guidance only due to the limited number of transplants performed.

TRANSPLANT LIST

Figure 1 shows the total number of patients on the intestine <u>active transplant list</u> at 31 March of each year between 2007 and 2015. Year-end transplant list data are not available before 2007. The number of patients waiting for a transplant increased each year from six in 2007 to 18 in 2010-2011 and fell slightly to 14 in 2012, then to 13 in 2014, and nine in 2015.

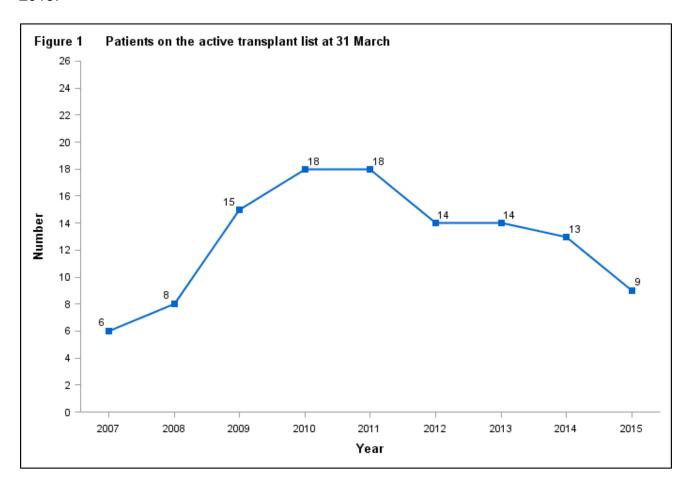
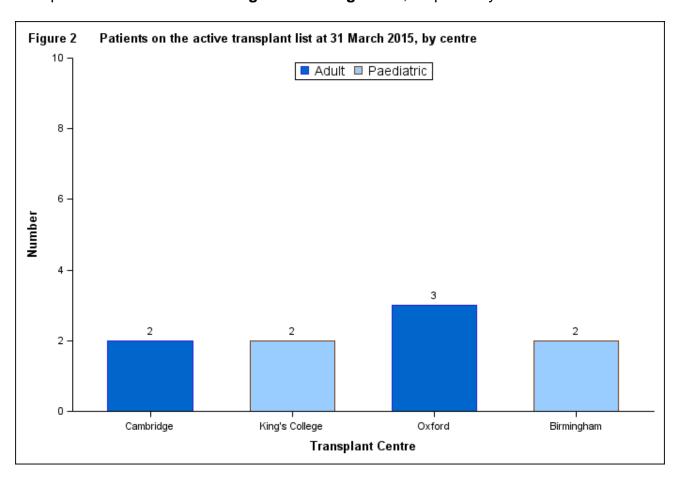


Figure 2 shows the number of adult and paediatric patients on the <u>active transplant list</u> at 31 March 2015 by centre. In total, there were five adult and four paediatric patients. 10-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown in **Figure 7** and **Figure 15**, respectively.



The outcomes of patients listed between 1 April 2011 and 31 March 2013 for an intestine transplant are summarised in **Figure 3.** This shows the proportion of patients transplanted, still waiting or dying (includes those removed due to deteriorating condition) while waiting six months, one year and two years after joining the transplant list. At one year post-registration 65% of patients had received a transplant and 18% were still waiting. The remaining percentage of patients died while on the transplant list.

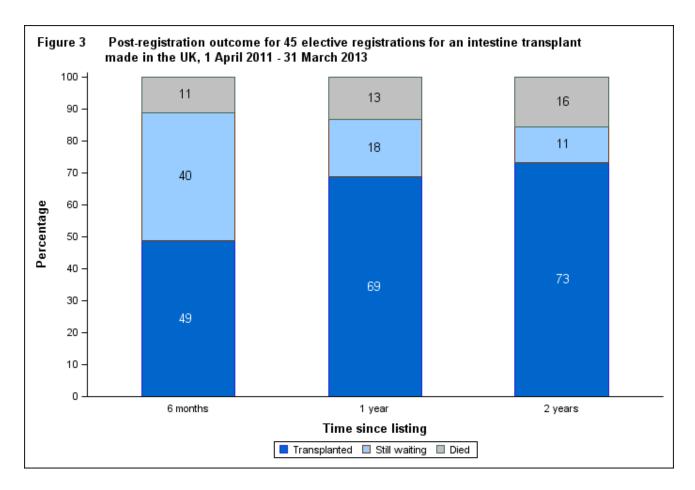


Table 1 shows <u>median waiting time</u> to <u>elective</u> intestine transplant by registration type (including re-registrations) for both adult and paediatric patients. Overall, on average, patients wait 124 days (approximately four months) for a transplant. The average wait is longer for patients who require a liver as part of their intestine graft but there was no statistically significant difference between registration types.

Table 1 Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2011 - 31 March 2014						
Registration type	Number of patients	Wai	ting time (days)			
	registered	Median	95% Confidence interval			
Intestine only ¹	20	39	0 - 89			
Liver, intestine and pancreas ¹	38	168	0 - 396			
Intestine and pancreas ¹	12	66	0 - 192			
TOTAL	70	124	52 - 196			
¹ May also include any of; stomach, spleen, abdominal wall, kidney, colon Note: any periods of suspension are included in the calculation of median waiting times						

TRANSPLANT ACTIVITY

Figure 4 shows the number of intestine transplants performed each year in the last 10 years. Currently in the UK, all intestine transplants are performed from donors after brain death (<u>DBD</u>). The total number of transplants was 162, with annual figures increasing from 9 in 2005/2006 to 24 in 2014/2015.

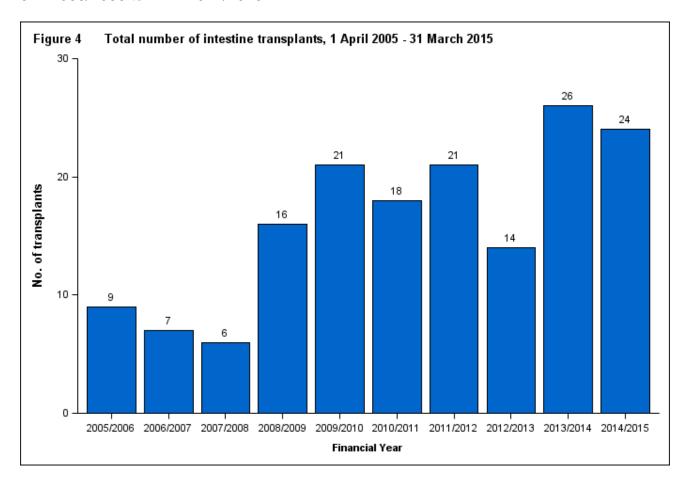
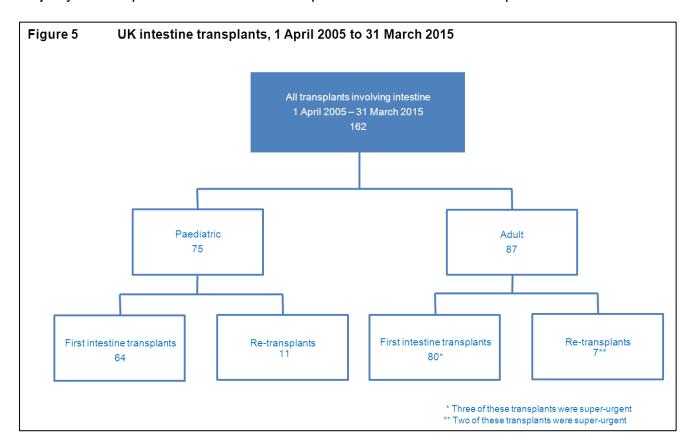


Figure 5 details the 162 intestine transplants performed in the UK in the 10 year period. Of these, 75 (46%) were in paediatric patients and 87 (54%) were in adult patients. The majority of both paediatric and adult transplants were in first time recipients.



ADULT INTESTINE TRANSPLANTATION

ADULT INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 6 shows the number of adult patients active or suspended on the intestine transplant list at 31 March of each year between 2007 and 2015. Year-end transplant list data are not available before 2007. The number of patients on the <u>active intestine</u> <u>transplant list</u> increased each year from three in 2007 to nine in 2010. It subsequently remained relatively stable until 2014, when it fell to three patients.

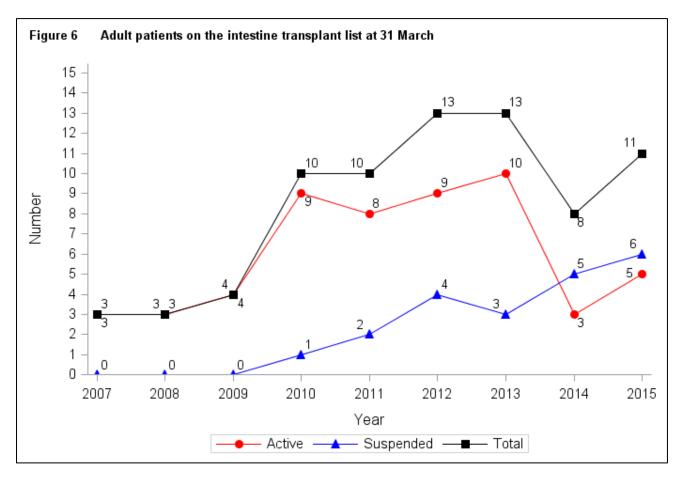
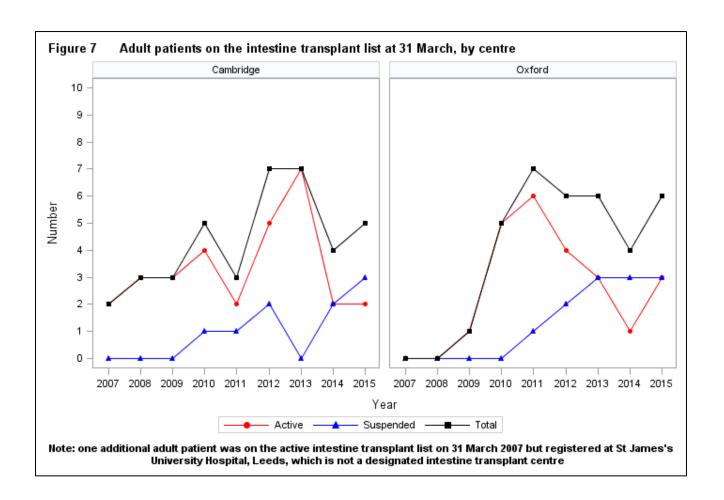


Figure 7 shows the number of adult patients on the intestine transplant list at 31 March of each year between 2007 and 2015, at each transplant centre. Cambridge had generally more adult patients on the national <u>active transplant list</u> than Oxford.



RESPONSE TO OFFERS

Potential <u>DBD</u> donors aged up to 55 years and with a weight of 80 kg or less are considered for intestine donation, however, centres are highly selective when accepting donor organs which leads to high decline rates. Between 1 April 2014 and 31 March 2015 Cambridge received intestine offers from 145 donors and Oxford received intestine offers from 108. Their offer decline rates were 92% and 96%, respectively.

TRANSPLANTS

Figure 8 shows the number of adult intestine transplants performed in the last 10 years, by transplant type. The annual number of adult transplants increased steadily over the time period to 23 in 2013/2014, but dropped to 15 in the last financial year.

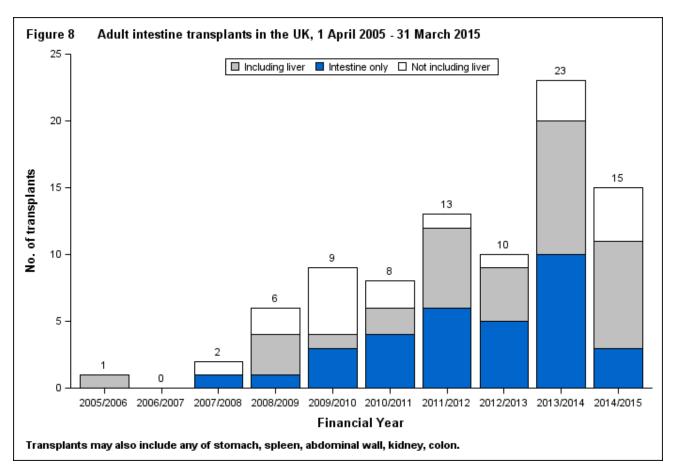


Figure 9 shows the number of adult intestine transplants performed in 2014/2015, by centre and transplant type. The majority of transplants (73%) performed at Cambridge were liver and intestine combined while intestine only transplants were most common at Oxford (75%).

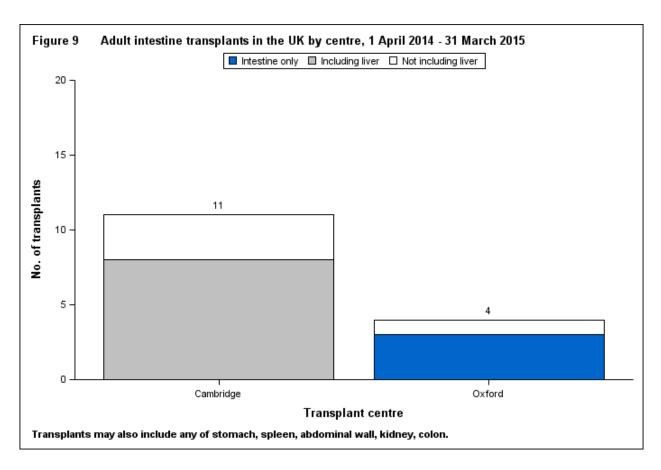
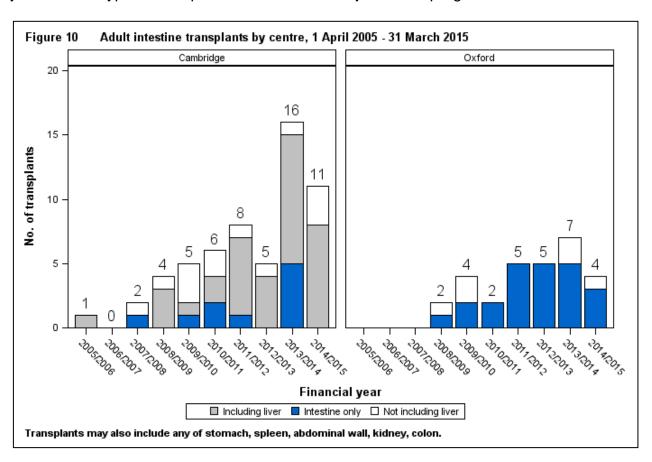


Figure 10 shows the number of adult intestine transplants performed in the last 10 years, by centre and type of transplant. Note that Oxford joined the programme in 2008.

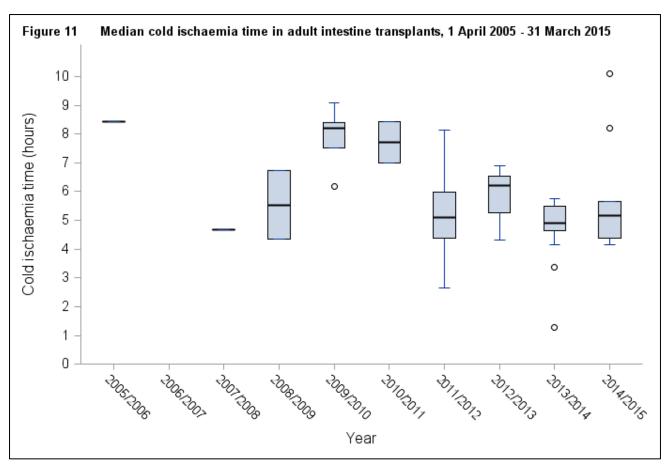


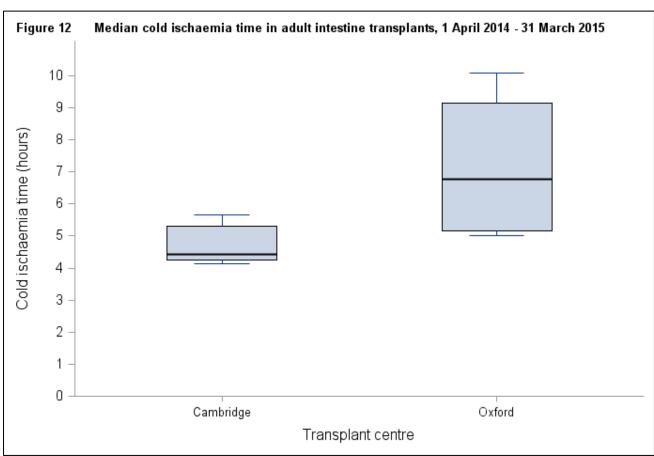
The demographic characteristics of 82 adult <u>elective</u> intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 2**. 57% of these recipients were male and the <u>median</u> age for recipients was 44 years old. The most common indication for transplantation was short bowel syndrome. The median recipient BMI was 21 kg/m². For some characteristics, percentages may not add up to 100 due to rounding.

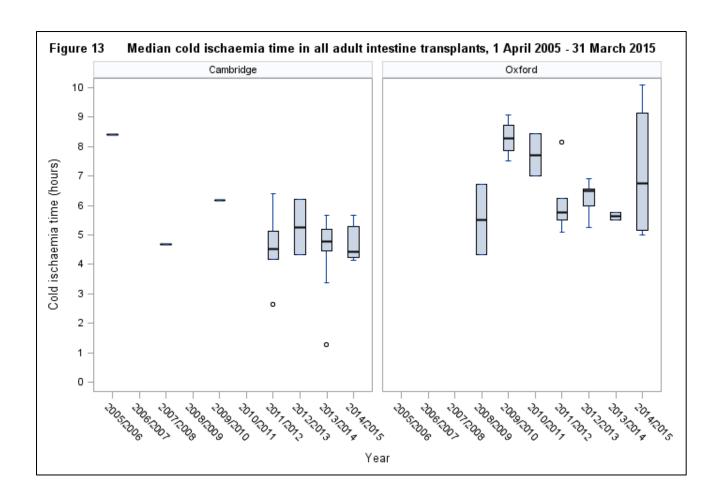
		On make the terr	0.4	TOTAL
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number		53	29	82 (100)
Recipient sex	Male Female	30 (57) 23 (43)	17 (59) 12 (41)	47 (57) 35 (43)
Recipient ethnicity group	White	48 (91)	27 (93)	75 (92)
Recipient etimicity group	Other	46 (91)	2 (7)	6 (7)
	Not reported	1 (2)	0	1 (1)
Indication group	Short bowel syndrome	23 (43)	14 (48)	37 (45)
	Motility disorders	3 (6)	5 (17)	8 (10)
	Malignancy	3 (6)	3 (10)	6 (7)
	Liver disease Other/not reported	3 (6) 18 (34)	1 (3) 5 (17)	4 (5) 23 (28)
	Retransplant	3 (6)	1 (3)	4 (5)
Patient location	Out-patient	24 (45)	24 (83)	48 (59)
	Ward	7 (13)	4 (14)	11 (13)
	ICU/HDU Not reported	2 (4) 20 (38)	0 1 (3)	2 (2) 21 (26)
Pre-transplant renal	No	33 (62)	26 (90)	59 (72)
support	Yes	1 (2)	2 (7)	3 (4)
	Not reported	19 (36)	1 (3)	20 (24)
Previous abdominal	No	5 (9)	2 (7)	7 (9)
surgery	Yes Not reported	28 (53) 20 (38)	26 (90) 1 (3)	54 (66) 21 (26)
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Life style activity	Normal Restricted	1 (2) 4 (8)	4 (14)	5 (6) 6 (7)
	Self-care	19 (36)	2 (7) 14 (48)	6 (7) 33 (40)
	Confined	6 (11)	6 (21)	12 (15)
	Reliant	3 (6)	2 (7)	5 (6)
	Not reported	20 (38)	1 (3)	21 (26)
Restricted venous access	No	37 (70)	16 (55)	53 (65)
at registration	Yes	10 (19)	12 (41)	22 (27)
	Not reported	6 (11)	1 (3)	7 (9)
Recipient age (years)	Median (IQR) Not reported	46 (35,53) 0	39 (33,47) 0	44 (34,52 0
Recipient BMI (kg/m²)	Median (IQR)	21 (19,23)	21 (19,24)	21 (19,23
1 - · · · · · · · · · · · · · · · · · ·	Not reported	23	7	30

Table 2 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2005 - 31 March 2015						
Serum bilirubin (umol/l)	Median (IQR) Not reported	Cambridge N (%) 20 (9,42) 20	Oxford N (%) 11 (7,14) 1	TOTAL N (%) 11 (8,26) 21		
Time on list (days)	Median (IQR)	46 (21,171)	36 (27,79)	41 (21,126)		
	Not reported	0	0	0		
Donor sex	Male	16 (30)	16 (55)	32 (39)		
	Female	37 (70)	13 (45)	50 (61)		
Donor ethnicity group	White	49 (92)	27 (93)	76 (93)		
	Other	2 (4)	1 (3)	3 (4)		
	Not reported	2 (4)	1 (3)	3 (4)		
Donor cause of death group	Stroke	44 (83)	15 (52)	59 (72)		
	Trauma	6 (11)	13 (45)	19 (23)		
	Other	3 (6)	1 (3)	4 (5)		
Donor history of diabetes	No	27 (51)	26 (90)	53 (65)		
	Yes	4 (8)	2 (7)	6 (7)		
	Not reported	22 (42)	1 (3)	23 (28)		
Donor age (years)	Median (IQR)	33 (21,39)	24 (20,35)	27 (21,39)		
	Not reported	0	0	0		
Donor BMI (kg/m²)	Median (IQR)	21 (19,23)	22 (21,23)	22 (20,23)		
	Not reported	0	0	0		
Transplant type	Intestine only	10 (19)	23 (79)	33 (40)		
	Including liver	30 (57)	0	30 (37)		
	Not including liver	13 (25)	6 (21)	19 (23)		
ABO match	Identical	39 (74)	27 (93)	66 (81)		
	Compatible	14 (26)	2 (7)	16 (20)		
Cold ischaemic time (mins)	Median (IQR)	282 (254,318)	390 (330,489)	325 (276,392)		
	Not reported	26	4	30		

Figure 11 shows boxplots of the cold ischaemic times (CIT) of adult intestine transplants over the last 10 years. The line inside the box indicates the median value. The median CIT has fallen over the time period from 8.4 hours in 2005/2006 to 5.2 hours in 2014/2015. **Figure 12** shows the median CITs in adult intestine transplants in 2014/2015 for each transplant centre, while **Figure 13** shows the same data but over the last 10 years. Note that prior to 2008/2009 Oxford did not perform any intestine transplants which means there are no boxplots presented for the first three years. All of these boxplots represent a small number of observations and as shown in **Table 2**, a proportion of CITs have not been reported.







TRANSPLANT SURVIVAL - FIRST TRANSPLANT

Survival by transplant centre

Table 3 shows the 90-day <u>patient survival rates</u> for adult <u>elective</u> first intestine transplants between 1 April 2005 and 31 March 2015, overall and by centre. Of the 77 transplants of this kind in the time period, survival information was known for 75 transplants. Of these, 87% of patients were alive at 90 days post-transplant.

Table 3	90-day patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre				
Centre	Number of transplants	90-day sı	urvival (95% CI)		
Cambridge Oxford TOTAL	47 28 75	87.2 85.7 86.7	(73.5-94.5) (67.2-94.5) (75.6-92.4)		

One- and five-year patient survival rates are shown in **Table 4** and **Table 5**, respectively. At one year post-transplant, 78% of transplanted patients were alive, while at five years post-transplant, the overall survival rate is 52%. Lower survival rates observed at Cambridge can be accounted for by differences in types of transplants (see next section, Tables 6-8).

Table 4	One-year patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre				
Centre	Number of transplants	1-year sı	ırvival (95% CI)		
Cambridge Oxford TOTAL	47 28 75	77.3 78.0 77.6	(60.9-86.1) (56.7-90.3) (65.1-86.1)		

Table 5	able 5 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre				
Centre	Number of transplants	5-year survival (95% CI)			
Cambridge Oxford TOTAL	47 28 75	49.7 62.0 52.0	(27.3-67.2) (37.8-79.8) (33.6-67.2)		

Survival by transplant type

Table 6, Table 7 and **Table 8** show the 90-day, one-year and five-year patient survival rates for adult <u>elective</u> first intestine transplants, by centre and transplant type.

Table 6 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant type						
Transplant type	Number of transplants	90-day	survival (95% CI)			
Cambridge Including liver	26	76.9	(56.7-88.2)			
Not including liver Oxford	21	100	-			
Not including liver TOTAL	28 75	85.7 86.7	(67.2-94.5) (75.6-92.4)			

Table 7 One-year patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant type						
Transplant type	Number of transplants	1-year su	ırvival (95% CI)			
Cambridge Including liver Not including liver Oxford	26	67.9	(46.2-81.9)			
	21	88.9	(63.0-96.6)			
Not including liver TOTAL	28	78.0	(56.7-90.3)			
	75	77.6	(65.1-86.1)			

Table 8 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant type						
Transplant type	Number of transplants	5-year su	rvival (95% CI)			
Cambridge Including liver Not including liver Oxford Not including liver TOTAL	26 21 28 75	26.3 77.8 62.0 52.0	(6.3-54.6) (42.0-92.4) (37.8-79.8) (33.6-67.2)			

PAEDIATRIC INTESTINE TRANSPLANTATION

PAEDIATRIC INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 14 shows the number of paediatric patients (aged<18 years) active and suspended on the intestine transplant list at 31 March of each year between 2007 and 2015. Year-end transplant list data are not available before 2007. The number of patients on the <u>active transplant list</u> increased each year from three in 2007 to 11 in 2009. It subsequently decreased until the number of patients reached a lowest value of four in 2013, which is the same as in 2015.

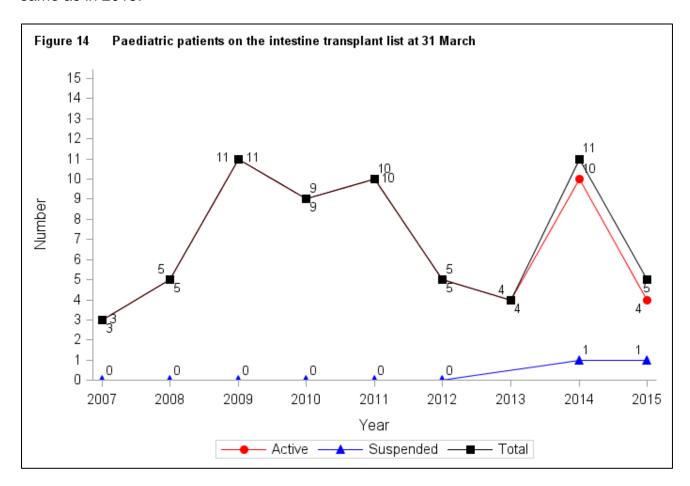
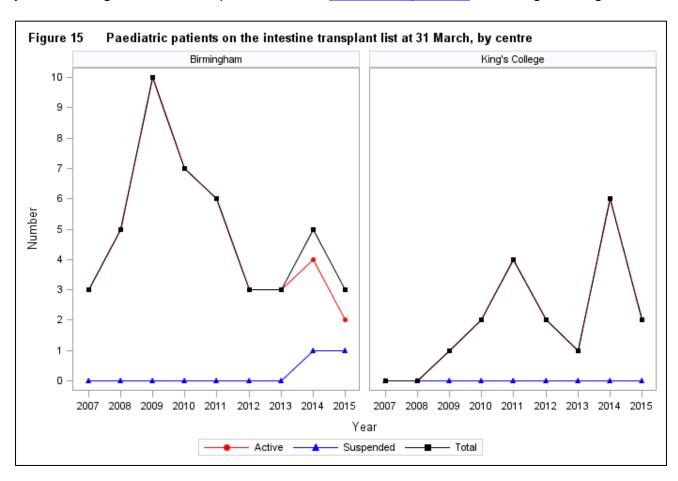


Figure 15 shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2007 and 2015, at each transplant centre. Until the last two years Birmingham had more patients on the <u>active transplant list</u> than King's College.



RESPONSE TO OFFERS

Between 1 April 2014 and 31 March 2015 Birmingham and King's College received offers from 163 and 121 donors, respectively, for intestine transplant patients at their centres. Their offer decline rates were 98% in both cases. These rates are very high because the donor criteria for offering are quite broad and centres are very selective, particularly about the size of the donor.

TRANSPLANTS

Figure 16 shows the number of paediatric intestine transplants performed in the last 10 years, by transplant type. The number of paediatric transplants decreased from eight in 2005/2006 to four in 2007/2008. This number subsequently increased over the following few years to decline again to three in 2013/2014, with a new increase to nine in 2014/2015.

Note the contrasting trends between **Figure 8** and **Figure 16**; while the overall number of transplants in adult recipients has increased over the last 10 years, this has not been the case for paediatric recipients.

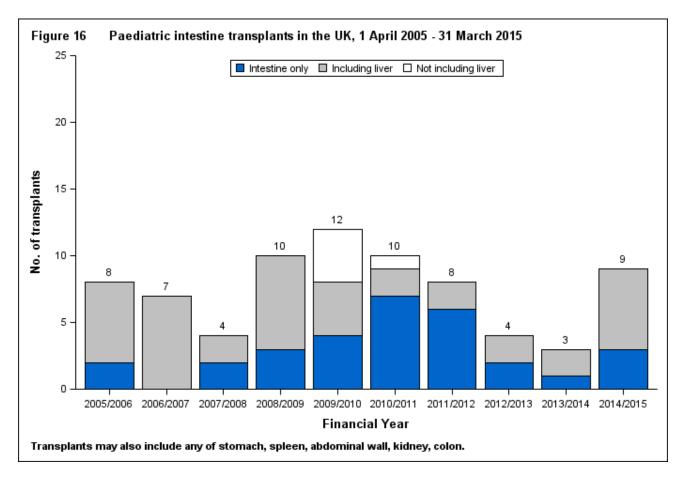


Figure 17 shows the number of paediatric intestine transplants performed in 2014/2015, by centre and transplant type. The majority of transplants (80%) performed at King's College were liver and intestine combined while half of transplants at Birmingham were intestine only and the other half were liver and intestine combined.

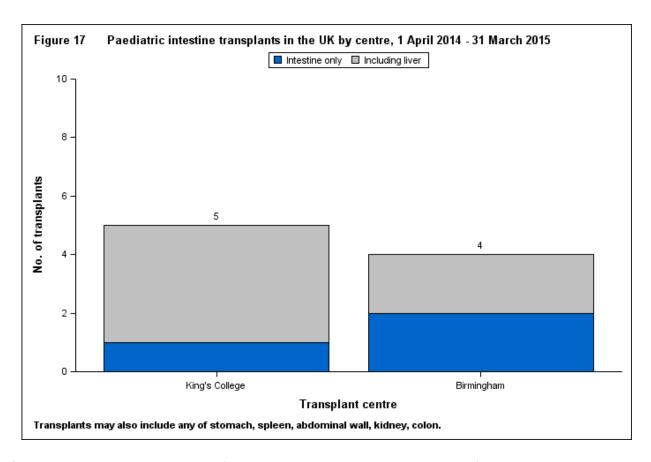
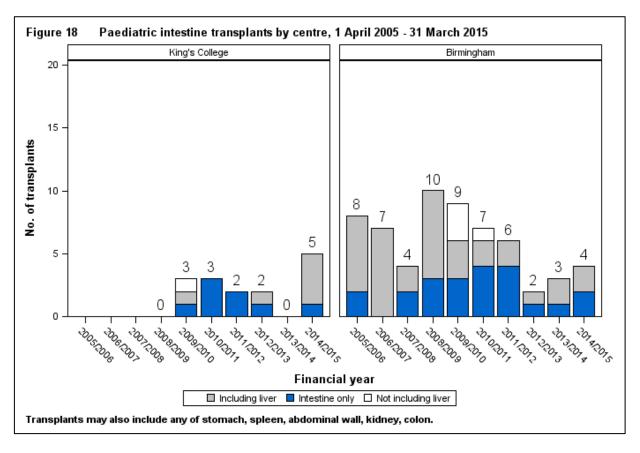


Figure 18 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and type of transplant. Note that King's College joined the programme in 2008 but their first intestine transplants were performed in 2009/2010.

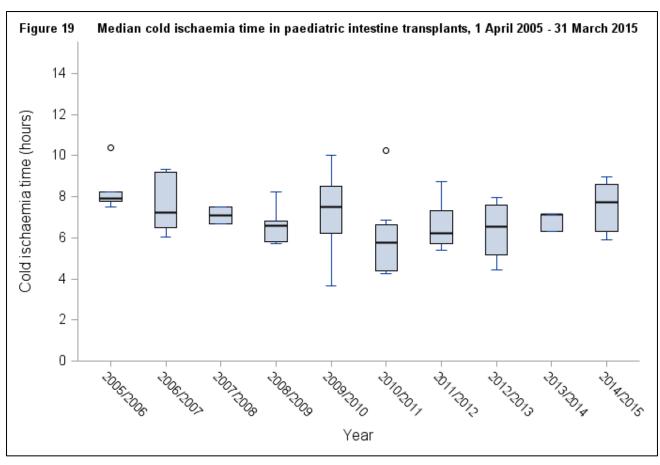


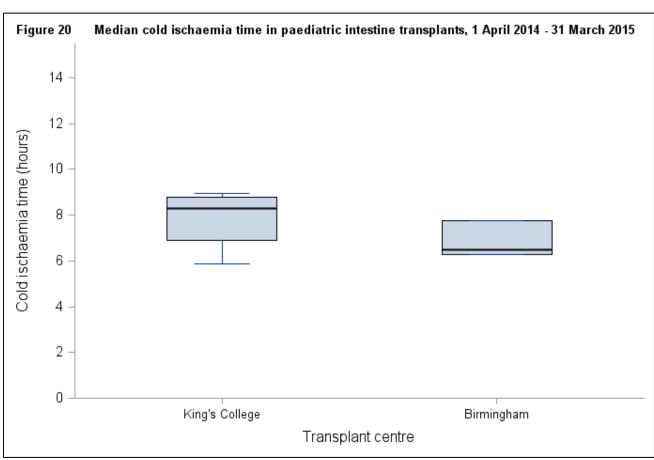
The demographic characteristics of 75 paediatric <u>elective</u> intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 9.** Fifty three percent of these recipients were male and the <u>median</u> age for recipients was four years old. The most common indication for transplantation was short bowel syndrome. The median recipient BMI was 18 kg/m². For some characteristics, percentages may not add up to 100 due to rounding.

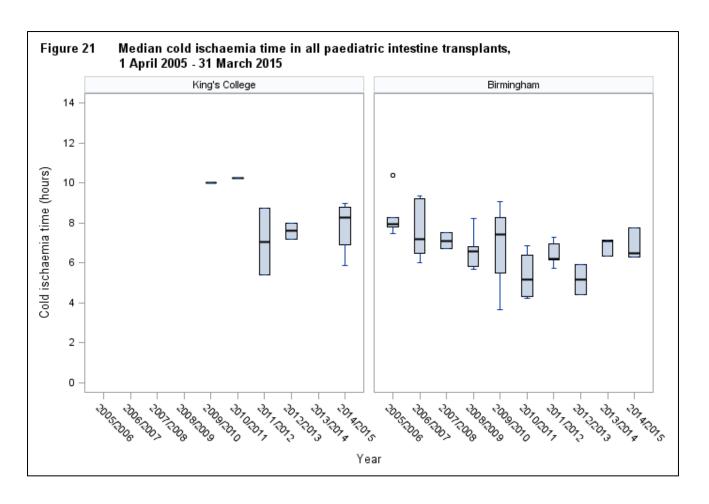
	hic characteristics of pag ,1 April 2005 - 31 March		intestine trans	plant
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Number		60	15	75 (100)
Recipient sex	Male	33 (55)	7 (47)	40 (53)
	Female	27 (45)	8 (53)	35 (47)
Recipient ethnicity group	White	49 (82)	12 (80)	61 (81)
	Other	9 (15)	3 (20)	12 (16)
	Not reported	2 (3)	0	2 (3)
Indication group	Short bowel syndrome Motility disorders Primary mucosal disorders	27 (45) 7 (12) 4 (7)	5 (33) 6 (40) 1 (7)	32 (43) 13 (17) 5 (7)
	Liver disease	9 (15)	0	9 (12)
	Other/not reported	10 (17)	2 (13)	12 (16)
	Retransplant	3 (5)	1 (7)	4 (5)
Patient location	Out-patient	41 (68)	12 (80)	53 (71)
	Ward	3 (5)	1 (7)	4 (5)
	ICU/HDU	0	1 (7)	1 (1)
	Not reported	16 (27)	1 (7)	17 (23)
Pre-transplant renal support	No	51 (85)	13 (87)	64 (85)
	Yes	0	1 (7)	1 (1)
	Not reported	9 (15)	1 (7)	10 (13)
Previous abdominal surgery	No	5 (8)	1 (7)	6 (8)
	Yes	45 (75)	13 (87)	58 (77)
	Not reported	10 (17)	1 (7)	11 (15)
Life style activity	Normal Restricted Self-care Reliant Aged five years or less Not reported	4 (7) 10 (17) 4 (7) 7 (12) 22 (37) 13 (22)	1 (7) 5 (33) 0 0 8 (53) 1 (7)	5 (7) 15 (20) 4 (5) 7 (9) 30 (40) 14 (19)
Restricted venous access at registration	No	11 (18)	9 (60)	20 (27)
	Yes	22 (37)	4 (27)	26 (35)
	Not reported	27 (45)	2 (13)	29 (39)
Recipient age (years)	Median (IQR)	3 (1,6)	5 (4,8)	4 (1,7)
	Not reported	0	0	0

Table 9 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2005 - 31 March 2015					
		Birmingham	King's	TOTAL	
Recipient BMI (kg/m²)	Median (IQR) Not reported	N (%) 17 (16,19) 51	College N (%) 18 (17,19) 1	N (%) 18 (16,19) 52	
Serum bilirubin (umol/l)	Median (IQR)	44 (9,175)	7 (4,10)	19 (7,137)	
	Not reported	12	1	13	
Time on list (days)	Median (IQR)	113 (58,226)	188 (85,408)	134 (60,259)	
	Not reported	0	0	0	
Donor sex	Male	27 (45)	11 (73)	38 (51)	
	Female	33 (55)	4 (27)	37 (49)	
Donor ethnicity group	White	48 (80)	11 (73)	59 (79)	
	Other	6 (10)	1 (7)	7 (9)	
	Not reported	6 (10)	3 (20)	9 (12)	
Donor cause of death group	Stroke	30 (50)	9 (60)	39 (52)	
	Trauma	14 (23)	3 (20)	17 (23)	
	Other	16 (27)	3 (20)	19 (25)	
Donor history of diabetes	No	33 (55)	14 (93)	47 (63)	
	Not reported	27 (45)	1 (7)	28 (37)	
Donor age (years)	Median (IQR)	7 (3,13)	4 (1,8)	6 (3,13)	
	Not reported	0	0	0	
Donor BMI (kg/m²)	Median (IQR)	16 (15,19)	15 (13,19)	16 (14,19)	
	Not reported	0	0	0	
Transplant type	Intestine only	22 (37)	8 (53)	30 (40)	
	Including liver	34 (57)	6 (40)	40 (53)	
	Not including liver	4 (7)	1 (7)	5 (7)	
ABO match	Identical	51 (85)	14 (93)	65 (87)	
	Compatible	9 (15)	1 (7)	10 (13)	
Cold ischaemic time (mins)	Median (IQR)	401 (365,465)	498 (432,538)	415 (368,479)	
	Not reported	12	5	17	

Figure 19 shows boxplots of the CITs of paediatric intestine transplants over the last 10 years. The line inside the box indicates the median value. The median CIT in paediatric transplants has remained reasonably stable over the time period at values between 5.7 and 7.9 hours. **Figure 20** shows the median CITs in paediatric intestine transplants in 2014/2015 for each transplant centre, while **Figure 21** shows the same data but over the last 10 years. Note that prior to 2009/2010 King's College did not perform any intestine transplants which means there are no boxplots presented for the first four years. All of these boxplots represent a small number of observations and as shown in **Table 9**, a proportion of CITs have not been reported.







TRANSPLANT SURVIVAL - FIRST TRANSPLANT

Survival by transplant centre

Table 10 shows the 90-day <u>patient survival rates</u> for paediatric <u>elective</u> first intestine transplants between 1 April 2005 and 31 March 2015, overall and by centre. There were 64 transplants of this kind in the time period and survival information was known in 61 cases; of these, 93% of patients were alive 90 days post-transplant.

Table 10 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre						
Centre	Number of transplants	90-day survival (95% CI)				
Birmingham King's College TOTAL	47 14 61	91.5 100.0 93.4	(79.8-96.6) - (84.0-96.6)			

One- and five-year patient survival rates are shown in **Table 11** and **Table 12**, respectively. One year post-transplant, 85% of transplanted patients are alive while, five years post-transplant, the survival rate is 66%. Note that the number of transplants at King's College is small and survival rates for this centre must be taken only as a guide.

Table 11 One-year patient survival (%) paediatric elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre						
Centre	Number of transplants	1-year sı	urvival (95% CI)			
Birmingham King's College TOTAL	47 14 61	82.8 90.0 84.5	(69.3-90.3) (48.3-98.7) (71.4-92.4)			

Table 12 Five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant centre						
Centre	Number of transplants	5-year survival (95% CI)				
Birmingham King's College TOTAL	47 14 61	60.4 90.0 65.5	(44.1-73.5) (48.3-98.7) (50.4-77.7)			

Survival by transplant type

Table 13, Table 14 and **Table 15** show the 90-day, one-year and five-year patient survival rates for paediatric <u>elective</u> first intestine transplants by transplant type. Due to the small number of transplants for some transplant types, these survival rates must be taken only as a guide.

Table 13 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant type							
Transplant type	Number of transplants	90-day s	survival (95% CI)				
Birmingham							
Including liver	28	85.7	(67.2-94.5)				
Not including liver	19	100.0	-				
King's College Including liver Not including liver TOTAL	6 ¹ 8 ¹ 61	- - 93.4	- - (84.0-96.6)				

One-year patient survival (%) paediatric elective first intestine transplants between 1 April 2005 Table 14 and 31 March 2015, by transplant type Transplant type Number of 1-year survival (95% CI) transplants Birmingham Including liver 28 (58.8-90.3) 78.3 Not including liver (65.1-96.6) 19 89.5 King's College Including liver 6¹ 8¹ Not including liver **TOTAL** (71.4-92.4) 61 84.5

Table 15 Five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2005 and 31 March 2015, by transplant type							
Transplant type	Number of transplants	5-year s	urvival (95% CI)				
Birmingham							
Including liver	28	51.9	(31.5-69.3)				
Not including liver	19	73.1	(39.9-90.3)				
King's College Including liver Not including liver TOTAL	6 ¹ 8 ¹ 61	- - 65.5	- (50.4-77.7)				

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¹ Survival rates for transplant types with less than 10 transplants are not presented due to small numbers.

FORM RETURN RATES

FORM RETURN RATES

Form return rates are reported in **Table 16** and **Table 17** for adult and paediatric centres, respectively. The forms included are the intestinal transplant record form and the three month and annual intestinal transplant follow-up forms that are reported to the UK Transplant Registry database. The tables show the number of forms issued between 1 January 2014 and 31 December 2014, for patients at each centre, and the percentage of forms that had been returned at time of analysis. Annual follow-up forms are broken down into those issued at one year post-transplant and "lifetime follow-up", which is two years or longer.

Table 16		n rates, by a cember 2014		olant centre,	for forms	issued betw	een 1 Janı	uary 2014
Centre	Transpla No. forms issued	ant record % returned	3 month No. forms issued	follow-up % returned	1 year f No. forms issued	ollow-up % returned	Lifetime No. forms issued	follow-up % returned
Cambridge	10	60	11	100	15	93	18	100
Oxford	5	100	5	100	5	100	13	100
Total	15	73	16	100	20	95	31	100

Table 17		ırn rates, by / 2014 and 3		transplant er 2014	centre, fo	r forms issu	ed betwee	n
Centre	Transpla No. forms issued	ant record % returned	3 month No. forms issued	follow-up % returned	1 year f No. forms issued	ollow-up % returned	Lifetime No. forms issued	follow-up % returned
Birmingham	4	75	2	100	3	100	63	71
King's College	5	80	5	100	0	0	9	89
Total	9	78	7	100	3	100	72	74

APPENDIX

APPENDIX

DATA

Data were obtained from the UK Transplant Registry for the 10 year time period, 1 April 2005 to 31 March 2015. NHS Group 2 transplants have been included while liver-only transplants because of intestinal failure have been excluded. Three transplants performed at Cambridge between 2007 and 2013 that included a short length of donor jejunum for recipient anatomical reasons but not because of intestinal failure have been excluded.

Table A1 shows the number of adult transplants including the intestine in the 10 year period by centre and urgency status. The left hand columns show the total number of transplants (including re-transplants) and the right hand columns show first-time transplants only.

Table A1 Number of adult intestine transplants, by transplant centre and urgency status, 1 April 2005 to 31 March 2015						
Centre	All tra	nsplants	First-time	transplants		
	Elective	Super-urgent	Elective	Super-urgent		
Cambridge	53	5	49	3		
Oxford	29	0	28	0		
TOTAL	82	5	77	3		

Table A2 shows the number of paediatric transplants including the intestine in the 10 year period by centre and urgency status. The left hand columns show the total number of transplants (including re-transplants) and the right hand columns shows first-time transplants only.

Table A2 Number of paediatric intestine transplants, by transplant centre and urgency status, 1 April 2005 to 31 March 2015						
Centre	All tra	transplants Super-urgent				
Birmingham King's College TOTAL	60 15 75	0 0 0	50 14 64	0 0 0		

METHODS

Waiting time to transplant

Waiting time was calculated from date of registration to date of transplant, for <u>elective</u> patients registered between 1 April 2011 and 31 March 2014 for an intestine transplant. Any periods of suspension were included in the calculation. Registrations for a re-transplant were included too. <u>Kaplan-Meier</u> methods were used to calculate median waiting times, where patients who were removed or died on the transplant list were censored at the date of event. Patients who were still active on the transplant list at time of analysis, 9 June 2015, were censored at that time.

Patient survival rates

Patient survival rates are based on the number of patients transplanted and the number and timing of those that die within the post-transplant period of interest. Kaplan-Meier methods were used to estimate the unadjusted survival rates at 90 days, one and five years post-transplantation. Patients can be included in this method of analysis irrespective of the length of follow-up recorded. If a patient is alive at the end of the follow-up then information about the survival of the patient is censored at time of analysis, 9 June 2015. Death, irrespective of whether the graft is still functioning or not, is classed as an event. For the purposes of this report, no adjustment was made for risk factors that might make a patient more or less likely to die. Comparison of unadjusted survival rates across centres and transplant types and to the national rate should therefore be made with caution.

Offer decline rates

Donor intestine offer decline rates were calculated for each intestine transplant centre. The denominator was equal to the number of intestines offered to them from UK <u>DBD</u> donors who met the criteria for intestine donation and whose family granted consent for intestine donation. The numerator was equal to the number of intestines each centre declined. Therefore, if a centre received two offers from the same donor for two of their patients and declined it for both, this counts as one offer and one decline; if they accepted it for one of these patients it counts as one offer and one acceptance. The general criteria for intestine donation is donor age less than or equal to 55 years and weight less than or equal to 80 kg at time of death, however, centres are highly selective when accepting a donor organ which leads to high decline rates. The time period analysed was 1 April 2014 to 31 March 2015.

GLOSSARY OF TERMS

Active transplant list

When a patient is registered for a transplant, they may be registered on what is called the 'active' transplant list. This means that when a donor organ becomes available, the patient is included among those who are matched against the donor to determine whether or not the organ is suitable for them. It may sometimes be necessary to take a patient off the active transplant list, either temporarily or permanently. This may be done, for example, if someone becomes too ill to receive a transplant. The patient is told about the decision to suspend them from the list and is informed whether the suspension is temporary or permanent. If a patient is suspended from the list, they are not included in the matching of any donor organs that become available.

Boxplots

The length of the box in this type of plot represents the <u>inter-quartile range</u>. The line inside the box indicates the <u>median</u> value. The vertical lines issuing from the box are called the whiskers and indicate the range of values that are outside of the inter-quartile range but are close enough not to be considered outliers. The circles that are outside the box indicate the outliers.

Cold ischaemic time (CIT)

The length of time that elapses between the chilling of the intestine after its blood supply has been cut off in the donor and its grafting into the recipient is called cold ischaemic time. Generally, the shorter this time, the better the long-term survival of the recipient.

Confidence interval (CI)

When an estimate of a quantity such as a survival rate is obtained from data, the value of the estimate depends on the set of patients whose data were used. If, by chance, data from a different set of patients had been used, the value of the estimate may have been different. There is therefore some uncertainty linked with any estimate. A confidence interval is a range of values whose width gives an indication of the uncertainty or precision of an estimate. The number of transplants or patients analysed influences the width of a confidence interval. Smaller data sets tend to lead to wider confidence intervals compared to larger data sets. Estimates from larger data sets are therefore more precise than those from smaller data sets. Confidence intervals are calculated with a stated probability, usually 95%.

Confidence limit

The upper and lower bounds of a confidence interval.

Donor after brain death (DBD)

A donor whose heart is still beating when their entire brain has stopped working so that they cannot survive without the use of a ventilator. Organs for transplant are removed from the donor while their heart is still beating, but only after extensive tests determine that the brain cannot recover and they have been certified dead.

Elective registration

A patient who is registered to the liver transplant list as a 'routine' rather than a 'superurgent' patient. The two groups have a different range of indications for transplantation with markedly different short-term prognoses. Similarly, the process of offering a donor liver is different for super-urgent and elective registrations, reflecting the difference in risk of death without transplantation for these two patient groups.

Inter-quartile range (IQR)

The values between which the middle 50% of the data are distributed. The lower boundary of the IQR is the lower quartile, the upper boundary the upper quartile. Quartiles divide a rank-ordered data set into four equal parts. The values that divide each part are called the first (or lower), second, and third (or upper) quartiles.

Kaplan-Meier method

A method that allows patients with incomplete follow-up information to be included in estimating survival rates. For example, in a cohort for estimating one-year patient survival rates, a patient was followed up for only nine months before they relocated. If we calculated a crude survival estimate using the number of patients who survived for at least a year, this patient would have to be excluded as it is not known whether or not the patient was still

alive at one year after transplant. The Kaplan-Meier method allows information about such patients to be used for the length of time that they are followed-up, when this information would otherwise be discarded. Such instances of incomplete follow-up are not uncommon and the Kaplan-Meier method allows the computation of estimates that are more meaningful in these cases.

Median

It is a measure of central tendency of a series of observations. The median is the midpoint in a rank-ordered dataset, so that half the data values are larger than the median, and half are smaller.

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