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NHS Blood and Transplant

ANNUAL REPORT ON INTESTINE TRANSPLANTATION

REPORT FOR 2016/2017 (1 APRIL 2007 – 31 MARCH 2017)

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This report presents key figures about intestine transplantation in the UK. The period covered is 10 years of transplant data, from 1 April 2007 to 31 March 2017. 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 2017, there were twelve patients on the UK active intestine **transplant list**, which represents a 33% decrease relative to six 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 two year period (1 April 2013 – 31 March 2015), 86% had received a transplant two years post-registration, while 4% died, 6% were removed and 4% were still waiting.

- There were 176 intestine **transplants** performed in the UK in the 10 year period. Fourteen of these were re-transplants (8%) and 38% of the total number of transplants were in paediatric recipients while 62% were in adult recipients.

- The number of **transplants** in **adult recipients** has generally increased each year over the last 10 years but has recently decreased. 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** (unadjusted) after first intestine transplantation for elective **adult patients** were estimated at 89%, 81% and 57% at 90 days, one and five years post-transplant, respectively.

- The national rates of **survival** after first intestine transplantation for elective **paediatric patients** (unadjusted) were estimated at 95%, 86% and 59% at 90 days, one and five years post-transplant, respectively.

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Annual Report on Intestine Transplantation 2016/2017. NHS Blood and Transplant.

INTRODUCTION

INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2007 and 31 March 2017, 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 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 number of transplants performed.

2.1 Transplant list

Figure 2.1 shows the total number of patients on the intestine active transplant list at 31 March of each year between 2008 and 2017. The number of patients waiting for a transplant increased each year from eight in 2008 to 18 in 2010-2011 and fell to 6 in 2016 but has increased again to 12 in 2017.

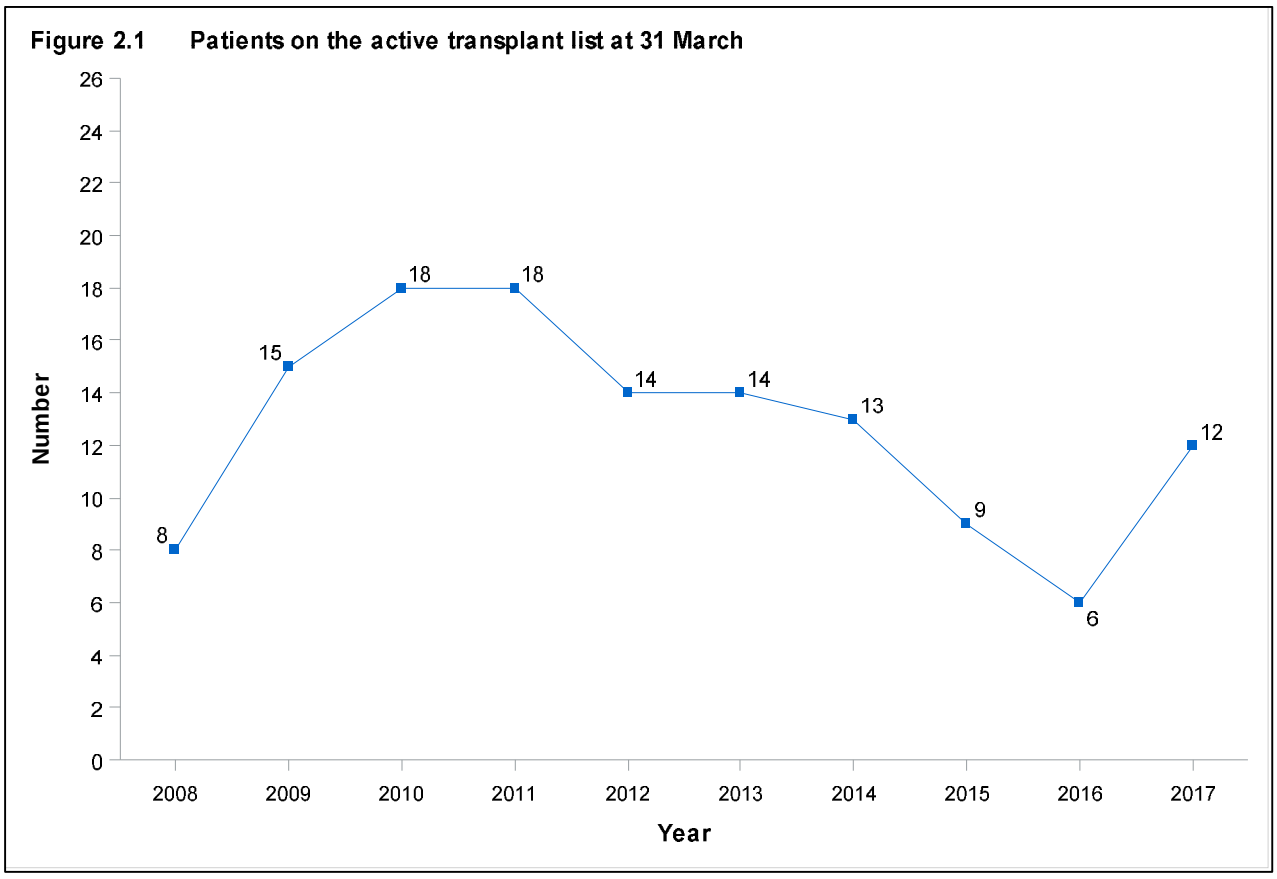
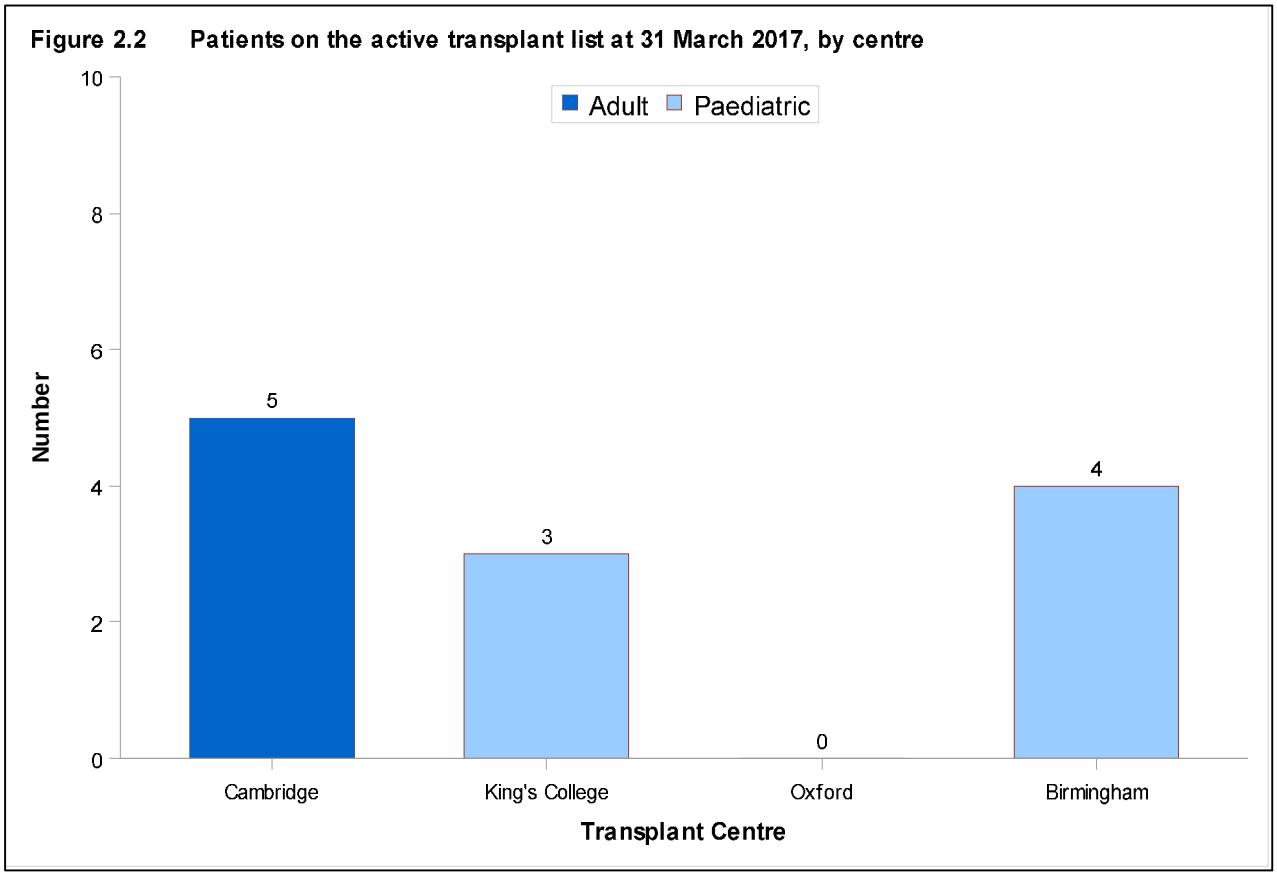


Figure 2.2 shows the number of adult and paediatric patients on the active transplant list at 31 March 2017 by centre. In total, there were five adult and seven paediatric patients, with no patients active at Oxford. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown in **Figure 3.2** and **Figure 7.2**, respectively.

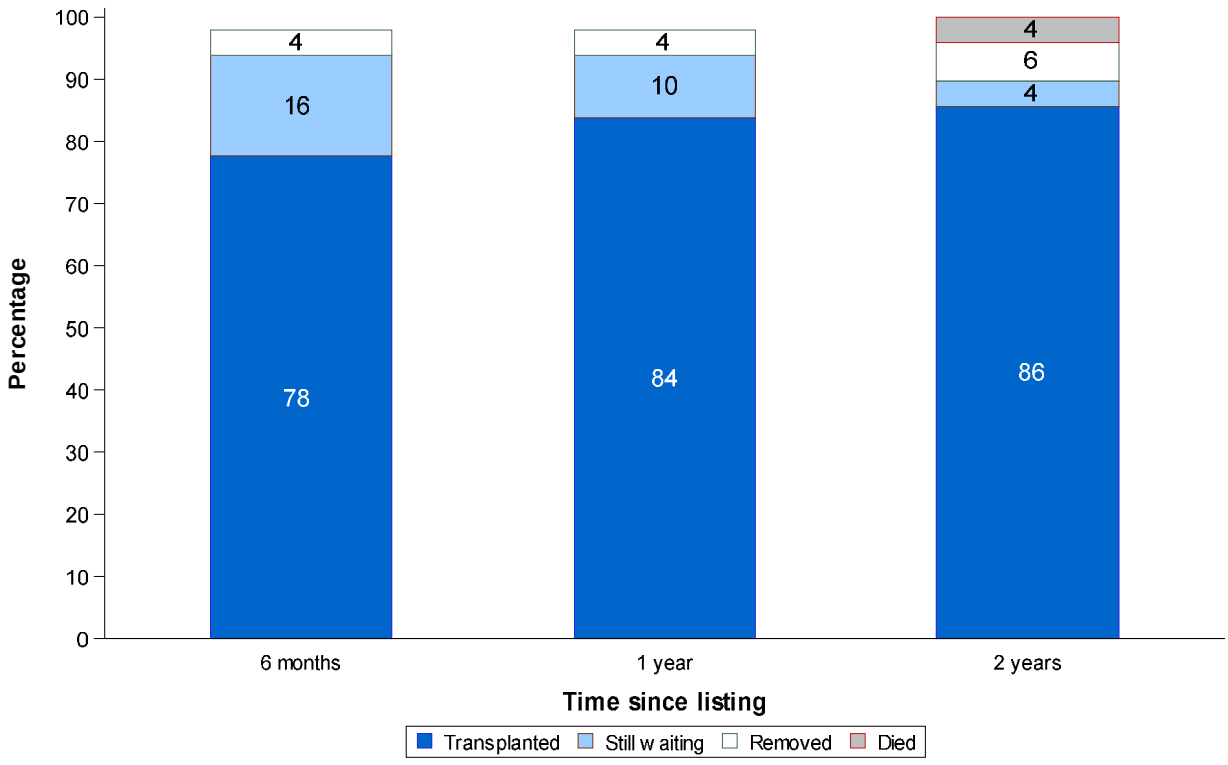
Figure 2.2 Patients on the active transplant list at 31 March 2017, by centre



2.1.1 Post-registration outcomes, 1 April 2013 – 31 March 2015

The registration outcomes of patients listed between 1 April 2013 and 31 March 2015 for an intestine transplant are summarised in **Figure 2.3.** 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 two years post-registration 86% of patients had received a transplant and 4% were still waiting, with 6% removed. The remaining percentage of patients died while on the transplant list.

Figure 2.3 Post-registration outcome for 49 elective registrations for an intestine transplant made in the UK, 1 April 2013 - 31 March 2015



2.1.2 Median waiting time to transplant, 1 April 2013 – 31 March 2016

Table 2.1 shows median waiting time to elective intestine transplant by registration type (including re-registrations) for both adult and paediatric patients. Overall, on average, patients wait 65 days (approximately two months) for a transplant. The average wait is longer for patients who require a liver as part of their intestine graft and this was found to be a statistically significant difference between registration types at a 5% significance level.

The decrease in median waiting time to transplant in this year's report compared to that published in some previous annual reports, is partly explained by the introduction of the National Bowel Allocation Scheme (NBAS) in July 2013. Since the NBAS was implemented we have seen a reduction in median waiting time for both liver requiring and non-liver requiring patients. Recent increases in consent and offering of donor bowels may have also contributed to this reduction.

Table 2.1 Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2013 - 31 March 2016

Registration type	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Intestine only[1]	10	58	12 – 104
Liver, intestine and pancreas[1]	36	119	21 – 217
Intestine and pancreas[1]	15	41	8 – 74
TOTAL	**61**	**65**	**50 – 80**

[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

2.2 Transplants

Figure 2.4 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 (DBD). The total number of transplants was 176, with annual figures increasing from 6 in 2007/2008 to 26 in 2013/2014 with a decrease in 2016/2017 to 15.

Figure 2.4 Total number of intestine transplants, 1 April 2007 - 31 March 2017

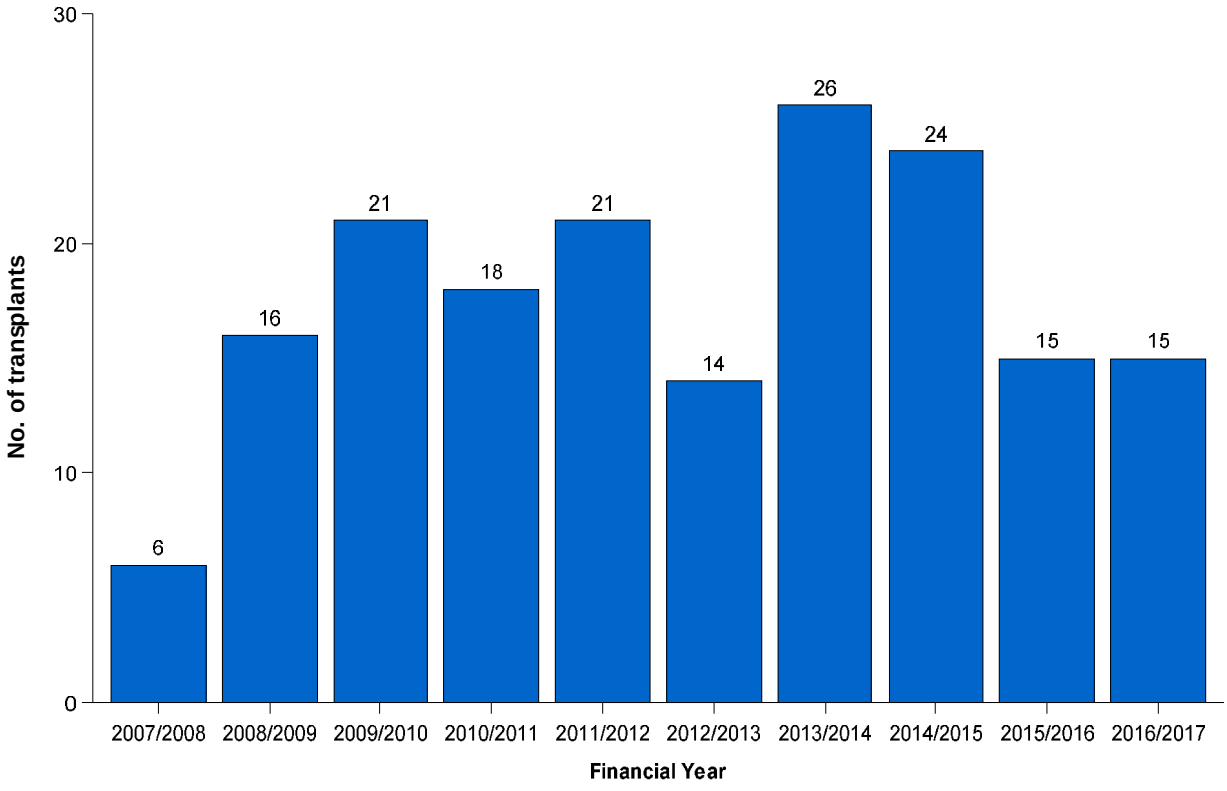
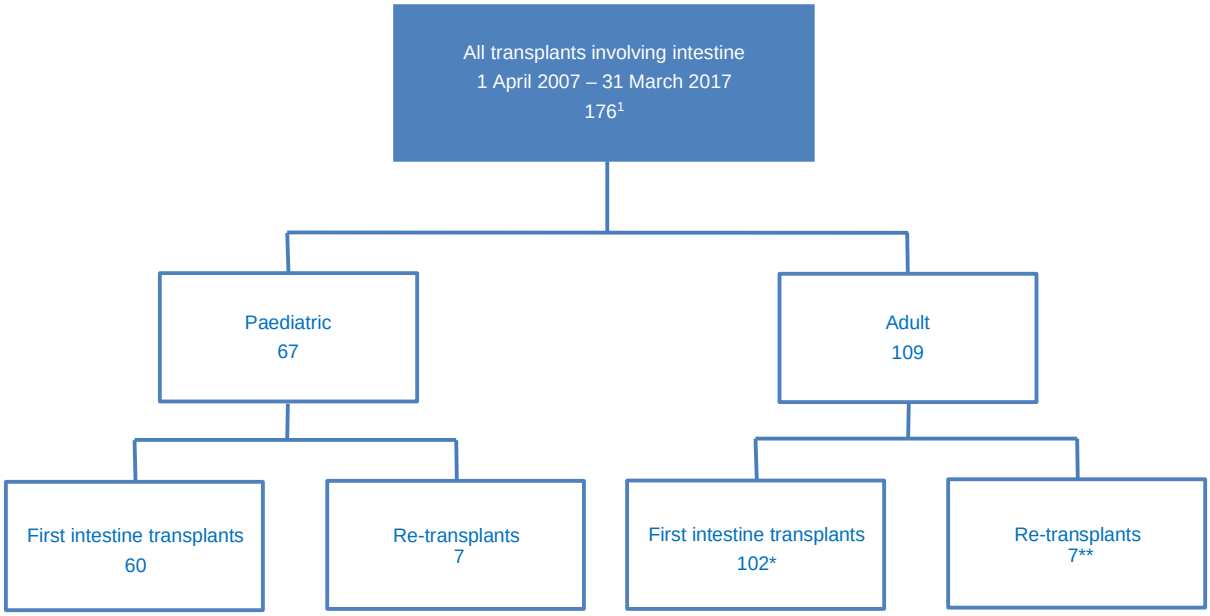


Figure 2.5 details the 176 intestine transplants performed in the UK in the 10 year period. Of these, 67 (38%) were in paediatric patients and 109 (62%) were in adult patients. The majority of both paediatric and adult transplants were in first time recipients.

Figure 2.5 UK intestine transplants, 1 April 2007 to 31 March 2017



[1] Excludes one abdominal wall only transplant (October 2016)

* Four of these transplants were super-urgent
** Two of these transplants were super-urgent

2.3 Geographical variation in registration and transplant rates

Figure 2.6 shows the annual average rate of registration to the intestinal transplant list per million population (pmp) based on registrations between 1 April 2007 and 31 March 2017 compared with the annual average intestinal transplant rates pmp for the same time period, by recipient country/Strategic Health Authority (SHA) of residence. **Table 2.2** shows the breakdown of these numbers by recipient country/Strategic Health Authority of residence. No adjustments have been made for potential demographic differences in populations. If a patient has had more than one registration/transplant in the period, each registration/ transplant is considered. Note that this analysis only considered NHS Group 1 patients.

Since there will inevitably be some random variation in rates between areas, the systematic component of variation (SCV) was used to identify if the variation is more (or less) than a random effect for the different SHAs in England only. Only first registrations and transplants in the period were used to calculate the SCV. The larger the SCV the greater the evidence of a high level of systematic variation between areas. Both registration and transplant rates yielded a low SCV at 0 and 0, respectively, and therefore, no evidence of geographical variation beyond what would be expected at random.

Figure 2.6 Comparison of average intestinal registration rates (pmp) with average transplant rates (pmp) by recipient country/Strategic Health Authority of residence

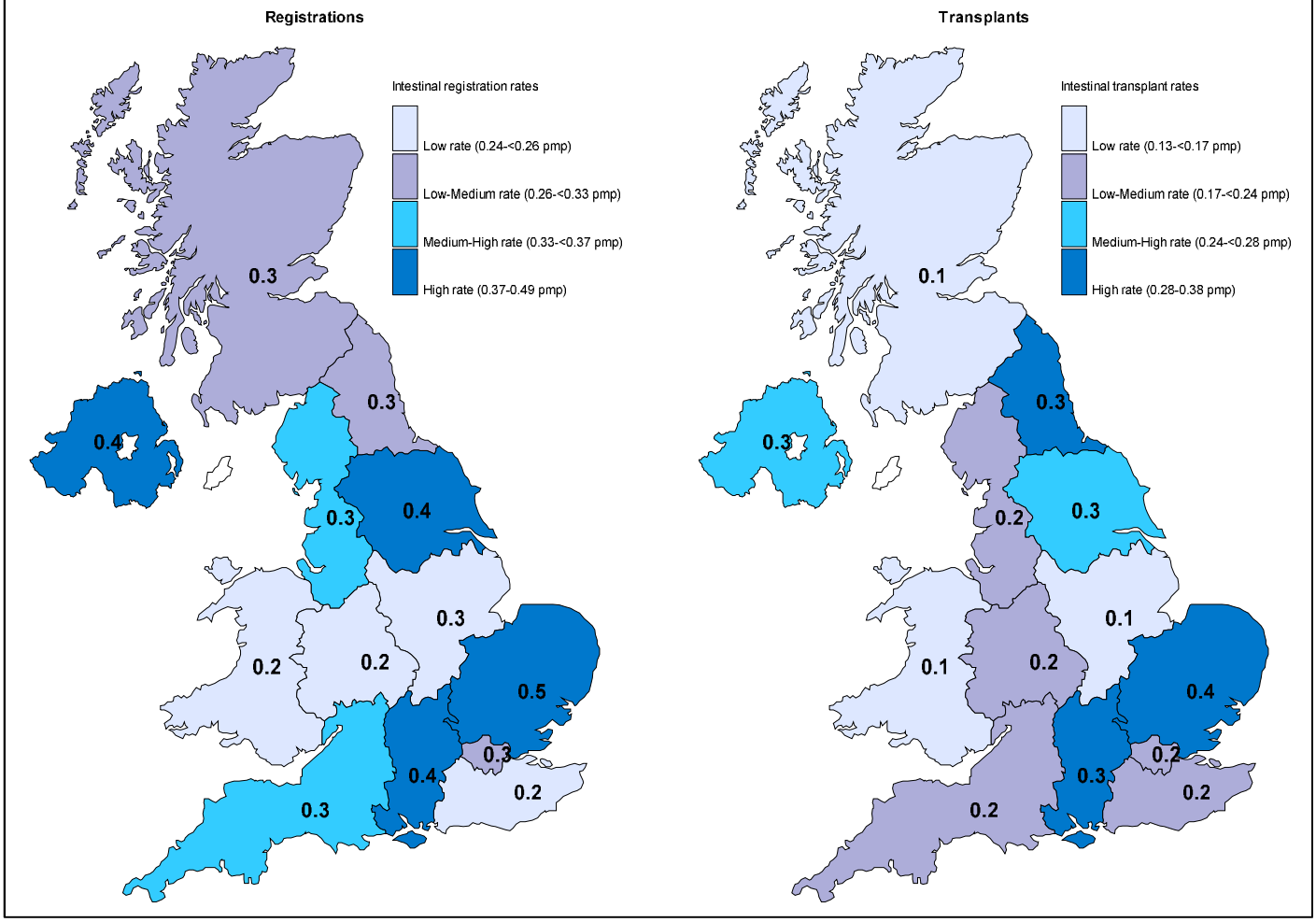


Table 2.2 Annual average intestinal registration and transplant rates per million population (pmp) in the UK, 1 April 2007 – 31 March 2017, by Country/Strategic Health Authority

Country/ Strategic Health Authority	Registrations	(pmp)	Transplants	(pmp)
North East	0.8	(0.3)	0.8	(0.3)
North West	2.5	(0.3)	1.7	(0.2)
Yorkshire and The Humber	2	(0.4)	1.5	(0.3)
North of England	**5.3**	**(0.3)**	**4**	**(0.3)**
East Midlands	1.2	(0.3)	0.7	(0.1)
West Midlands	1.4	(0.2)	1.2	(0.2)
East of England	3	(0.5)	2.3	(0.4)
Midlands and East	**5.6**	**(0.3)**	**4.2**	**(0.3)**
London	**2.7**	**(0.3)**	**1.9**	**(0.2)**
South East Coast	1.1	(0.2)	0.8	(0.2)
South Central	1.8	(0.4)	1.4	(0.3)
South West	1.9	(0.3)	1.3	(0.2)
South of England	**4.8**	**(0.3)**	**3.5**	**(0.2)**
England	**18.4**	**(0.3)**	**13.6**	**(0.2)**
Isle of Man	**0.1**	**(1.3)**	**0.1**	**(1.3)**
Channel Islands	**0**		**0**	
Wales	**0.7**	**(0.2)**	**0.4**	**(0.1)**
Scotland	**1.7**	**(0.3)**	**0.8**	**(0.1)**
Northern Ireland	**0.7**	**(0.4)**	**0.5**	**(0.3)**
TOTAL	**22**	**(0.3)**	**15.5**	**(0.2)**

[1] Total registrations in the period include 4 recipients whose postcode was unknown and excludes 2 recipients who reside in the Republic of Ireland and 4 recipients who reside overseas

[2] Total transplants in the period include 1 recipients whose postcode was unknown and excludes 1 recipients who reside in the Republic of Ireland and 3 recipients who reside overseas

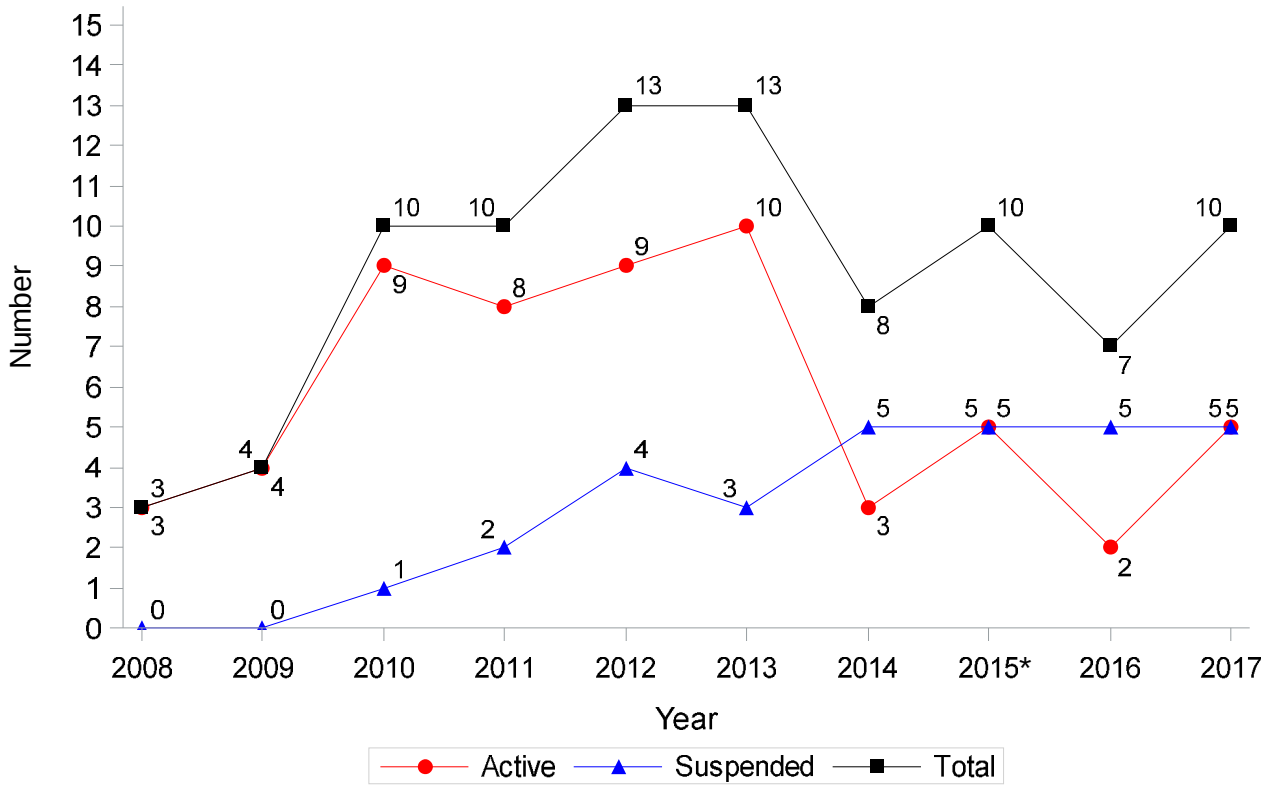
ADULT INTESTINE TRANSPLANTATION

3. Transplant list

3.1 Adult intestinal transplant list as at 31 March, 2008 – 2017

Figure 3.1 shows the number of adult patients active or suspended on the intestine transplant list at 31 March of each year between 2008 and 2017. The number of patients on the active intestine transplant list increased each year from three in 2008 to nine in 2010. It subsequently remained relatively stable until 2014, when it fell to three patients and has since risen to five.

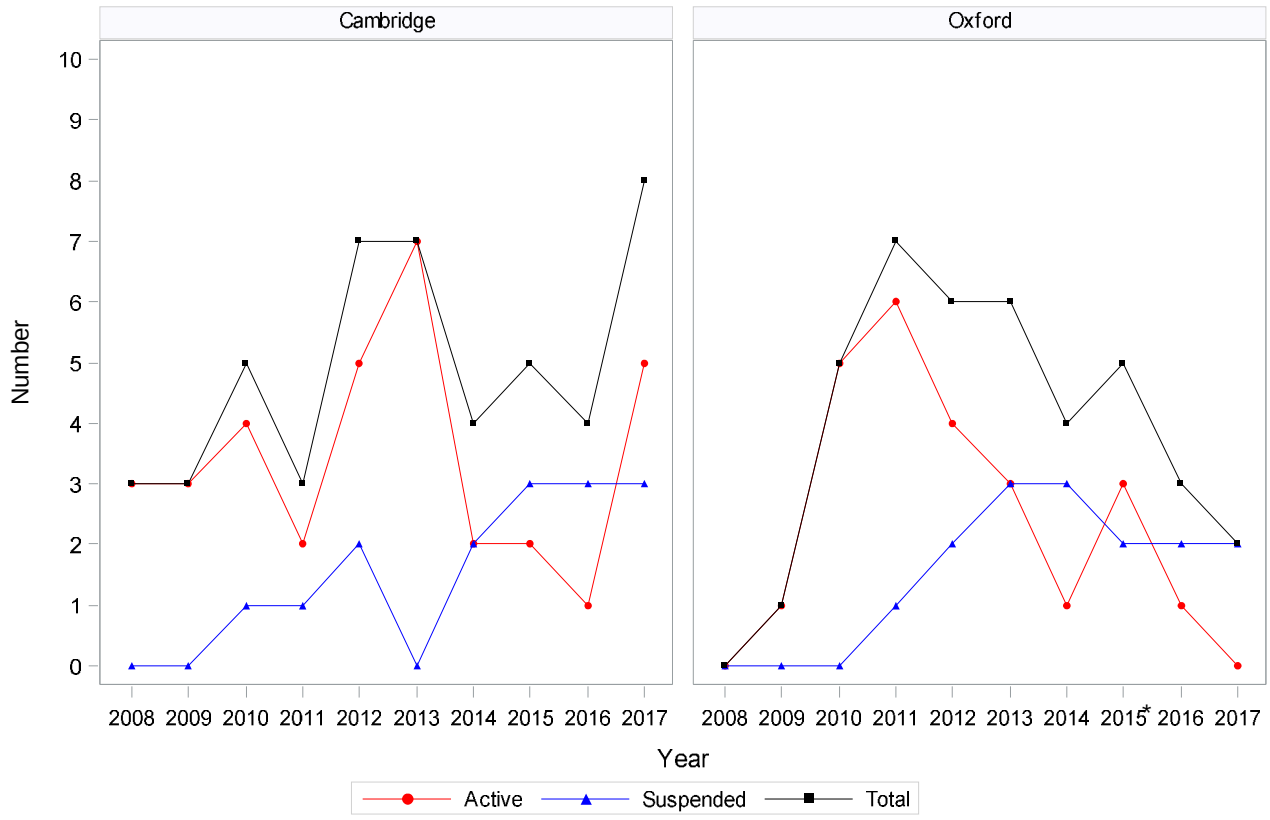
Figure 3.1 Adult patients on the intestine transplant list at 31 March



* Excludes one patient at Oxford registered for abdominal wall only

Figure 3.2 shows the number of adult patients on the intestine transplant list at 31 March of each year between 2008 and 2017, at each transplant centre. Cambridge had generally more adult patients on the national active transplant list than Oxford.

Figure 3.2 Adult patients on the intestine transplant list at 31 March, by centre



* Excludes one patient registered for abdominal wall only

The demographic characteristics of 139 adult intestine transplant recipient registrations in the 10 year period are shown by centre and overall in **Table 3.1**. 50% of these recipients were male and the median age for recipients was 45 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 22 kg/m^2. For some characteristics, percentages may not add up to 100 due to rounding.

Table 3.1 Demographic characteristics of adult intestine transplant recipient registrations, 1 April 2007 - 31 March 2017

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Number		95	44	**139 (100)**
Registration type	Elective	89 (94)	44 (100)	**133 (96)**
	Super-urgent	6 (6)	0	**6 (4)**
Transplant type required	Intestine only	5 (5)	23 (52)	**28 (20)**
	Including liver	62 (65)	0	**62 (45)**
	Not including liver	28 (29)	21 (48)	**49 (35)**
Recipient sex	Male	45 (47)	24 (55)	**69 (50)**
	Female	50 (53)	20 (45)	**70 (50)**
Recipient ethnicity group	White	87 (92)	42 (95)	**129 (93)**
	Other	7 (7)	2 (5)	**9 (7)**
	Not reported	1 (1)	0	**1 (1)**
Indication group	Short bowel syndrome	31 (33)	17 (39)	**48 (35)**
	Motility disorders	5 (5)	7 (16)	**12 (9)**
	Malignancy	4 (4)	3 (7)	**7 (5)**
	Liver disease	9 (9)	1 (2)	**10 (7)**
	Other/not reported	39 (41)	15 (34)	**54 (39)**
	Retransplant	7 (7)	1 (2)	**8 (6)**
Pre-transplant renal support	No	83 (87)	41 (93)	**124 (89)**
	Yes	8 (8)	1 (2)	**9 (7)**
	Not reported	4 (4)	2 (5)	**6 (4)**
Previous abdominal surgery	No	12 (13)	0	**12 (9)**
	Yes	73 (77)	43 (98)	**116 (84)**
	Not reported	10 (11)	1 (2)	**11 (8)**
Recipient blood group	O	35 (37)	18 (41)	**53 (38)**
	A	41 (43)	19 (43)	**60 (43)**
	B	13 (14)	5 (11)	**18 (13)**
	AB	6 (6)	2 (5)	**8 (6)**
Recipient age (years)	Median (IQR)	46 (33,54)	41 (35,52)	**45 (34,52)**
Recipient BMI (kg/m^2)	Median (IQR)	22 (20,26)	21 (19,24)	**22 (20,24)**
	Not reported	5	1	**6**

4. Response to offers

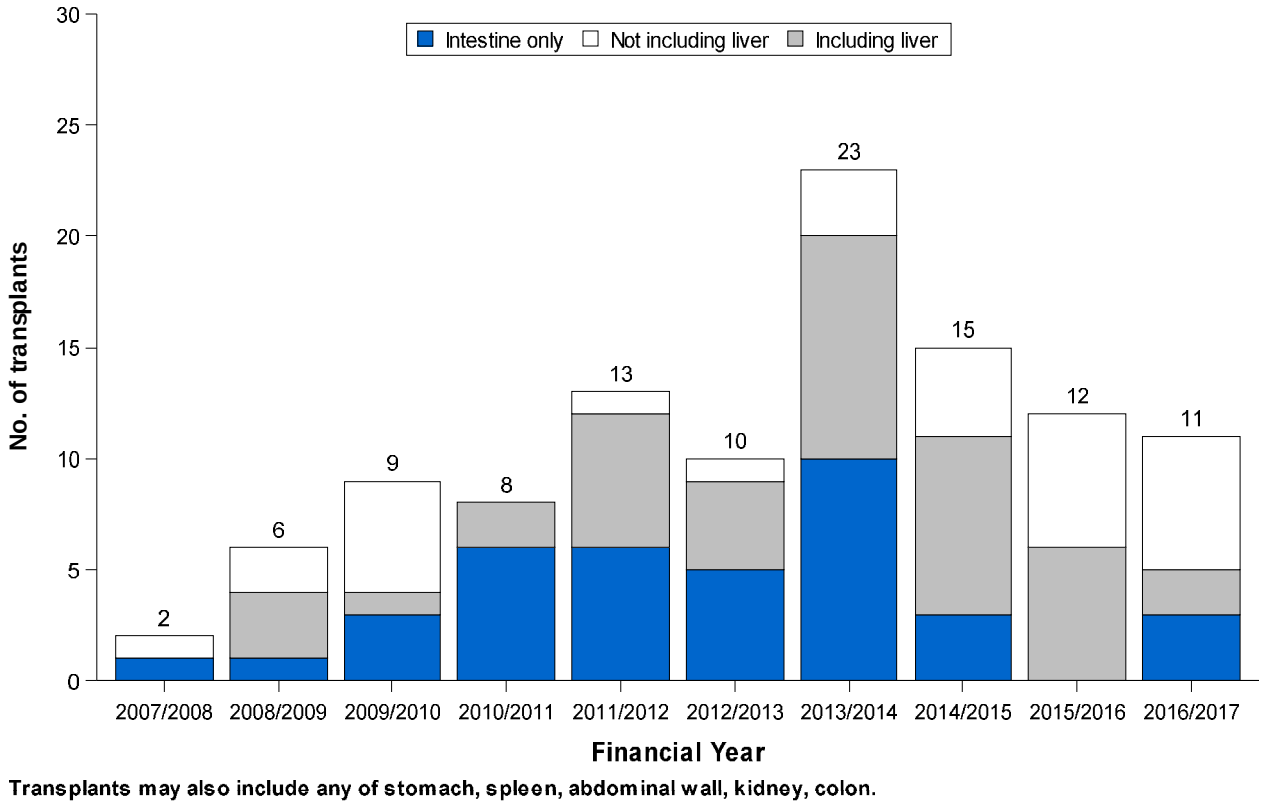
Potential DBD donors aged up to 55 years and with a weight of less than 80 kg are considered for intestine donation, however, centres are highly selective when accepting donor organs which leads to high decline rates. Between 1 April 2016 and 31 March 2017 Cambridge received intestine offers from 115 donors and Oxford received intestine offers from 85. Their offer decline rates were 96% and 94%, respectively.

5. Transplants

5.1 Adult intestinal transplants, 1 April 2007 – 31 March 2017

Figure 5.1 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 11 in the last financial year.

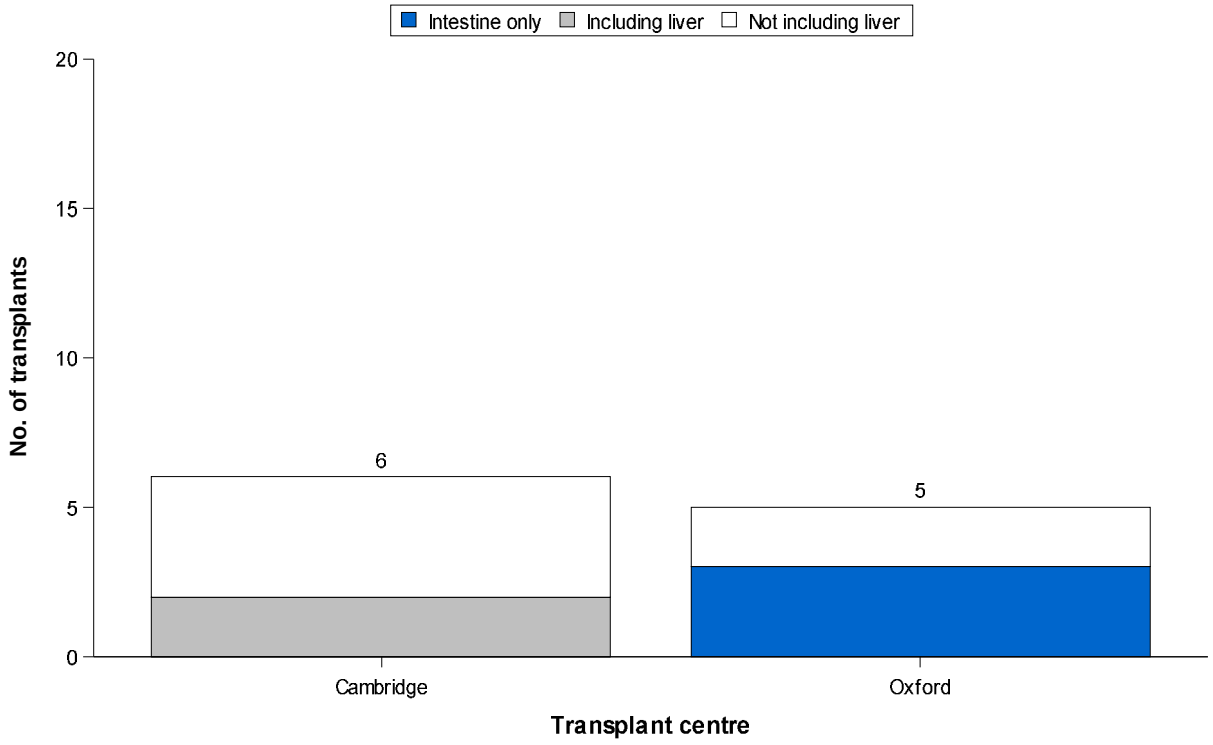
Figure 5.1 Adult intestine transplants in the UK, 1 April 2007 - 31 March 2017



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

Figure 5.2 shows the number of adult intestine transplants performed in 2016/2017, by centre and transplant type. The majority of transplants (67%) performed at Cambridge did not include the liver while majority of transplants (60%) performed at Oxford were intestine only.

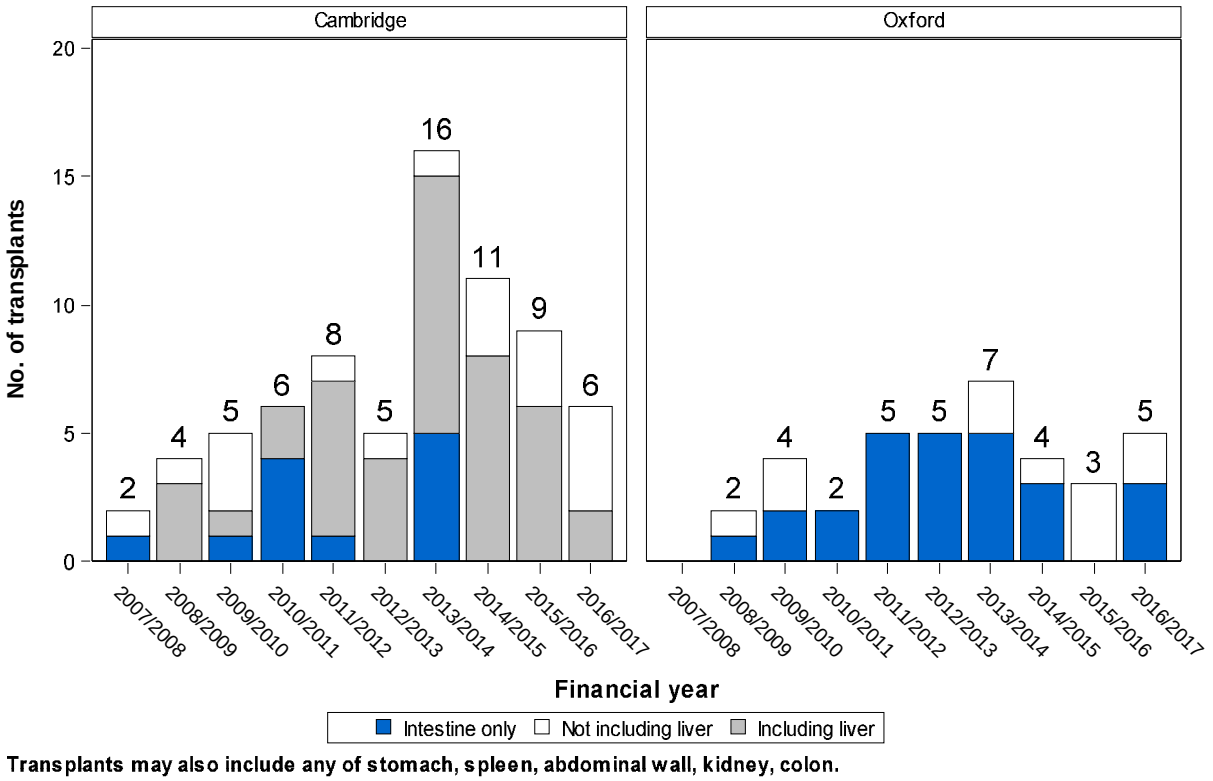
Figure 5.2 Adult intestine transplants in the UK by centre, 1 April 2016 - 31 March 2017



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

Figure 5.3 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.

Figure 5.3 Adult intestine transplants by centre, 1 April 2007 - 31 March 2017



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

The demographic characteristics of 103 adult elective intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 5.1**. 56% of these recipients were male and the median age for recipients was 45 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 22 kg/m^2. For some characteristics, percentages may not add up to 100 due to rounding.

Table 5.1 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2007 - 31 March 2017

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Number		66	37	**103 (100)**
Recipient sex	Male	36 (55)	22 (59)	**58 (56)**
	Female	30 (45)	15 (41)	**45 (44)**
Recipient ethnicity group	White	60 (91)	35 (95)	**95 (92)**
	Other	5 (8)	2 (5)	**7 (7)**
	Not reported	1 (2)	0	**1 (1)**
Indication group	Short bowel syndrome	23 (35)	15 (41)	**38 (37)**
	Motility disorders	5 (8)	5 (14)	**10 (10)**
	Malignancy	4 (6)	3 (8)	**7 (7)**
	Liver disease	3 (5)	1 (3)	**4 (4)**
	Other/not reported	27 (41)	12 (32)	**39 (38)**
	Retransplant	4 (6)	1 (3)	**5 (5)**
Patient location	Out-patient	39 (59)	32 (86)	**71 (69)**
	Ward	13 (20)	5 (14)	**18 (18)**
	ICU/HDU	3 (5)	0	**3 (3)**
	Not reported	11 (17)	0	**11 (11)**
Pre-transplant renal support	No	55 (83)	35 (95)	**90 (87)**
	Yes	0	2 (5)	**2 (2)**
	Not reported	11 (17)	0	**11 (11)**
Previous abdominal surgery	No	9 (14)	2 (5)	**11 (11)**
	Yes	46 (70)	35 (95)	**81 (79)**
	Not reported	11 (17)	0	**11 (11)**
Life style activity	Normal	1 (2)	4 (11)	**5 (5)**
	Restricted	13 (20)	3 (8)	**16 (16)**
	Self-care	25 (38)	21 (57)	**46 (45)**
	Confined	10 (15)	6 (16)	**16 (16)**
	Reliant	6 (9)	3 (8)	**9 (9)**
	Not reported	11 (17)	0	**11 (11)**
Restricted venous access at registration	No	46 (70)	21 (57)	**67 (65)**
	Yes	14 (21)	15 (41)	**29 (28)**
	Not reported	6 (9)	1 (3)	**7 (7)**
Recipient age (years)	Median (IQR)	46 (34,54)	40 (35,51)	**45 (34,53)**
Recipient BMI (kg/m^2)	Median (IQR)	22 (20,24)	22 (20,24)	**22 (20,24)**
	Not reported	13	8	**21**

Table 5.1 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2007 - 31 March 2017

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Serum bilirubin (umol/l)	Median (IQR)	20 (8,42)	10 (5,11)	**12 (7,26)**
	Not reported	11	0	**11**
Time on list (days)	Median (IQR)	44 (18,152)	34 (13,71)	**40 (16,124)**
Donor sex	Male	24 (36)	20 (54)	**44 (43)**
	Female	42 (64)	17 (46)	**59 (57)**
Donor ethnicity group	White	63 (95)	35 (95)	**98 (95)**
	Other	3 (5)	2 (5)	**5 (5)**
Donor cause of death group	Stroke	53 (80)	21 (57)	**74 (72)**
	Trauma	8 (12)	14 (38)	**22 (21)**
	Other	5 (8)	2 (5)	**7 (7)**
Donor history of diabetes	No	66 (100)	36 (97)	**102 (99)**
	Not reported	0	1 (3)	**1 (1)**
Donor age (years)	Median (IQR)	27 (18,39)	25 (21,35)	**26 (20,39)**
Donor BMI (kg/m^2)	Median (IQR)	22 (20,23)	22 (21,23)	**22 (20,23)**
Transplant type	Intestine only	12 (18)	26 (70)	**38 (37)**
	Including liver	36 (55)	0	**36 (35)**
	Not including liver	18 (27)	11 (30)	**29 (28)**
ABO match	Identical	46 (70)	34 (92)	**80 (78)**
	Compatible	20 (30)	3 (8)	**23 (22)**
Cold ischaemic time (hours)	Median (IQR)	4.7 (4.2,5.2)	6.3 (5.6,7.4)	**5.2 (4.5,6.4)**
	Not reported	17	5	**22**

5.2 Cold ischaemia time, 1 April 2007 – 31 March 2017

Figure 5.4 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 8.2 hours in 2009/2010 to 5.3 hours in 2016/2017.

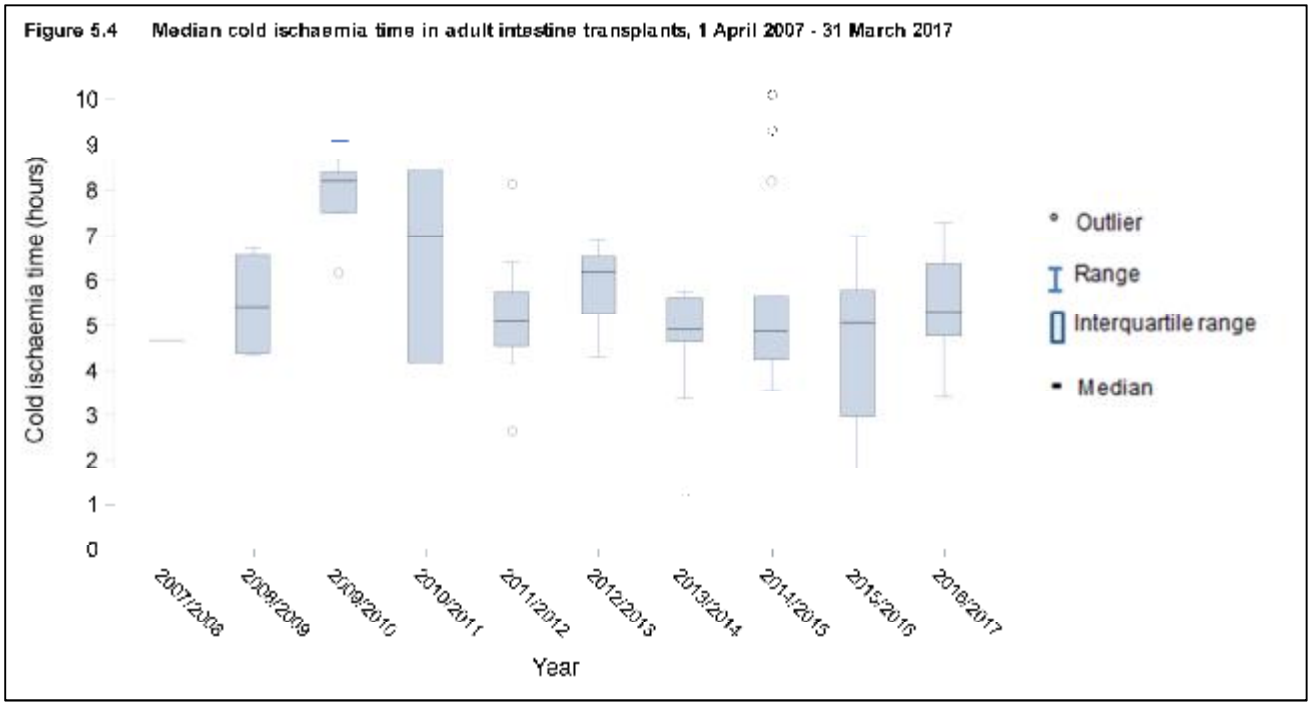


Figure 5.5 shows the median CITs in adult intestine transplants in 2016/2017 for each transplant centre, while **Figure 5.6** shows the same data but over the last 10 years. Note that prior to 2008/2009 Oxford did not perform any intestine transplants which means there are no boxplots presented for the first year. All of these boxplots represent a small number of observations and, as shown in **Table 5.1**, a proportion of CITs have not been reported.

Figure 5.5 Median cold ischaemia time in adult intestine transplants, 1 April 2016 - 31 March 2017

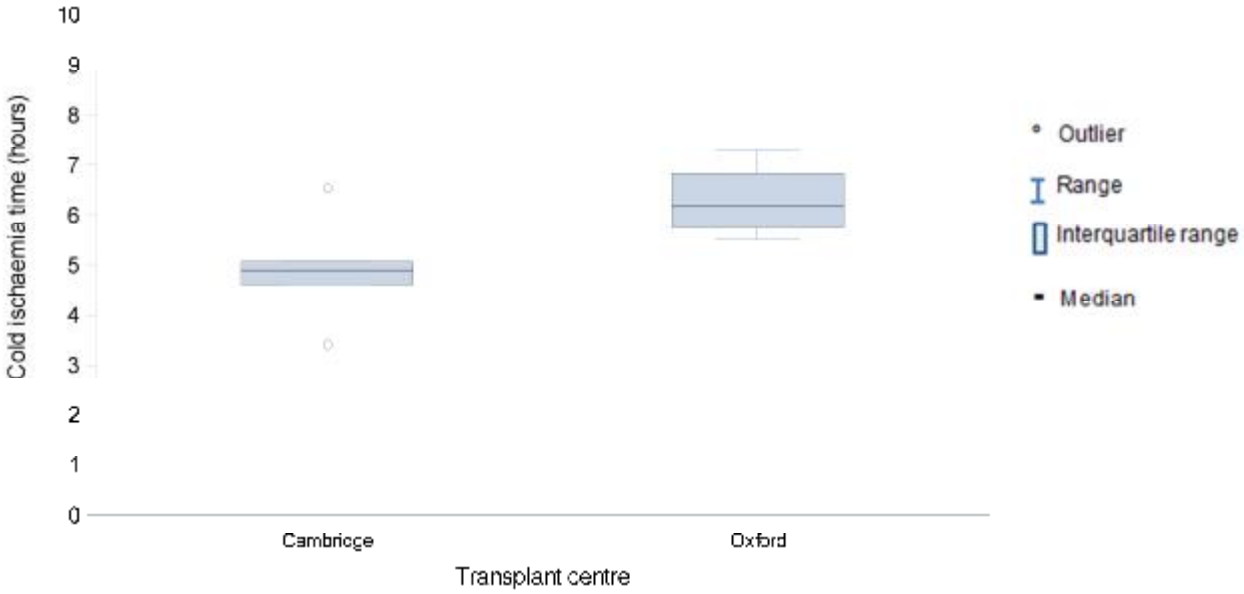
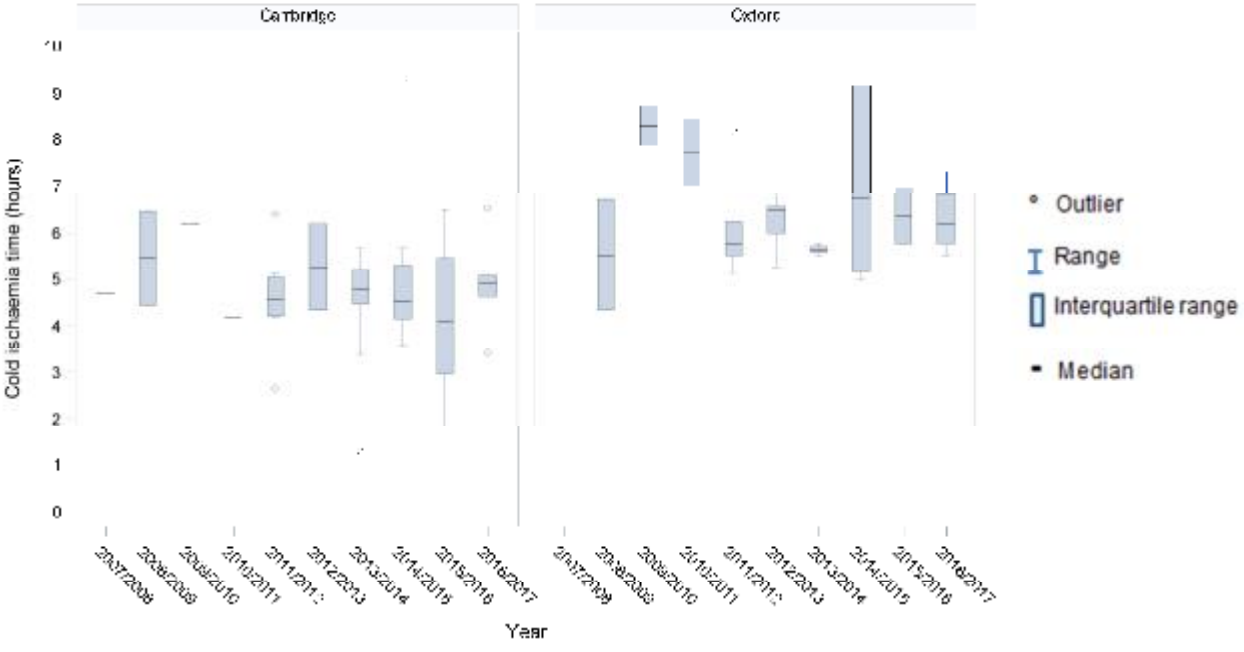


Figure 5.6 Median cold ischaemia time in all adult intestine transplants, 1 April 2007 - 31 March 2017



6. Post-transplant survival

6.1 Survival by transplant centre

Table 6.1 shows the 90-day patient survival rates for adult elective first intestine transplants between 1 April 2007 and 31 March 2017, overall and by centre. Of the 98 transplants of this kind in the time period, survival information was known for 97 transplants. Of these, 89% of patients were alive at 90 days post-transplant (unadjusted).

Table 6.1 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	90-day survival (95% CI) Unadjusted	
Cambridge	62	90.3	(79.7-95.5)
Oxford	35	85.7	(69.0-93.8)
TOTAL	**97**	**88.7**	**(80.5-93.6)**

One- and five-year patient survival rates are shown in **Table 6.2** and **Table 6.3**, respectively. At one year post-transplant, 81% of transplanted patients were alive, while at five years post-transplant, the overall survival rate is 57%. Note that both centres perform different types of transplants and the next section (**Table 6.4**), therefore, presents a breakdown by centre and transplant type.

Table 6.2 One-year patient survival (%) for adult elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	1-year survival (95% CI) Unadjusted	
Cambridge	62	81.5	(69.0-89.3)
Oxford	35	79.2	(61.2-89.6)
TOTAL	**97**	**80.7**	**(71.0-87.4)**

Table 6.3 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	5-year survival (95% CI) Unadjusted	
Cambridge	62	55.6	(37.8-70.2)
Oxford	35	59.8	(35.7-77.3)
TOTAL	**97**	**57.4**	**(43.5-69.1)**

6.2 Survival by transplant type

Table 6.4 shows the unadjusted 90-day, one-year and five-year patient survival rates for adult elective first intestine transplants, by centre and transplant type.

Table 6.4 Unadjusted patient survival (%) for adult elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI)		1-year survival (95% CI)		5-year survival (95% CI)	
Cambridge							
Including liver	34	82.4	(64.9-91.7)	76.1	(57.9-87.3)	32.9	(10.6-57.6)
Not including liver	28	100	-	88.0	(67.3-96.0)	76.6	(51.2-90.0)
Oxford							
Not including liver	35	85.7	(69.0-93.8)	79.2	(61.2-89.6)	59.8	(35.7-77.3)
TOTAL	**97**	**88.7**	**(80.5-93.6)**	**80.7**	**(71.0-87.4)**	**57.4**	**(43.5-69.1)**

PAEDIATRIC INTESTINE TRANSPLANTATION

7. Transplant list

7.1 Paediatric intestinal transplant list as at 31 March, 2008 – 2017

Figure 7.1 shows the number of paediatric patients (aged<18 years) active and suspended on the intestine transplant list at 31 March of each year between 2008 and 2017. The number of patients on the active transplant list decreased each year from eleven in 2009 to four in 2013, but has since increased to seven in 2017.

Figure 7.1 Paediatric patients on the intestine transplant list at 31 March

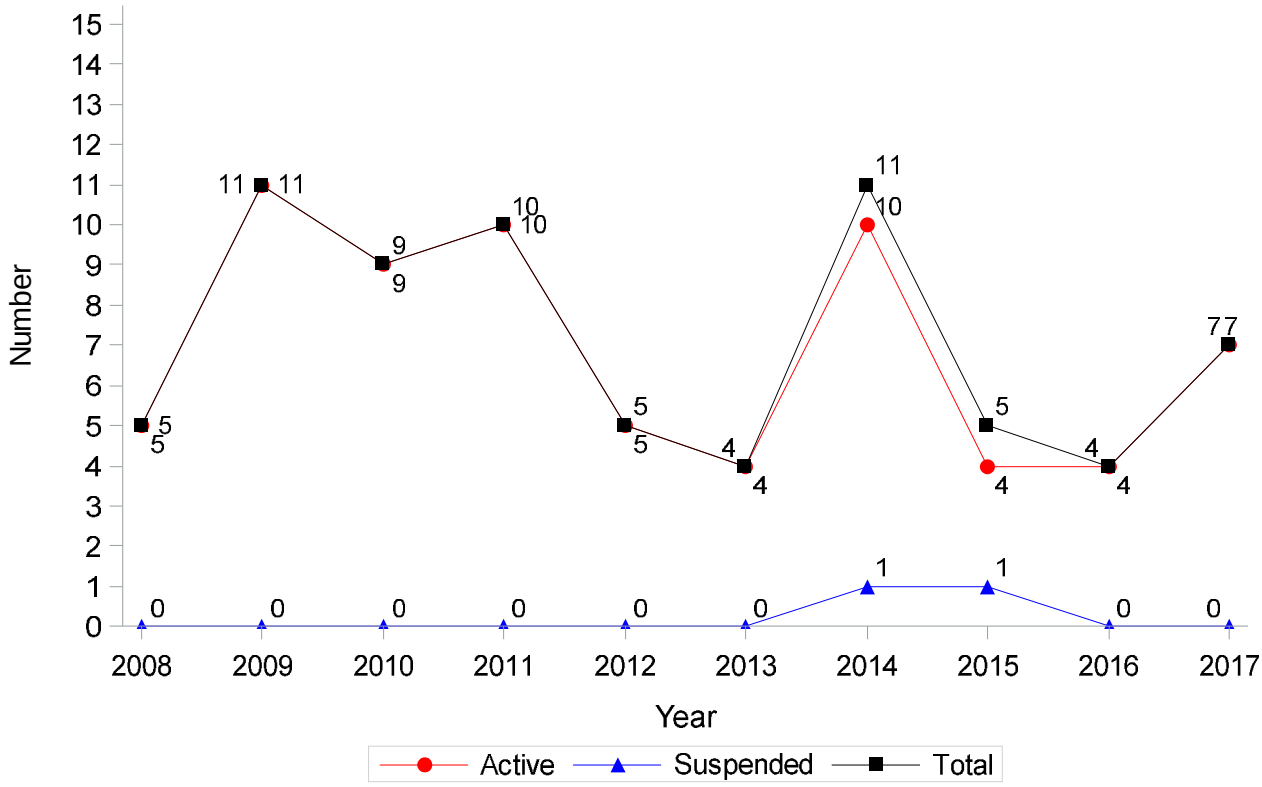
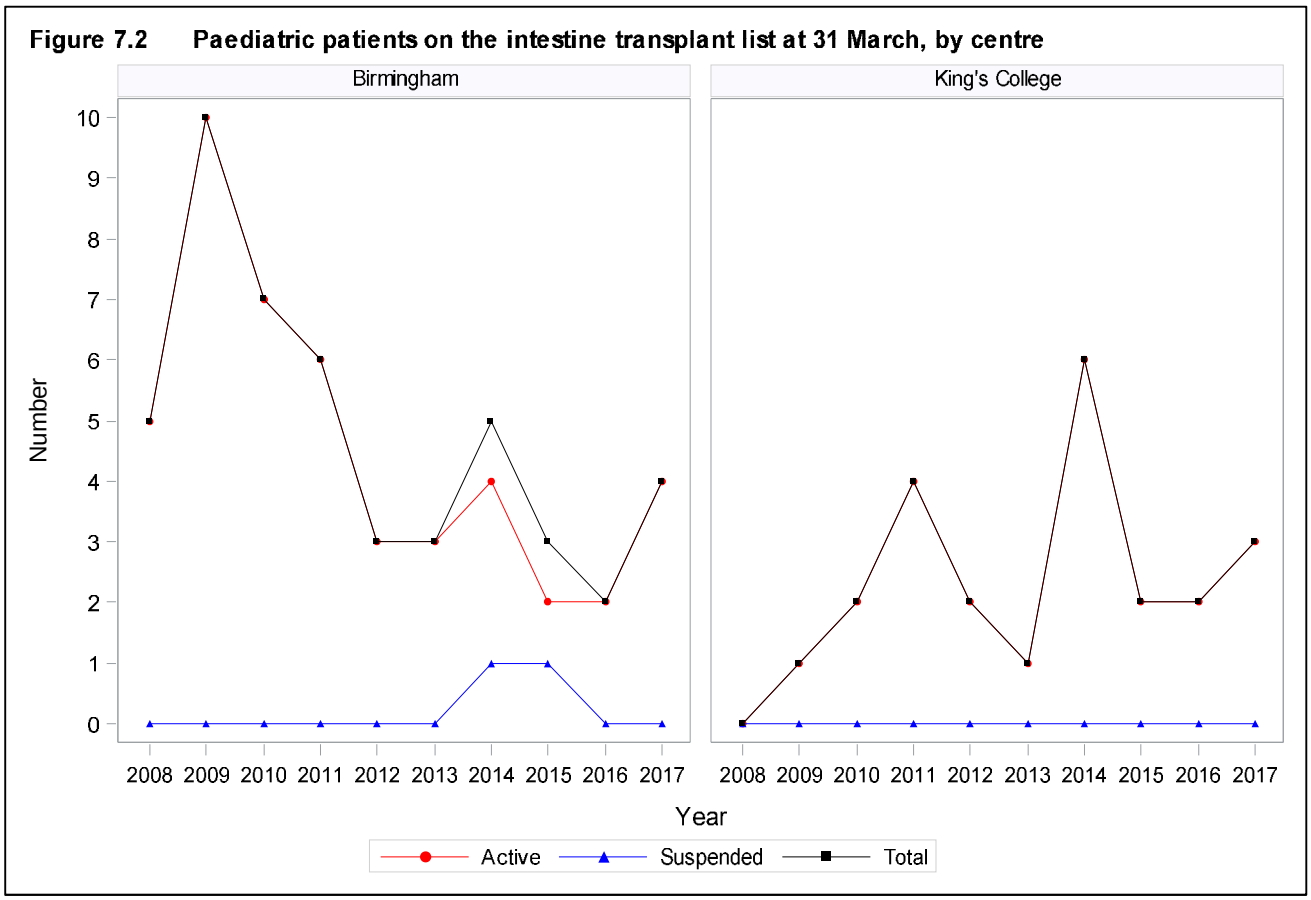


Figure 7.2 shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2008 and 2017, at each transplant centre. Until the last few years Birmingham had more patients on the active transplant list than King's College.



The demographic characteristics of 100 paediatric intestine transplant recipient registrations in the 10 year period are shown by centre and overall in **Table 7.1**. 59% of these recipients were male and the median age for recipients was 2 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 17 kg/m^2. For some characteristics, percentages may not add up to 100 due to rounding.

Table 7.1 Demographic characteristics of paediatric intestine transplant recipient registrations, 1 April 2007 - 31 March 2017

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Number		73	27[1]	**100 (100)**
Registration type	Elective	73 (100)	27 (100)	**100 (100)**
Transplant type required	Intestine only	19 (26)	11 (41)	**30 (30)**
	Including liver	46 (63)	15 (56)	**61 (61)**
	Not including liver	8 (11)	1 (4)	**9 (9)**
Recipient sex	Male	44 (60)	15 (56)	**59 (59)**
	Female	28 (38)	12 (44)	**40 (40)**
Recipient ethnicity group	White	61 (84)	19 (70)	**80 (80)**
	Other	11 (15)	8 (30)	**19 (19)**
	Not reported	1 (1)	0	**1 (1)**
Indication group	Short bowel syndrome	33 (45)	10 (37)	**43 (43)**
	Motility disorders	9 (12)	6 (22)	**15 (15)**
	Primary mucosal disorders	9 (12)	2 (7)	**11 (11)**
	Liver disease	3 (4)	0	**3 (3)**
	Other/not reported	12 (16)	6 (22)	**18 (18)**
	Retransplant	7 (10)	3 (11)	**10 (10)**
Pre-transplant renal support	No	61 (84)	26 (96)	**87 (87)**
	Yes	3 (4)	0	**3 (3)**
	Not reported	9 (12)	1 (4)	**10 (10)**
Previous abdominal surgery	No	9 (12)	2 (7)	**11 (11)**
	Yes	55 (75)	24 (89)	**79 (79)**
	Not reported	9 (12)	1 (4)	**10 (10)**
Recipient blood group	O	36 (49)	8 (30)	**44 (44)**
	A	25 (34)	15 (56)	**40 (40)**
	B	11 (15)	4 (15)	**15 (15)**
	AB	1 (1)	0	**1 (1)**
Recipient age (years)	Median (IQR)	1 (0,6)	4 (2,7)	**2 (0,6)**
Recipient BMI (kg/m^2)	Median (IQR)	17 (16,18)	18 (16,19)	**17 (16,19)**
	Not reported	4	0	**4**

[1] One patient from King's College received a liver only graft and this patient has not been included in the reported intestinal transplant numbers.

8. Response to offers

Between 1 April 2016 and 31 March 2017 Birmingham and King's College received offers from 71 and 143 donors, respectively, for intestine transplant patients at their centres. Their offer decline rates were 98% and 99% respectively. 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.

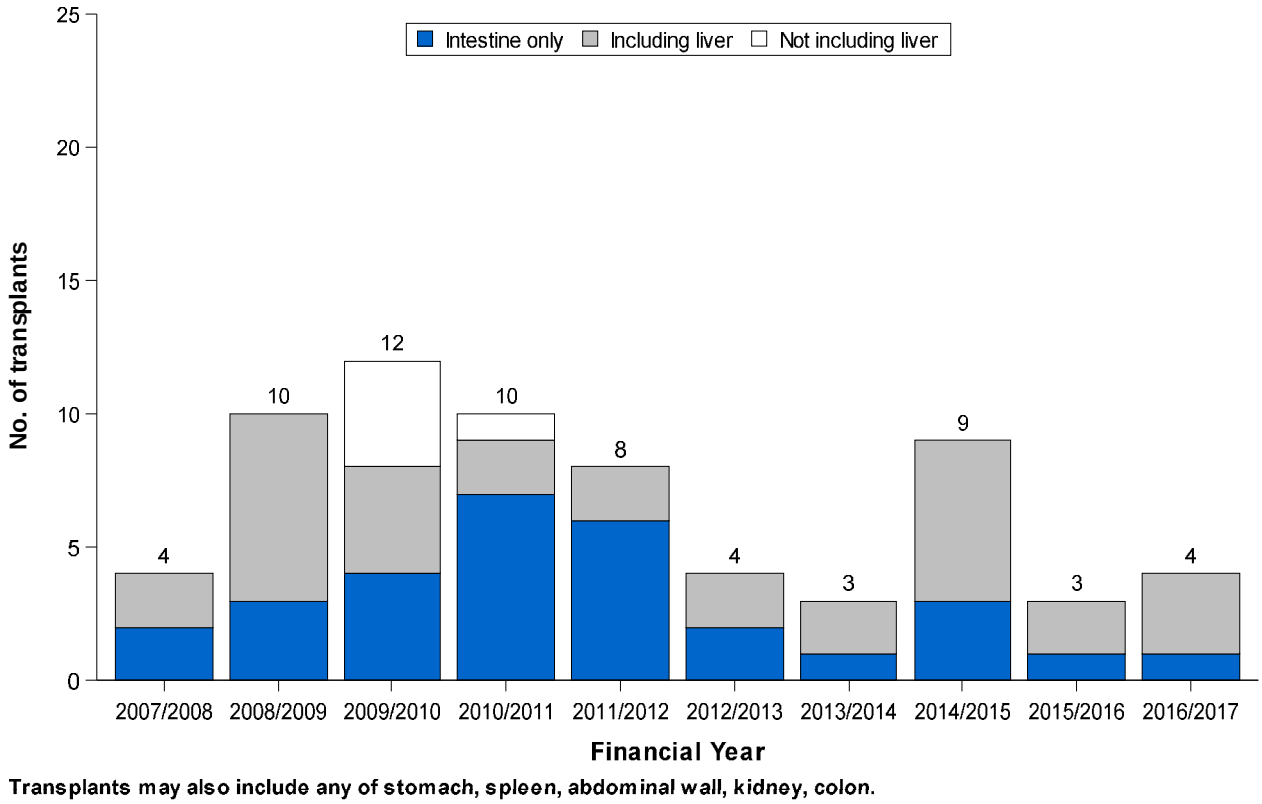
9. Transplants

9.1 Paediatric intestinal transplants, 1 April 2007 – 31 March 2017

Figure 9.1 shows the number of paediatric intestine transplants performed in the last 10 years, by transplant type. The number of paediatric transplants increased from four in 2007/2008 to 12 in 2009/2010. This number subsequently decreased over the following few years to three in 2013/2014, with a peak to nine in 2014/2015.

Note the contrasting trends between **Figure 5.1** and **Figure 9.1**; while the overall number of transplants in adult recipients has generally increased over the last 10 years, this has not been the case for paediatric recipients.

Figure 9.1 Paediatric intestine transplants in the UK, 1 April 2007 - 31 March 2017



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

Figure 9.2 shows the number of paediatric intestine transplants performed in 2016/2017, by centre and transplant type. The only transplant performed at Birmingham was liver and intestine combined while one of transplants at King's College was intestine only and the other two were liver and intestine combined.

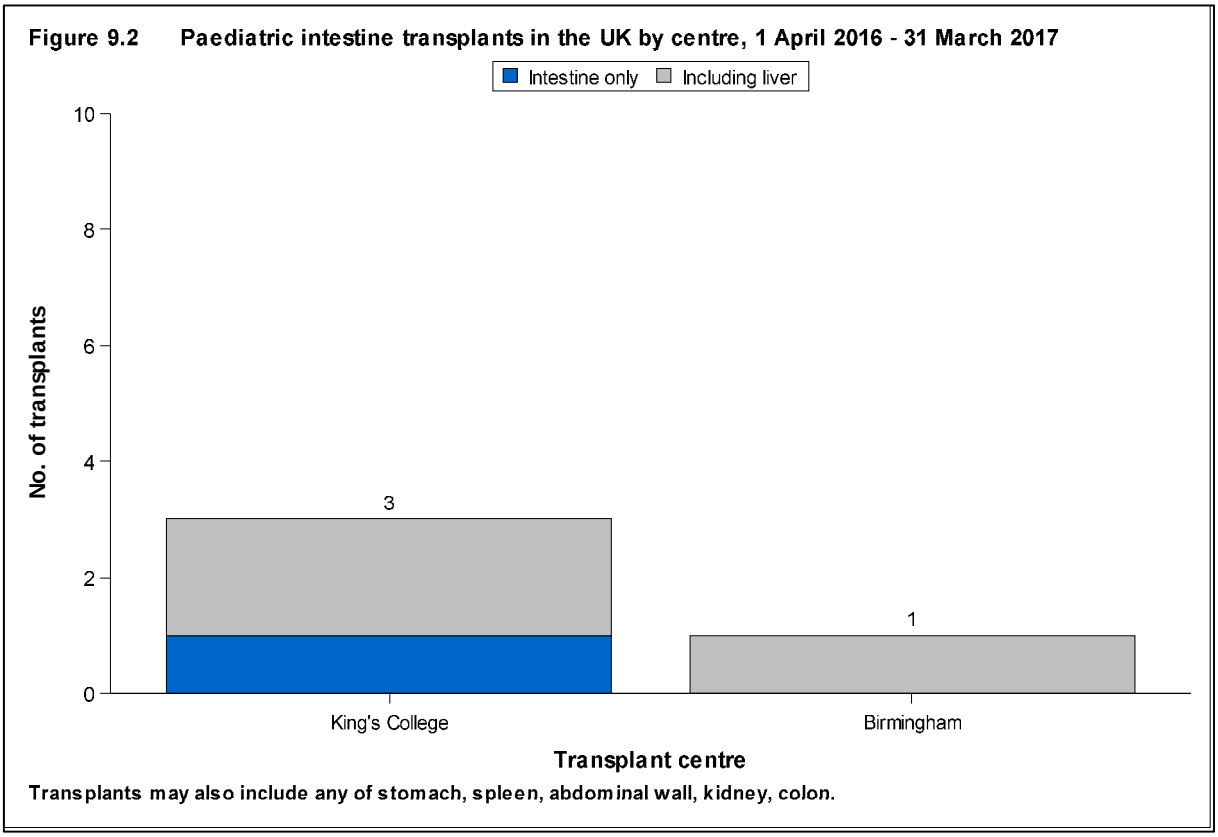
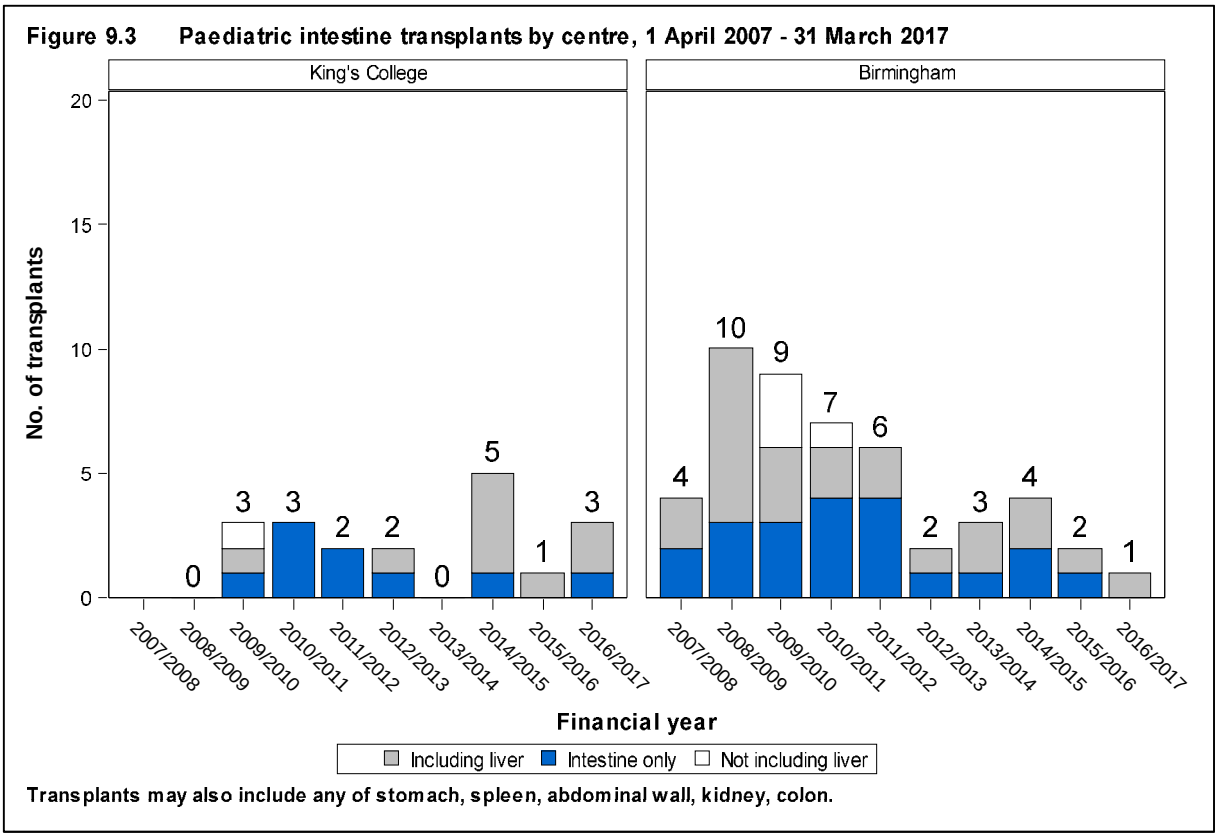


Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and type of transplant. Note that King's College joined the programme in 2008 but their first intestine transplants were performed in 2009/2010.



The demographic characteristics of 67 paediatric elective intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 9.1.** 60% of these recipients were male and the median age for recipients was four years old. The most common indication for transplantation was short bowel syndrome. The median recipient BMI was 18 kg/m^2. For some characteristics, percentages may not add up to 100 due to rounding.

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2007 - 31 March 2017

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Number		48	19	**67 (100)**
Recipient sex	Male	29 (60)	11 (58)	**40 (60)**
	Female	19 (40)	8 (42)	**27 (40)**
Recipient ethnicity group	White	39 (81)	13 (68)	**52 (78)**
	Other	8 (17)	6 (32)	**14 (21)**
	Not reported	1 (2)	0	**1 (2)**
Indication group	Short bowel syndrome	25 (52)	7 (37)	**32 (48)**
	Motility disorders	5 (10)	6 (32)	**11 (16)**
	Primary mucosal disorders	6 (13)	1 (5)	**7 (10)**
	Liver disease	2 (4)	0	**2 (3)**
	Other/not reported	7 (15)	2 (11)	**9 (13)**
	Retransplant	3 (6)	3 (16)	**6 (9)**
Patient location	Out-patient	36 (75)	14 (74)	**50 (75)**
	Ward	4 (8)	3 (16)	**7 (10)**
	ICU/HDU	0	2 (11)	**2 (3)**
	Not reported	8 (17)	0	**8 (12)**
Pre-transplant renal support	No	42 (88)	18 (95)	**60 (90)**
	Yes	0	1 (5)	**1 (2)**
	Not reported	6 (13)	0	**6 (9)**
Previous abdominal surgery	No	7 (15)	1 (5)	**8 (12)**
	Yes	35 (73)	18 (90)	**53 (79)**
	Not reported	6 (13)	0	**6 (9)**
Life style activity	Normal	1 (2)	1 (5)	**2 (3)**
	Restricted	7 (15)	6 (32)	**13 (19)**
	Self-care	3 (6)	0	**3 (5)**
	Reliant	2 (4)	3 (16)	**5 (8)**
	Aged five years or less	25 (52)	9 (47)	**34 (51)**
	Not reported	10 (21)	0	**10 (15)**
Restricted venous access at registration	No	13 (27)	11 (58)	**24 (36)**
	Yes	23 (48)	6 (32)	**29 (43)**
	Not reported	12 (25)	2 (11)	**14 (21)**
Recipient age (years)	Median (IQR)	3 (1,6)	5 (4,8)	**4 (1,6)**

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2007 - 31 March 2017

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Recipient BMI (kg/m^2)	Median (IQR)	17 (16,19)	18 (16,19)	**18 (16,19)**
	Not reported	39	0	**39**
Serum bilirubin (umol/l)	Median (IQR)	12 (8,96)	9 (6,18)	**10 (7,76)**
	Not reported	9	0	**9**
Time on list (days)	Median (IQR)	175 (58,240)	188 (85,330)	**179 (62,291)**
Donor sex	Male	23 (48)	14 (74)	**37 (55)**
	Female	25 (52)	5 (26)	**30 (45)**
Donor ethnicity group	White	38 (79)	13 (68)	**51 (76)**
	Other	6 (13)	2 (11)	**8 (12)**
	Not reported	4 (8)	4 (21)	**8 (12)**
Donor cause of death group	Stroke	23 (48)	12 (63)	**35 (52)**
	Trauma	12 (25)	3 (16)	**15 (22)**
	Other	13 (27)	4 (21)	**17 (25)**
Donor history of diabetes	No	40 (83)	16 (84)	**56 (84)**
	Yes	1 (2)	0	**1 (2)**
	Not reported	7 (15)	3 (16)	**10 (15)**
Donor age (years)	Median (IQR)	7 (3,14)	4 (1,8)	**5 (2,13)**
Donor BMI (kg/m^2)	Median (IQR)	16 (15,19)	15 (13,19)	**16 (14,19)**
Transplant type	Intestine only	21 (44)	9 (47)	**30 (45)**
	Including liver	23 (48)	9 (47)	**32 (48)**
	Not including liver	4 (8)	1 (5)	**5 (8)**
ABO match	Identical	40 (83)	17 (89)	**57 (85)**
	Compatible	8 (17)	2 (11)	**10 (15)**
Cold ischaemic time (hours)	Median (IQR)	6.4 (5.6,7.1)	7.9 (5.9,8.7)	**6.7 (5.7,7.5)**
	Not reported	8	4	**12**

9.2 Cold ischaemia time, 1 April 2007 – 31 March 2017

Figure 9.4 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 7.5 hours.

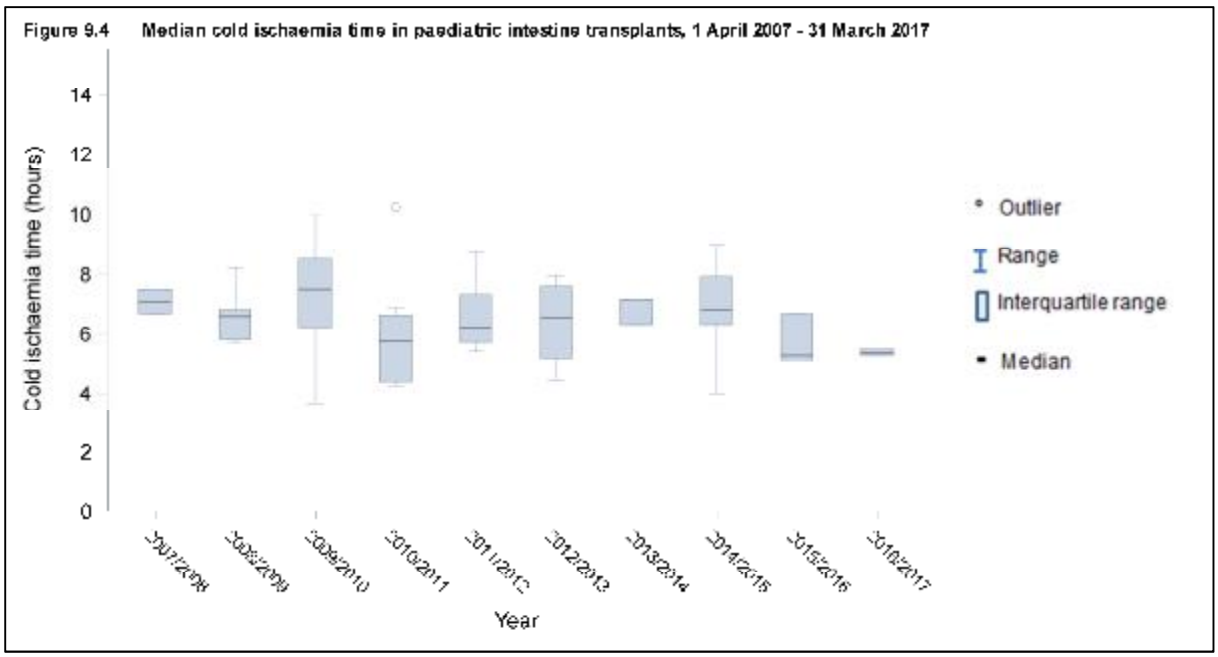
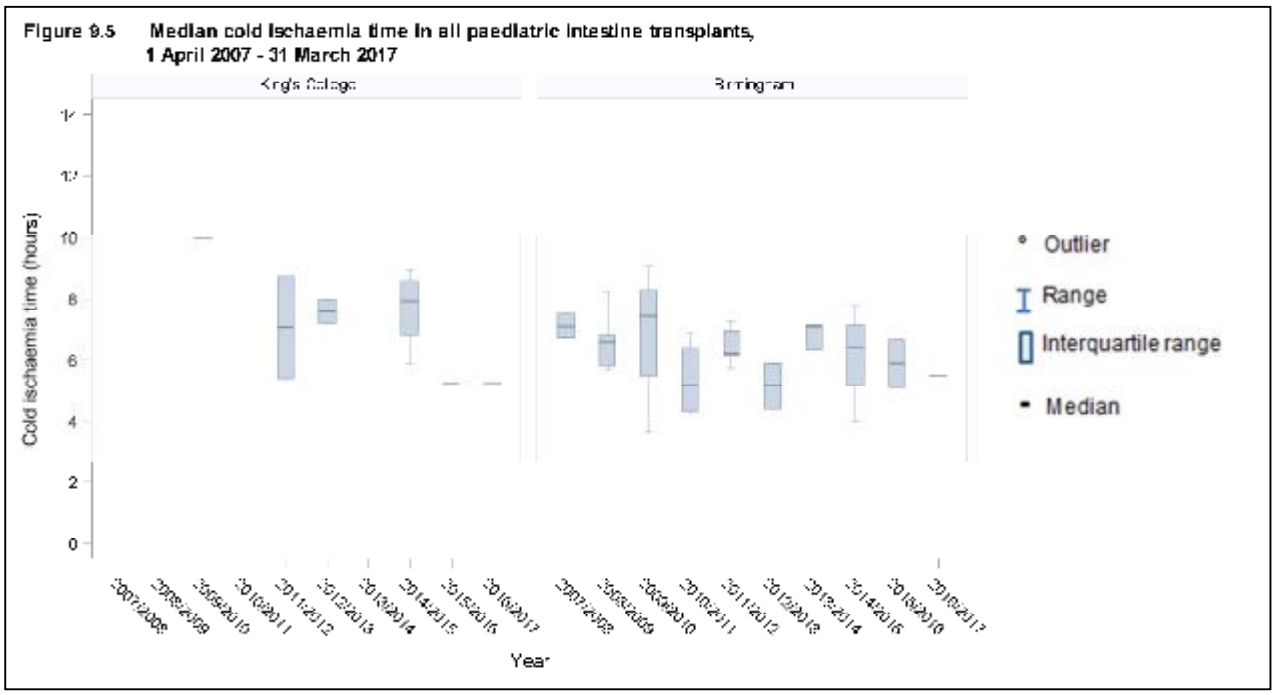


Figure 9.5 shows the median CITs in paediatric intestine transplants by centre over the last 10 years. Note that prior to 2009/2010 King's College did not perform any intestine transplants which means there are no boxplots presented for the first three years. All of these boxplots represent a small number of observations and, as shown in **Table 9.1**, a proportion of CITs have not been reported.



10. Post-transplant survival

10.1 Survival by transplant centre

Table 10.1 shows the 90-day unadjusted patient survival rates for paediatric elective first intestine transplants between 1 April 2007 and 31 March 2017, overall and by centre. There were 60 transplants of this kind in the time period and survival information was known in 58 cases; of these, 95% of patients were alive 90 days post-transplant.

Table 10.1 Unadjusted 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	90-day survival (95% CI)	
Birmingham	43	93.0	(79.9-97.7)
King's College	15	100.0	-
TOTAL	**58**	**94.8**	**(84.8-98.3)**

Unadjusted one- and five-year patient survival rates are shown in **Table 10.2** and **Table 10.3**, respectively. One year post-transplant, 86% of transplanted patients are alive while, five years post-transplant, the survival rate is 62%. 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 10.2 Unadjusted one-year patient survival (%) paediatric elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	1-year survival (95% CI)	
Birmingham	43	83.7	(68.9-91.9)
King's College	15	93.3	(61.3-99.0)
TOTAL	**58**	**86.1**	**(74.2-92.8)**

Table 10.3 Unadjusted five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant centre

Centre	Number of transplants	5-year survival (95% CI)	
Birmingham	43	54.4	(37.4-68.6)
King's College	15	71.1	(39.8-88.1)
TOTAL	**58**	**58.8**	**(44.2-70.8)**

10.2 Survival by transplant type

Table 10.4 shows the unadjusted 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 10.4 Unadjusted patient survival (%) for paediatric elective first intestine transplants between 1 April 2007 and 31 March 2017, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI)		1-year survival (95% CI)		5-year survival (95% CI)	
Birmingham							
Including liver	20	85.0	(63.0-90.3)	75.0	(50.0-88.7)	37.9	(17.3-58.5)
Not including liver	23	100.0	-	91.3	(69.5-97.8)	69.3	(43.0-85.2)
King's College							
Including liver	6[1]	-	-	-	-	-	-
Not including liver	9[1]	-	-	-	-	-	-
TOTAL	**58**	**94.8**	**(84.8-98.3)**	**86.1**	**(74.2-92.8)**	**58.8**	**(44.2-70.8)**

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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

11.1 Adult form return rates, 1 January – 31 December 2016

Form return rates are reported in **Table 11.1** for centres. 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 2016 and 31 December 2016, for patients at each centre, and the percentage of forms that had been returned at time of analysis (23 May 2017). 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 11.1 Form return rates, by adult transplant centre, for forms issued between 1 January 2016 and 31 December 2016

Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up	
	No. forms issued	% returned	No. forms issued	% returned	No. forms issued	% returned	No. forms issued	% returned
Cambridge	9	100	12	100	8	100	37	100
Oxford	2	100	2	100	3	100	17	100
Total	**11**	**100**	**14**	**100**	**11**	**100**	**54**	**100**

11.2 Paediatric form return rates, 1 January – 31 December 2016

Form return rates are reported in **Table 11.2** for paediatric centres. 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 2016 and 31 December 2016, for patients at each centre, and the percentage of forms that had been returned at time of analysis (23 May 2017). 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 11.2 Form return rates, by paediatric transplant centre, for forms issued between 1 January 2016 and 31 December 2016

Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up	
	No. forms issued	% returned	No. forms issued	% returned	No. forms issued	% returned	No. forms issued	% returned
Birmingham	1	100	4	75	1	100	39	100
King's College	3	100	2	100	2	100	10	90
Total	**4**	**100**	**6**	**83**	**3**	**100**	**49**	**98**

APPENDIX

A1: Number of patients analysed

Data were obtained from the UK Transplant Registry for the 10 year time period, 1 April 2007 to 31 March 2017. 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. Additionally, one transplant at Oxford in 2016 involving the abdominal wall only where the patient was registered using the Intestinal Transplant Recipient Registration form has also been exluded.

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 2007 to 31 March 2017

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Cambridge	66	6	62	4
Oxford	37	0	36	0
TOTAL	**103**	**6**	**98**	**4**

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 2007 to 31 March 2017

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Birmingham	48	0	43	0
King's College	19	0	17	0
TOTAL	**67**	**0**	**60**	**0**

Geographical variation analysis

Registration rates

All NHS group 1 patients who were registered onto the intestinal transplant lists with an active status between 1 April 2007 and 31 March 2017 were extracted from the UK Transplant Registry on 10 August 2017. This was then divided by 10 to give the average number of registrations per year (numerator). Patients were assigned to Strategic Health Authorities (SHA) in England using their postcode of residence, as reported at registration. The number of registrations per million population (pmp) by SHA was obtained using mid-2015 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No SHA age- or sex-specific standardisation of rates was performed.

The registration rates pmp were categorised into four groups – low, low-medium, medium-high and high – based on the quartiles of their distribution and visualised in a map using contrasting colours.

Transplant rates

Transplant rates pmp were obtained as the annual average number of intestinal transplants on NHS group 1 recipients from deceased donors based on transplants between 1 April 2007 and 31 March 2017 (numerator), divided by the mid-2015 population estimates from the ONS (denominator). Transplant rates pmp were categorised and visualised in a map as done for the registration rates.

Systematic component of variation

Only registrations or transplants in England between 1 April 2007 and 31 March 2017 were included. If a patient was re-registered during the time period, only the first registration was considered. If a patient underwent more than one intestinal transplant in the time period, only the first transplant was considered.

A2: Methods

Waiting time to transplant

Waiting time was calculated from date of registration to date of transplant, for elective patients registered between 1 April 2013 and 31 March 2016 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, 23 May 2017, were censored at that time.

Unadjusted survival rates

Unadjusted patient survival rates were estimated using Kaplan-Meier methods. 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. 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 the time of analysis. Death, irrespective of whether the graft is still functioning or not, is classed as an event.

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 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 2016 to 31 March 2017.

Geographical variation analysis

For a given individual who is a resident in a given English Strategic Health Authority (SHA), registration to the transplant list is modelled as a Bernoulli trial. At the whole area level, this becomes a Binomial process which can be approximated by a Poisson distribution when rare events are modelled. Transplant counts follow similar assumptions.

To allow for the possibility that, even after allowing for area-specific Poisson rates, area differences remain, introduce an additional multiplicative rate factor which varies from area to area. Postulate a non-parametric distribution for the multiplicative factor, with variance σ^2. If the factor is one for all areas, then area differences are fully explained by the area-specific Poisson rate. If the factor varies with a nonzero variance, σ^2, then we conclude that there are unexplained area differences.

The systematic component of variation (SCV; McPherson *et al., N Engl J Med* 1982, **307:** 1310-4) is the moment estimator of σ^2. Under the null hypothesis of homogeneity across areas, the SCV would be zero. The SCV, therefore, allows us to detect variability across areas beyond that expected by chance; the larger the SCV, the greater the evidence of systematic variation across areas.

A3: 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 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.

Case mix
The types of patients treated at a unit for a common condition. This can vary across units depending on the facilities available at the unit as well as the types of people in the catchment area of the unit. The definition of what type of patient a person is depends on the patient characteristics that influence the outcome of the treatment.

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 intestine 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 intestine 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.

Patient survival rate
The percentage of patients who are still alive (whether the graft is still functioning or not). This is usually specified for a given time period after first transplant. For example, a five-year patient survival rate is the percentage of patients who are still alive five years after their first transplant.

***p* value**
In the context of comparing survival rates across centres, the *p* value is the probability that the differences observed in the rates across centres occurred by chance. As this is a probability, it takes values between 0 and 1. If the *p* value is small, say less than 0.05, this implies that the differences are unlikely to be due to chance and there may be some identifiable cause for these differences. If the *p* value is large, say greater than 0.1, then it is quite likely that any differences seen are due to chance.

Transplant type
To achieve homogeneous groups in terms of clinical complexity and for simplicity in analysing intestinal transplants, the range of transplants in this report are grouped into the following three groups:

Intestine only. This refers to a transplant where the small bowel is transplanted either on its own or with one or more of: kidney, spleen, stomach, abdominal wall, colon.

Not including liver. This refers to a transplant where the small bowel and pancreas are transplanted together and may include one or more of: kidney, spleen, stomach, abdominal wall, colon. In the post-transplant survival analysis, this group also includes the intestine only patients.

Including liver. This refers to a transplant where the small bowel and liver are transplanted together and may include one or more of: pancreas, kidney, spleen, stomach, abdominal wall, colon.

Unadjusted survival rate
Unadjusted survival rates are based only on the number of transplants at a given centre and the number and timing of those patients who die within the post-transplant period of interest. In this case, all patients are assumed to be equally likely to die at any given time. However, some centres may have lower unadjusted survival rates than others simply because they tend to undertake transplants that have increased risks of failure. Comparison of unadjusted survival rates across centres and to the national rate is therefore inappropriate.

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