NHS Blood and Transplant

ANNUAL REPORT ON INTESTINE TRANSPLANTATION

REPORT FOR 2015/2016
(1 APRIL 2006 – 31 MARCH 2016)

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EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

This report presents key figures about intestine transplantation in the UK. The period covered is 10 years of transplant data, from 1 April 2006 to 31 March 2016. 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 2016, there were six patients on the UK active intestine **transplant list**, which represents a 67% decrease relative to five 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 2012 – 31 March 2014), 75% had received a transplant two years post-registration, while 11% died, 7% were removed and 7% were still waiting.

- There were 168 intestine **transplants** performed in the UK in the 10 year period. Fifteen of these were re-transplants (9%) and 42% of the total number of transplants were in paediatric recipients while 58% were in adult recipients.

- The number of **transplants** in **adult recipients** has generally increased each year over the last 10 years. This has not been the case for **paediatric recipients**, for which the number was roughly the same at the start of the time period and the end.

- The national rates of **survival** (unadjusted) after first intestine transplantation for elective **adult patients** were estimated at 87%, 79% and 54% 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 94%, 85% and 60% at 90 days, one and five years post-transplant, respectively.

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INTRODUCTION

INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2006 and 31 March 2016, 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.

TRANSPLANT LIST

Figure 1 shows the total number of patients on the intestine active transplant list at 31 March of each year between 2007 and 2016. Year-end transplant list data are not available before 2007. The number of patients waiting for a transplant increased each year from six in 2007 to 18 in 2010-2011 and fell slightly to 14 in 2012 and further down to 6 in 2016.

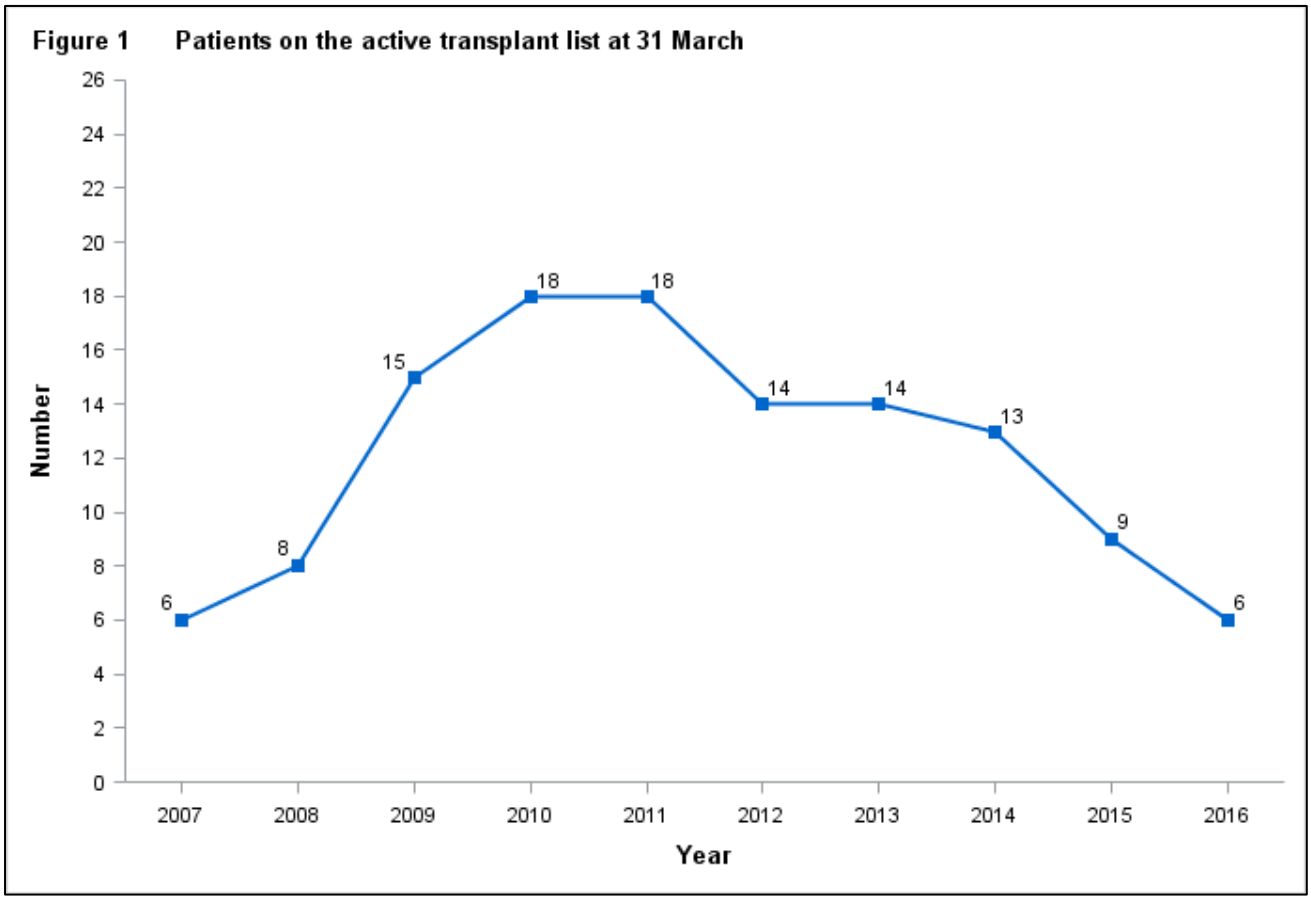
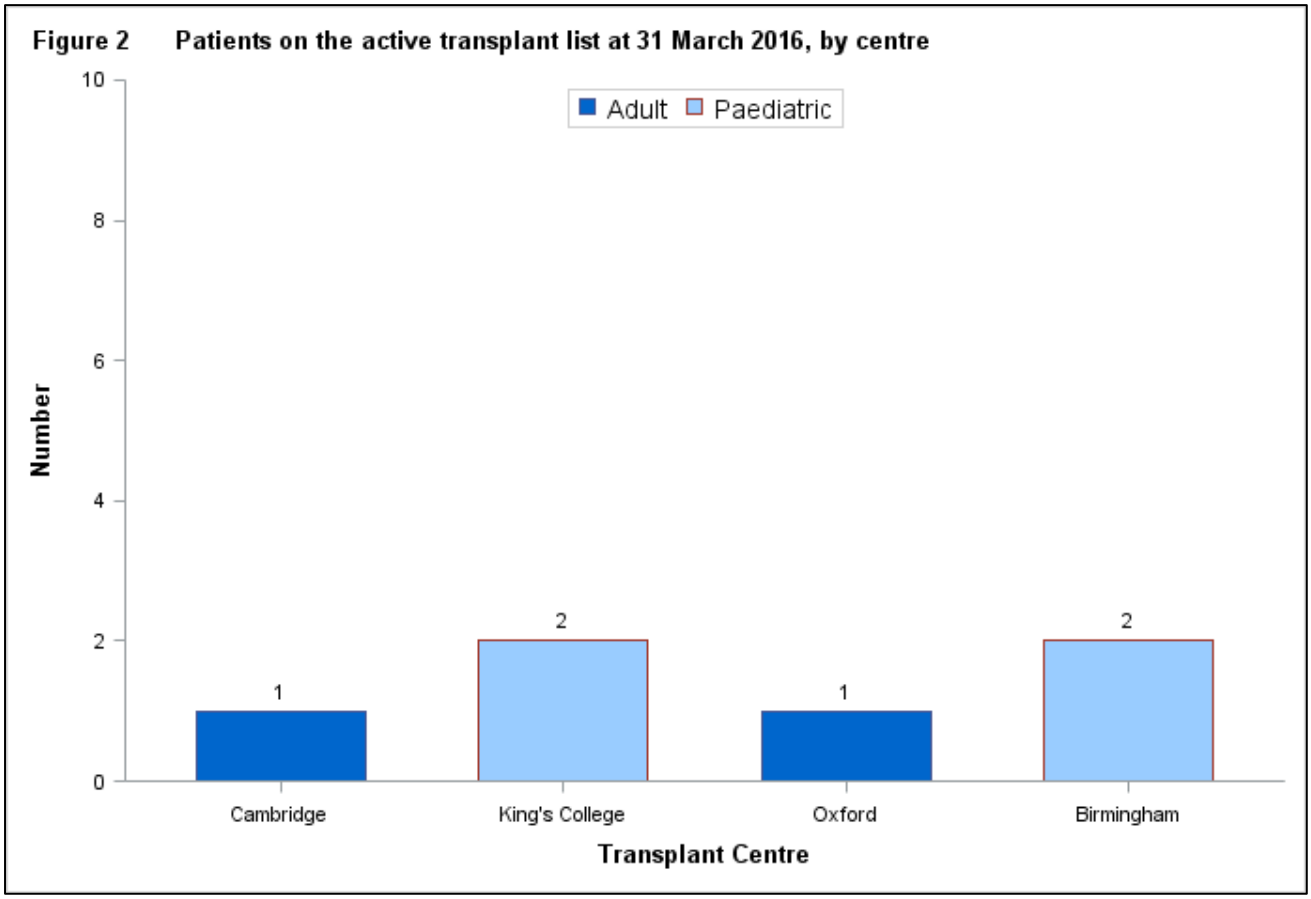


Figure 2 shows the number of adult and paediatric patients on the active transplant list at 31 March 2016 by centre. In total, there were two adult and four paediatric patients. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown in **Figure 7** and **Figure 15**, respectively.



The registration outcomes of patients listed between 1 April 2012 and 31 March 2014 for an intestine transplant are summarised in **Figure 3.** This shows the proportion of patients transplanted, still waiting or dying (includes those removed due to deteriorating condition) while waiting six months, one year and two years after joining the transplant list. At two years post-registration 75% of patients had received a transplant and 7% were still waiting, with 7% removed. The remaining percentage of patients died while on the transplant list.

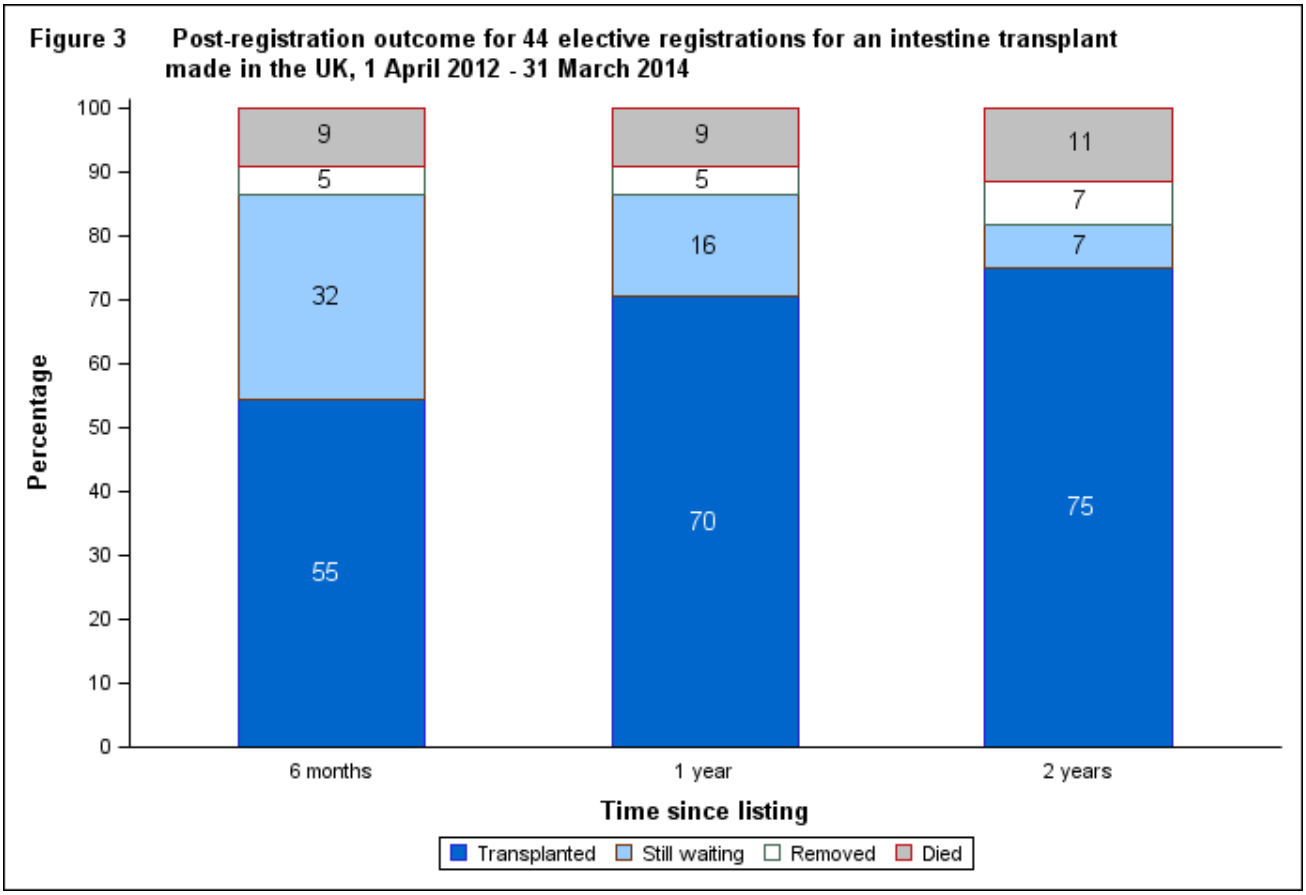


Table 1 shows median waiting time to elective intestine transplant by registration type (including re-registrations) for both adult and paediatric patients. Overall, on average, patients wait 68 days (approximately two months) for a transplant. The average wait is longer for patients who require a liver as part of their intestine graft but there was no statistically significant difference between registration types at a 5% significance level.

The decrease in median waiting time to transplant in this year's report compared to that published in 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 1 **Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2012 - 31 March 2015**

Registration type	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Intestine only[1]	17	34	0 – 69
Liver, intestine and pancreas[1]	34	86	0 – 202
Intestine and pancreas[1]	14	68	63 – 73
TOTAL	**65**	**68**	**40 – 96**

[1] May also include any of; stomach, spleen, abdominal wall, kidney, colon
Note: any periods of suspension are included in the calculation of median waiting times

TRANSPLANT ACTIVITY

Figure 4 shows the number of intestine transplants performed each year in the last 10 years. Currently in the UK, all intestine transplants are performed from donors after brain death (DBD). The total number of transplants was 168, with annual figures increasing from 7 in 2006/2007 to 26 in 2013/2014 with a decrease in 2015/2016 to 15.

Figure 4 **Total number of intestine transplants, 1 April 2006 - 31 March 2016**

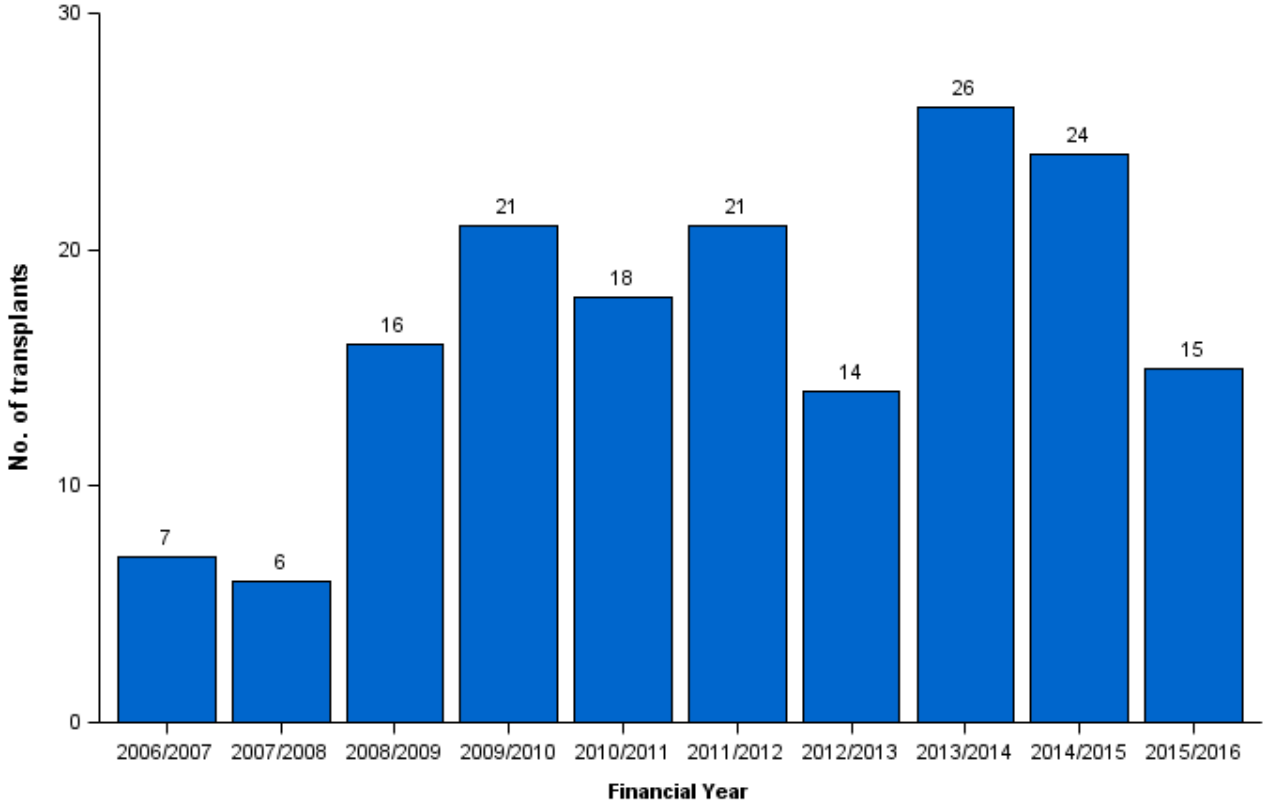


Figure 5 details the 168 intestine transplants performed in the UK in the 10 year period. Of these, 70 (42%) were in paediatric patients and 98 (58%) were in adult patients. The majority of both paediatric and adult transplants were in first time recipients.

Figure 5 UK intestine transplants, 1 April 2006 to 31 March 2016

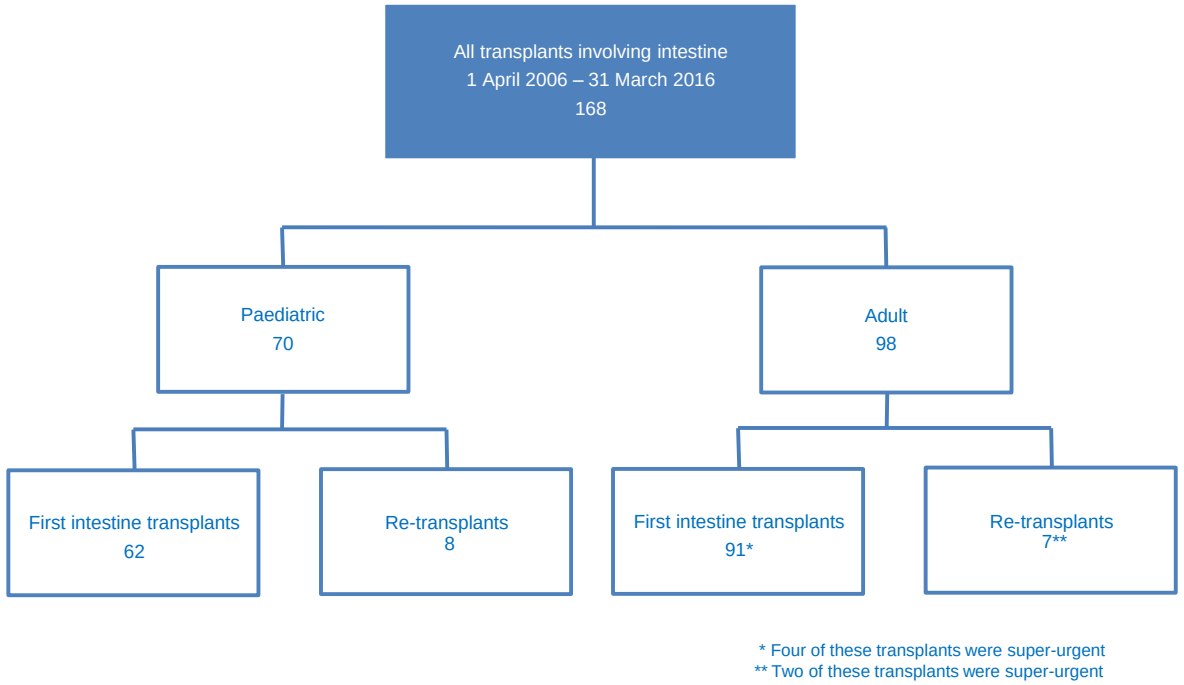


Table 2 shows the intestinal transplant list rate in the UK by country/Strategic Health Authority of patient's residence. At 31 March 2016, the overall transplant list rate was 0.1 pmp and ranged from 0 to 0.2 pmp across the Strategic Health Authorities, although these numbers are very small so differences are not meaningful.

Table 2 Active intestinal transplant list at 31 March, by Country/ Strategic Health Authority of patient residence

Country/ Strategic Health Authority of residence	Intestinal transplant list (pmp) 2016		2015	
North East	-		-	
North West	-		1	(0.1)
Yorkshire and The Humber	-		-	
North of England	**-**		**1**	**(0.1)**
East Midlands	1	(0.2)	2	(0.4)
West Midlands	1	(0.2)	-	
East of England	1	(0.2)	3	(0.5)
Midlands and East	**3**	**(0.2)**	**5**	**(0.3)**
London	**1**	**(0.1)**	**-**	
South East Coast	-		1	(0.2)
South Central	1	(0.2)	-	
South West	1	(0.2)	1	(0.2)
South of England	**2**	**(0.1)**	**2**	**(0.1)**
England	**6**	**(0.1)**	**8**	**(0.1)**
Isle of Man	**-**		**-**	
Channel Islands	**-**		**-**	
Wales	**-**		**-**	
Scotland	**-**		**-**	
Northern Ireland	**-**		**-**	
TOTAL[1]	**6**	**(0.1)**	**9**	**(0.1)**

[1]Includes patients in 2016 (2015) resident Overseas 0 (1)

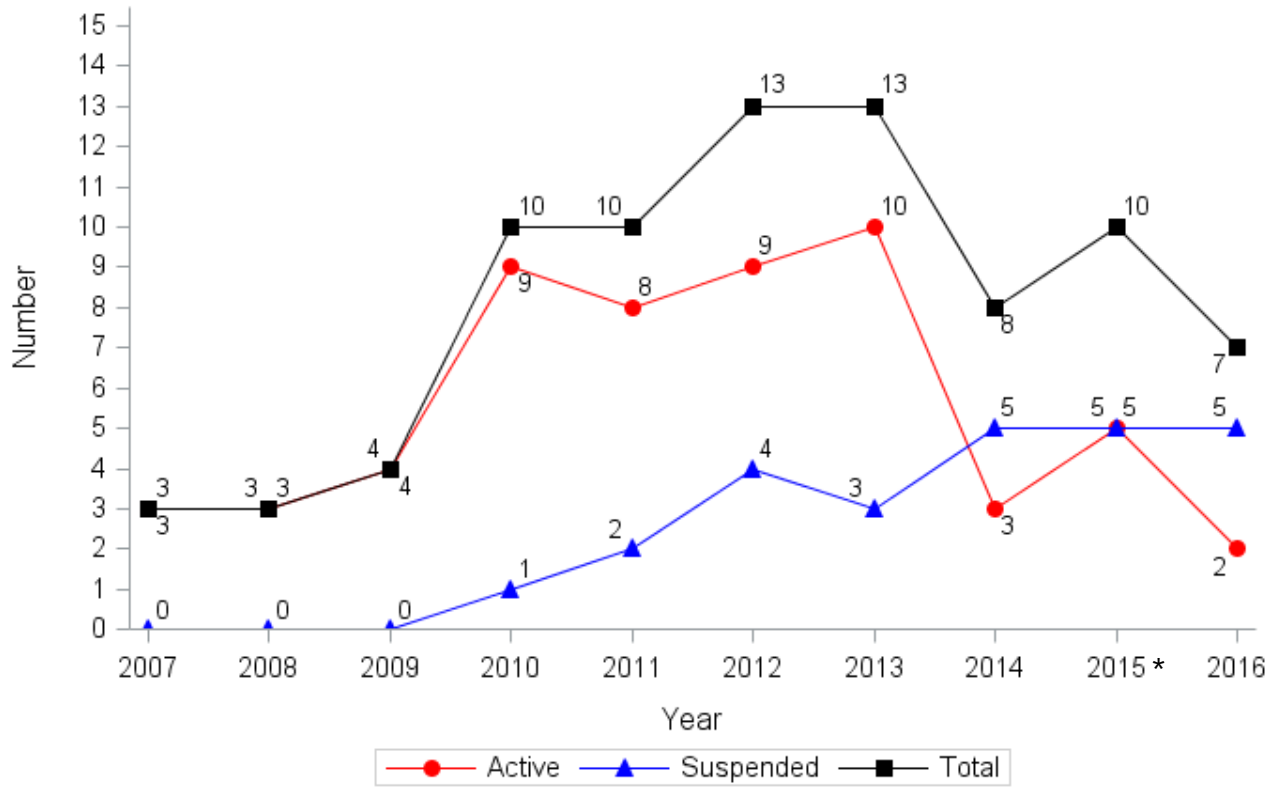
ADULT INTESTINE TRANSPLANTATION

ADULT INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 6 shows the number of adult patients active or suspended on the intestine transplant list at 31 March of each year between 2007 and 2016. Year-end transplant list data are not available before 2007. The number of patients on the active intestine transplant list increased each year from three in 2007 to nine in 2010. It subsequently remained relatively stable until 2014, when it fell to three patients and has since fallen to two.

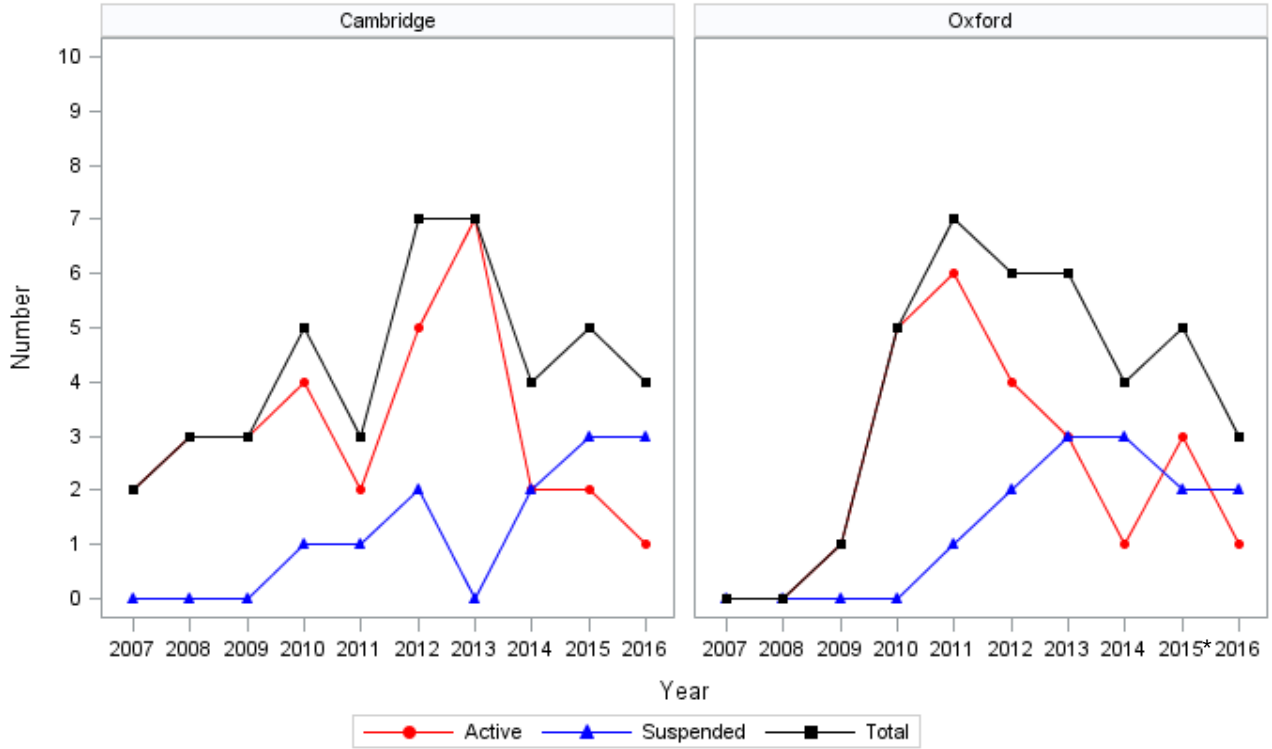
Figure 6 Adult patients on the intestine transplant list at 31 March



* Excludes one patient at Oxford registered for abdominal wall only

Figure 7 shows the number of adult patients on the intestine transplant list at 31 March of each year between 2007 and 2016, at each transplant centre. Cambridge had generally more adult patients on the national active transplant list than Oxford.

Figure 7 Adult patients on the intestine transplant list at 31 March, by centre



Note: one additional adult patient was on the active intestine transplant list on 31 March 2007 but registered at St James's University Hospital, Leeds, which is not a designated intestine transplant centre

* Excludes one patient registered for abdominal wall only

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 2015 and 31 March 2016 Cambridge received intestine offers from 94 donors and Oxford received intestine offers from 43. Their offer decline rates were 90% and 93%, respectively.

TRANSPLANTS

Figure 8 shows the number of adult intestine transplants performed in the last 10 years, by transplant type. The annual number of adult transplants increased steadily over the time period to 23 in 2013/2014, but dropped to 12 in the last financial year.

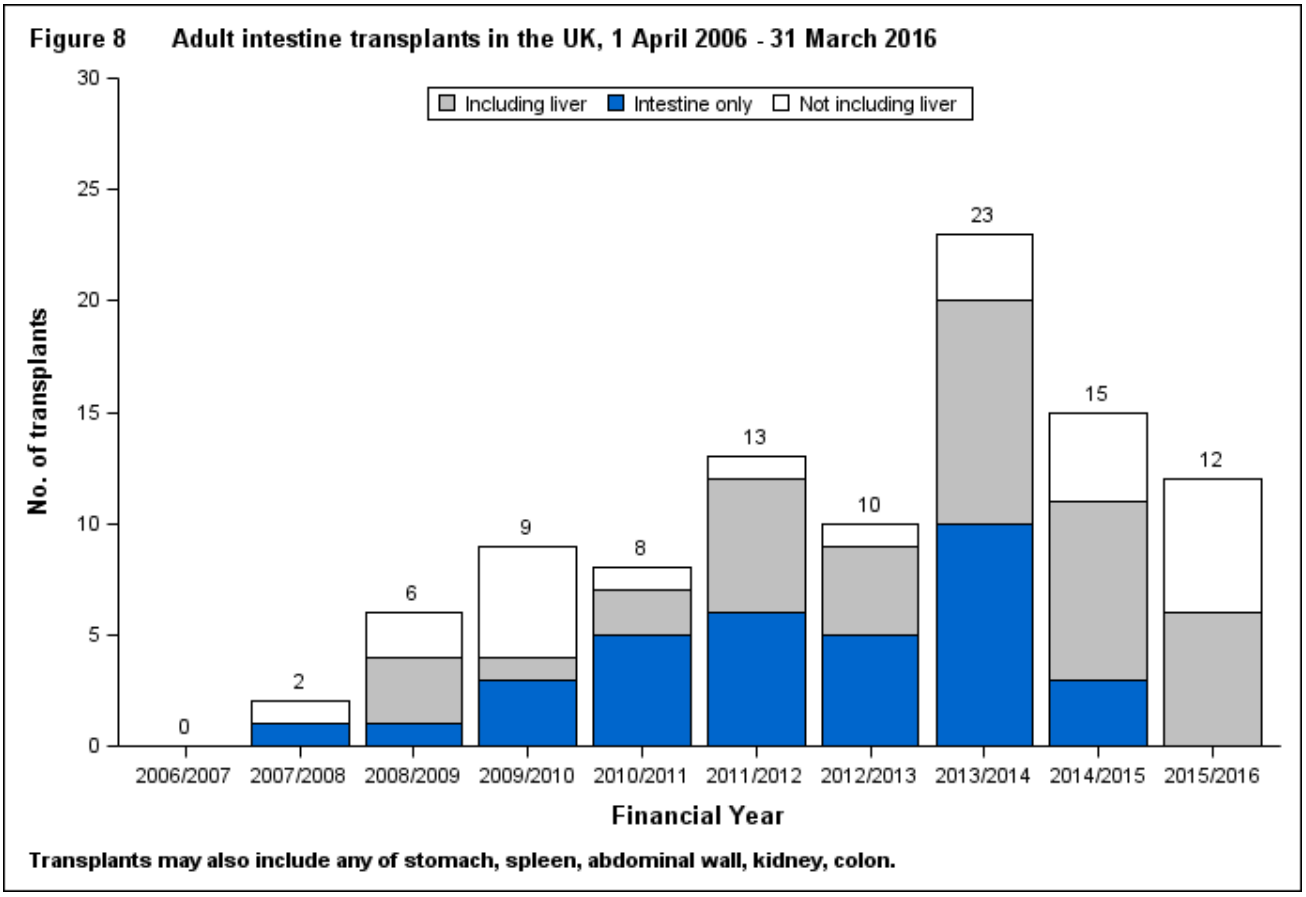


Figure 9 shows the number of adult intestine transplants performed in 2015/2016, by centre and transplant type. The majority of transplants (67%) performed at Cambridge were liver and intestine combined while only transplants not including the liver were performed at Oxford.

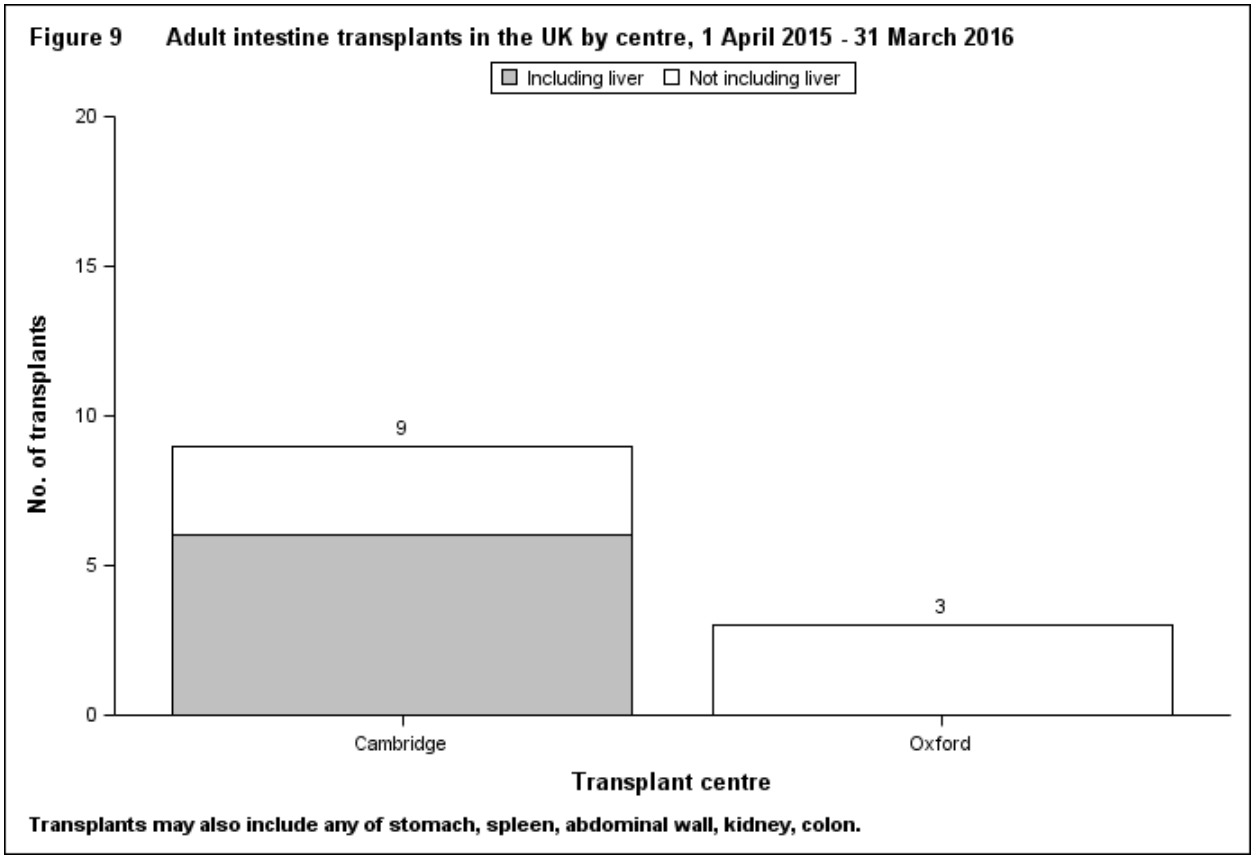
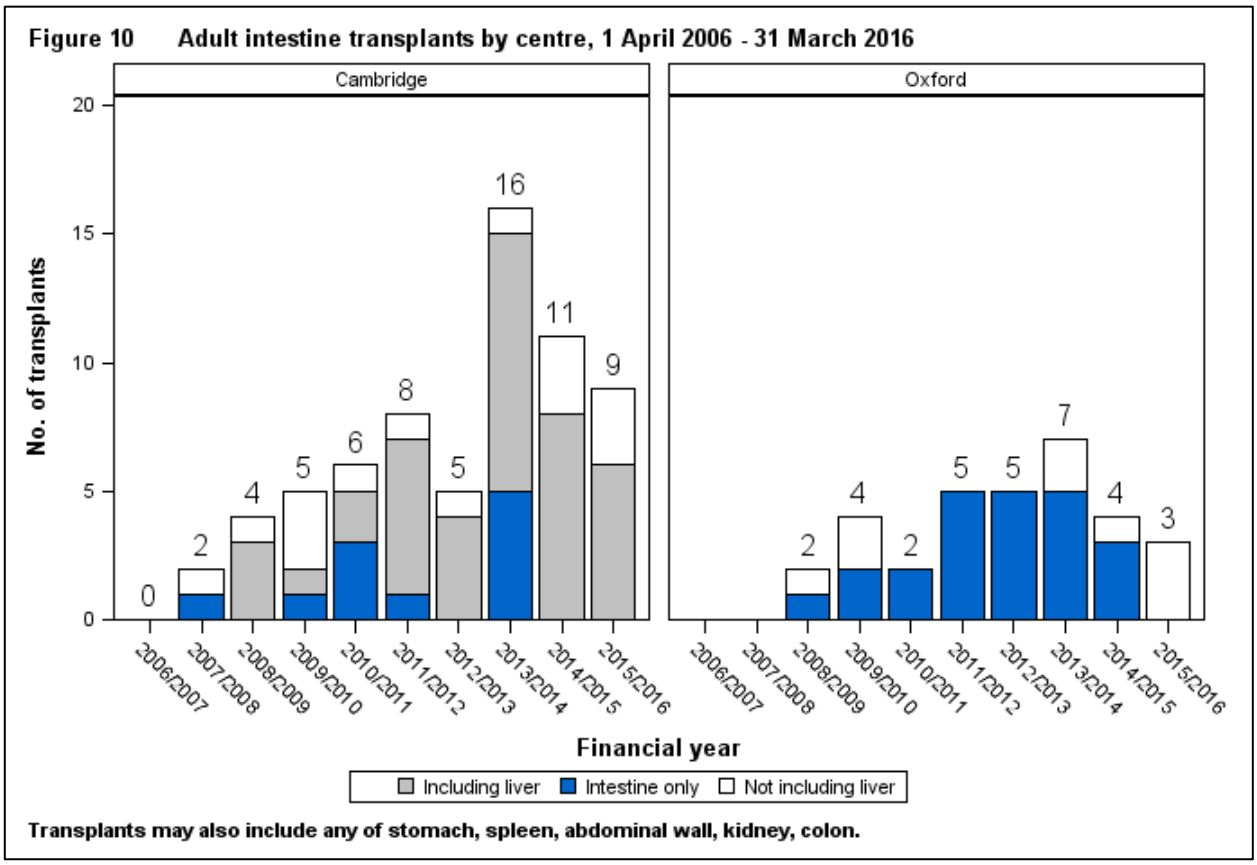


Figure 10 shows the number of adult intestine transplants performed in the last 10 years, by centre and type of transplant. Note that Oxford joined the programme in 2008.



The demographic characteristics of 92 adult elective intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 3**. 55% 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/m^2. For some characteristics, percentages may not add up to 100 due to rounding.

Table 3 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2006 - 31 March 2016

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Number		60	32	**92 (100)**
Recipient sex	Male	33 (55)	18 (56)	**51 (55)**
	Female	27 (45)	14 (44)	**41 (45)**
Recipient ethnicity group	White	55 (92)	30 (94)	**85 (92)**
	Other	4 (7)	2 (6)	**6 (7)**
	Not reported	1 (2)	0	**1 (1)**
Indication group	Short bowel syndrome	22 (37)	14 (44)	**36 (39)**
	Motility disorders	5 (8)	5 (16)	**10 (11)**
	Malignancy	3 (5)	3 (9)	**6 (7)**
	Liver disease	3 (5)	1 (3)	**4 (4)**
	Other/not reported	23 (38)	8 (25)	**31 (34)**
	Retransplant	4 (7)	1 (3)	**5 (5)**
Patient location	Out-patient	33 (55)	27 (84)	**60 (65)**
	Ward	12 (20)	5 (16)	**17 (19)**
	ICU/HDU	3 (5)	0	**3 (3)**
	Not reported	12 (20)	0	**12 (13)**
Pre-transplant renal support	No	48 (80)	30 (94)	**78 (85)**
	Yes	0	2 (6)	**2 (2)**
	Not reported	12 (20)	0	**12 (13)**
Previous abdominal surgery	No	8 (13)	2 (6)	**10 (11)**
	Yes	40 (67)	30 (94)	**70 (76)**
	Not reported	12 (20)	0	**12 (13)**
Life style activity	Normal	1 (2)	4 (13)	**5 (5)**
	Restricted	8 (13)	3 (9)	**11 (12)**
	Self-care	24 (40)	16 (50)	**40 (44)**
	Confined	9 (15)	6 (19)	**15 (16)**
	Reliant	6 (10)	3 (9)	**9 (10)**
	Not reported	12 (20)	0	**12 (13)**
Restricted venous access at registration	No	42 (70)	18 (56)	**60 (65)**
	Yes	13 (22)	13 (41)	**26 (28)**
	Not reported	5 (8)	1 (3)	**6 (7)**
Recipient age (years)	Median (IQR)	46 (35,55)	40 (34,47)	**44 (34,54)**
Recipient BMI (kg/m^2)	Median (IQR)	21 (19,23)	21 (19,23)	**21 (19,23)**
	Not reported	14	7	**21**

Table 3 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2006 - 31 March 2016

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Serum bilirubin (umol/l)	Median (IQR)	20 (9,43)	10 (6,13)	**13 (8,28)**
	Not reported	12	0	**12**
Time on list (days)	Median (IQR)	44 (21,159)	35 (16,89)	**40 (19,125)**
Donor sex	Male	21 (35)	18 (56)	**39 (42)**
	Female	39 (65)	14 (44)	**53 (58)**
Donor ethnicity group	White	55 (92)	30 (94)	**85 (92)**
	Other	2 (3)	1 (3)	**3 (3)**
	Not reported	3 (5)	1 (3)	**4 (4)**
Donor cause of death group	Stroke	49 (82)	18 (56)	**67 (73)**
	Trauma	7 (12)	13 (41)	**20 (22)**
	Other	4 (7)	1 (3)	**5 (5)**
Donor history of diabetes	No	60 (100)	31 (97)	**91 (99)**
	Not reported	0	1 (3)	**1 (1)**
Donor age (years)	Median (IQR)	31 (21,39)	25 (21,36)	**27 (21,39)**
Donor BMI (kg/m^2)	Median (IQR)	21 (20,23)	22 (21,23)	**22 (20,23)**
Transplant type	Intestine only	12 (20)	23 (72)	**35 (38)**
	Including liver	34 (57)	0	**34 (37)**
	Not including liver	14 (23)	9 (28)	**23 (25)**
ABO match	Identical	44 (73)	30 (94)	**74 (80)**
	Compatible	16 (27)	2 (6)	**18 (20)**
Cold ischaemic time (hours)	Median (IQR)	4.6 (4.2,5.2)	6.4 (5.6,7.8)	**5.2 (4.4,6.4)**
	Not reported	18	4	**22**

Figure 11 shows boxplots of the cold ischaemic times (CIT) of adult intestine transplants over the last 10 years. The line inside the box indicates the median value. The median CIT has fallen over the time period from 8.2 hours in 2009/2010 to 4.1 hours in 2015/2016.

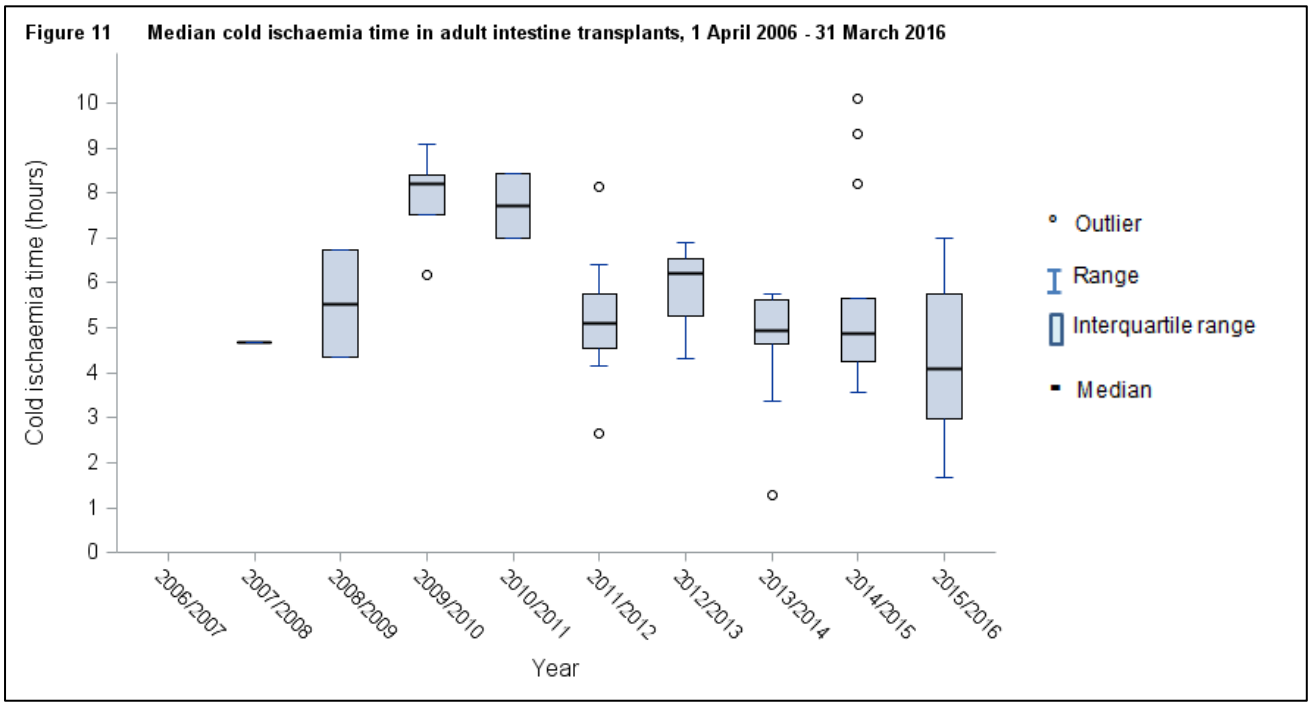
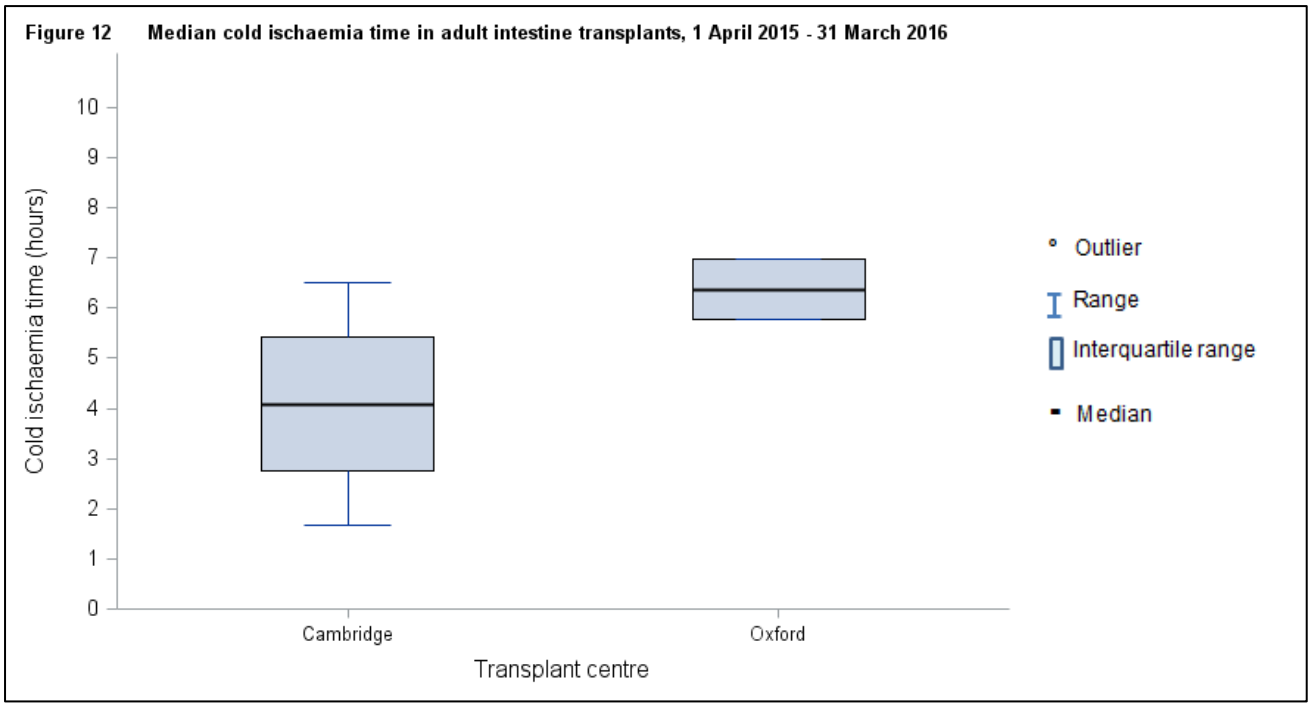
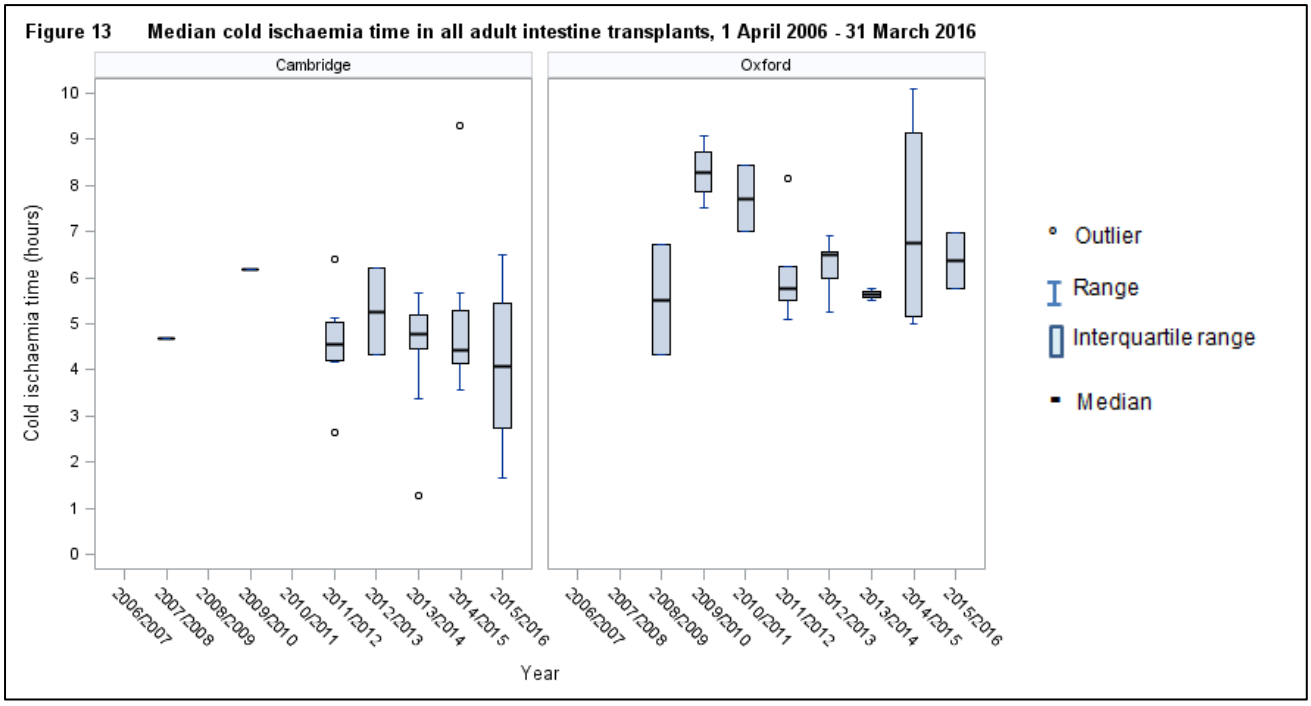


Figure 12 shows the median CITs in adult intestine transplants in 2015/2016 for each transplant centre, while **Figure 13** shows the same data but over the last 10 years. Note that prior to 2008/2009 Oxford did not perform any intestine transplants which means there are no boxplots presented for the first two years. All of these boxplots represent a small number of observations and, as shown in **Table 3**, a proportion of CITs have not been reported.





TRANSPLANT SURVIVAL – FIRST TRANSPLANT

Survival by transplant centre

Table 4 shows the 90-day patient survival rates for adult elective first intestine transplants between 1 April 2006 and 31 March 2016, overall and by centre. Of the 87 transplants of this kind in the time period, survival information was known for all 87 transplants. Of these, 87% of patients were alive at 90 days post-transplant (unadjusted).

Table 4 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre

Centre	Number of transplants	90-day survival (95% CI) Unadjusted	
Cambridge	56	89.3	(77.7-94.5)
Oxford	31	83.9	(65.1-92.4)
TOTAL	**87**	**87.3**	**(77.7-92.4)**

One- and five-year patient survival rates are shown in **Table 5** and **Table 6**, respectively. At one year post-transplant, 79% of transplanted patients were alive, while at five years post-transplant, the overall survival rate is 54%. Note that both centres perform different types of transplants and the next section (**Table 7**), therefore, presents a breakdown by centre and transplant type.

Table 5	One-year patient survival (%) for adult elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre		
Centre	**Number of transplants**	**1-year survival (95% CI) Unadjusted**	
Cambridge	56	80.8	(67.2-88.2)
Oxford	31	76.9	(56.7-88.2)
TOTAL	**87**	**79.4**	**(69.3-86.1)**

Table 6	Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre		
Centre	**Number of transplants**	**5-year survival (95% CI) Unadjusted**	
Cambridge	56	55.4	(35.7-71.4)
Oxford	31	49.8	(21.0-73.5)
TOTAL	**87**	**54.3**	**(39.9-67.2)**

Survival by transplant type

Table 7 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 7 Unadjusted patient survival (%) for adult elective first intestine transplants between 1 April 2006 and 31 March 2016, 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	32	81.3	(63.0-90.3)	73.5	(54.6-86.1)	35.4	(12.6-60.9)
Not including liver	24	100	-	90.5	(67.2-96.6)	76.6	(46.2-90.3)
Oxford							
Not including liver	31	83.9	(65.1-92.4)	76.9	(56.7-88.2)	49.8	(21.0-73.5)
TOTAL	**87**	**87.3**	**(77.7-92.4)**	**79.4**	**(69.3-86.1)**	**54.3**	**(39.9-67.2)**

PAEDIATRIC INTESTINE TRANSPLANTATION

PAEDIATRIC INTESTINE TRANSPLANTATION

TRANSPLANT LIST

Figure 14 shows the number of paediatric patients (aged<18 years) active and suspended on the intestine transplant list at 31 March of each year between 2007 and 2016. Year-end transplant list data are not available before 2007. The number of patients on the active transplant list increased each year from three in 2007 to 11 in 2009. It subsequently decreased until the number of patients reached a lowest value of four in 2013, which is the same as in 2016.

Figure 14 Paediatric patients on the intestine transplant list at 31 March

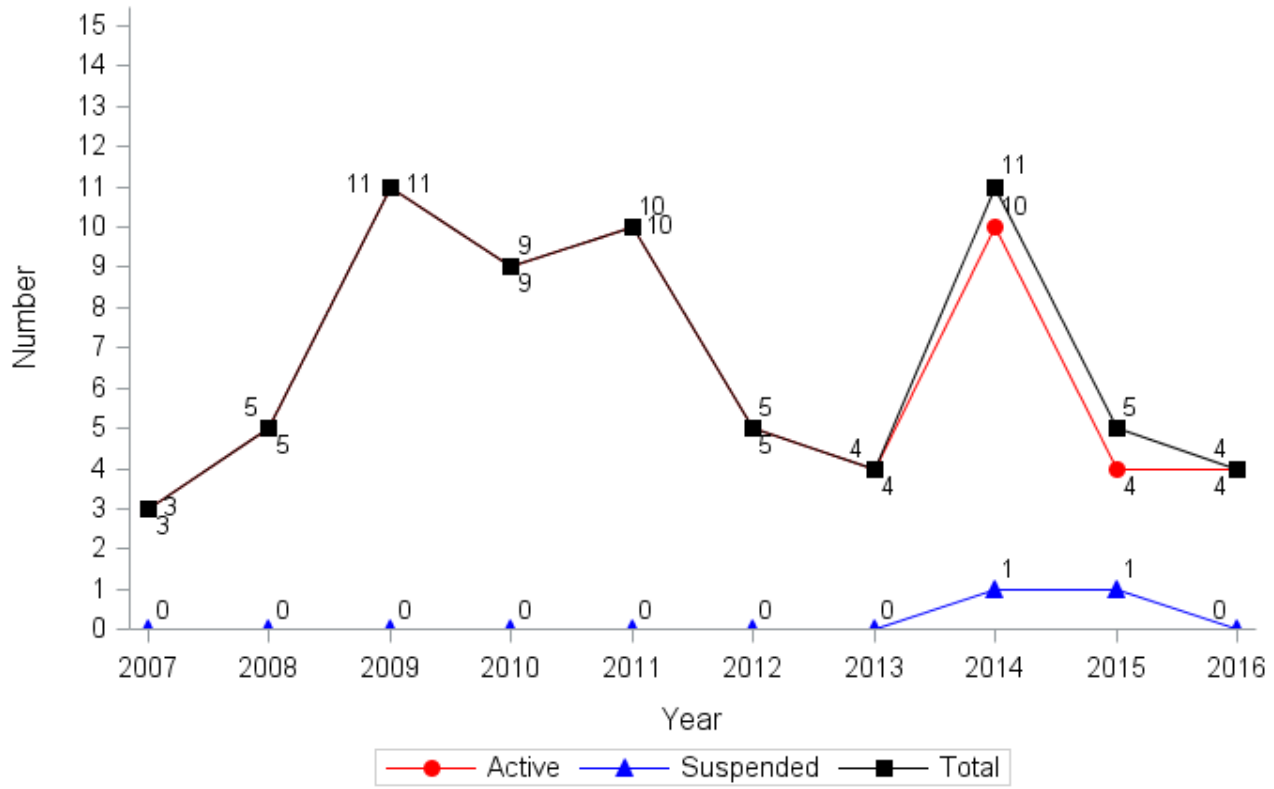
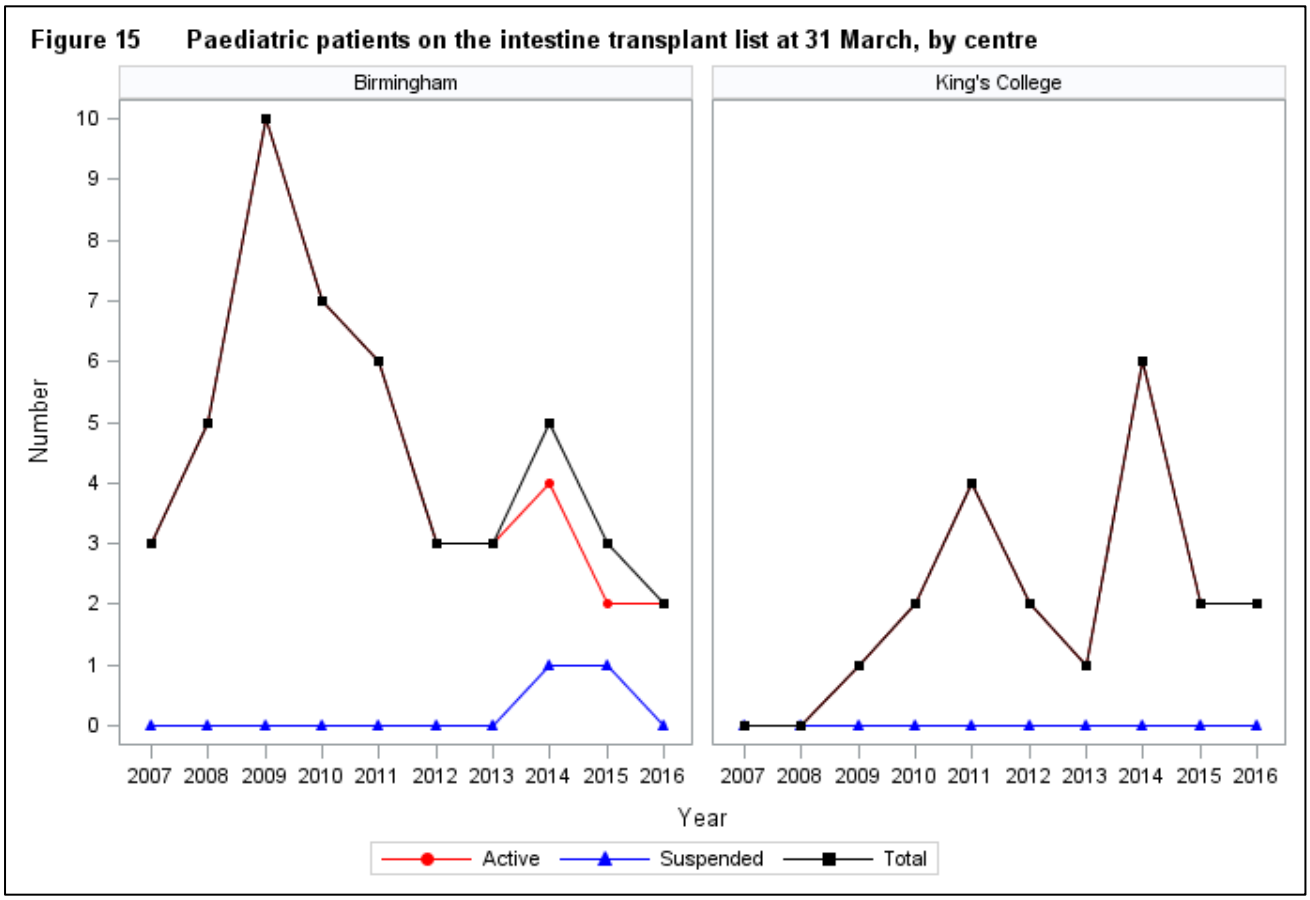


Figure 15 shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2007 and 2016, at each transplant centre. Until the last few years Birmingham had more patients on the active transplant list than King's College.



RESPONSE TO OFFERS

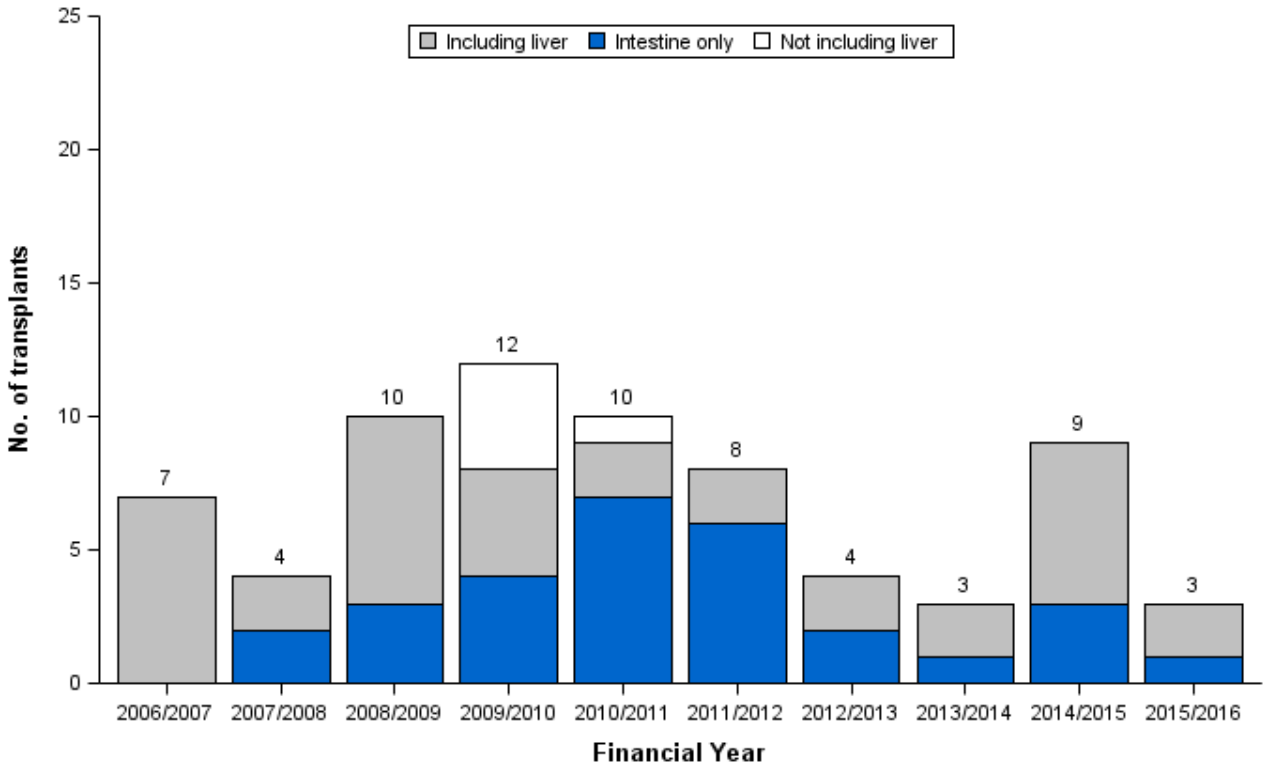
Between 1 April 2015 and 31 March 2016 Birmingham and King's College received offers from 74 and 80 donors, respectively, for intestine transplant patients at their centres. Their offer decline rates were 97% and 99% respectively. These rates are very high because the donor criteria for offering are quite broad and centres are very selective, particularly about the size of the donor.

TRANSPLANTS

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

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

Figure 16 Paediatric intestine transplants in the UK, 1 April 2006 - 31 March 2016



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

Figure 17 shows the number of paediatric intestine transplants performed in 2015/2016, by centre and transplant type. The only transplant performed at King's College were liver and intestine combined while half of transplants at Birmingham were intestine only and the other half were liver and intestine combined.

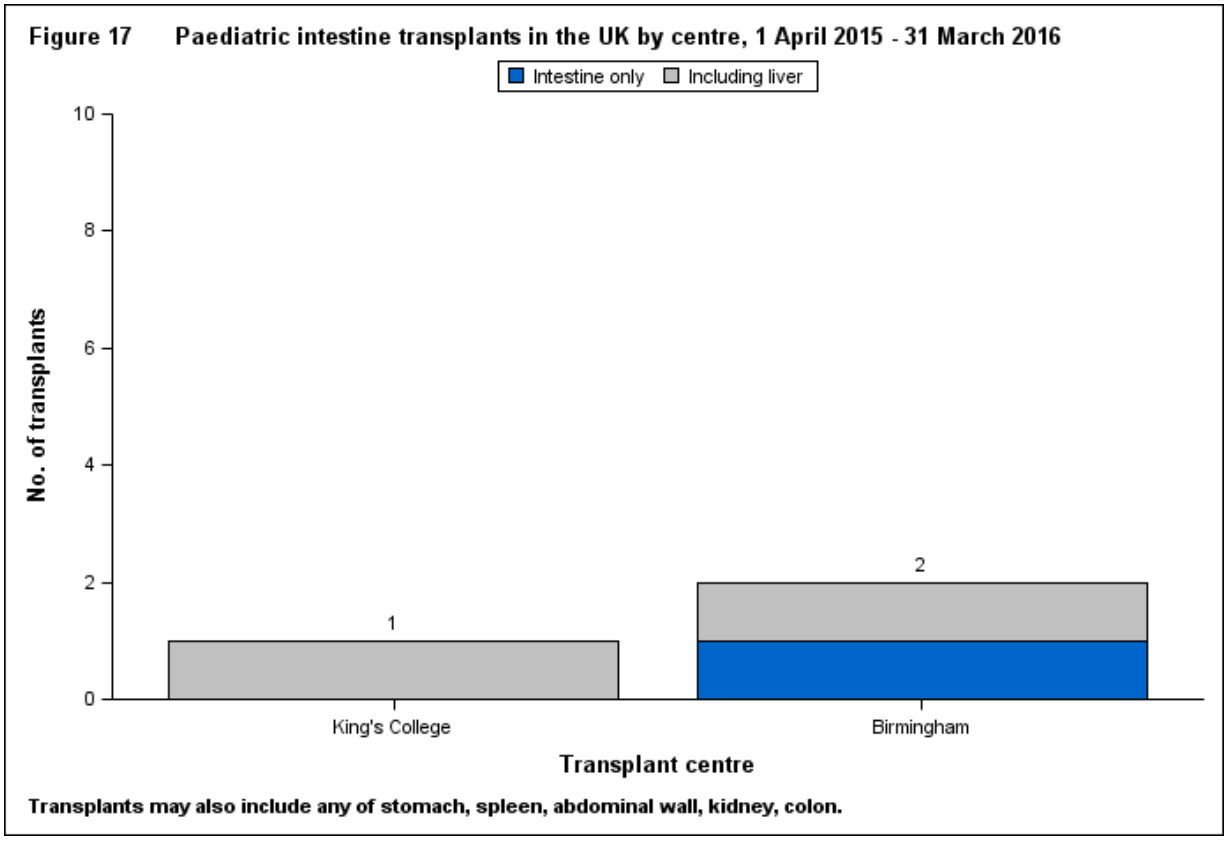
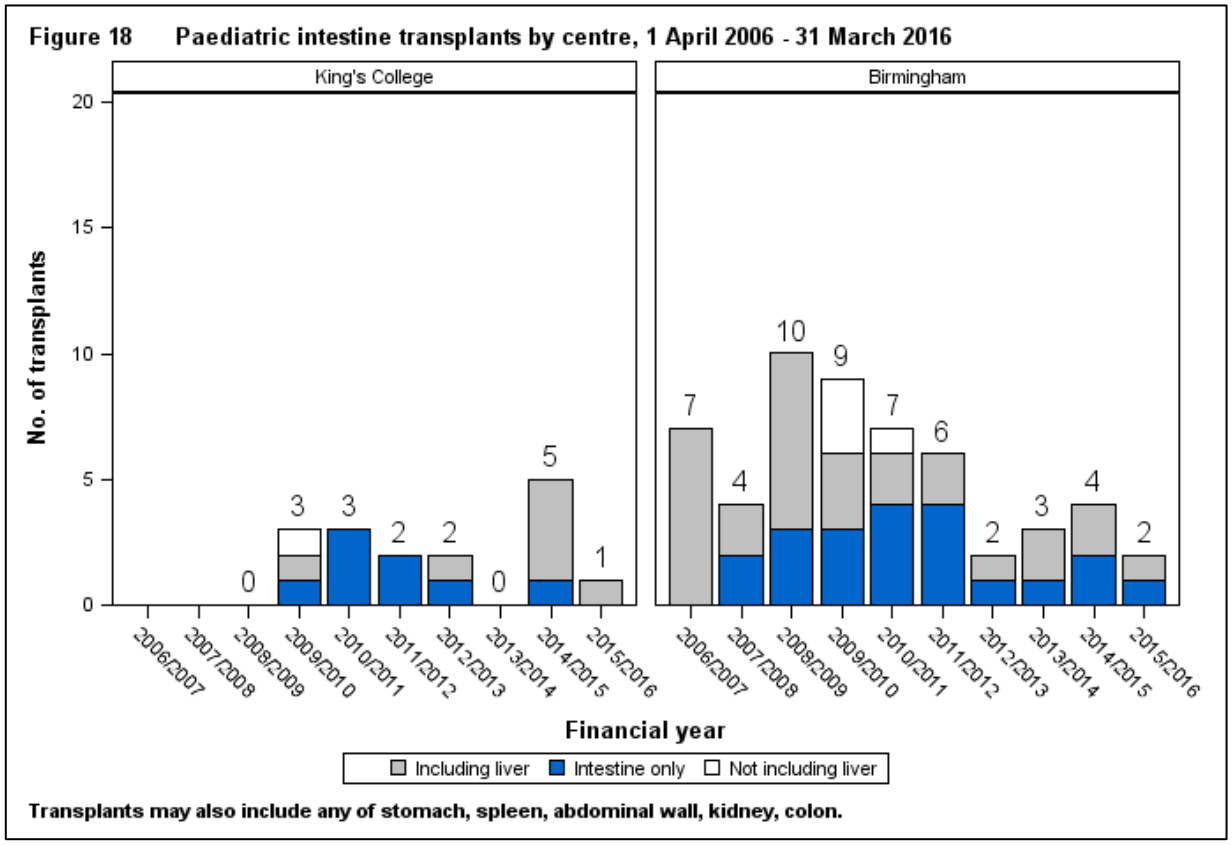


Figure 18 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and type of transplant. Note that King's College joined the programme in 2008 but their first intestine transplants were performed in 2009/2010.



The demographic characteristics of 70 paediatric elective intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 9.** 54% 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 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2006 - 31 March 2016

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Number		54	16	**70 (100)**
Recipient sex	Male	30 (56)	8 (50)	**38 (54)**
	Female	24 (44)	8 (50)	**32 (46)**
Recipient ethnicity group	White	44 (81)	12 (75)	**56 (80)**
	Other	9 (17)	4 (25)	**13 (19)**
	Not reported	1 (2)	0	**1 (1)**
Indication group	Short bowel syndrome	27 (50)	5 (31)	**32 (46)**
	Motility disorders	6 (11)	6 (38)	**12 (17)**
	Primary mucosal disorders	6 (11)	1 (6)	**7 (10)**
	Liver disease	4 (7)	0	**4 (6)**
	Other/not reported	8 (15)	2 (13)	**10 (14)**
	Retransplant	3 (6)	2 (13)	**5 (7)**
Patient location	Out-patient	41 (76)	12 (75)	**53 (76)**
	Ward	3 (6)	3 (19)	**6 (9)**
	ICU/HDU	0	1 (6)	**1 (1)**
	Not reported	10 (19)	0	**10 (14)**
Pre-transplant renal support	No	48 (89)	15 (94)	**63 (90)**
	Yes	0	1 (6)	**1 (1)**
	Not reported	6 (11)	0	**6 (9)**
Previous abdominal surgery	No	7 (13)	1 (6)	**8 (11)**
	Yes	40 (74)	15 (94)	**55 (79)**
	Not reported	7 (13)	0	**7 (10)**
Life style activity	Normal	3 (6)	1 (6)	**4 (6)**
	Restricted	9 (17)	5 (31)	**14 (20)**
	Self-care	4 (7)	0	**4 (6)**
	Reliant	3 (6)	2 (13)	**5 (7)**
	Aged five years or less	25 (46)	8 (50)	**33 (47)**
	Not reported	10 (19)	0	**10 (14)**
Restricted venous access at registration	No	12 (22)	9 (56)	**21 (30)**
	Yes	23 (43)	5 (31)	**28 (40)**
	Not reported	19 (35)	2 (13)	**21 (30)**
Recipient age (years)	Median (IQR)	3 (1,6)	5 (4,8)	**4 (1,6)**
Recipient BMI (kg/m^2)	Median (IQR)	17 (16,19)	18 (17,19)	**18 (16,19)**
	Not reported	45	0	**45**

Table 9	**Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2006 - 31 March 2016**			
		Birmingham N (%)	King's College N (%)	**TOTAL** **N (%)**
Serum bilirubin (umol/l)	Median (IQR)	29 (8,134)	8 (5,11)	**11 (7,96)**
	Not reported	9	0	**9**
Time on list (days)	Median (IQR)	130 (57,227)	178 (105,369)	**149 (62,259)**
Donor sex	Male	28 (52)	12 (75)	**40 (57)**
	Female	26 (48)	4 (25)	**30 (43)**
Donor ethnicity group	White	43 (80)	12 (75)	**55 (79)**
	Other	6 (11)	1 (6)	**7 (10)**
	Not reported	5 (9)	3 (19)	**8 (11)**
Donor cause of death group	Stroke	26 (48)	10 (63)	**36 (51)**
	Trauma	13 (24)	3 (19)	**16 (23)**
	Other	15 (28)	3 (19)	**18 (26)**
Donor history of diabetes	No	46 (85)	14 (88)	**60 (86)**
	Yes	1 (2)	0	**1 (1)**
	Not reported	7 (13)	2 (13)	**9 (13)**
Donor age (years)	Median (IQR)	7 (3,13)	4 (1,8)	**6 (2,12)**
Donor BMI (kg/m^2)	Median (IQR)	16 (15,19)	15 (13,18)	**16 (14,19)**
Transplant type	Intestine only	21 (39)	8 (50)	**29 (41)**
	Including liver	29 (54)	7 (44)	**36 (51)**
	Not including liver	4 (7)	1 (6)	**5 (7)**
ABO match	Identical	45 (83)	14 (88)	**59 (84)**
	Compatible	9 (17)	2 (13)	**11 (16)**
Cold ischaemic time (hours)	Median (IQR)	6.5 (5.8,7.3)	8.0 (6.4,8.9)	**6.7 (5.9,7.8)**
	Not reported	9	4	**13**

Figure 19 shows boxplots of the CITs of paediatric intestine transplants over the last 10 years. The line inside the box indicates the median value. The median CIT in paediatric transplants has remained reasonably stable over the time period at values between 5.7 and 7.5 hours.

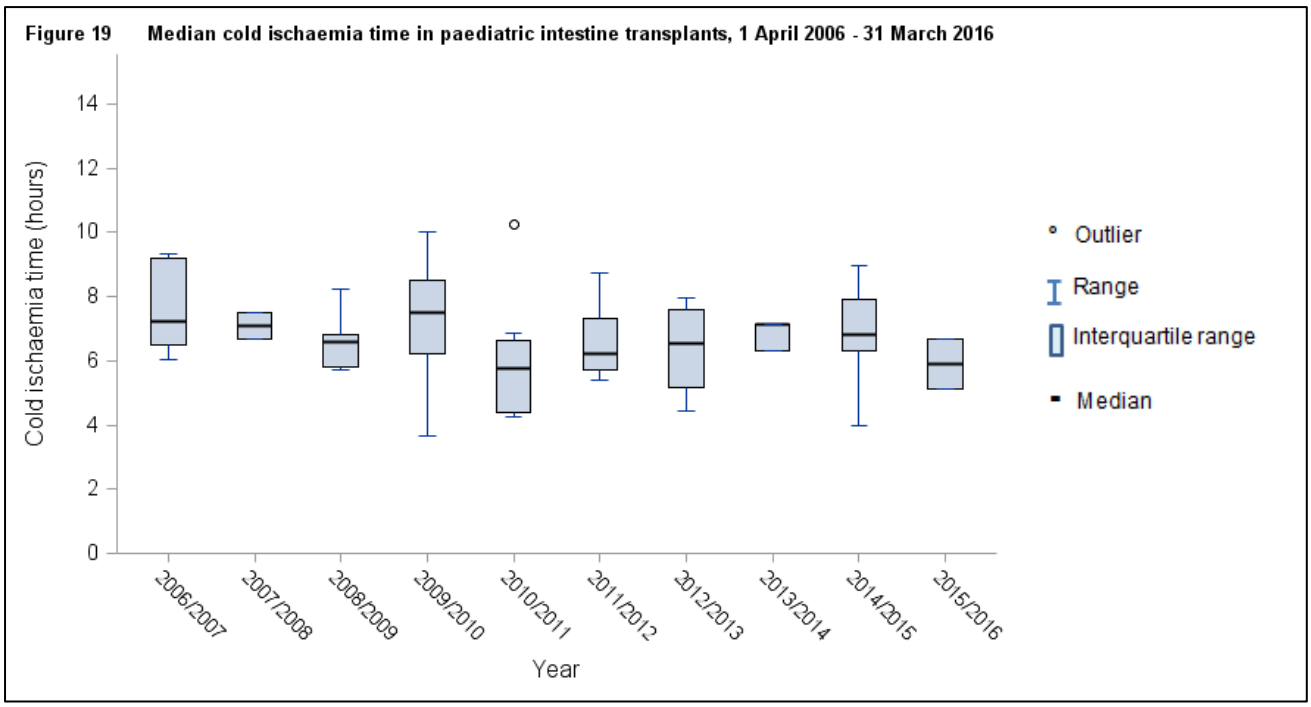
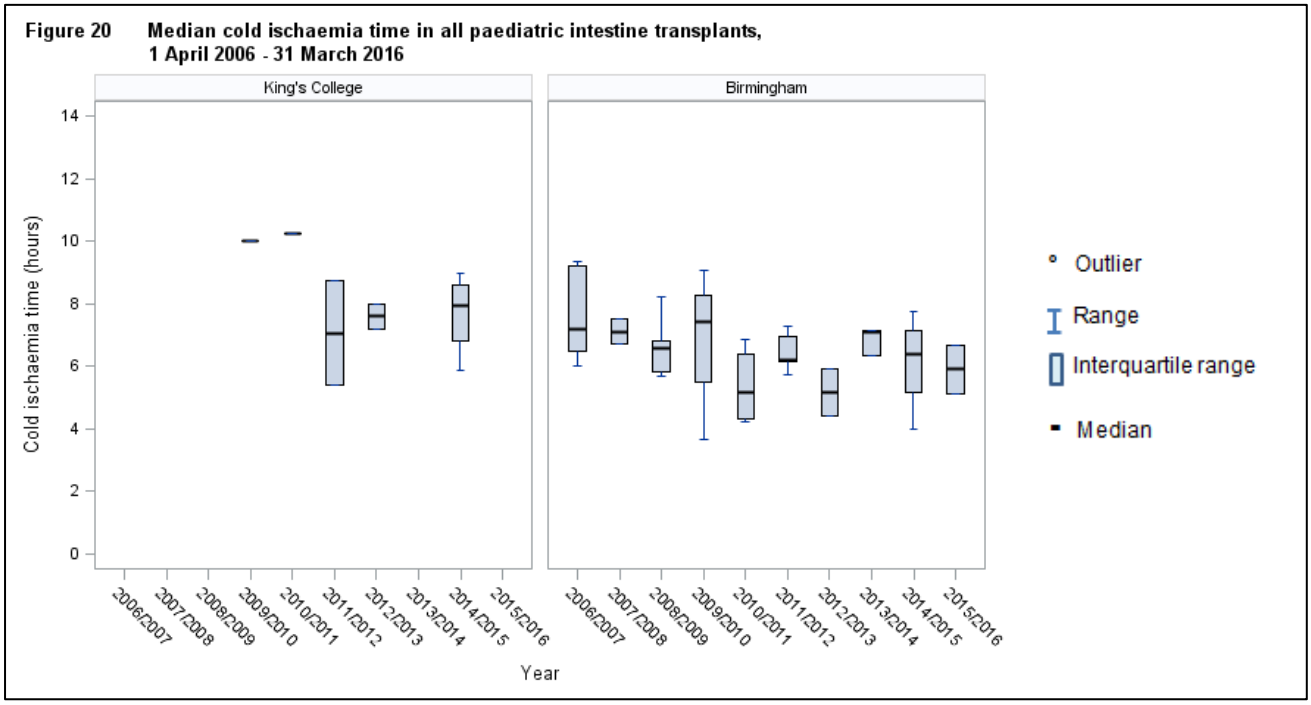


Figure 20 shows the median CITs in paediatric intestine transplants by centre over the last 10 years. Note that prior to 2009/2010 King's College did not perform any intestine transplants which means there are no boxplots presented for the first three years. All of these boxplots represent a small number of observations and, as shown in **Table 9**, a proportion of CITs have not been reported.



TRANSPLANT SURVIVAL – FIRST TRANSPLANT

Survival by transplant centre

Table 10 shows the 90-day unadjusted patient survival rates for paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, overall and by centre. There were 62 transplants of this kind in the time period and survival information was known in all 62 cases; of these, 94% of patients were alive 90 days post-transplant.

Table 10 Unadjusted 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre

Centre	Number of transplants	90-day survival (95% CI)	
Birmingham	48	91.7	(79.8-96.6)
King's College	14	100	-
TOTAL	**62**	**93.5**	**(84.0-96.6)**

Unadjusted one- and five-year patient survival rates are shown in **Table 11** and **Table 12**, respectively. One year post-transplant, 85% of transplanted patients are alive while, five years post-transplant, the survival rate is 60%. Note that the number of transplants at King's College is small and survival rates for this centre must be taken only as a guide.

Table 11 Unadjusted one-year patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre

Centre	Number of transplants	1-year survival (95% CI)	
Birmingham	48	83.3	(69.3-90.3)
King's College	14	92.9	(58.8-98.7)
TOTAL	**62**	**85.4**	**(73.5-92.4)**

Table 12 Unadjusted five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant centre

Centre	Number of transplants	5-year survival (95% CI)	
Birmingham	48	54.4	(37.8-67.2)
King's College	14	84.4	(50.4-96.6)
TOTAL	**62**	**60.3**	**(46.2-71.4)**

Survival by transplant type

Table 13, Table 14 and **Table 15** show 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 13 Unadjusted 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI)	
Birmingham			
Including liver	25	84.0	(63.0-94.5)
Not including liver	23	100.0	-
King's College			
Including liver	6[1]	-	-
Not including liver	8[1]	-	-
TOTAL	**62**	**93.5**	**(84.0-96.6)**

Table 14 Unadjusted one-year patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant type

Transplant type	Number of transplants	1-year survival (95% CI)	
Birmingham			
Including liver	25	75.8	(54.6-88.2)
Not including liver	23	91.3	(69.3-98.7)
King's College			
Including liver	6[1]	-	-
Not including liver	8[1]	-	-
TOTAL	**62**	**85.4**	**(73.5-92.4)**

Table 15 Unadjusted five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2006 and 31 March 2016, by transplant type

Transplant type	Number of transplants	5-year survival (95% CI)	
Birmingham			
Including liver	25	42.1	(23.1-60.9)
Not including liver	23	68.5	(42.0-84.0)
King's College			
Including liver	6[1]	-	-
Not including liver	8[1]	-	-
TOTAL	**62**	**60.3**	**(46.2-71.4)**

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

FORM RETURN RATES

FORM RETURN RATES

Form return rates are reported in **Table 16** and **Table 17** for adult and paediatric centres, respectively. The forms included are the intestinal transplant record form and the three month and annual intestinal transplant follow-up forms that are reported to the UK Transplant Registry database. The tables show the number of forms issued between 1 January 2015 and 31 December 2015, for patients at each centre, and the percentage of forms that had been returned at time of analysis (27 July 2016). Annual follow-up forms are broken down into those issued at one year post-transplant and "lifetime follow-up", which is two years or longer.

Table 16 **Form return rates, by adult transplant centre, for forms issued between 1 January 2015 and 31 December 2015**

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	8	100	9	100	7	100	23	100
Oxford	3	100	4	100	4	100	12	83
Total	**11**	**100**	**13**	**100**	**11**	**100**	**35**	**94**

Table 17 **Form return rates, by paediatric transplant centre, for forms issued between 1 January 2015 and 31 December 2015**

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	3	100	6	100	10	100	44	100
King's College	1	100	1	100	3	100	8	88
Total	**4**	**100**	**7**	**100**	**13**	**100**	**52**	**98**

APPENDIX

APPENDIX

DATA

Data were obtained from the UK Transplant Registry for the 10 year time period, 1 April 2006 to 31 March 2016. NHS Group 2 transplants have been included while liver-only transplants because of intestinal failure have been excluded. Three transplants performed at Cambridge between 2007 and 2013 that included a short length of donor jejunum for recipient anatomical reasons but not because of intestinal failure have been excluded.

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

Table A1 Number of adult intestine transplants, by transplant centre and urgency status, 1 April 2006 to 31 March 2016

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Cambridge	60	6	56	4
Oxford	32	0	31	0
TOTAL	**92**	**6**	**87**	**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 2006 to 31 March 2016

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Birmingham	54	0	48	0
King's College	16	0	14	0
TOTAL	**70**	**0**	**62**	**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 2012 and 31 March 2015 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, 11 July 2016, 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 2015 to 31 March 2016.

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.

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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