



Blood and Transplant

**ANNUAL REPORT ON
INTESTINE TRANSPLANTATION**

**REPORT FOR 2013/2014
(1 APRIL 2004 – 31 MARCH 2014)**

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EXECUTIVE SUMMARY



EXECUTIVE SUMMARY

This report presents key figures about intestine transplantation in the UK. The period covered is ten years of transplant data, from 1 April 2004 to 31 March 2014. 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 survival should be regarded as guidance only due to the limited amount of data available.

Key findings

- On 31 March 2014, there were 13 patients on the UK active intestine **transplant list**, which represents a 28% decrease relative to 2010-2011, when the list reached its maximum figure within the reported time period. The number of patients on the transplant list steadily increased from 2007 to 2010, subsequently either remaining stable or falling. Of those patients on the transplant list, approximately 75% had received a transplant two years post registration.
- There were 148 intestine **transplants** performed in the UK in the ten year period; 51% of these were in paediatric recipients and 49% were in adult recipients.
- The number of **transplants** in **adult recipients** has increased over the last ten years. This has not been the case for **paediatric recipients**, for which numbers have either remained reasonably stable or decreased over time.
- The national rates of **survival** after first intestine transplantation of [elective adult patients](#) were estimated at 87%, 80% and 60% at 90 days, one and five years post transplant, respectively.
- The national rates of **survival** after first intestine transplantation of elective **paediatric patients** were estimated at 92%, 80% 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 2004 and 31 March 2014, for all four designated centres performing intestine transplantation in the UK. Data were obtained from the UK Transplant Registry, at NHS Blood and Transplant, that 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 [patient survival rates](#) 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 amount of data available.

TRANSPLANT LIST

Figure 1 shows the total number of patients on the intestine [active transplant list](#) at 31 March each year between 2007 and 2014. The number of patients waiting for a transplant increased each year from 6 in 2007 to 18 in 2010-2011 and fell slightly to 14 in 2012, then to 13 in 2014.

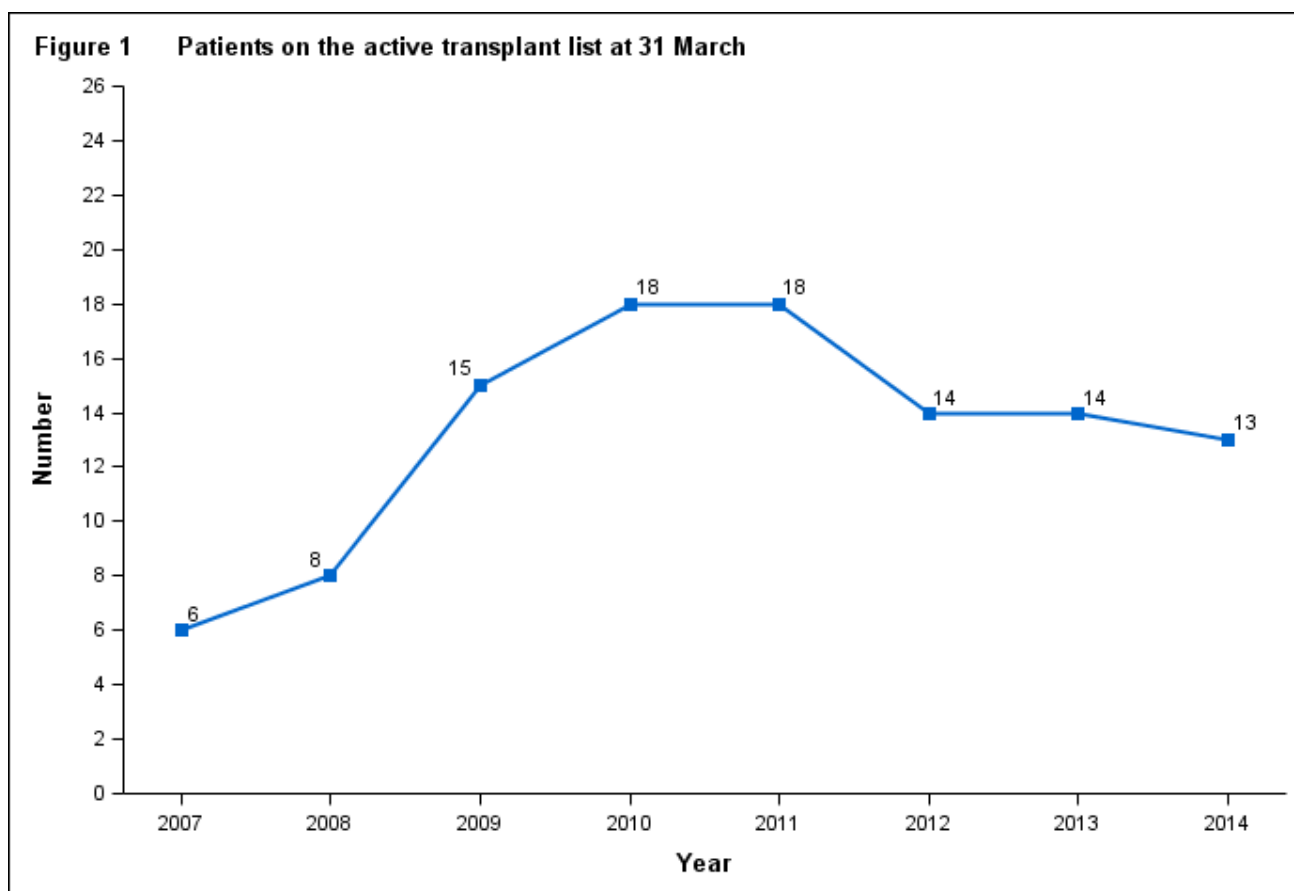
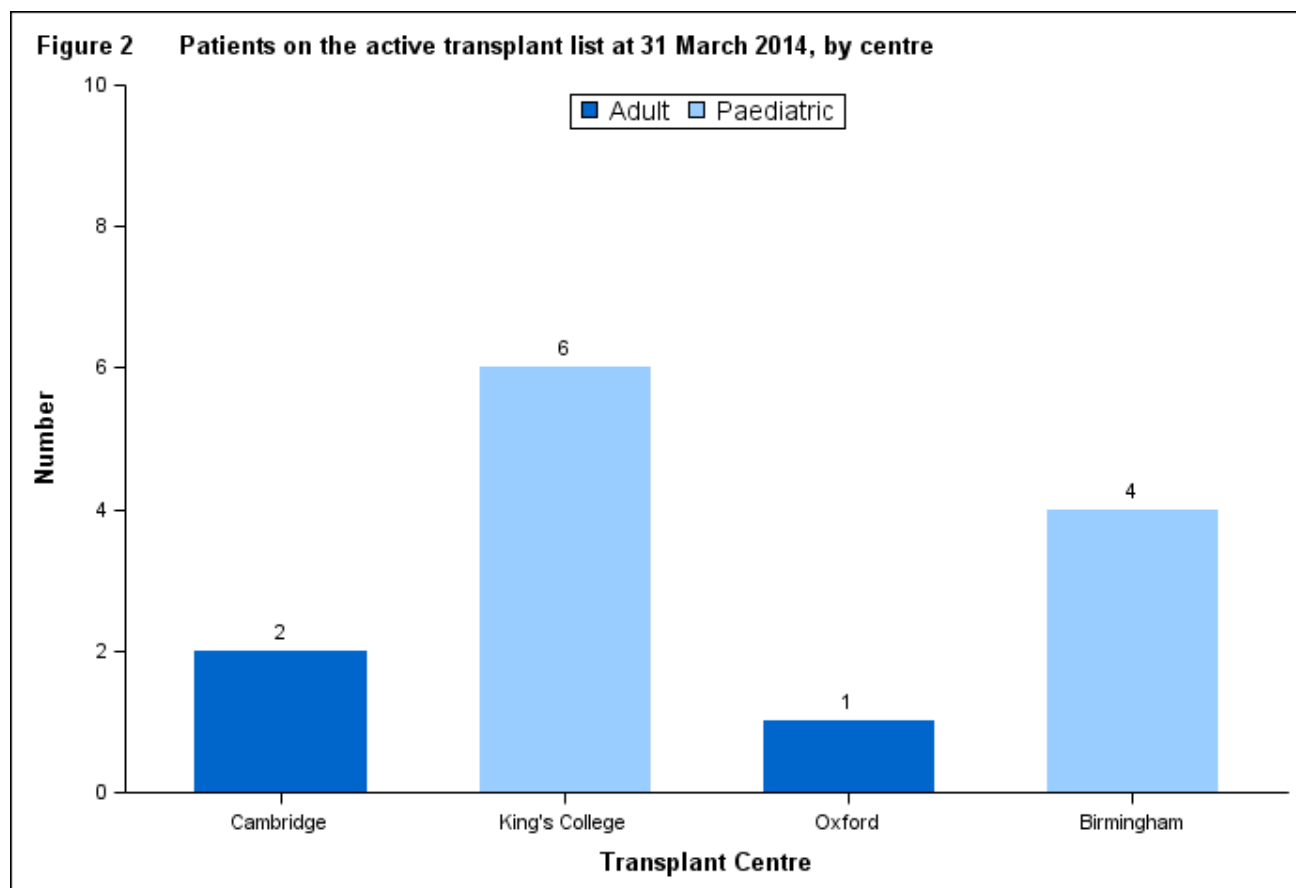


Figure 2 shows the number of adult and paediatric patients on the [active transplant list](#) at 31 March 2014 by centre. In total, there were 3 adult and 10 paediatric patients. King's College Hospital, in London, had the largest proportion of patients on the transplant list (46%) and Churchill Hospital, in Oxford, had the smallest (7%). Ten-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 16**, respectively.



The outcomes of patients listed between April 2011 and March 2012 for an intestine transplant are summarised in **Figure 3**. This shows the proportion of patients transplanted, still waiting or dying while waiting six months, one year and two years after joining the transplant list. At one year post-registration 71% of patients had received a transplant and 18% were still waiting. The remaining percentage of patients died while on the transplant list.

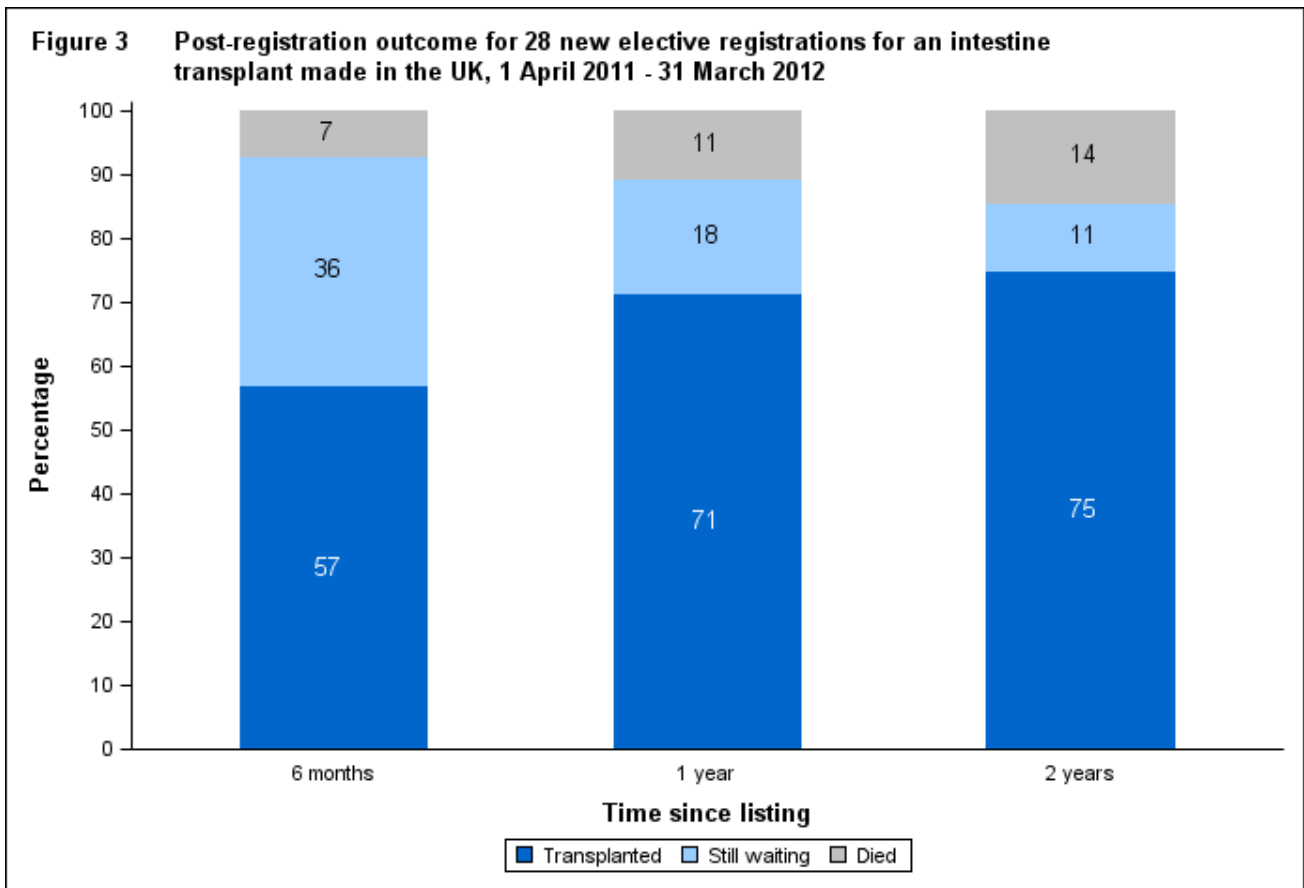


Table 1 shows [median waiting time](#) to elective intestine transplant by registration type (including re-registrations) for both adult and paediatrics. Overall, on average, patients wait 183 days for a transplant. The average wait is longer for patients who require a liver as part of their intestine 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 2010 - 31 March 2013			
Registration type	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Intestine only ¹	22	125	22 – 228
Liver, intestine and pancreas ¹	30	274	110 – 438
Intestine and pancreas ¹	15	215	4 – 426
TOTAL	67	183	112 – 254

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 total number of intestine transplants performed in the last ten years. Currently in the UK, all intestine transplants are performed from donors after brain death ([DBD](#)). The total number of transplants was 148, with annual figures increasing from 10 in 2004/05 to 26 in 2013/14.

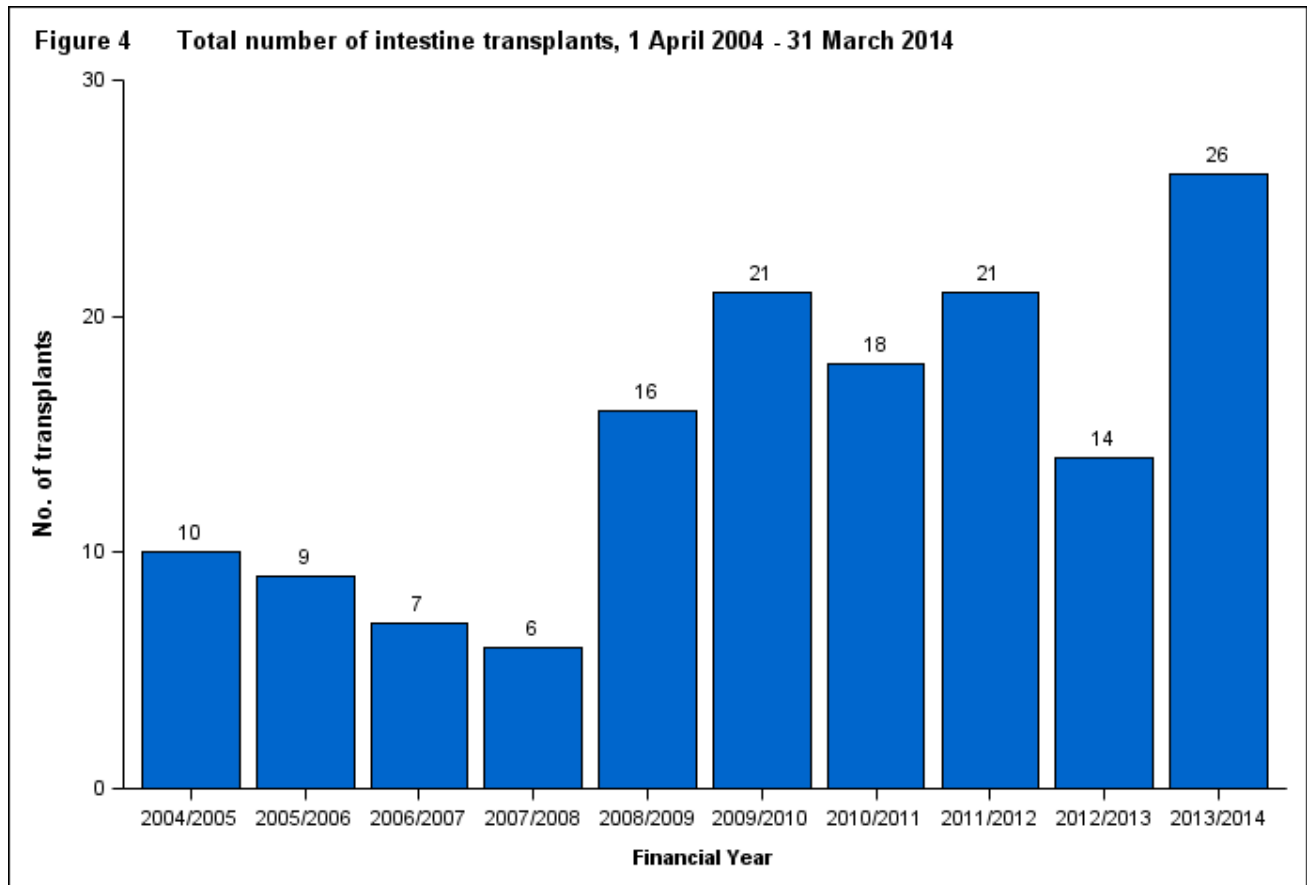
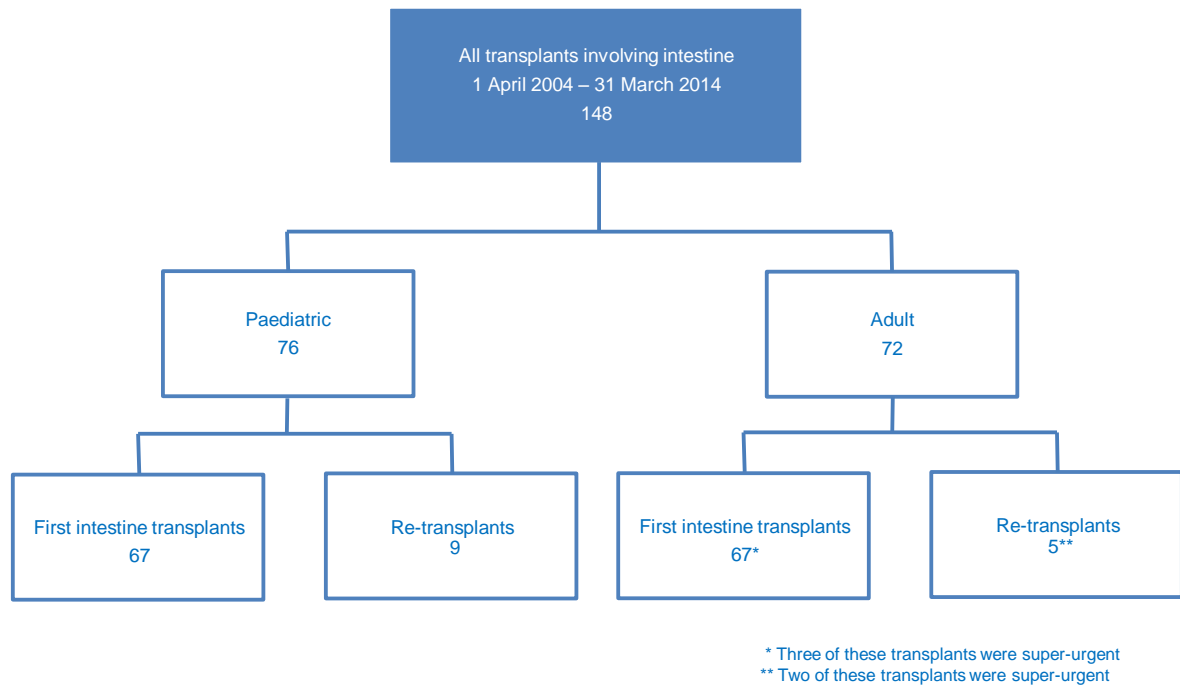


Figure 5 details the 148 intestine transplants performed in the UK in the ten year period. Of these, 76 (51%) were in paediatric patients and 72 (49%) were in adult patients. The majority of both paediatric and adult transplants were in first time recipients.

Figure 5 UK intestine transplants, 1 April 2004 to 31 March 2014



ADULT INTESTINE TRANSPLANTATION



ADULT INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 6 shows the number of adult patients on the transplant list for a transplant including the intestine at 31 March each year between 2007 and 2014. Year-end transplant list data are not available before 2007. The number of patients on the active intestine transplant list increased each year from 3 in 2007 to 9 in 2010. It subsequently remained relatively stable until 2014, when it fell to 3 patients.

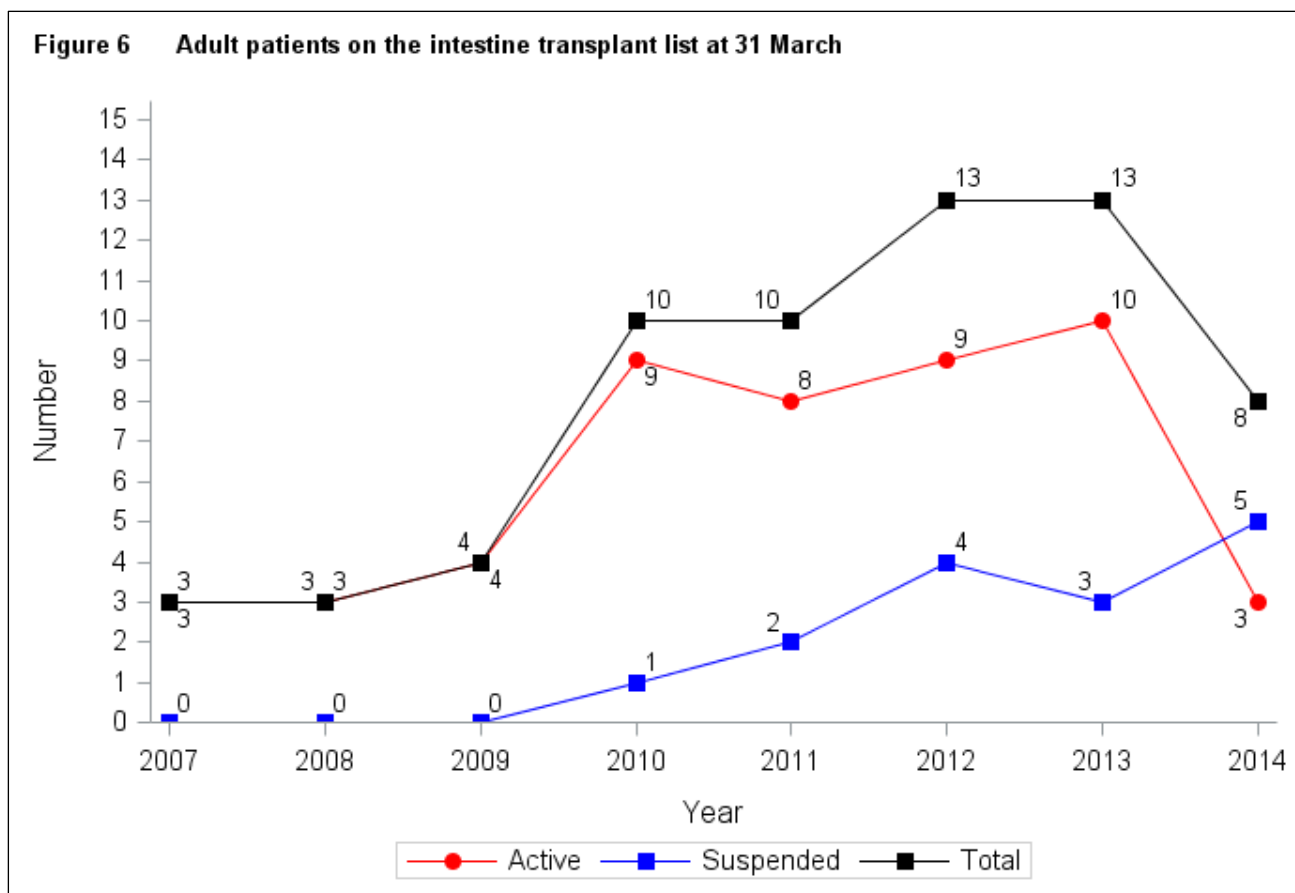
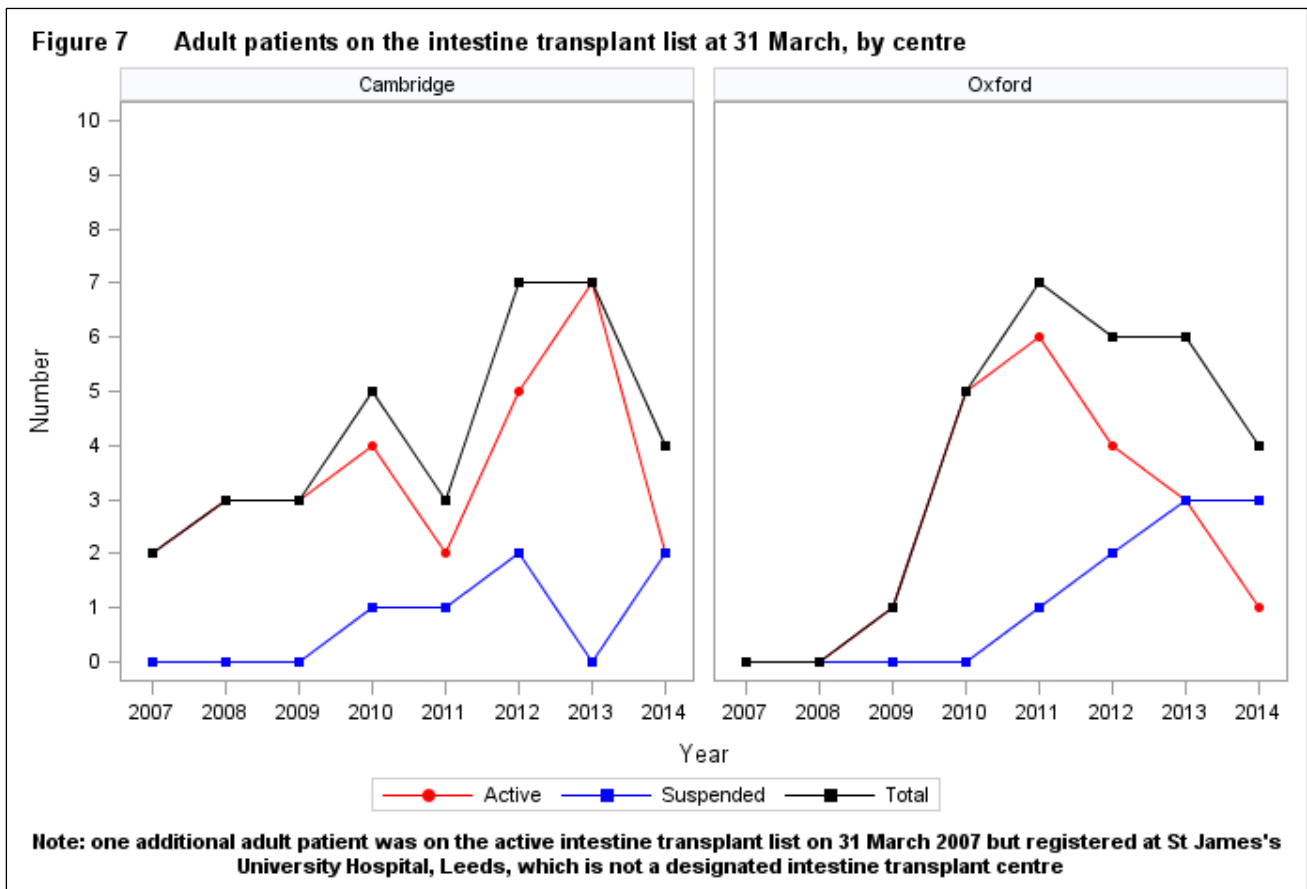


Figure 7 shows the number of adult patients on the transplant list for a transplant involving the intestine at 31 March each year between 2007 and 2014, for each transplant centre. In all years except 2010 and 2011, Cambridge had a larger proportion of patients on the national active transplant list than Oxford.



RESPONSE TO OFFERS

Intestine transplant centres are offered organs from [DBD](#) donors aged less than or equal to 55 years and with a weight less than or equal to 80 kg via the UK National Bowel Allocation Scheme. Between 1 April 2013 and 31 March 2014 Cambridge received intestine offers from 133 such donors and Oxford received intestine offers from 70. Their [offer decline rates](#) were 88% and 90%, respectively.

TRANSPLANTS

Figure 8 shows the total number of adult intestine transplants performed in the last ten years, by transplant type. The total number of adult transplants has been steadily increasing over the time period to 23 in the last financial year.

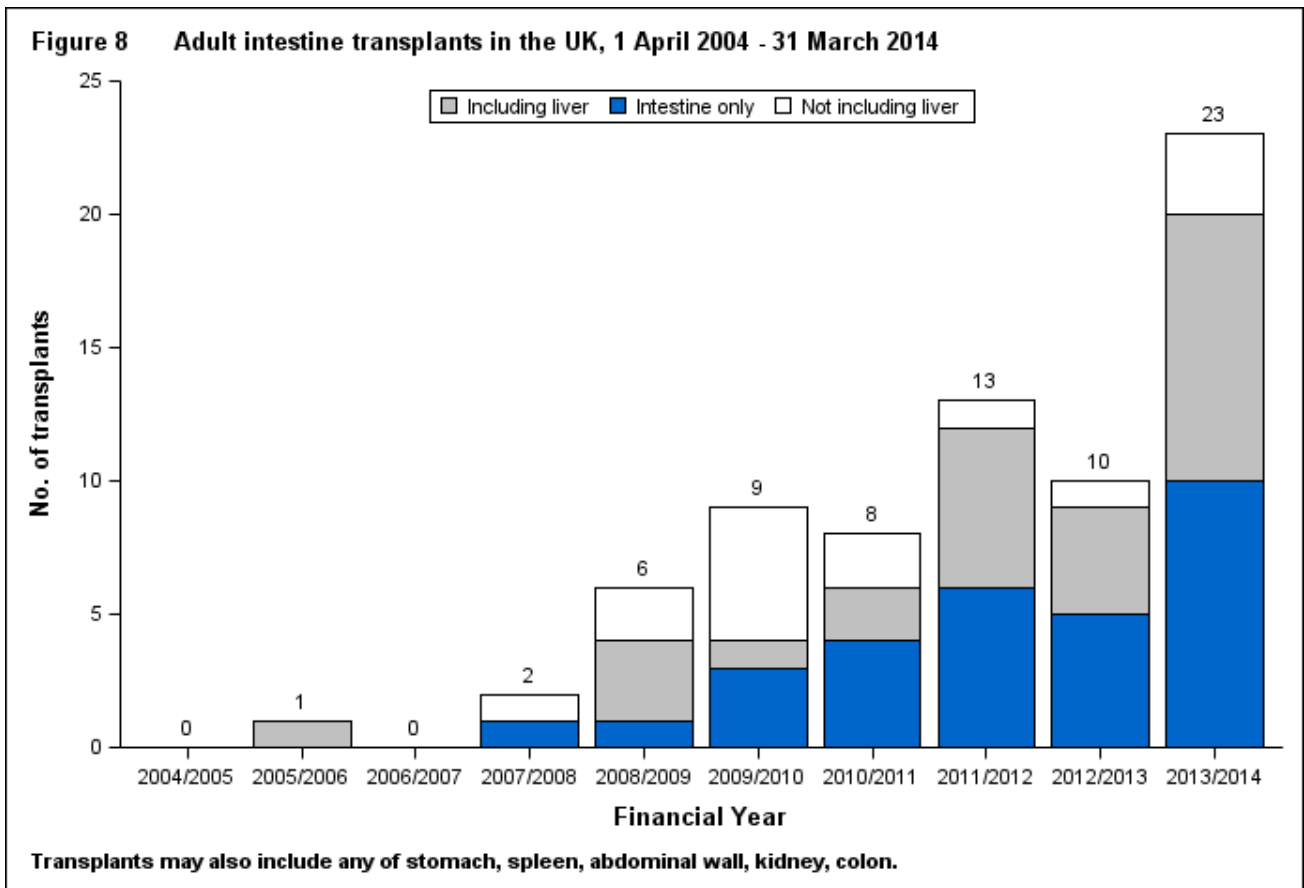
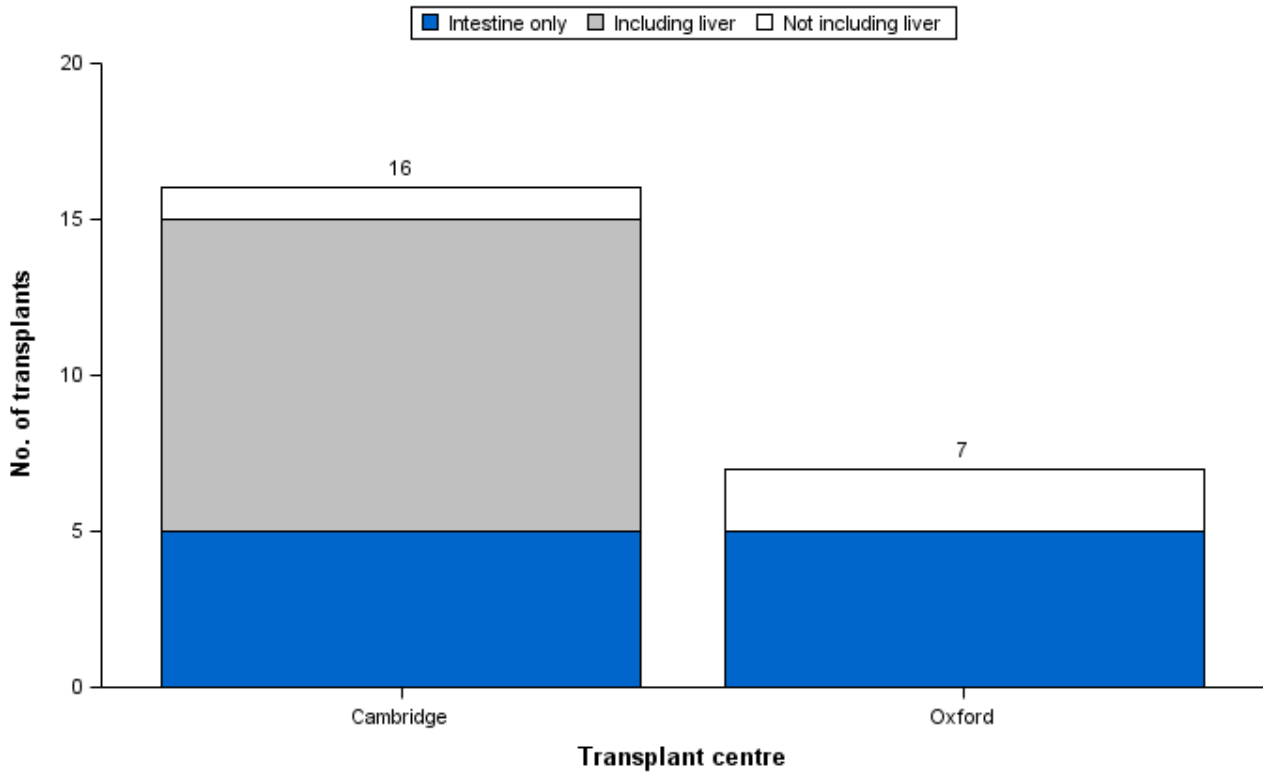


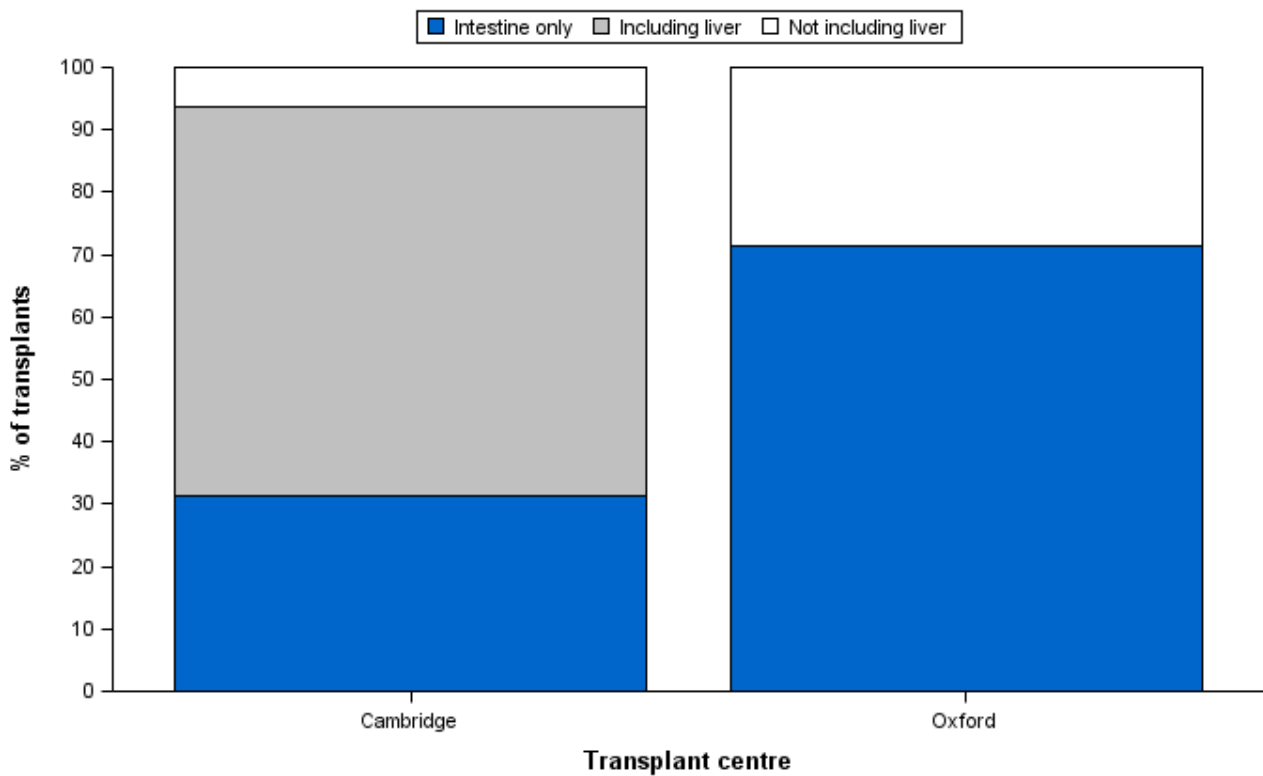
Figure 9 shows the total number of adult intestine transplants performed in 2013/14, by centre and transplant type. The same information is presented in **Figure 10** but this shows the proportion of each transplant type performed at each centre.

Figure 9 Adult intestine transplants in the UK by centre, 1 April 2013 - 31 March 2014



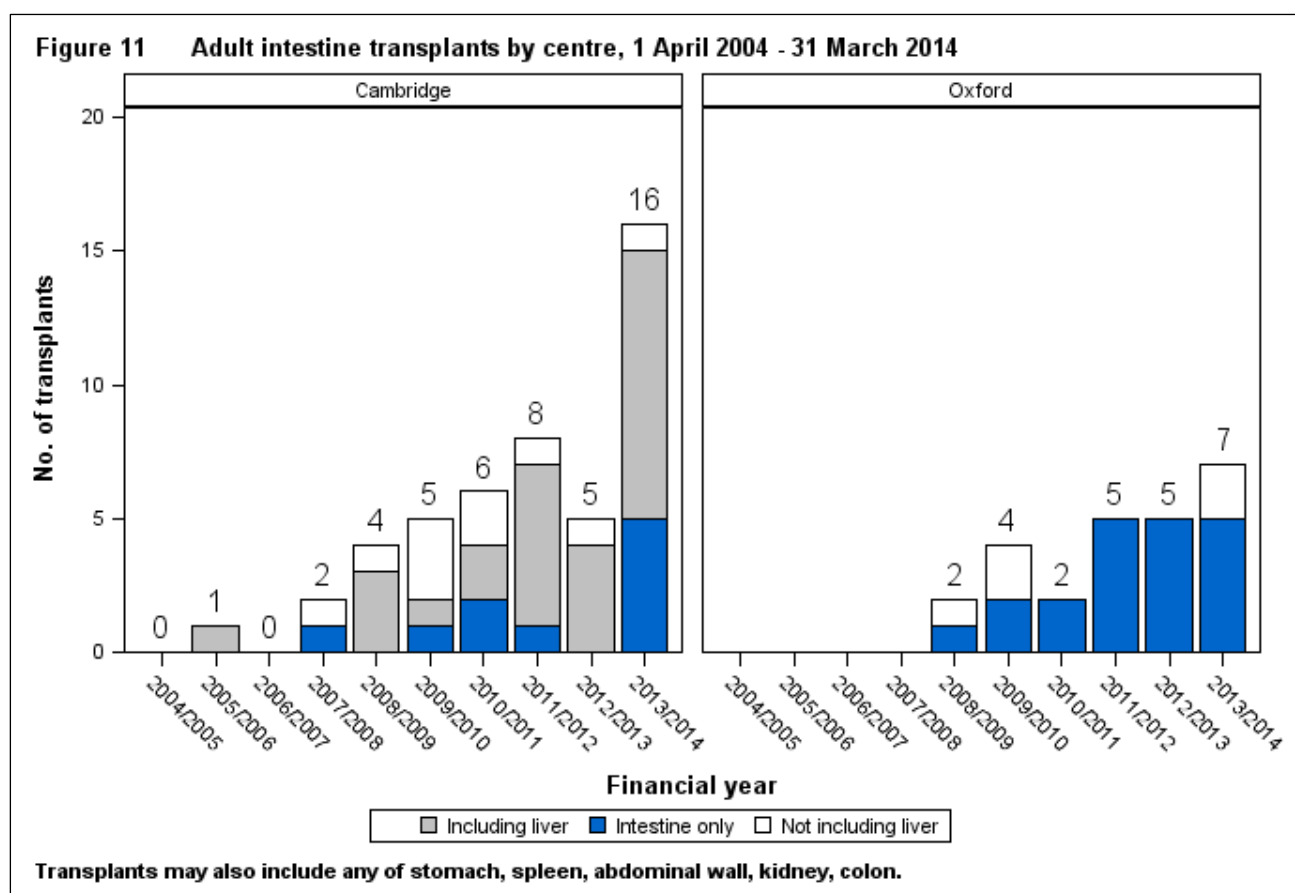
Transplants may also include any of stomach, spleen, abdominal wall, kidney, colon.

Figure 10 Adult intestine transplants in the UK by centre, 1 April 2013 - 31 March 2014



Transplants may also include any of stomach, spleen, abdominal wall, kidney, colon.

Figure 11 shows the total number of adult intestine transplants performed in the last ten years, by centre and type of transplant.



The demographic characteristics of 67 adult [elective](#) intestine transplant recipients in the ten year period are shown by centre and overall in **Table 2**. Nearly two thirds of these recipients were male and the [median](#) 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.

Table 2 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2004 - 31 March 2014				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number		42	25	67 (100)
Recipient sex	Male	23 (55)	15 (60)	38 (57)
	Female	19 (45)	10 (40)	29 (43)

Table 2 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2004 - 31 March 2014				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Recipient ethnicity group	White	37 (88)	23 (92)	60 (90)
	Other	4 (10)	2 (8)	6 (9)
	Missing	1 (2)	0	1 (2)
Indication group	Short bowel syndrome	19 (45)	13 (52)	32 (48)
	Motility disorders	3 (7)	5 (20)	8 (12)
	Malignancy	3 (7)	2 (8)	5 (8)
	Liver disease	2 (5)	1 (4)	3 (5)
	Other/missing	12 (29)	4 (16)	16 (24)
	Retransplant	3 (7)	0	3 (5)
Patient location	Out-patient	22 (52)	22 (88)	44 (66)
	Ward	4 (10)	1 (4)	5 (8)
	ICU/HDU	1 (2)	0	1 (2)
	Missing	15 (36)	2 (8)	17 (25)
Pre-transplant renal support	No	27 (64)	21 (84)	48 (72)
	Yes	1 (2)	2 (8)	3 (5)
	Missing	14 (33)	2 (8)	16 (24)
Previous abdominal surgery	No	2 (5)	1 (4)	3 (5)
	Yes	25 (60)	22 (88)	47 (70)
	Missing	15 (36)	2 (8)	17 (25)
Life style activity	Normal	0	2 (8)	2 (3)
	Restricted	3 (7)	2 (8)	5 (8)
	Self-care	19 (45)	14 (56)	33 (49)
	Confined	4 (10)	5 (20)	9 (13)
	Reliant	1 (2)	0	1 (2)
	Missing	15 (36)	2 (8)	17 (25)
Restricted venous access at registration	No	26 (62)	14 (56)	40 (60)
	Yes	10 (24)	10 (40)	20 (30)
	Unknown	6 (14)	1 (4)	7 (10)
Recipient age years	Median (IQR)	46 (36,53)	40 (35,47)	44 (35,52)
	Missing	0	0	0
Recipient BMI kg/m2	Median (IQR)	20 (19,23)	22 (20,24)	21 (19,23)
	Missing	18	6	24
Serum bilirubin umol/l	Median (IQR)	15 (8,32)	11 (8,16)	11 (8,25)
	Missing	15	2	17
Time on list days	Median (IQR)	41 (20,177)	36 (27,71)	40 (20,140)
	Missing	0	0	0
Donor sex	Male	12 (29)	14 (56)	26 (39)
	Female	30 (71)	11 (44)	41 (61)
Donor ethnicity group	White	39 (93)	24 (96)	63 (94)
	Other	1 (2)	1 (4)	2 (3)
	Missing	2 (5)	0	2 (3)

Table 2		Demographic characteristics of adult elective intestine transplant recipients, 1 April 2004 - 31 March 2014		
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Donor cause of death group	Stroke	34 (81)	14 (56)	48 (72)
	Trauma	5 (12)	11 (44)	16 (24)
	Other	3 (7)	0	3 (5)
Donor history of diabetes	No	23 (55)	21 (84)	44 (66)
	Yes	2 (5)	2 (8)	4 (6)
	Missing	17 (40)	2 (8)	19 (28)
Donor age years	Median (IQR)	33 (21,39)	25 (22,37)	31 (21,39)
	Missing	0	0	0
Donor BMI kg/m2	Median (IQR)	21 (19,23)	22 (21,23)	21 (20,23)
	Missing	0	0	0
Transplant type	Intestine only	10 (24)	20 (80)	30 (45)
	Including liver	22 (52)	0	22 (33)
	Not including liver	10 (24)	5 (20)	15 (22)
ABO match	Identical	34 (81)	23 (92)	57 (85)
	Compatible	8 (19)	2 (8)	10 (15)
Cold ischaemic time mins	Median (IQR)	282 (254,312)	390 (338,451)	334 (282,393)
	Missing	21	4	25

Figure 12 shows [boxplots](#) of the [cold ischaemic times](#) (CIT) of adult intestine transplants over the last ten years. The line inside the box indicates the [median](#) value. The median CIT has fallen over the time period from 8.4 hours in 2005/06 to 4.9 hours in 2013/14. Note that these boxplots represent a small number of observations.

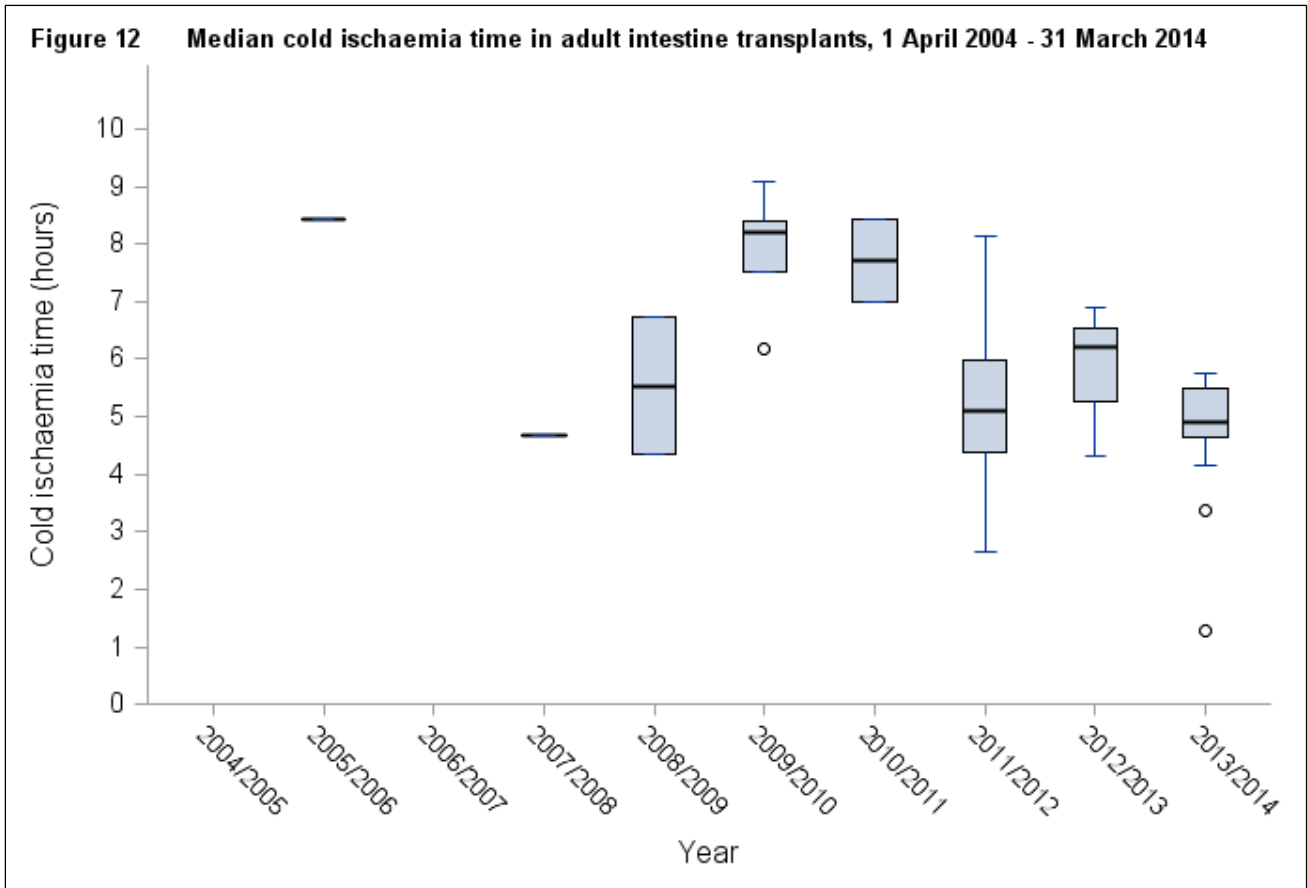


Figure 13 shows the median CITs in adult intestine transplants in 2013/14 for each transplant centre, while **Figure 14** shows the same data but over the last ten years. Note that these boxplots represent a very small number of observations.

Figure 13 Median cold ischaemia time in adult intestine transplants, 1 April 2013 - 31 March 2014

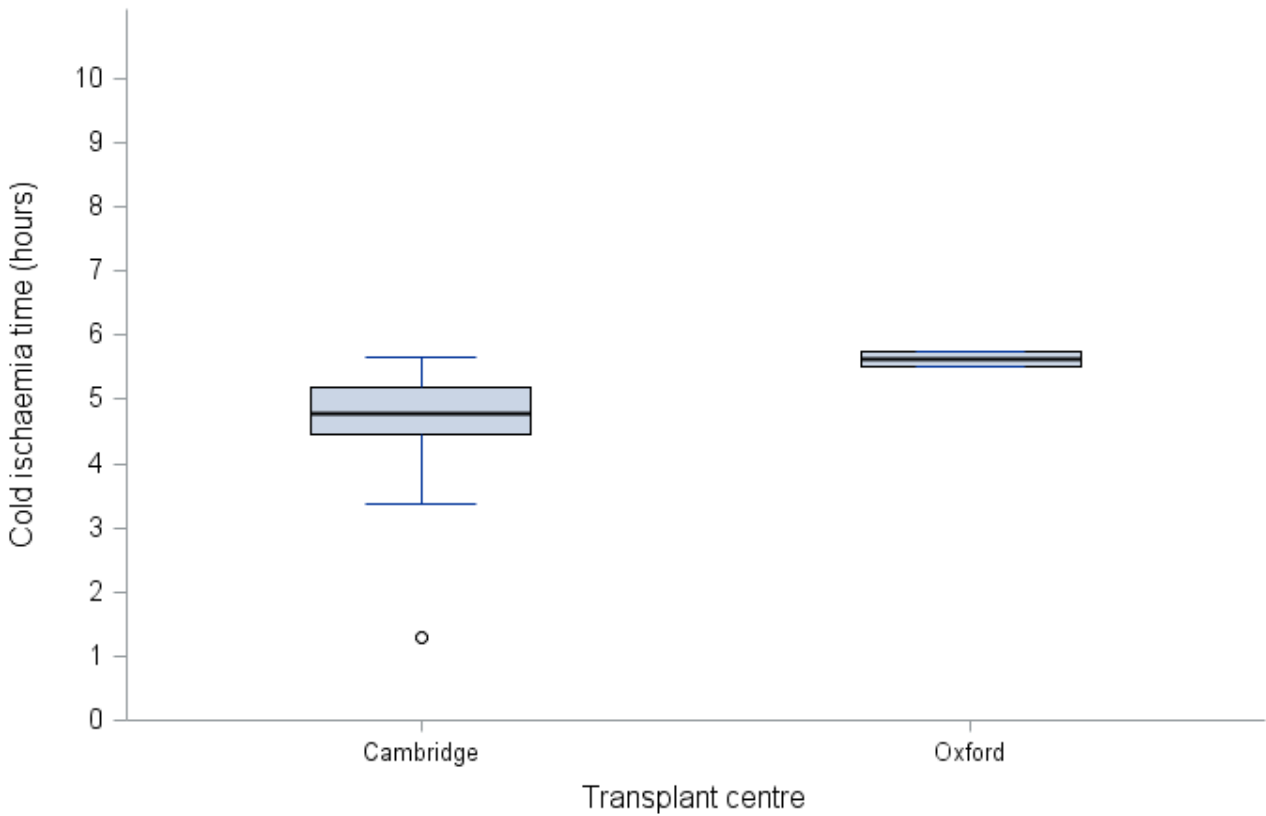
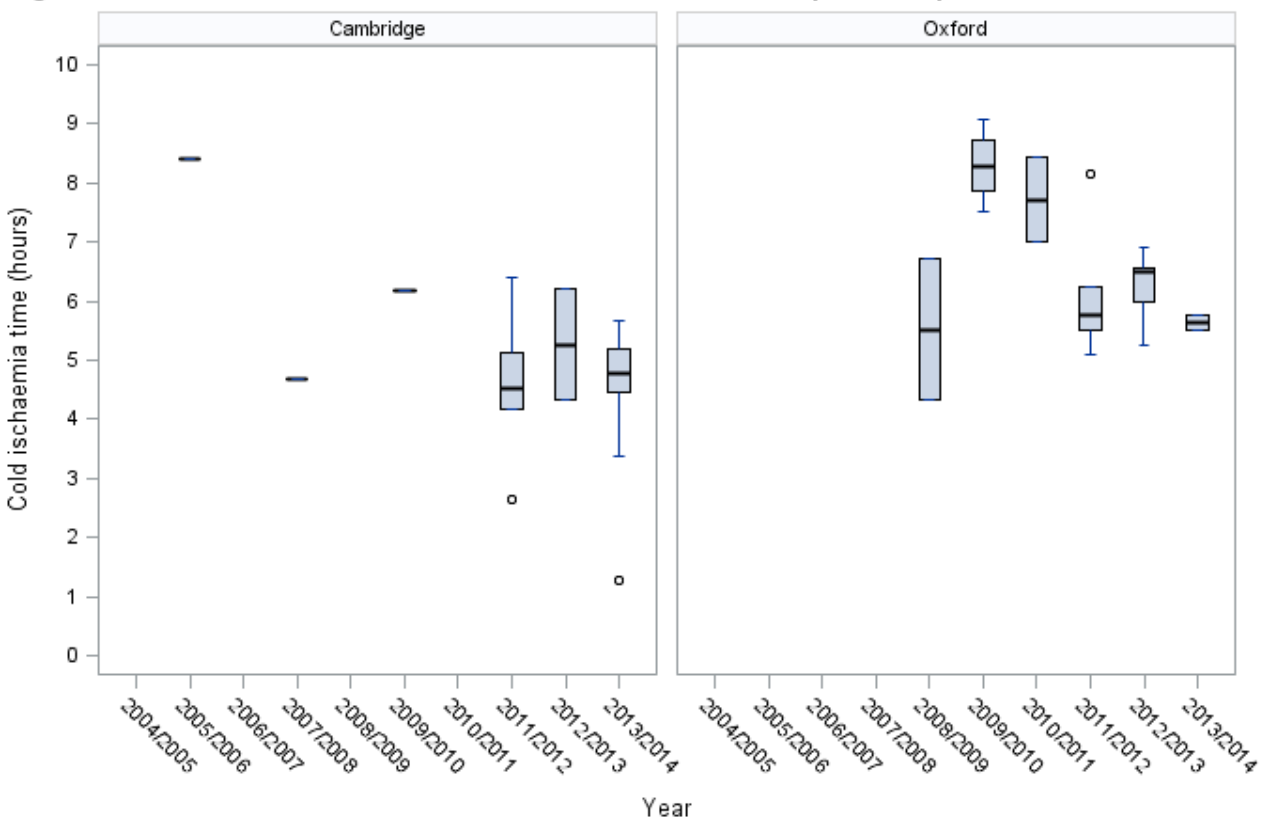


Figure 14 Median cold ischaemia time in all adult intestine transplants, 1 April 2004 - 31 March 2014



TRANSPLANT SURVIVAL – FIRST TRANSPLANT

Survival by transplant centre

Table 3 shows the 90-day [patient survival rates](#) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, overall and by centre. Of the 64 transplants of this kind in the time period, survival information was known for 63 transplants. Of these, 87% of patients were alive 90 days post-transplant.

Table 3 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	90-day survival (95% CI)	
Cambridge	39	87.2	(71.4-94.5)
Oxford	24	87.3	(65.1-96.6)
TOTAL	63	87.3	(75.6-92.4)

One and five year patient survival rates are shown in **Table 4** and **Table 5**, respectively. One year post-transplant, 80% of transplanted patients are alive while, five years post-transplant, the overall survival rate is 60%.

Table 4 One-year patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	1-year survival (95% CI)	
Cambridge	39	80.8	(63.0-90.3)
Oxford	24	78.6	(56.7-90.3)
TOTAL	63	79.9	(67.2-88.2)

Table 5 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	5-year survival (95% CI)	
Cambridge	39	61.9	(37.8-77.7)
Oxford	24	59.8	(33.6-77.7)
TOTAL	63	60.2	(42.0-73.5)

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 elective first intestine transplants by transplant type.

Table 6 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant type			
Transplant type	Number of transplants	90-day survival (95% CI)	
Cambridge			
Including liver	21	76.2	(52.5-90.3)
Not including liver	18	100	-
Oxford			
Not including liver	24	87.3	(65.1-96.6)
TOTAL	63	87.3	(75.6-92.4)

Table 7 One-year patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant type			
Transplant type	Number of transplants	1-year survival (95% CI)	
Cambridge			
Including liver	21	66.7	(42.0-81.9)
Not including liver	18	88.9	(63.0-96.6)
Oxford			
Not including liver	24	78.6	(56.7-90.3)
TOTAL	63	79.9	(67.2-88.2)

Table 8 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant type			
Transplant type	Number of transplants	5-year survival (95% CI)	
Cambridge			
Including liver	21	32.3	(8.4-60.9)
Not including liver	18	77.8	(42.0-92.4)
Oxford			
Not including liver	24	59.8	(33.6-77.7)
TOTAL	63	60.2	(42.0-73.5)

PAEDIATRIC INTESTINE TRANSPLANTATION



PAEDIATRIC INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 15 shows the number of paediatric patients on the intestine transplant list at 31 March each year between 2007 and 2014. Year-end transplant list data are not available before 2007. The number of patients on the active transplant list increased each year from 3 in 2007 to 11 in 2009. It subsequently decreased until reaching a lowest value of 4 in 2013. In 2014, the number of patients on the active transplant list increased again to 10.

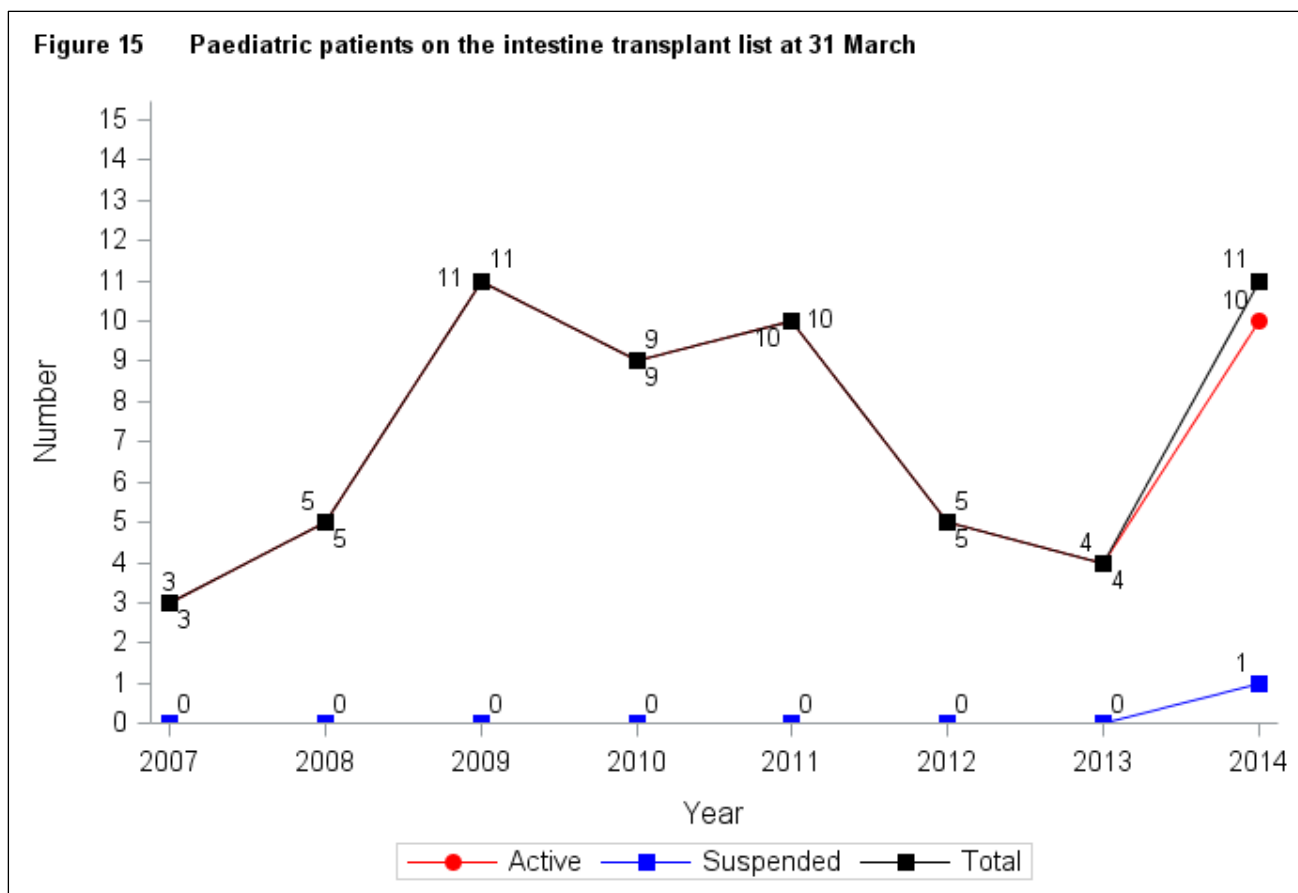
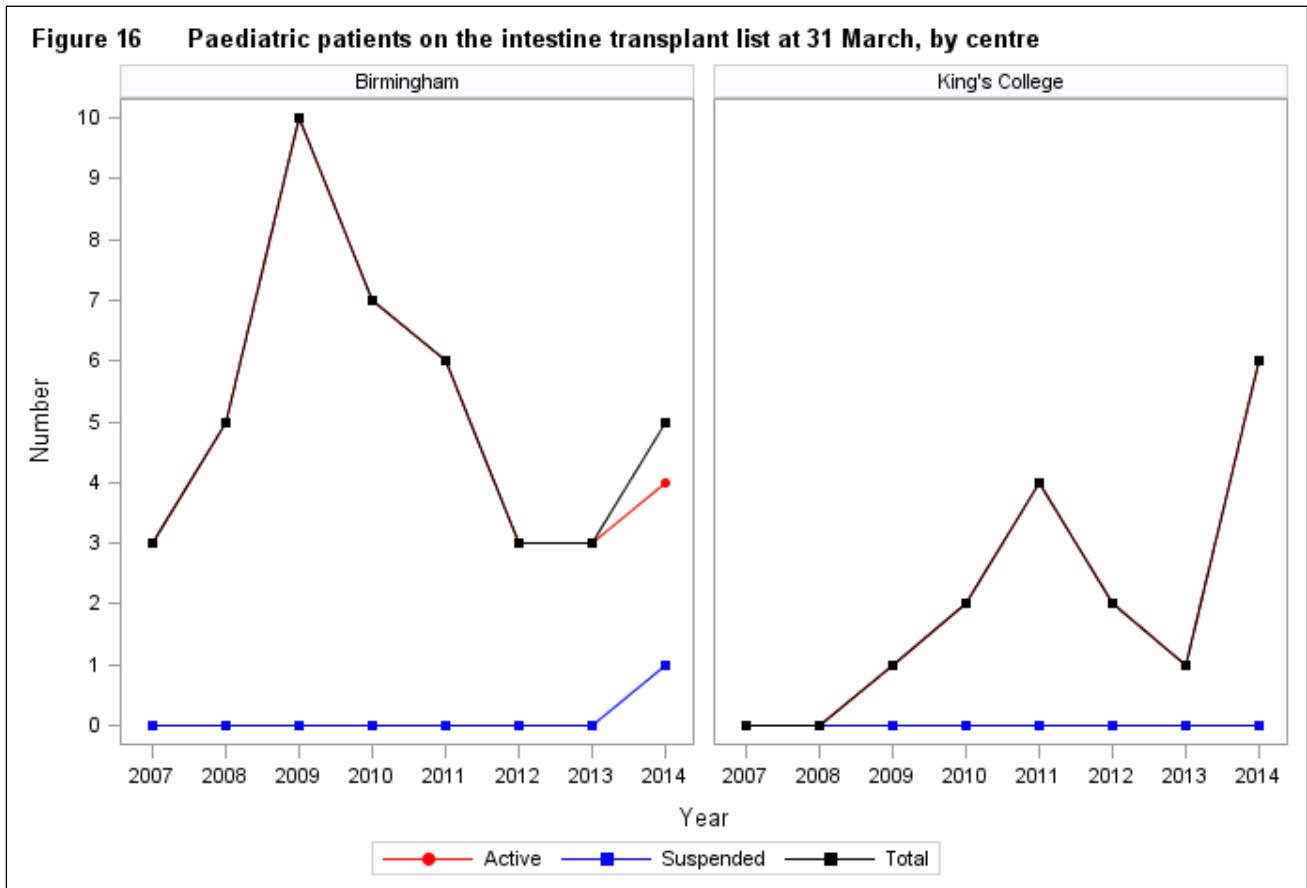


Figure 16 shows the number of paediatric patients on the intestine transplant list at 31 March each year between 2007 and 2014 for each transplant centre. In all years except 2014, Birmingham had a larger proportion of patients on the active transplant list than King's College.



RESPONSE TO OFFERS

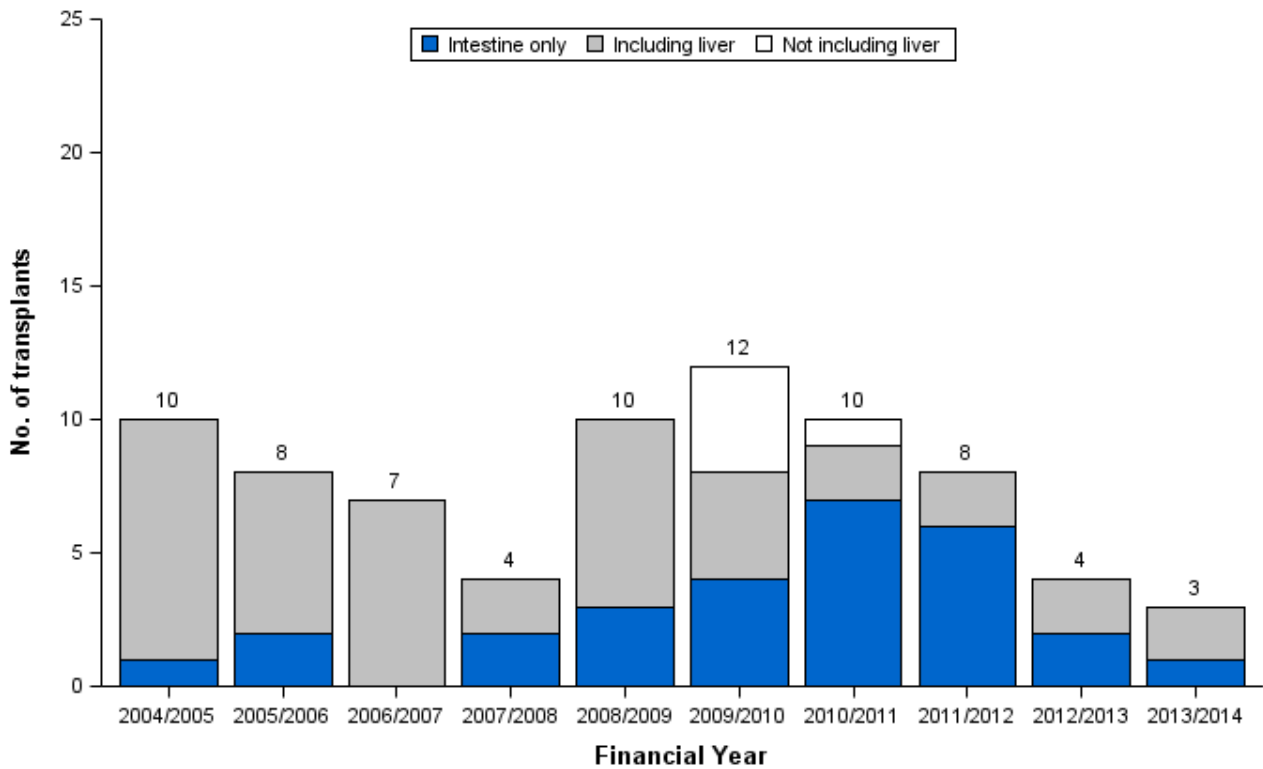
Between 1 April 2013 and 31 March 2014, Birmingham received intestine offers from 108 donors and King's College received offers from 109. Their [offer decline rates](#) were 98% and 100%, respectively.

TRANSPLANTS

Figure 17 shows the total number of paediatric intestine transplants performed in the last ten years, by transplant type. The total number of paediatric transplants decreased from 10 in 2004/05 to 4 in 2007/08. This number subsequently increased over the following few years to decline again to 3 in 2013/14.

Note the contrasting trends between **Figure 8** and **Figure 17**; while the overall number of transplants in adult recipients has been increasing over the last ten years, this has not been the case for paediatric recipients.

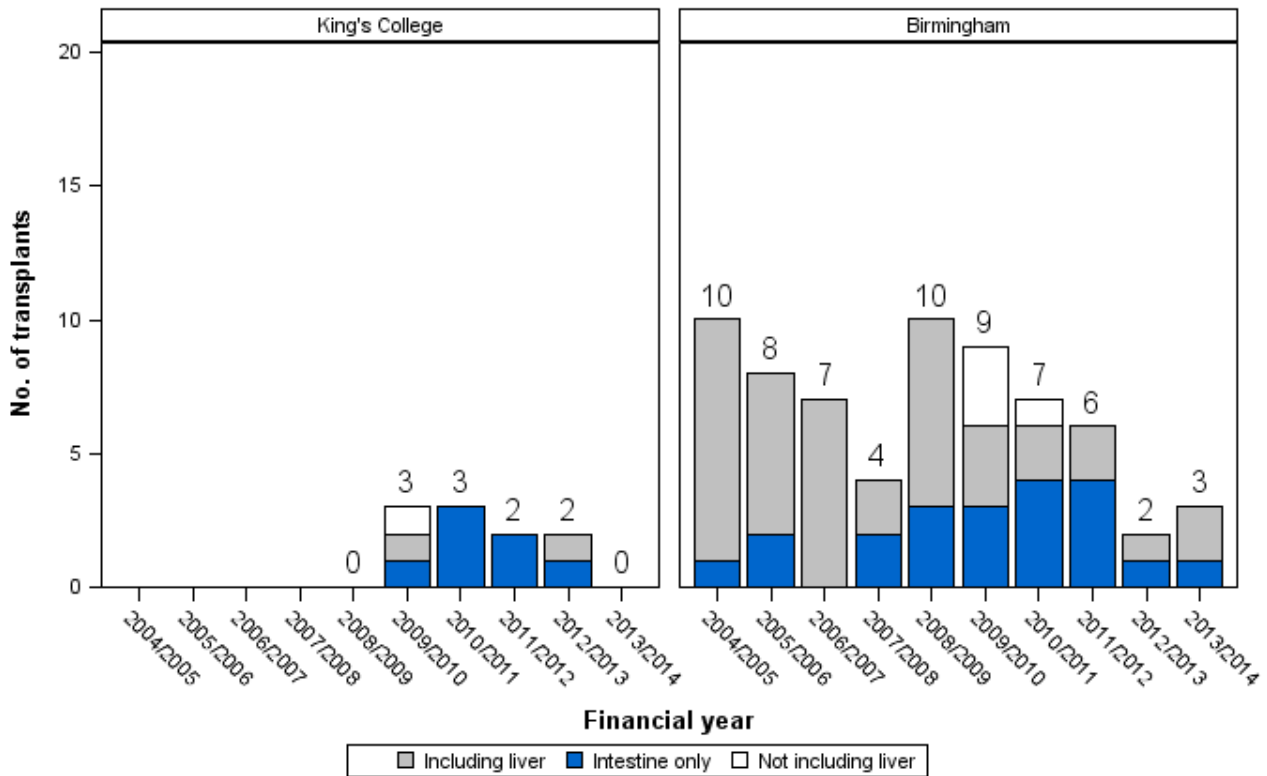
Figure 17 Paediatric intestine transplants in the UK, 1 April 2004 - 31 March 2014



Transplants may also include any of stomach, spleen, abdominal wall, kidney, colon.

Figure 18 shows the total number of paediatric intestine transplants performed in the last ten years, by centre and type of transplant.

Figure 18 Paediatric intestine transplants by centre, 1 April 2004 - 31 March 2014



Transplants may also include any of stomach, spleen, abdominal wall, kidney, colon.

The demographic characteristics of 76 paediatric elective intestine transplant recipients in the ten year period are shown by centre and overall in **Table 9**. Nearly two thirds of these recipients were male and the median age for recipients was 3 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.

Table 9 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2004 - 31 March 2014				
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Number		66	10	76 (100)
Recipient sex	Male	38 (58)	5 (50)	43 (57)
	Female	28 (42)	5 (50)	33 (43)
Recipient ethnicity group	White	55 (83)	9 (90)	64 (84)
	Other	9 (14)	1 (10)	10 (13)
	Missing	2 (3)	0	2 (3)

Table 9		Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2004 - 31 March 2014		
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Indication group	Short bowel syndrome	25 (38)	5 (50)	30 (40)
	Motility disorders	7 (11)	3 (30)	10 (13)
	Primary mucosal disorders	4 (6)	1 (10)	5 (7)
	Liver disease	11 (17)	0	11 (15)
	Other/missing	17 (26)	1 (10)	18 (24)
	Retransplant	2 (3)	0	2 (3)
Patient location	Out-patient	40 (61)	8 (80)	48 (63)
	Ward	3 (5)	1 (10)	4 (5)
	ICU/HDU	0	1 (10)	1 (1)
	Missing	23 (35)	0	23 (30)
Pre-transplant renal support	No	56 (85)	9 (90)	65 (86)
	Yes	0	1 (10)	1 (1)
	Missing	10 (15)	0	10 (13)
Previous abdominal surgery	No	5 (8)	1 (10)	6 (8)
	Yes	50 (76)	9 (90)	59 (78)
	Missing	11 (17)	0	11 (15)
Life style activity	Normal	5 (8)	1 (10)	6 (8)
	Restricted	9 (14)	3 (30)	12 (16)
	Self-care	4 (6)	0	4 (5)
	Reliant	14 (21)	0	14 (18)
	Aged five years or less	20 (30)	6 (60)	26 (34)
	Missing	14 (21)	0	14 (18)
Restricted venous access at registration	No	10 (15)	6 (60)	16 (21)
	Yes	19 (29)	2 (20)	21 (28)
	Unknown	37 (56)	2 (20)	39 (51)
Recipient age years	Median (IQR)	3 (1,6)	5 (1,7)	3 (1,7)
	Missing	0	0	0
Recipient BMI kg/m2	Median (IQR)	18 (16,19)	18 (17,19)	18 (17,19)
	Missing	58	0	58
Serum bilirubin umol/l	Median (IQR)	84 (10,240)	6 (4,10)	43 (8,228)
	Missing	13	0	13
Time on list days	Median (IQR)	103 (46,209)	178 (64,408)	113 (57,226)
	Missing	0	0	0
Donor sex	Male	32 (48)	7 (70)	39 (51)
	Female	34 (52)	3 (30)	37 (49)
Donor ethnicity group	White	56 (85)	8 (80)	64 (84)
	Other	6 (9)	1 (10)	7 (9)
	Missing	4 (6)	1 (10)	5 (7)

Table 9		Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2004 - 31 March 2014		
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Donor cause of death group	Stroke	31 (47)	6 (60)	37 (49)
	Trauma	17 (26)	2 (20)	19 (25)
	Other	18 (27)	2 (20)	20 (26)
Donor history of diabetes	No	29 (44)	10 (100)	39 (51)
	Missing	37 (56)	0	37 (49)
Donor age years	Median (IQR)	8 (3,13)	4 (0,6)	7 (3,13)
	Missing	0	0	0
Donor BMI kg/m ²	Median (IQR)	17 (15,19)	17 (14,21)	17 (14,19)
	Missing	0	0	0
Transplant type	Intestine only	21 (32)	7 (70)	28 (37)
	Including liver	41 (62)	2 (20)	43 (57)
	Not including liver	4 (6)	1 (10)	5 (7)
ABO match	Identical	56 (85)	10 (100)	66 (87)
	Compatible	10 (15)	0	10 (13)
Cold ischaemic time mins	Median (IQR)	405 (360,470)	502 (432,600)	415 (361,480)
	Missing	12	4	16

Figure 19 shows [boxplots](#) of the [CITs](#) of paediatric intestine transplants over the last ten 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. Note that these boxplots represent a small number of observations.

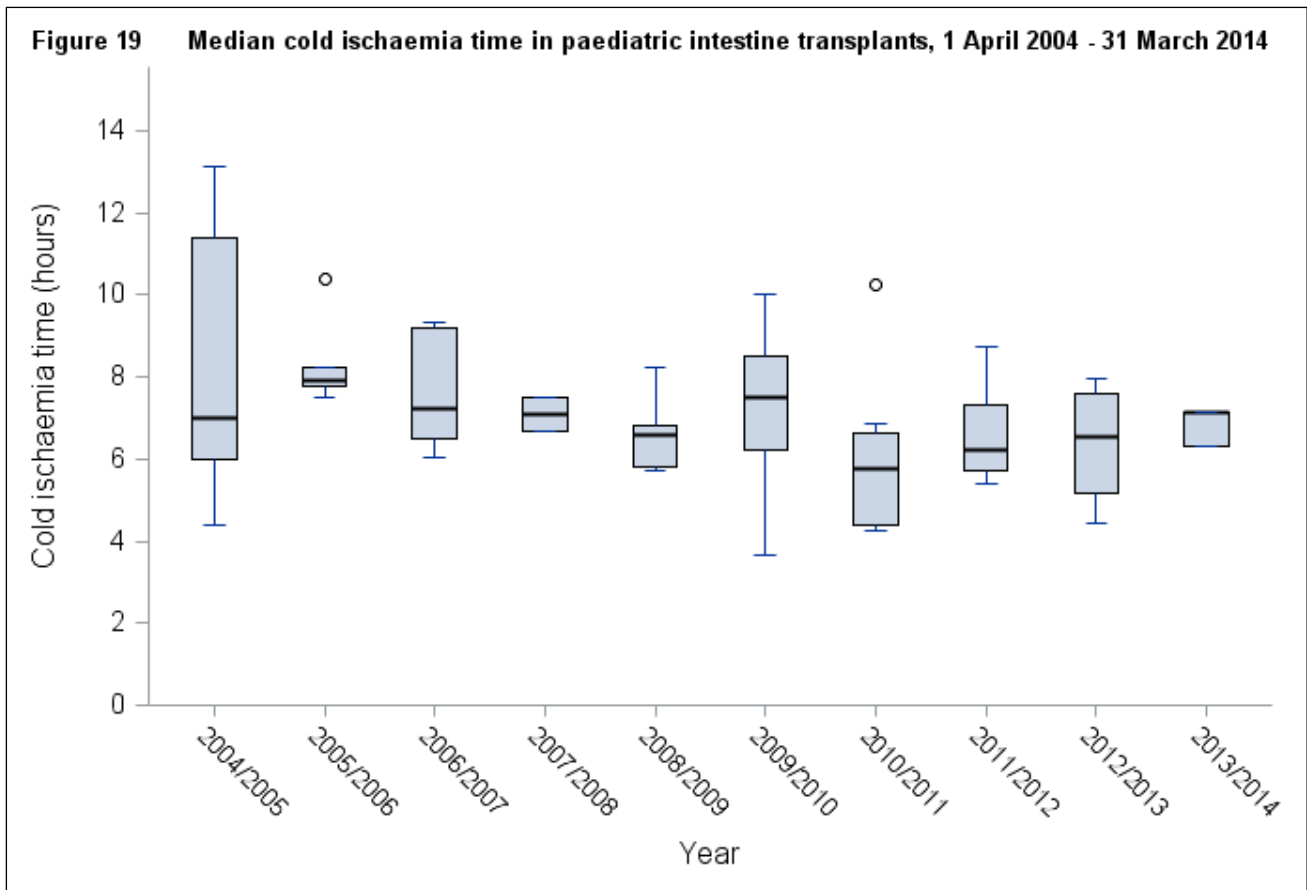
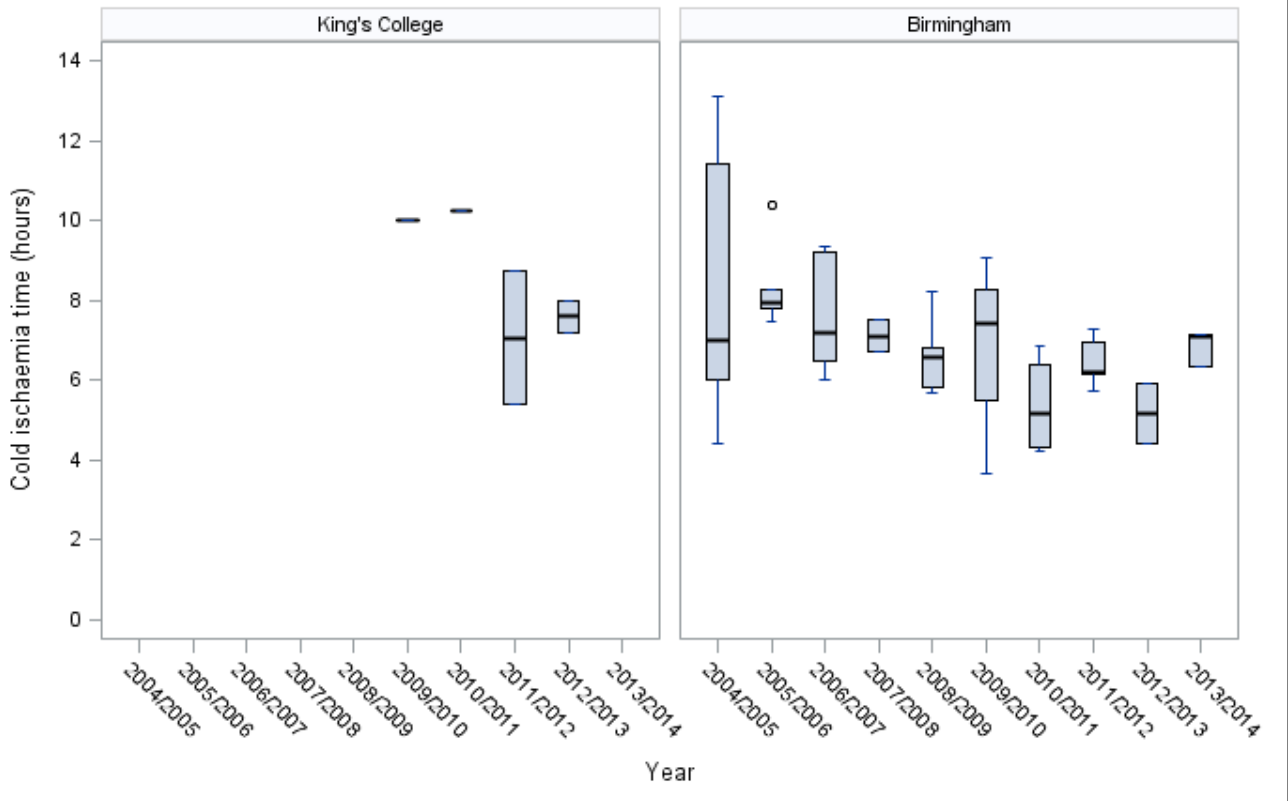


Figure 20 shows the median CITs in paediatric intestine transplants over the last ten years, by transplant centre. Note that these boxplots represent a very small number of observations.

Figure 20 Median cold ischaemia time in all paediatric intestine transplants, 1 April 2004 - 31 March 2014



TRANSPLANT SURVIVAL – FIRST TRANSPLANT

Survival by transplant centre

Table 10 shows the 90-day [patient survival rates](#) for paediatric elective first intestine transplants between 1 April 2004 and 31 March 2014, overall and by centre. There were 67 transplants of this kind in the time period and survival information was known in 64 cases; of these, 92% of patients were alive 90 days post-transplant.

Table 10 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	90-day survival (95% CI)	
Birmingham	55	90.9	(79.8-96.6)
King's College	9	100	-
TOTAL	64	92.2	(81.9-96.6)

One and five year patient survival rates are shown in **Table 11** and **Table 12**, respectively. One year post-transplant, 80% 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 very 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 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	1-year survival (95% CI)	
Birmingham	55	78.1	(65.1-86.1)
King's College	9	88.9	(44.1-98.7)
TOTAL	64	79.6	(67.2-88.2)

Table 12 Five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant centre			
Centre	Number of transplants	5-year survival (95% CI)	
Birmingham	55	62.3	(46.2-73.5)
King's College	9	88.9	(44.1-98.7)
TOTAL	64	65.7	(52.5-75.6)

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 elective 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 2004 and 31 March 2014, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI)	
Birmingham			
Including liver	36	86.1	(69.3-94.5)
Not including liver	19	100	-
King's College			
Including liver	2 ¹	-	-
Not including liver	7 ¹	-	-
TOTAL	64	92.2	(81.9-96.6)

Table 14 One-year patient survival (%) paediatric elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant type

Transplant type	Number of transplants	1-year survival (95% CI)	
Birmingham			
Including liver	36	74.9	(56.7-86.1)
Not including liver	19	84.2	(58.8-94.5)
King's College			
Including liver	2 ¹	-	-
Not including liver	7 ¹	-	-
TOTAL	64	79.6	(67.2-88.2)

Table 15 Five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2004 and 31 March 2014, by transplant type

Transplant type	Number of transplants	5-year survival (95% CI)	
Birmingham			
Including liver	36	58.7	(39.9-73.5)
Not including liver	19	67.4	(35.7-86.1)
King's College			
Including liver	2 ¹	-	-
Not including liver	7 ¹	-	-
TOTAL	64	65.7	(52.5-75.6)

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

APPENDIX



APPENDIX

DATA

Data were obtained from the UK Transplant Registry for the ten year time period, 1 April 2004 to 31 March 2014. 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's anatomical reasons but not because of intestinal failure have been excluded.

Table A1 shows the number of adult transplants including the intestine in the ten 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 correspond to first-time transplants only.

Table A1 Number of adult intestine transplants, by transplant centre and urgency status, 1 April 2004 to 31 March 2014				
Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Cambridge	42	5	39	3
Oxford	25	0	25	0
TOTAL	67	5	64	3

Table A2 shows the number of paediatric transplants including the intestine in the ten 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 correspond to first-time transplants only.

Table A2 Number of paediatric intestine transplants, by transplant centre and urgency status, 1 April 2004 to 31 March 2014				
Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Birmingham	66	0	57	0
King's College	10	0	10	0
TOTAL	76	0	67	0

METHODS

Waiting time to transplant

Waiting time was calculated from date of registration to date of transplant, for elective patients registered between 1 April 2010 and 31 March 2013 for an intestine transplant. Any periods of suspension were included in the calculation. Registrations for a re-transplant were included too. [Kaplan-Meier](#) 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 December 2014, 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 December 2014. 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 [DBD](#) 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 2013 to 31 March 2014. During this time period there were changes in the UK allocation policy for donor intestines which may have some minor impact on these rates.

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 [inter-quartile range](#). The line inside the box indicates the median 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%. We then say that there is a 95% chance that the confidence interval includes the true value of the quantity we wish to estimate.

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 'super-urgent' 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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