



**Blood and Transplant**

**ANNUAL REPORT ON  
INTESTINE TRANSPLANTATION**

**REPORT FOR 2017/2018  
(1 APRIL 2008 – 31 MARCH 2018)**

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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 2008 to 31 March 2018. 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 2018, there were six patients on the UK active intestine **transplant list**, which represents a 50% decrease compared to the previous year. Of those patients registered onto the transplant list in a recent two year period (1 April 2014 – 31 March 2016), 84% had received a transplant two years post-registration, while 8% died, 3% were removed and 5% were still waiting.
- **Median waiting time** to intestine transplant for registrations between 1 April 2014 and 31 March 2017 was 86 days, or 2.8 months. This was calculated for adult and paediatric patients combined.
- There were 196 intestine **transplants** performed in the UK over the 10 year period. Sixteen of these were re-transplants (8%) and 37% of all transplants were in paediatric recipients while 63% were in adult recipients.
- 2017/2018 was a particularly active year with 26 **transplants** performed nationally; 73% more than in 2016/2017 and joint highest with 2013/2014. By age group, 18 adult transplants were performed, which was 64% more than 2016/2017, and 8 paediatric transplants were performed, which was 100% more than 2016/2017.
- The national rates of **survival** ([unadjusted](#)) after first intestine transplantation for elective **adult patients** were estimated at 90%, 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 95%, 86% and 59% at 90 days, one and five years post-transplant, respectively.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Intestine Transplantation 2017/2018, NHS Blood and Transplant*

# **INTRODUCTION**



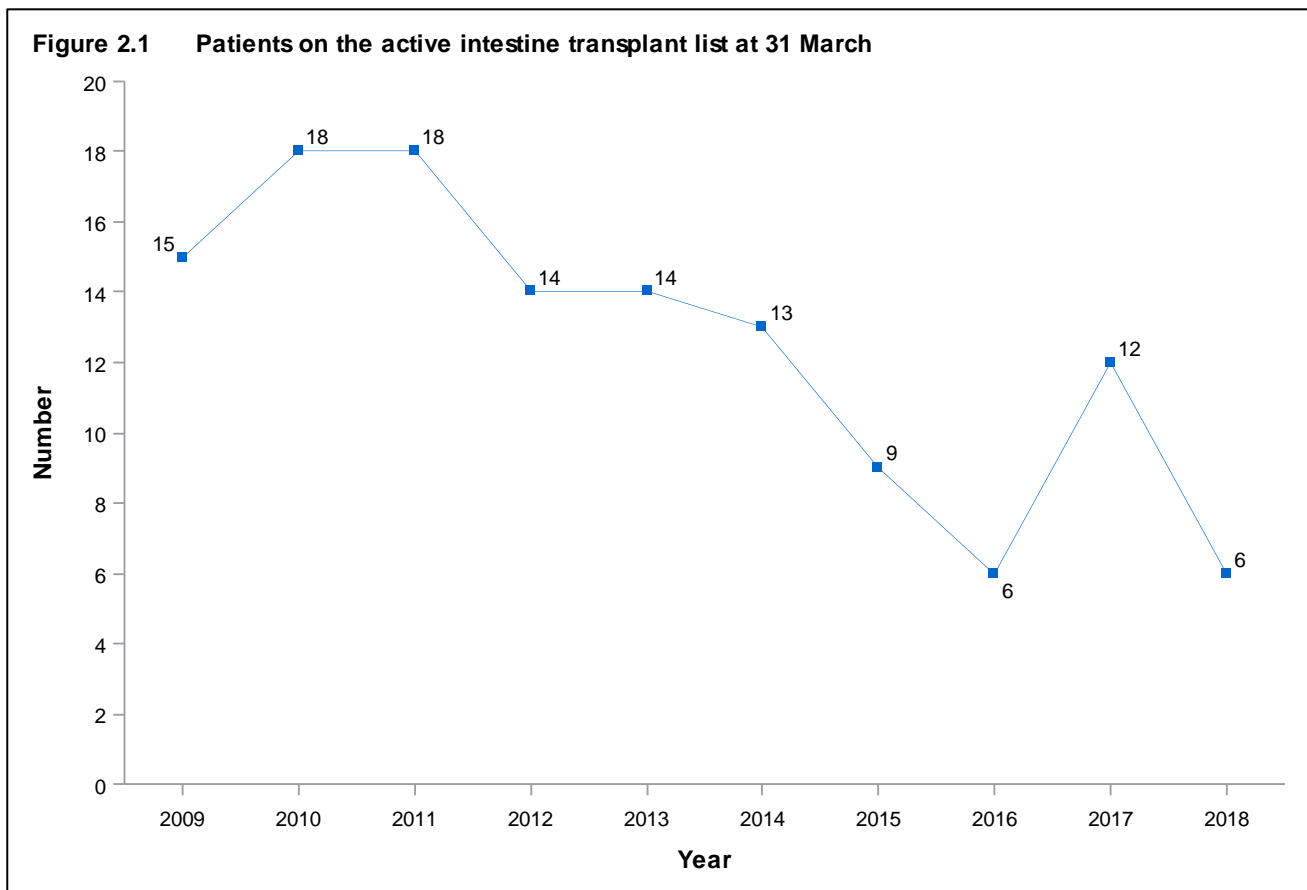
# INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2008 and 31 March 2018, 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.

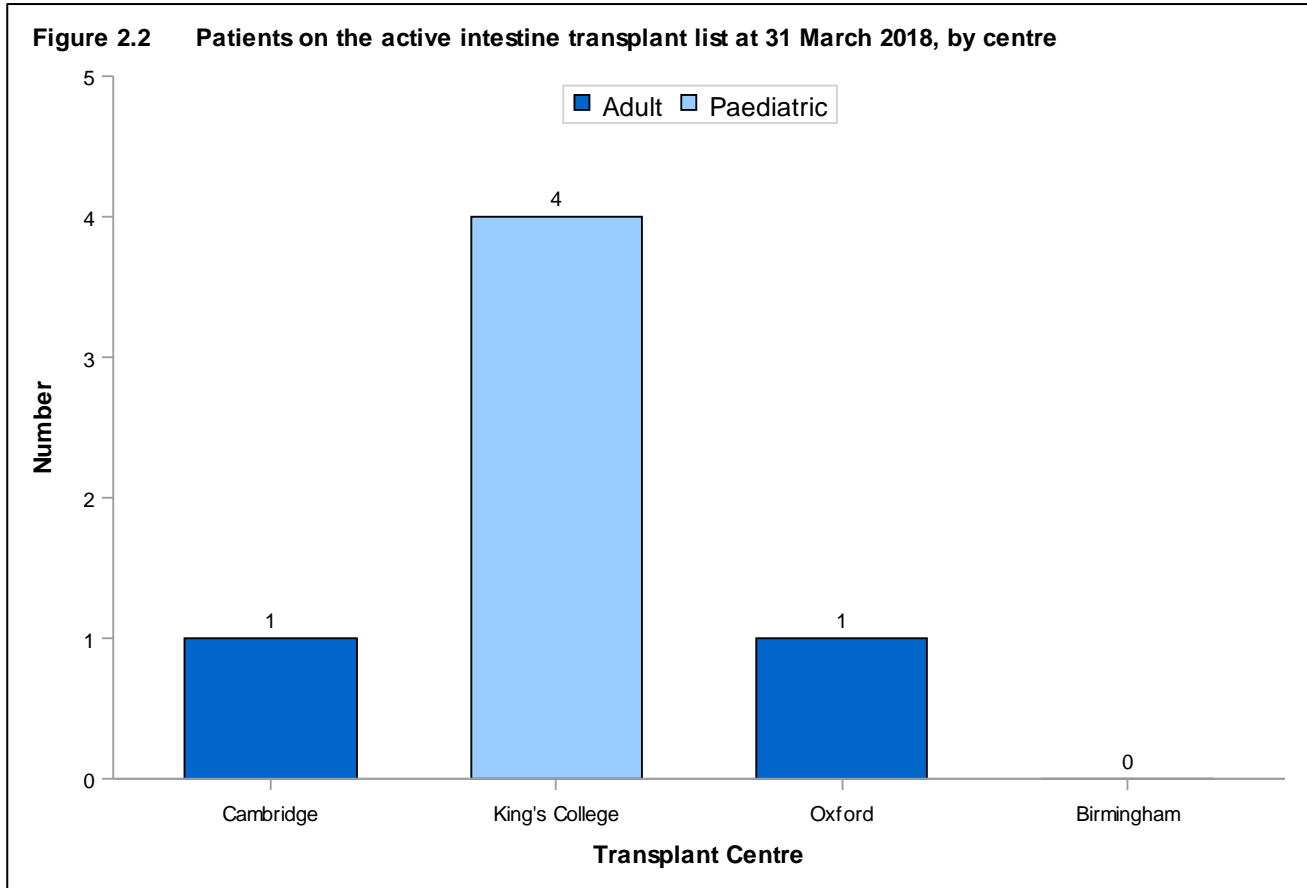
The report is divided into two main sections; one for adult recipients (aged  $\geq 18$  years) and one for paediatric recipients (aged  $< 18$  years). Any transplants carried out at Cambridge or Oxford in patients aged less than 18 are included in the adult section, and any transplants carried out at Birmingham or King’s College Hospital in patients 18 or over are included in the paediatric section. 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 2009 and 2018. The number of patients waiting for a transplant has generally fallen over the past ten years, with a peak of 18 in 2010 and 2011. As at 31 March 2018, there were six patients on the national intestine transplant list.



**Figure 2.2** shows the number of adult and paediatric patients on the [active transplant list](#) at 31 March 2018 by centre. In total, there were two adult and four paediatric patients, with no patients active at Birmingham. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown later in the report, in **Figure 3.2** and **Figure 7.2**, respectively.

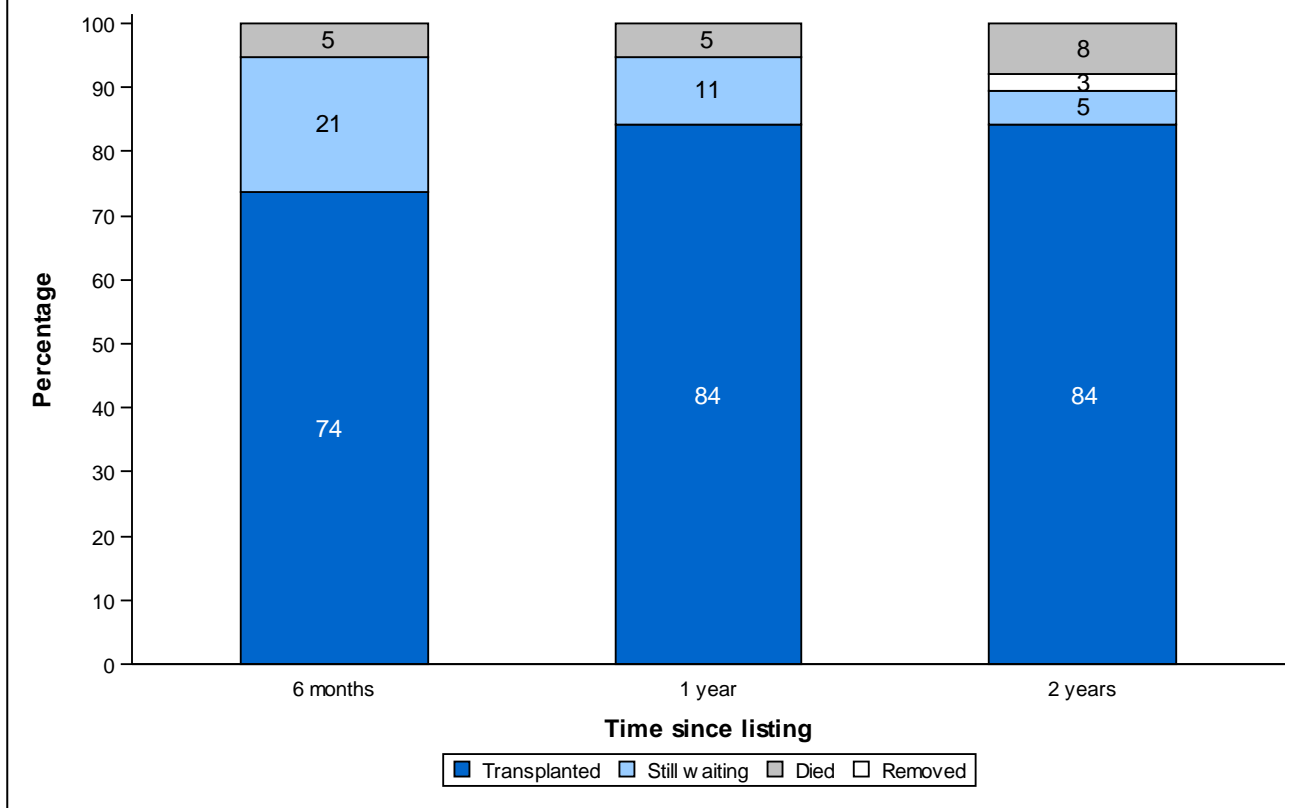


### 2.1.1 Post-registration outcomes, 1 April 2014 – 31 March 2016

The registration outcomes of patients listed between 1 April 2014 and 31 March 2016 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 84% of patients had received a transplant, 8% had died on the list, 5% were still waiting, and 3% had been removed.



**Figure 2.3 Post-registration outcome for 38 elective registrations for an intestine transplant made in the UK, 1 April 2014 - 31 March 2016**



### 2.1.2 Median waiting time to transplant, 1 April 2014 – 31 March 2017

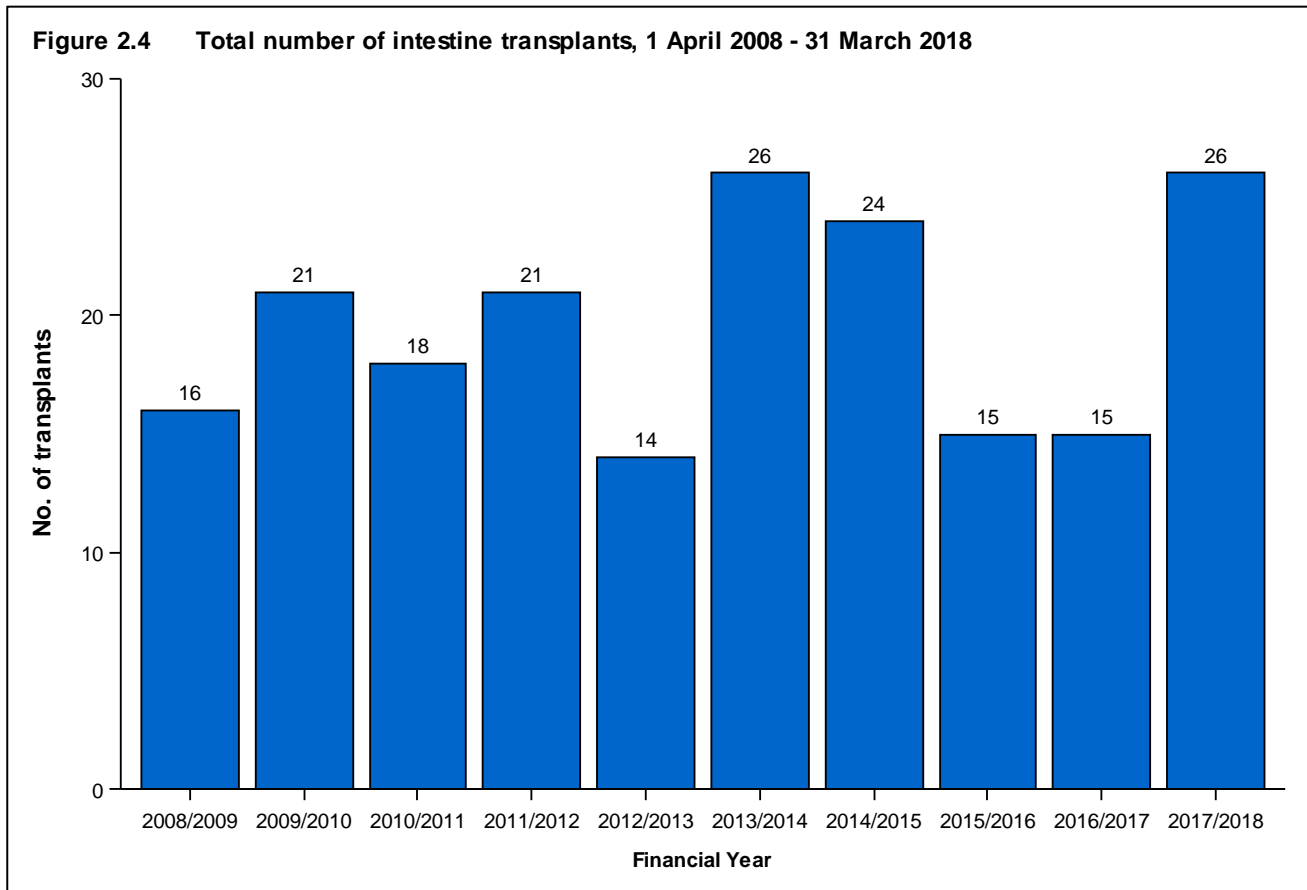
Table 2.1 shows [median waiting time](#) to [elective](#) intestine transplant by registration type (including re-registrations) for adult and paediatric patients combined. Overall, on average, patients waited 86 days (approximately three months) for a transplant. The average wait is longer for patients who require a liver as part of their intestine graft and this was found to be a statistically significant difference at a 5% significance level.

<b>Table 2.1 Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2014 - 31 March 2017</b>			
<b>Registration type</b>	<b>Number of patients registered</b>	<b>Waiting time (days)</b>	
		<b>Median</b>	<b>95% Confidence interval</b>
Intestine only <sup>1</sup>	8	59	25 – 93
Liver, intestine and pancreas <sup>1</sup>	34	161	115 – 207
Intestine and pancreas <sup>1</sup>	18	18	0 – 64
<b>TOTAL</b>	<b>60</b>	<b>86</b>	<b>42 – 130</b>

<sup>1</sup> May also include any of; stomach, spleen, abdominal wall, kidney, colon  
 Note: any periods of suspension from the list are included in the calculation of median waiting times

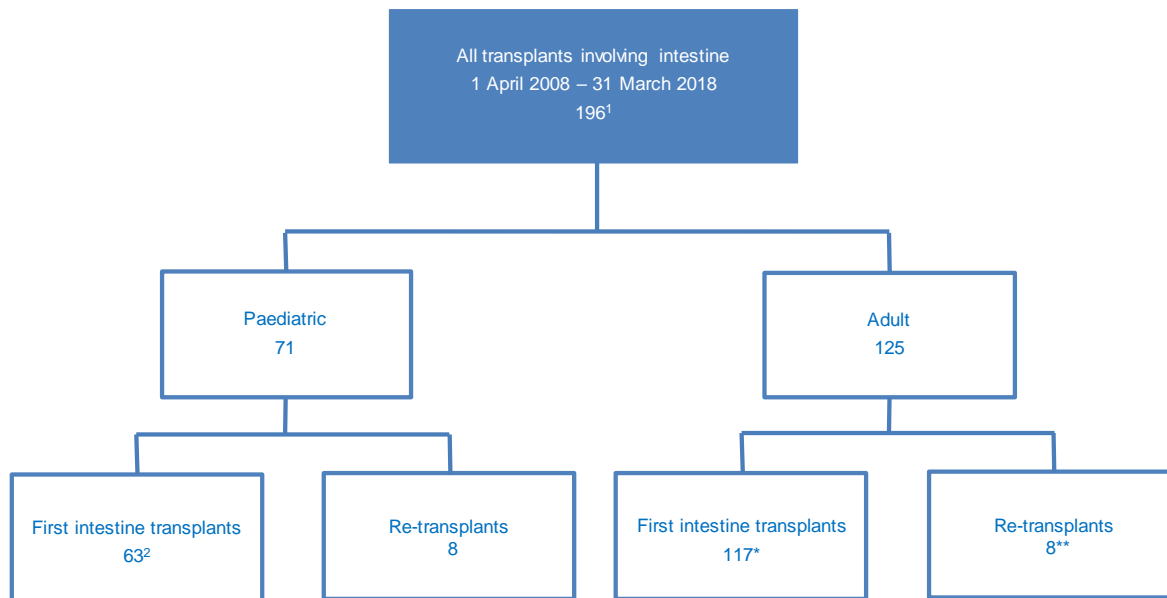
## 2.2 Transplants

**Figure 2.4** shows the number of intestine transplants performed each year in the last 10 years. Currently in the UK, intestine transplants are performed from donors after brain death ([DBD](#)), however, there has been one transplant in 2017/2018 performed using a living donor. The total number of transplants over the decade was 196, with annual figures fluctuating between 14 and 26. 2017/2018 was a relatively active year.



**Figure 2.5** details the 196 intestine transplants performed in the UK in the 10 year period. Of these, 72 (37%) were in paediatric patients and 124 (63%) 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 2008 to 31 March 2018**



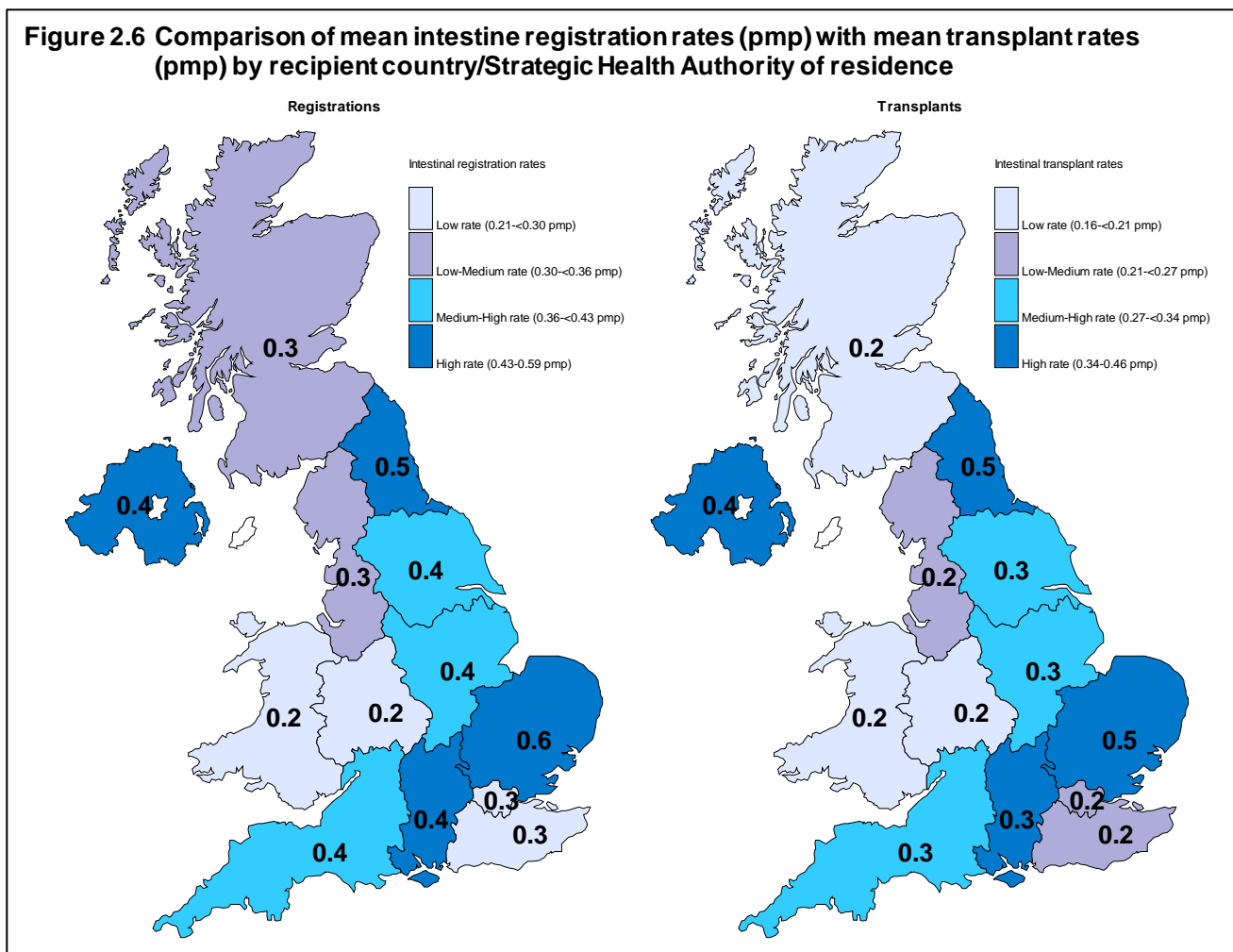
<sup>1</sup> Excludes one abdominal wall only transplant (October 2016)  
<sup>2</sup> Includes one living donor liver and bowel transplant (June 2017)

\* Five 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 intestine transplant list per million population (pmp) based on registrations between 1 April 2008 and 31 March 2018 compared with the annual average intestine 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.



<b>Table 2.2 Annual mean intestine registration and transplant rates per million population (pmp) in the UK, 1 April 2008 – 31 March 2018, by Country/Strategic Health Authority</b>				
<b>Country/ Strategic Health Authority</b>	<b>Mean no. of registrations (pmp)</b>		<b>Mean no. of transplants (pmp)</b>	
North East	1.1	(0.4)	1.1	(0.4)
North West	2.2	(0.3)	1.6	(0.2)
Yorkshire and The Humber	2.2	(0.4)	1.6	(0.3)
<b>North of England</b>	<b>5.5</b>	<b>(0.4)</b>	<b>4.3</b>	<b>(0.3)</b>
East Midlands	1.8	(0.4)	1.4	(0.3)
West Midlands	1.2	(0.2)	1.2	(0.2)
East of England	3.4	(0.6)	2.6	(0.4)
<b>Midlands and East</b>	<b>6.4</b>	<b>(0.4)</b>	<b>5.2</b>	<b>(0.3)</b>
<b>London</b>	<b>2.6</b>	<b>(0.3)</b>	<b>2.1</b>	<b>(0.2)</b>
South East Coast	1.3	(0.3)	0.9	(0.2)
South Central	1.8	(0.4)	1.4	(0.3)
South West	1.9	(0.3)	1.4	(0.3)
<b>South of England</b>	<b>5.0</b>	<b>(0.3)</b>	<b>3.7</b>	<b>(0.3)</b>
<b>England</b>	<b>19.5</b>	<b>(0.4)</b>	<b>15.3</b>	<b>(0.3)</b>
<b>Isle of Man</b>	<b>0.1</b>	<b>(1.3)</b>	<b>0.1</b>	<b>(1.3)</b>
<b>Channel Islands</b>	<b>0</b>	<b>(0.0)</b>	<b>0</b>	<b>(0.0)</b>
<b>Wales</b>	<b>0.7</b>	<b>(0.2)</b>	<b>0.5</b>	<b>(0.2)</b>
<b>Scotland</b>	<b>1.7</b>	<b>(0.3)</b>	<b>1</b>	<b>(0.2)</b>
<b>Northern Ireland</b>	<b>0.8</b>	<b>(0.4)</b>	<b>0.6</b>	<b>(0.3)</b>
<b>TOTAL</b>	<b>23.2<sup>1</sup></b>	<b>(0.4)</b>	<b>17.8<sup>2</sup></b>	<b>(0.3)</b>

<sup>1</sup> Registrations include 4 recipients whose postcode was unknown and excludes 2 recipients who reside in the Republic of Ireland and 5 recipients who reside overseas

<sup>2</sup> Transplants include 3 recipients whose postcode was unknown and excludes 1 recipient who reside in the Republic of Ireland and 4 recipients who reside overseas

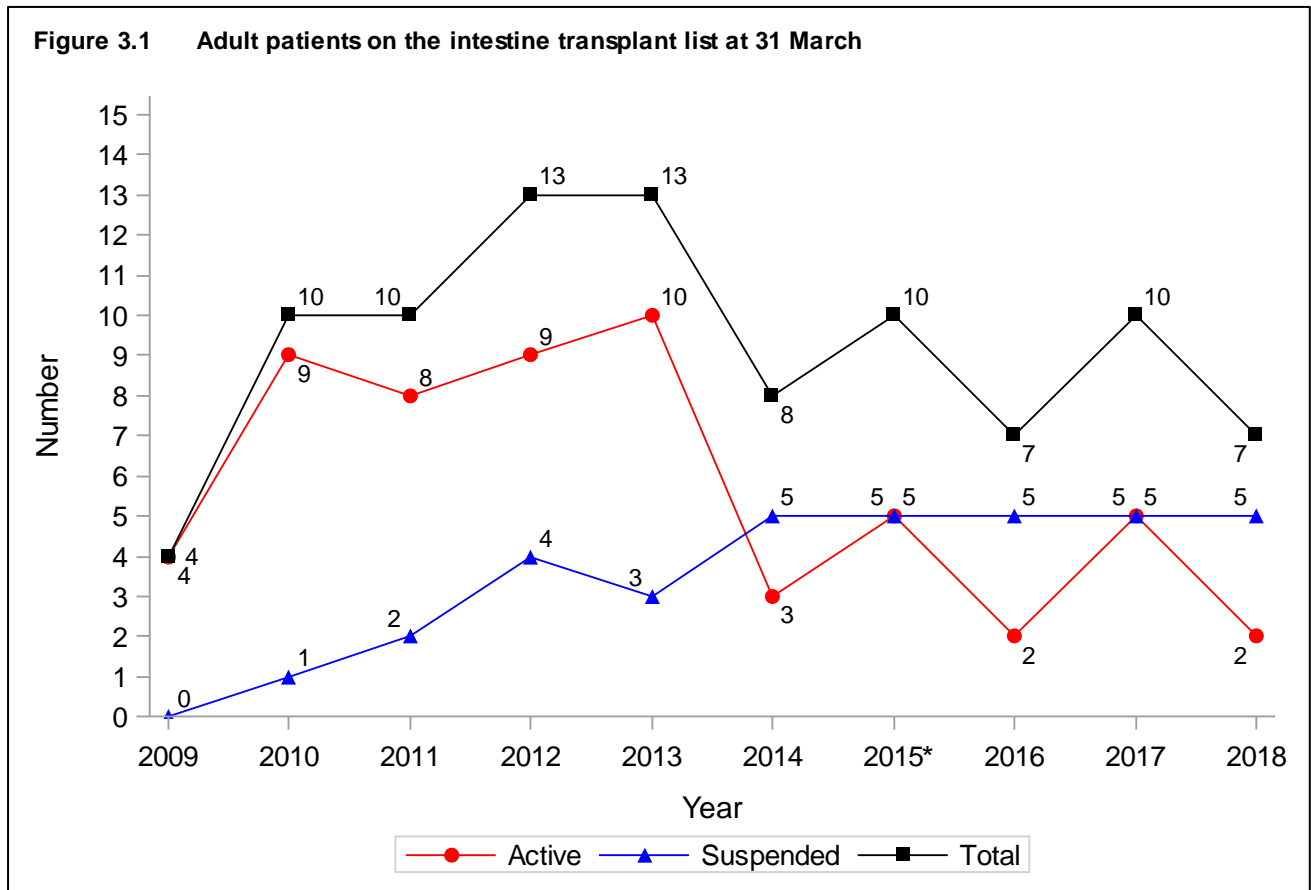
# **ADULT INTESTINE TRANSPLANTATION**



### 3. Transplant list

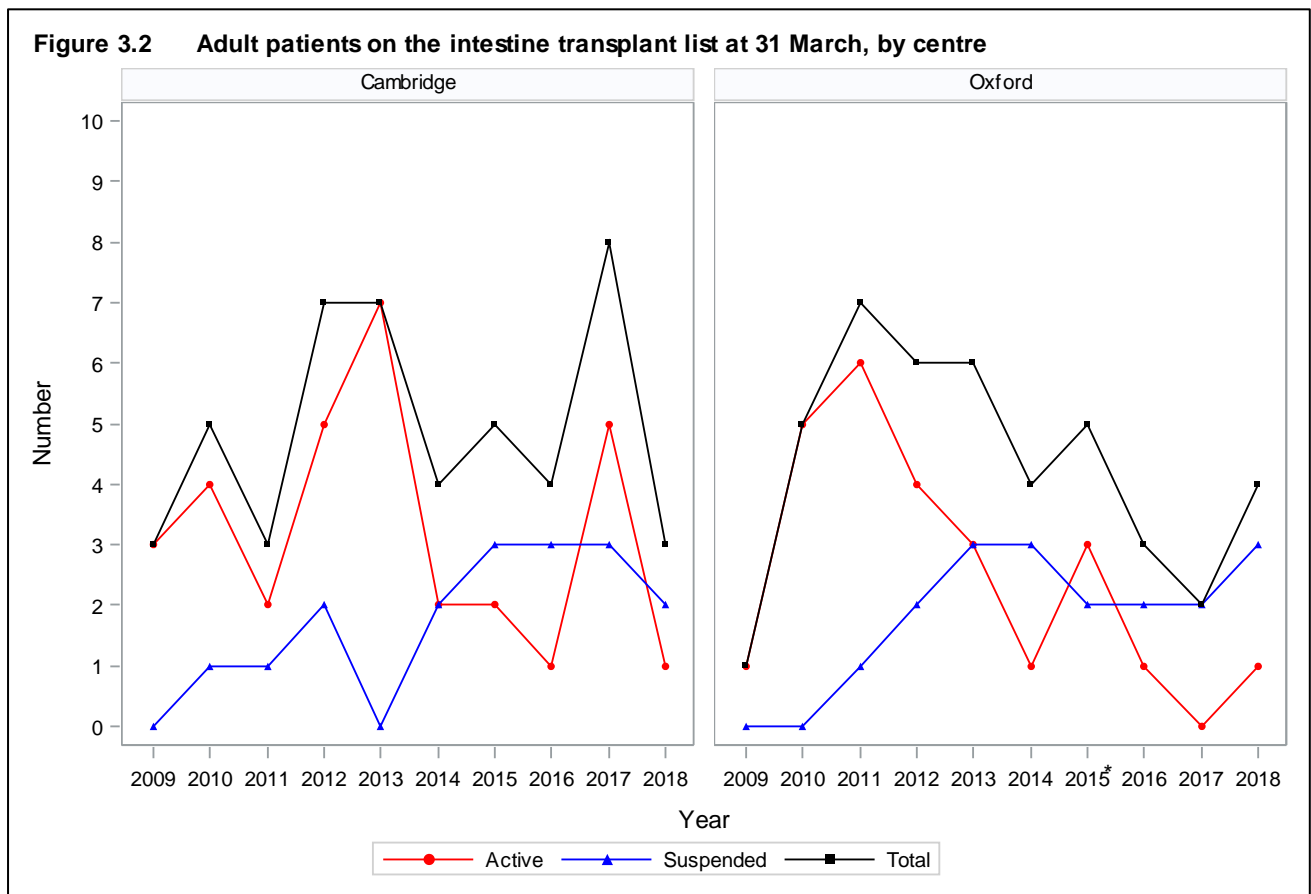
#### 3.1 Adult intestine transplant list as at 31 March, 2009 – 2018

Figure 3.1 shows the number of adult patients active or suspended on the intestine transplant list at 31 March of each year between 2009 and 2018. The number of patients on the [active intestine transplant list](#) increased between 2009 and 2013, when it reached a peak of 10, but in recent years it has fallen and was 2 in 2018.



\* 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 2009 and 2018, at each transplant centre. Cambridge had generally more adult patients on the national [active transplant list](#) than Oxford.



\* Excludes one patient registered for abdominal wall only

The demographic characteristics of 152 adult intestine transplant recipient registrations in the 10 year period are shown by centre and overall in **Table 3.1**. Nationally, 51% of patients were male and the [median](#) age was 43 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 21 kg/m<sup>2</sup>. 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 2008 - 31 March 2018**

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of registrations		101 (100)	51 (100)	<b>152 (100)</b>
Number of patients		87	48	<b>135</b>
Registration type	Elective	94 (93)	51 (100)	<b>145 (95)</b>
	Super-urgent	7 (7)	0	<b>7 (5)</b>
Transplant type required	Intestine only	4 (4)	28 (55)	<b>32 (21)</b>
	Including liver	66 (65)	0	<b>66 (43)</b>
	Not including liver	31 (31)	23 (45)	<b>54 (36)</b>
Recipient sex	Male	51 (50)	26 (51)	<b>77 (51)</b>
	Female	50 (50)	25 (49)	<b>75 (49)</b>
Recipient ethnicity group	White	90 (89)	49 (96)	<b>139 (91)</b>
	Other	11 (11)	2 (4)	<b>13 (9)</b>
Indication group	Short bowel syndrome	31 (31)	20 (39)	<b>51 (34)</b>
	Motility disorders	5 (5)	8 (16)	<b>13 (9)</b>
	Malignancy	7 (7)	3 (6)	<b>10 (7)</b>
	Liver disease	9 (9)	1 (2)	<b>10 (7)</b>
	Other/not reported	41 (41)	17 (33)	<b>58 (38)</b>
	Retransplant	8 (8)	2 (4)	<b>10 (7)</b>
Pre-transplant renal support	No	89 (88)	48 (94)	<b>137 (90)</b>
	Yes	12 (12)	1 (2)	<b>13 (9)</b>
	Not reported	0	2 (4)	<b>2 (1)</b>
Previous abdominal surgery	No	12 (12)	0	<b>12 (8)</b>
	Yes	82 (81)	50 (98)	<b>132 (87)</b>
	Not reported	7 (7)	1 (2)	<b>8 (5)</b>
Recipient blood group	O	38 (38)	22 (43)	<b>60 (40)</b>
	A	40 (40)	22 (43)	<b>62 (41)</b>
	B	16 (16)	5 (10)	<b>21 (14)</b>
	AB	7 (7)	2 (4)	<b>9 (6)</b>
Recipient age (years)	Median (IQR)	46 (33,53)	40 (33,51)	<b>43 (33,52)</b>
	Not reported	0	0	<b>0</b>
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (19,25)	21 (19,24)	<b>21 (19,24)</b>
	Not reported	2	1	<b>3</b>

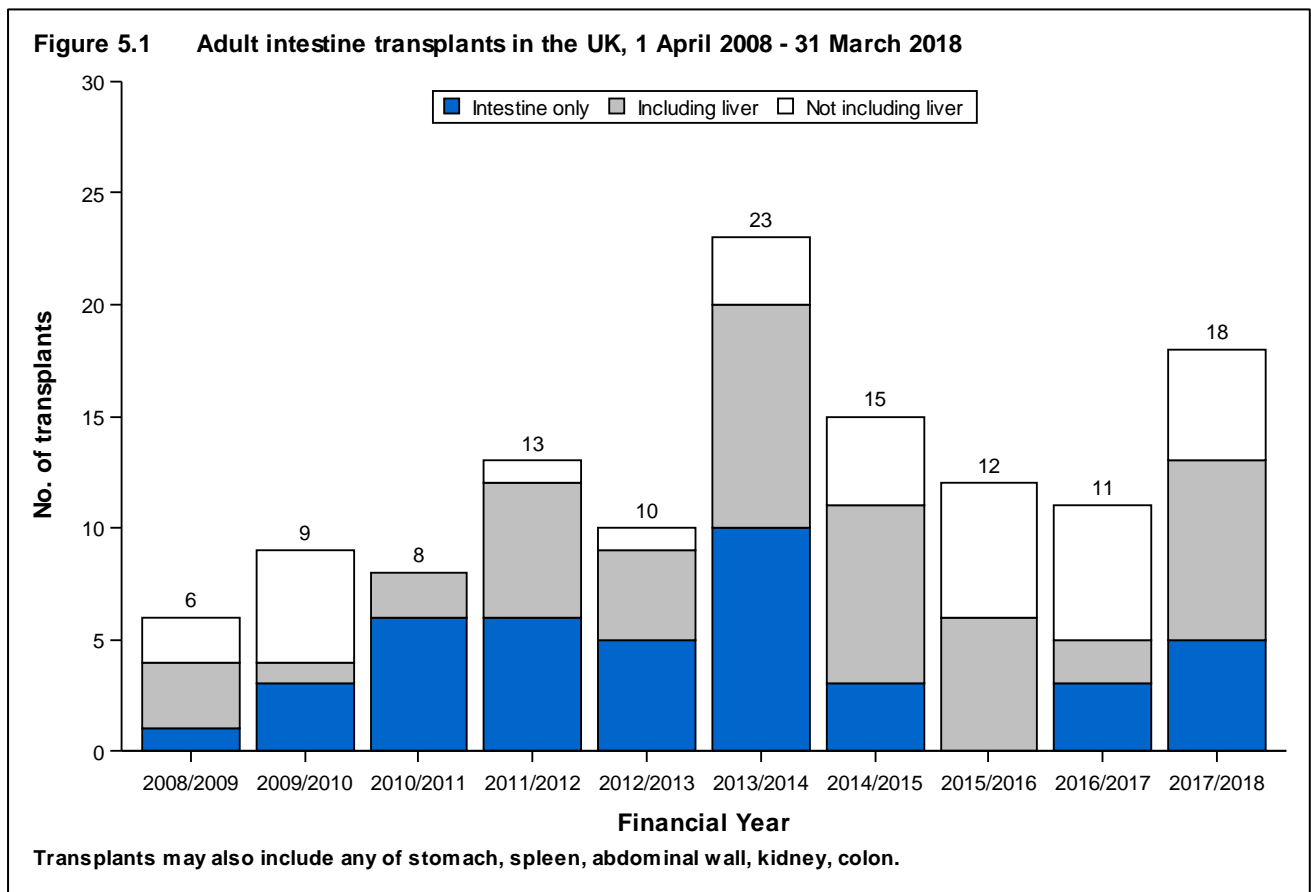
#### 4. Response to offers

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 2017 and 31 March 2018 Cambridge received intestine offers from 122 donors and Oxford received intestine offers from 50. Their [offer decline rates](#) were 89% and 92%, respectively.

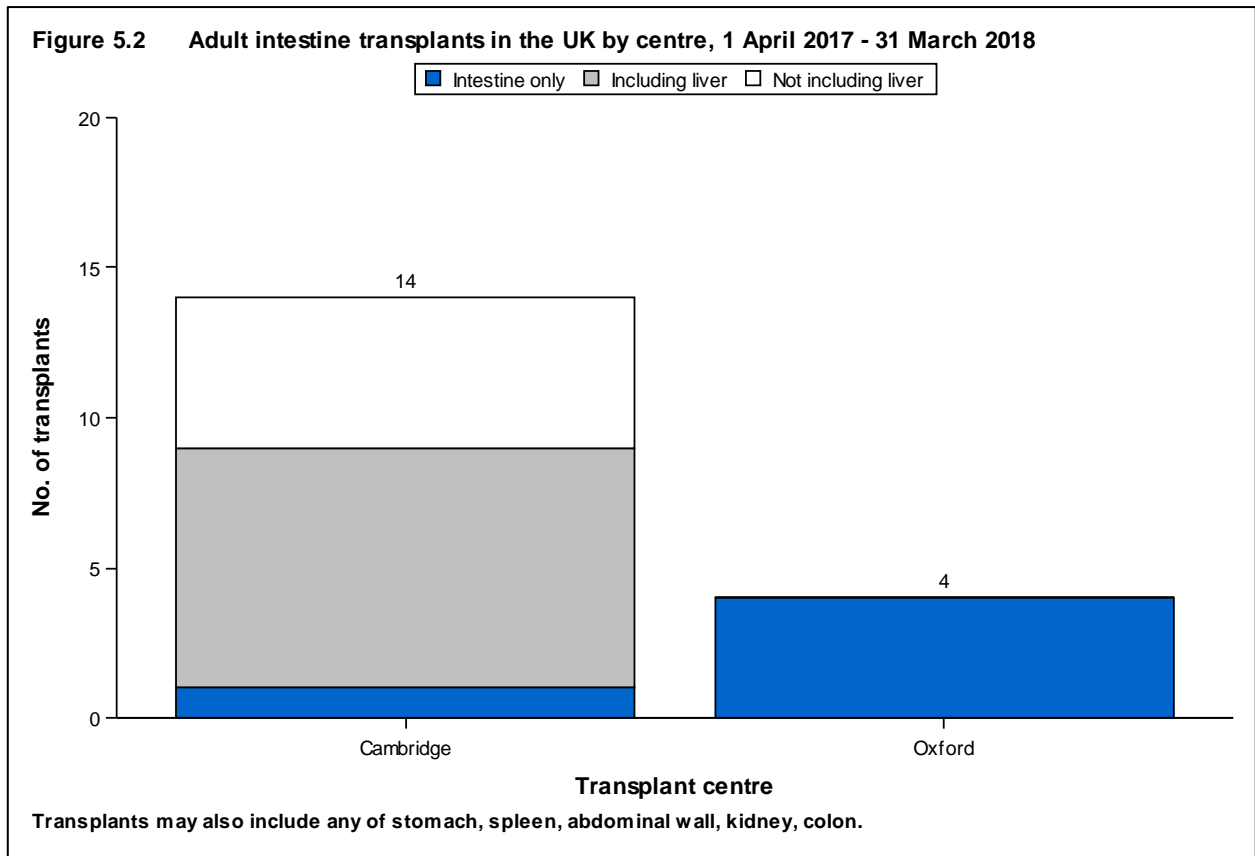
#### 5. Transplants

##### 5.1 Adult intestine transplants, 1 April 2008 – 31 March 2018

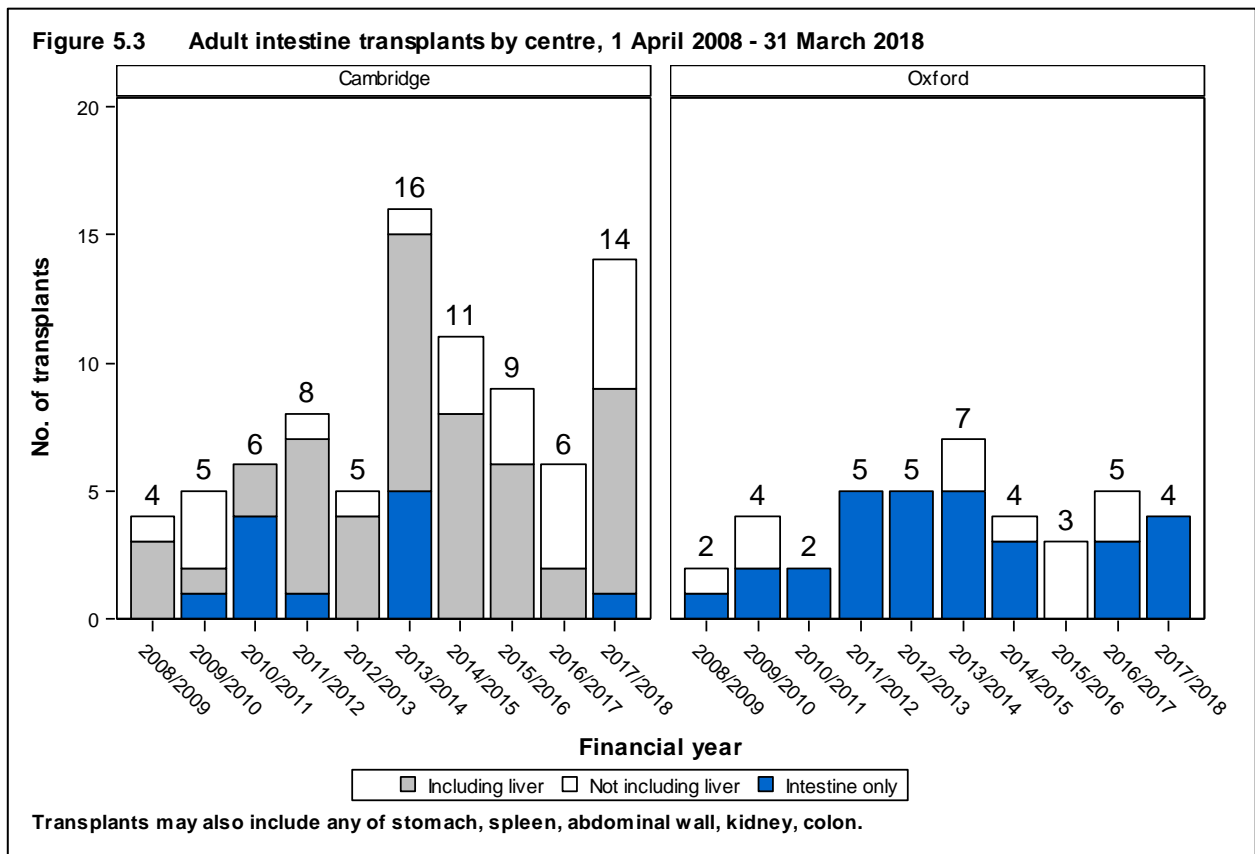
**Figure 5.1** shows the number of adult intestine transplants performed in the last 10 years, by [transplant type](#). The annual number of adult transplants increased steadily over the time period to 23 in 2013/2014, but dropped to 18 in the last financial year.



**Figure 5.2** shows the number of adult intestine transplants performed in 2017/2018, by centre and [transplant type](#). More than half (57%) of transplants performed at Cambridge included the liver while all performed at Oxford were categorised as intestine only.



**Figure 5.3** shows the number of adult intestine transplants performed in the last 10 years, by centre and [type of transplant](#).



The demographic characteristics of 118 adult [elective](#) intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 5.1**. Nationally, 57% of recipients were male and the [median](#) age was 45 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 22 kg/m<sup>2</sup>. For some characteristics, percentages may not add up to 100 due to rounding.

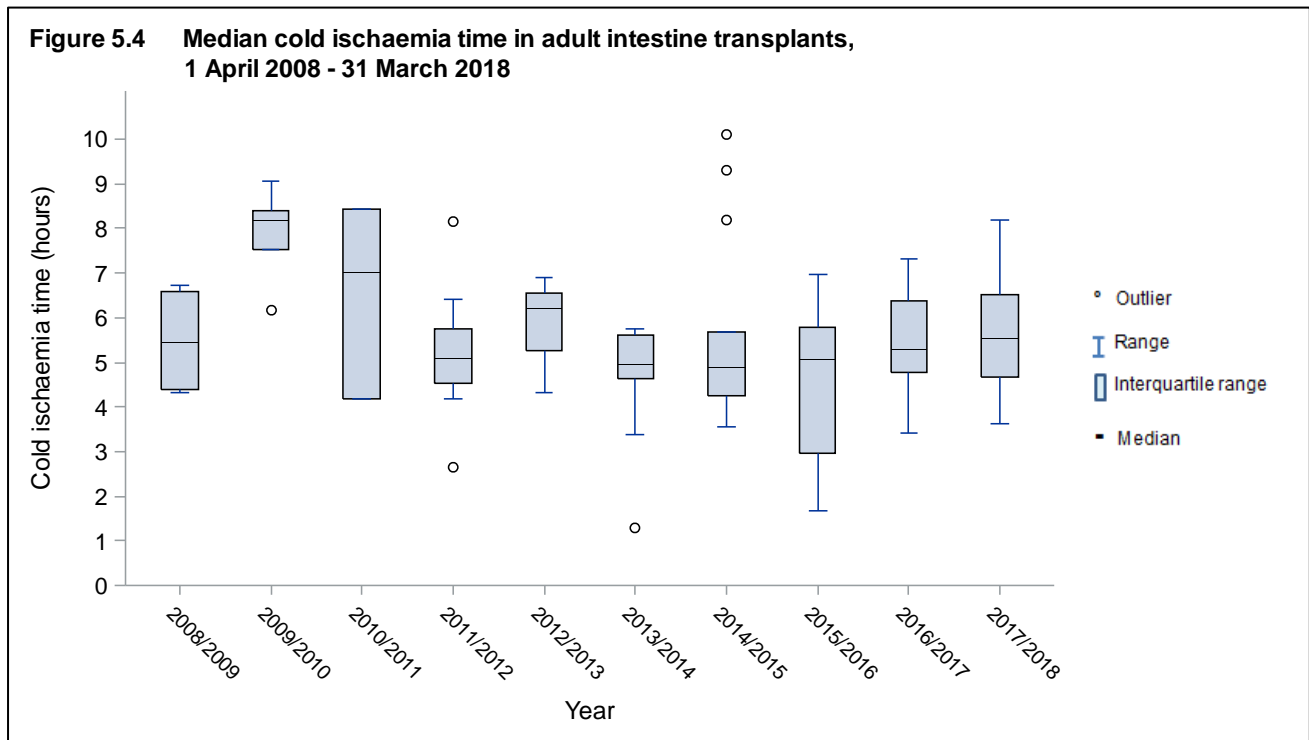
<b>Table 5.1 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2008 - 31 March 2018</b>				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of transplants		77 (100)	41 (100)	<b>118 (100)</b>
Recipient sex	Male	44 (57)	23 (56)	<b>67 (57)</b>
	Female	33 (43)	18 (44)	<b>51 (43)</b>
Recipient ethnicity group	White	71 (92)	39 (95)	<b>110 (93)</b>
	Other	6 (8)	2 (5)	<b>8 (7)</b>
Indication group	Short bowel syndrome	24 (31)	17 (41)	<b>41 (35)</b>
	Motility disorders	4 (5)	6 (15)	<b>10 (9)</b>
	Malignancy	6 (8)	3 (7)	<b>9 (8)</b>
	Liver disease	4 (5)	1 (2)	<b>5 (4)</b>
	Other/not reported	34 (44)	13 (32)	<b>47 (40)</b>
	Retransplant	5 (6)	1 (2)	<b>6 (5)</b>
Patient location	Out-patient	46 (60)	34 (83)	<b>80 (68)</b>
	Ward	17 (22)	6 (15)	<b>23 (20)</b>
	ICU/HDU	4 (5)	0	<b>4 (3)</b>
	Not reported	10 (13)	1 (2)	<b>11 (9)</b>
Pre-transplant renal support	No	64 (83)	38 (93)	<b>102 (86)</b>
	Yes	3 (4)	2 (5)	<b>5 (4)</b>
	Not reported	10 (13)	1 (2)	<b>11 (9)</b>
Previous abdominal surgery	No	11 (14)	2 (5)	<b>13 (11)</b>
	Yes	56 (73)	38 (93)	<b>94 (80)</b>
	Not reported	10 (13)	1 (2)	<b>11 (9)</b>
Life style activity	Normal	1 (1)	4 (10)	<b>5 (4)</b>
	Restricted	15 (19)	4 (10)	<b>19 (16)</b>
	Self-care	30 (39)	22 (54)	<b>52 (44)</b>
	Confined	10 (13)	7 (17)	<b>17 (14)</b>
	Reliant	11 (14)	3 (7)	<b>14 (12)</b>
	Not reported	10 (13)	1 (2)	<b>11 (9)</b>
Restricted venous access at registration	No	50 (65)	25 (61)	<b>75 (64)</b>
	Yes	23 (30)	15 (37)	<b>38 (32)</b>
	Not reported	4 (5)	1 (2)	<b>5 (4)</b>
Recipient age (years)	Median (IQR)	46 (34,54)	40 (34,51)	<b>45 (34,53)</b>
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (19,23)	22 (19,24)	<b>22 (19,24)</b>
	Not reported	12	10	<b>22</b>

**Table 5.1 Demographic characteristics of adult elective intestine transplant recipients, 1 April 2008 - 31 March 2018**

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Serum bilirubin (umol/l)	Median (IQR)	18 (8,42)	10 (5,12)	<b>12 (7,26)</b>
	Not reported	10	1	<b>11</b>
Time on list (days)	Median (IQR)	48 (20,142)	34 (13,71)	<b>41 (16,117)</b>
Donor sex	Male	28 (36)	22 (54)	<b>50 (42)</b>
	Female	49 (64)	19 (46)	<b>68 (58)</b>
Donor ethnicity group	White	73 (95)	39 (95)	<b>112 (95)</b>
	Other	4 (5)	2 (5)	<b>6 (5)</b>
Donor cause of death group	Stroke	61 (79)	23 (56)	<b>84 (71)</b>
	Trauma	10 (13)	16 (39)	<b>26 (22)</b>
	Other	6 (8)	2 (5)	<b>8 (7)</b>
Donor history of diabetes	No	77 (100)	40 (98)	<b>117 (99)</b>
	Not reported	0	1 (2)	<b>1 (1)</b>
Donor age (years)	Median (IQR)	27 (21,39)	25 (20,35)	<b>27 (20,39)</b>
Donor BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (20,23)	22 (21,23)	<b>22 (21,23)</b>
Transplant type	Intestine only	12 (16)	30 (73)	<b>42 (36)</b>
	Including liver	43 (56)	0	<b>43 (36)</b>
	Not including liver	22 (29)	11 (27)	<b>33 (28)</b>
ABO match	Identical	52 (68)	38 (93)	<b>90 (76)</b>
	Compatible	25 (32)	3 (7)	<b>28 (24)</b>
Cold ischaemic time (hours)	Median (IQR)	4.7 (4.2,5.4)	6.4 (5.6,7.5)	<b>5.3 (4.4,6.4)</b>
	Not reported	16	6	<b>22</b>

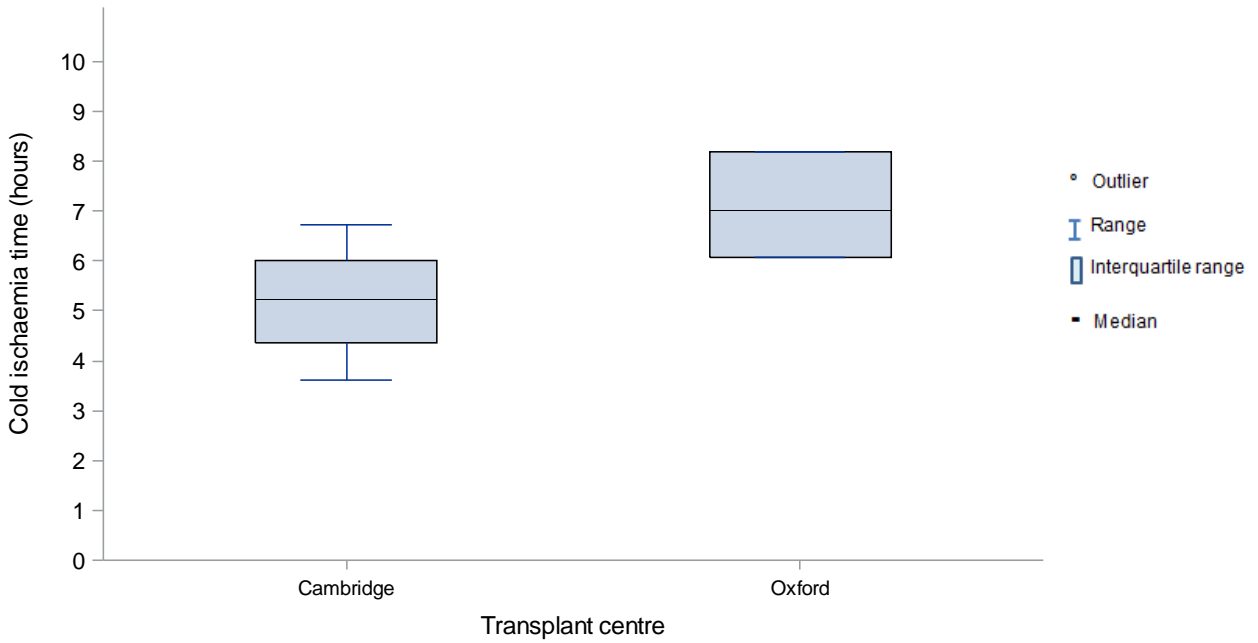
## 5.2 Cold ischaemia time, 1 April 2008 – 31 March 2018

**Figure 5.4** shows [boxplots](#) of the [cold ischaemic times](#) (CIT) of deceased donor organs used in adult intestine transplants over the last 10 years. This is the elapsed time from removal of the organs from the donor to removal from ice prior to implant. The line inside the box indicates the [median](#) value. The median CIT has been particularly high in 2009/2010, at 8.2 hours, but in 2017/2018 was down to 5.5 hours.

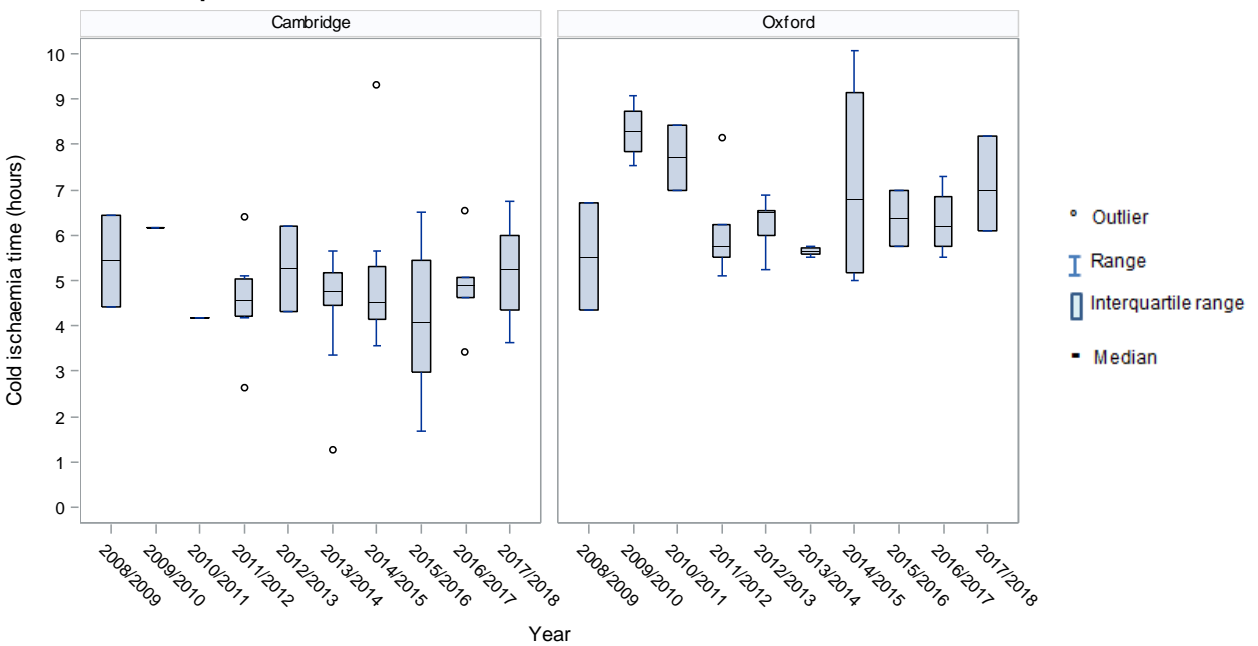


**Figure 5.5** shows the median CITs in adult intestine transplants in 2017/2018 for each transplant centre, while **Figure 5.6** shows the same data but over the last 10 years. Generally CITs were longer for transplants performed by Oxford. All of these boxplots represent a small number of observations 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 2017 - 31 March 2018**



**Figure 5.6 Median cold ischaemia time in all adult intestine transplants, 1 April 2008 - 31 March 2018**



## 6. Post-transplant survival

This section presents survival post adult intestine transplantation. Due to small numbers, [unadjusted survival rates](#) are presented, but these do not account for differences in the [case mix](#) at each centre and transplant type.

### 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 2008 and 31 March 2018, overall and by centre. Of the 112 transplants of this kind in the time period, survival information was known for 107 transplants. Of these, 89.7% of patients were alive at 90 days post-transplant ([unadjusted](#)).

<b>Table 6.1 90-day patient survival (%) for adult elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI) <a href="#">Unadjusted</a></b>	
Cambridge	69	91.3	(81.7-96.0)
Oxford	38	86.8	(71.2-94.3)
<b>TOTAL</b>	<b>107</b>	<b>89.7</b>	<b>(82.2-94.2)</b>

One- and five-year patient survival rates are shown in **Table 6.2** and **Table 6.3**, respectively. At one year post-transplant, 79.3% of transplanted patients were alive, while at five years post-transplant, the overall survival rate is 53.5%. Note that both centres perform different types of transplants and therefore the next section (**Table 6.4**) presents a breakdown by centre and transplant type.

<b>Table 6.2 One-year patient survival (%) for adult elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>1-year survival (95% CI) <a href="#">Unadjusted</a></b>	
Cambridge	69	79.9	(67.8-87.8)
Oxford	38	78.2	(61.1-88.5)
<b>TOTAL</b>	<b>107</b>	<b>79.3</b>	<b>(70.0-86.0)</b>

<b>Table 6.3 Five-year patient survival (%) for adult elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>5-year survival (95% CI) <a href="#">Unadjusted</a></b>	
Cambridge	69	49.1	(32.4-63.8)
Oxford	38	61.9	(41.0-77.3)
<b>TOTAL</b>	<b>107</b>	<b>53.5</b>	<b>(40.3-65.0)</b>



## 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](#). Due to small numbers, the intestine only group has been included with the not including liver group.

<b>Table 6.4 Unadjusted patient survival (%) for adult elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant type</b>							
<b>Transplant type</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI)</b>		<b>1-year survival (95% CI)</b>		<b>5-year survival (95% CI)</b>	
<b>Cambridge</b>							
Including liver	39	84.6	(68.9-92.8)	75.5	(58.1-86.5)	28.1	(10.1-49.5)
Not including liver <sup>1</sup>	30	100.0	-	85.6	(66.0-94.3)	75.0	(51.4-88.3)
<b>Oxford</b>							
Not including liver <sup>1</sup>	38	86.8	(71.2-94.3)	78.2	(61.1-88.5)	61.9	(41.0-77.3)
<b>TOTAL</b>	<b>107</b>	<b>89.7</b>	<b>(82.2-94.2)</b>	<b>79.3</b>	<b>(70.0-86.0)</b>	<b>53.5</b>	<b>(40.3-65.0)</b>

<sup>1</sup> Includes intestine only

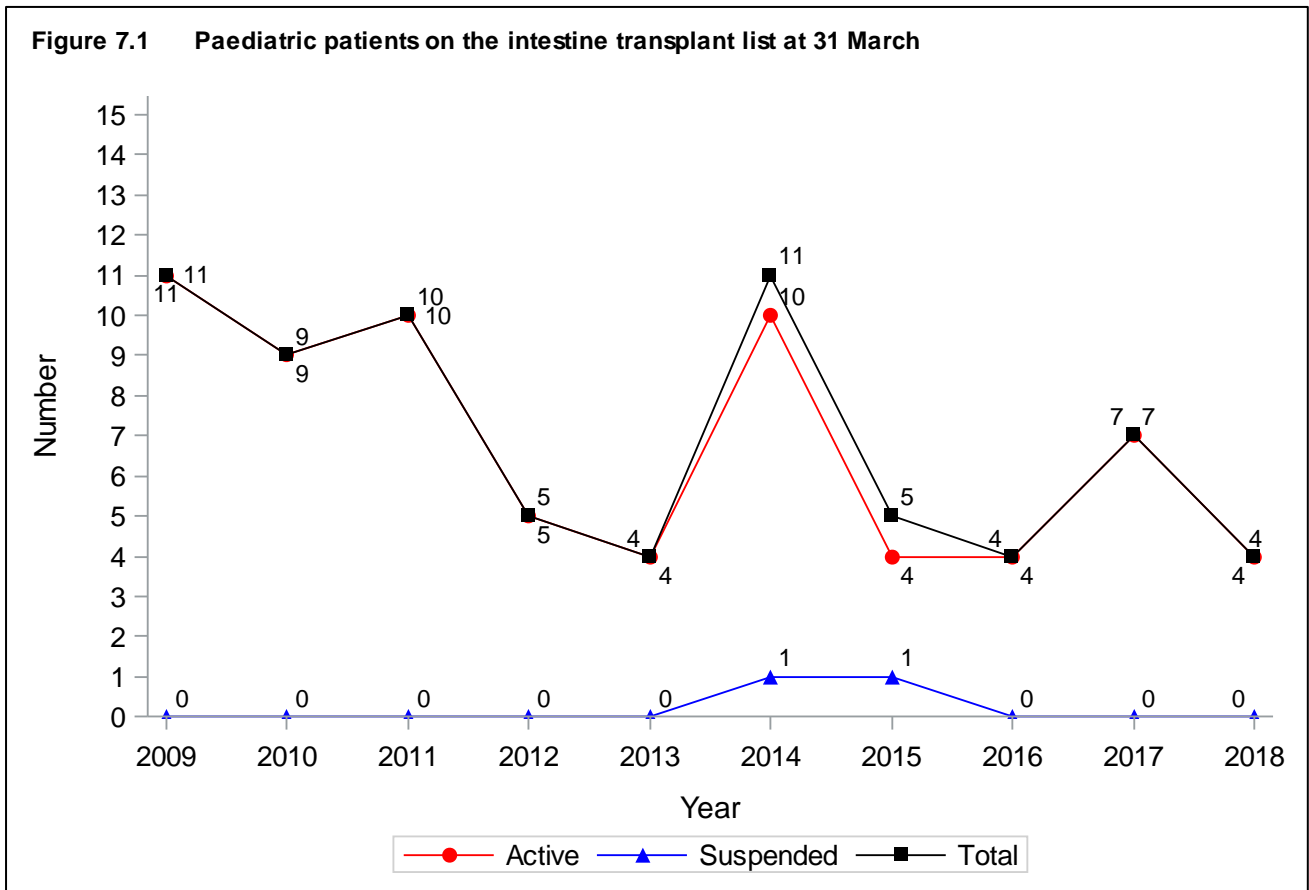
# **PAEDIATRIC INTESTINE TRANSPLANTATION**



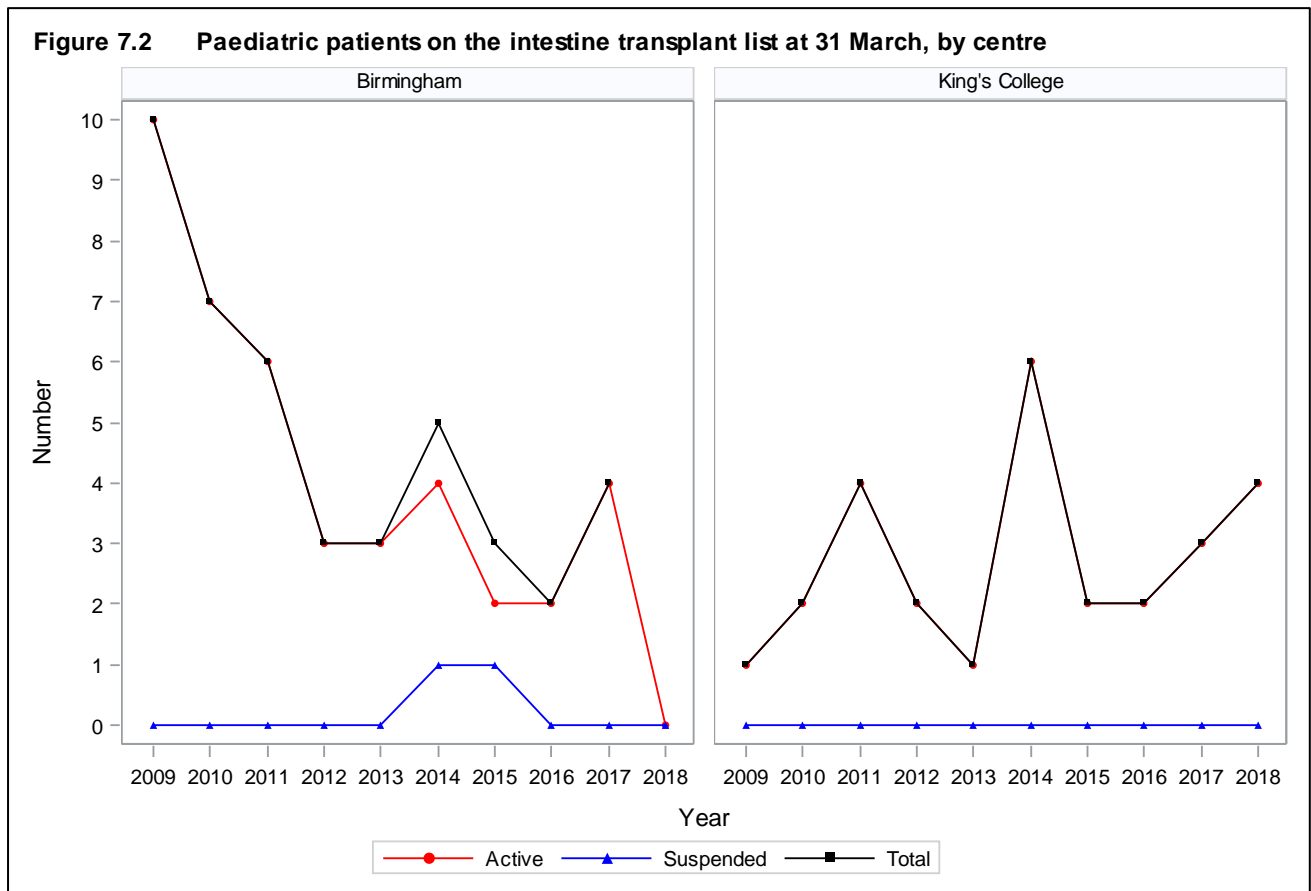
## 7. Transplant list

### 7.1 Paediatric intestine transplant list as at 31 March, 2009 – 2018

**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 2009 and 2018. The number of patients on the [active transplant list](#) varied between 4 and 11 each year, but on the whole has decreased over time.



**Figure 7.2** shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2009 and 2018, at each transplant centre. The number of patients waiting at Birmingham has decreased over the decade while there has been no noticeable trend in the number waiting at King's College Hospital.



The demographic characteristics of 93 paediatric intestine transplant recipient registrations in the 10 year period are shown by centre and overall in **Table 7.1**. Nationally, 58% of patients were male and the [median](#) age was 3 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 17 kg/m<sup>2</sup>. 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 2008 - 31 March 2018**

		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		60 (100)	33 (100)	<b>93 (100)</b>
Number of patients		57	28	<b>85</b>
Registration type	Elective	60 (100)	33 (100)	<b>93 (100)</b>
Transplant type required	Intestine only	16 (27)	11 (33)	<b>27 (29)</b>
	Including liver	37 (62)	21 (64)	<b>58 (62)</b>
	Not including liver	7 (12)	1 (3)	<b>8 (9)</b>
Recipient sex	Male	36 (60)	18 (55)	<b>54 (58)</b>
	Female	23 (38)	15 (45)	<b>38 (41)</b>
	Not reported	1 (2)	0 (0)	<b>1 (1)</b>
Recipient ethnicity group	White	51 (85)	24 (73)	<b>75 (81)</b>
	Other	8 (13)	9 (27)	<b>17 (18)</b>
	Not reported	1 (2)	0	<b>1 (1)</b>
Indication group	Short bowel syndrome	29 (48)	12 (36)	<b>41 (44)</b>
	Motility disorders	8 (13)	6 (18)	<b>14 (15)</b>
	Primary mucosal disorders	9 (15)	2 (6)	<b>11 (12)</b>
	Other/not reported	8 (13)	7 (21)	<b>15 (16)</b>
	Retransplant	6 (10)	6 (18)	<b>12 (13)</b>
Pre-transplant renal support	No	57 (95)	32 (97)	<b>89 (96)</b>
	Yes	1 (2)	0	<b>1 (1)</b>
	Not reported	2 (3)	1 (3)	<b>3 (3)</b>
Previous abdominal surgery	No	9 (15)	2 (6)	<b>11 (12)</b>
	Yes	49 (82)	30 (91)	<b>79 (85)</b>
	Not reported	2 (3)	1 (3)	<b>3 (3)</b>
Recipient blood group	O	29 (48)	8 (24)	<b>37 (40)</b>
	A	22 (37)	20 (61)	<b>42 (45)</b>
	B	8 (13)	4 (12)	<b>12 (13)</b>
	AB	1 (2)	1 (3)	<b>2 (2)</b>
Recipient age (years)	Median (IQR)	2 (0,6)	3 (1,6)	<b>3 (0,6)</b>
	Not reported	0	0	<b>0</b>
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	17 (16,18)	18 (16,19)	<b>17 (16,19)</b>
	Not reported	1	0	<b>1</b>

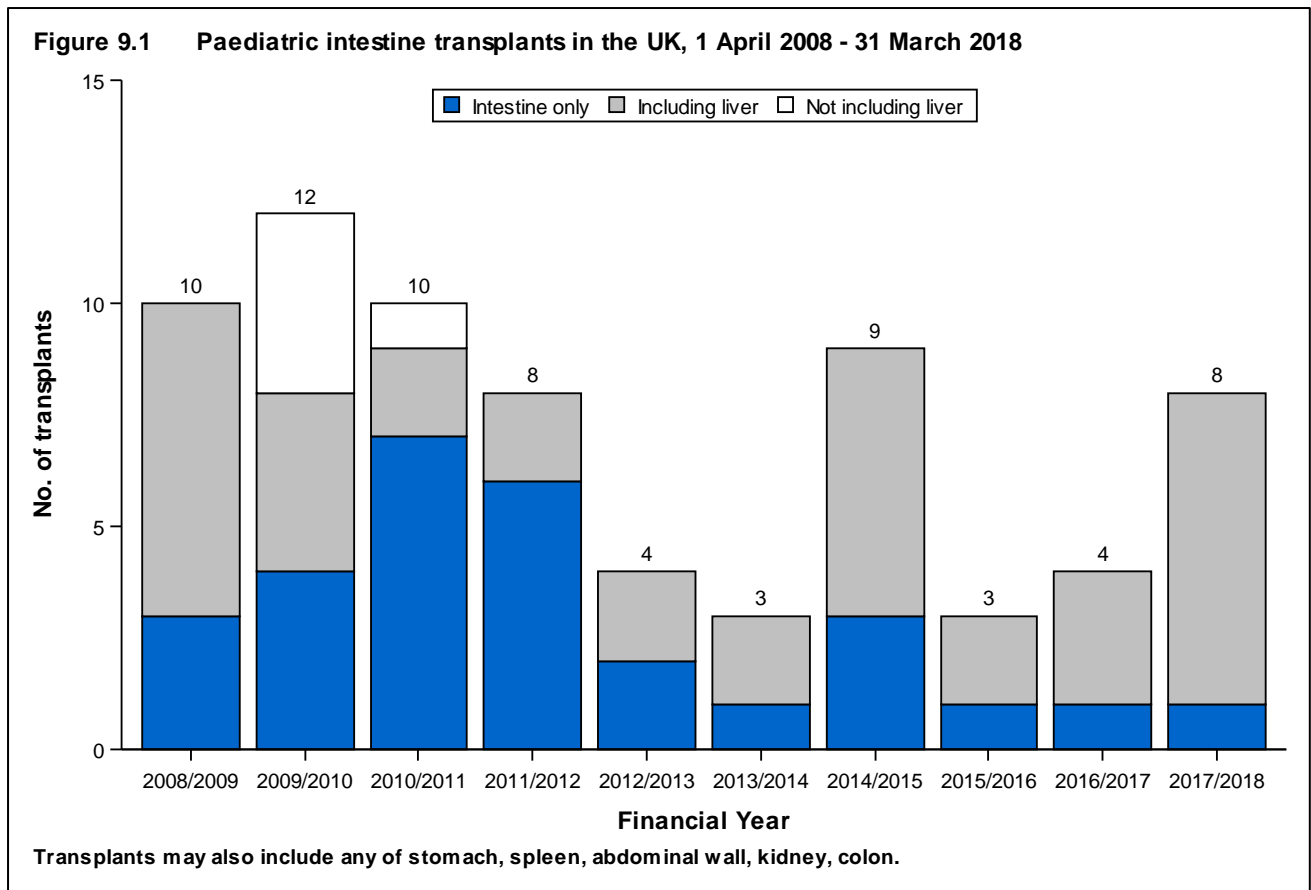
## 8. Response to offers

Between 1 April 2017 and 31 March 2018 Birmingham and King’s College Hospital received offers from 97 and 125 donors, respectively, for intestine transplant patients at their centres. Their [offer decline rates](#) were 96% and 98% 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 intestine transplants, 1 April 2008 – 31 March 2018

**Figure 9.1** shows the number of paediatric intestine transplants performed in the last 10 years, by [transplant type](#). The number of paediatric transplants fell in the first part of the period from 12 in 2009/2010 to 3 in 2013/2014. In the last year, 8 transplants were performed. In 2017/2018, a living liver and bowel transplant was performed by King’s College Hospital. This transplant is included in the numbers presented in this section.



**Figure 9.2** shows the number of paediatric intestine transplants performed in 2017/2018, by centre and [transplant type](#). There were four transplants at each centre; all transplants performed by Birmingham were liver and intestine combined, while one of transplants at King’s College Hospital was intestine only and the other three were liver and intestine combined.

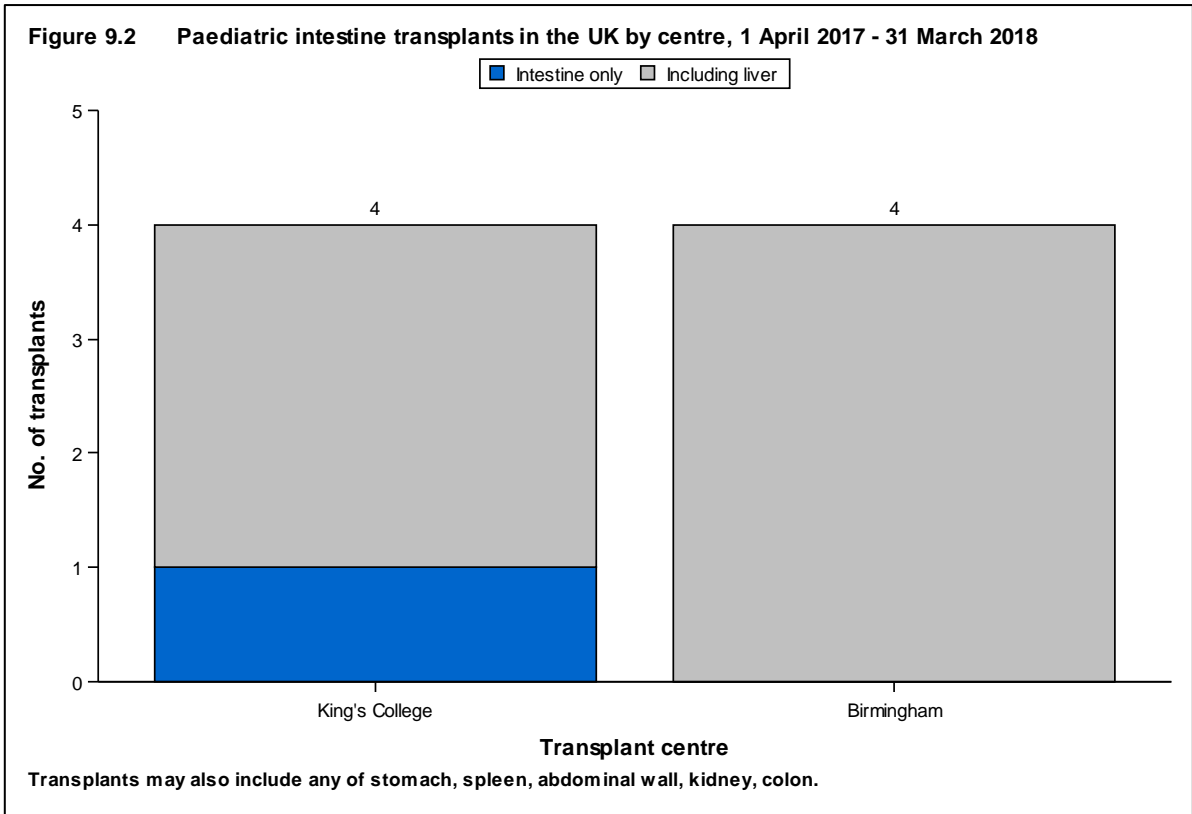
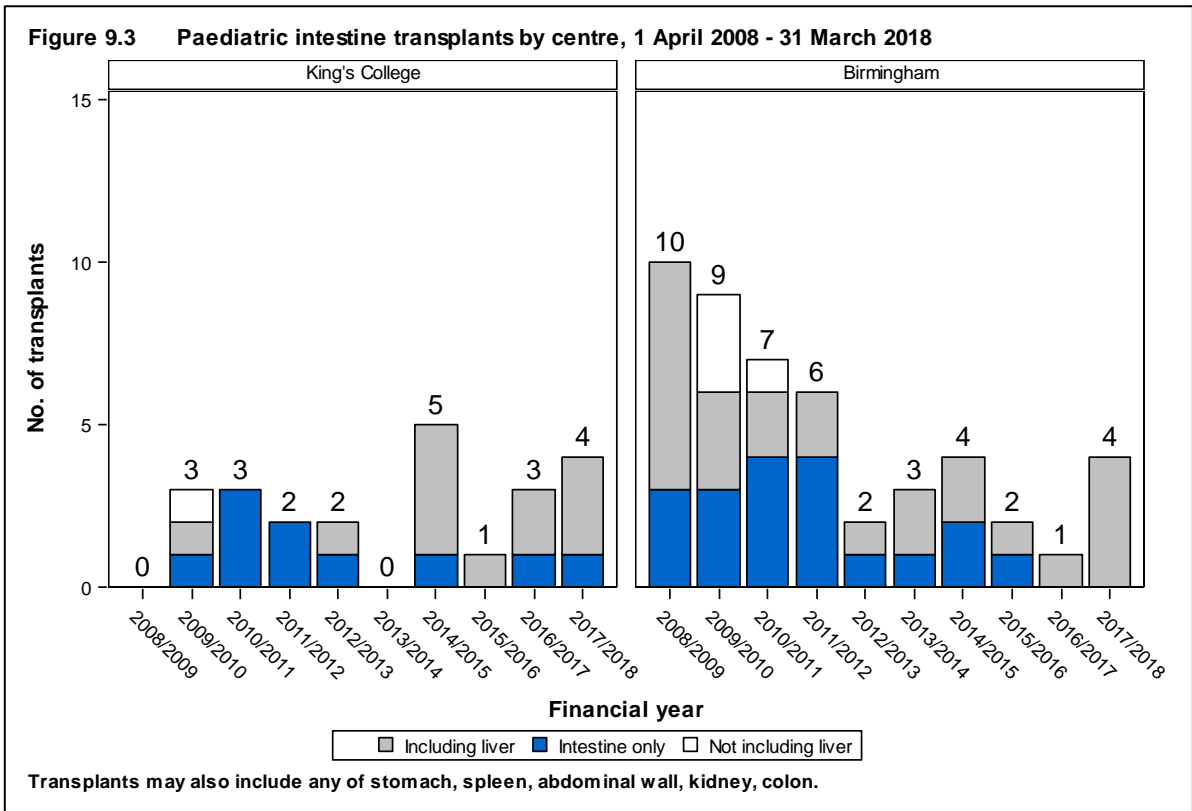


Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and [type of transplant](#). Note that King's College Hospital joined the programme in 2008 but their first intestine transplants were performed in 2009/2010. There is a decreasing trend in the number of transplants performed by Birmingham.



The demographic characteristics of 71 paediatric [elective](#) intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 9.1**. Nationally, 55% of recipients were male and the [median](#) age was four years old. The most common indication for transplantation was short bowel syndrome. The median recipient BMI was 18 kg/m<sup>2</sup>. For some characteristics, percentages may not add up to 100 due to rounding.

<b>Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2008 - 31 March 2018</b>				
		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		48 (100)	23 (100)	<b>71 (100)</b>
Recipient sex	Male	27 (56)	12 (52)	<b>39 (55)</b>
	Female	21 (44)	11 (48)	<b>32 (45)</b>
Recipient ethnicity group	White	37 (77)	17 (74)	<b>54 (76)</b>
	Other	10 (21)	6 (26)	<b>16 (23)</b>
	Not reported	1 (2)	0	<b>1 (1)</b>
Indication group	Short bowel syndrome	26 (54)	8 (35)	<b>34 (48)</b>
	Motility disorders	5 (10)	7 (30)	<b>12 (17)</b>
	Primary mucosal disorders	6 (13)	1 (4)	<b>7 (10)</b>
	Liver disease	1 (2)	0	<b>1 (1)</b>
	Other/not reported	7 (15)	2 (9)	<b>9 (13)</b>
	Retransplant	3 (6)	5 (22)	<b>8 (11)</b>
Patient location	Out-patient	38 (79)	15 (65)	<b>53 (75)</b>
	Ward	5 (10)	3 (13)	<b>8 (11)</b>
	ICU/HDU	0	2 (9)	<b>2 (3)</b>
	Not reported	5 (10)	3 (13)	<b>8 (11)</b>
Pre-transplant renal support	No	43 (90)	19 (83)	<b>62 (87)</b>
	Yes	1 (2)	1 (4)	<b>2 (3)</b>
	Not reported	4 (8)	3 (13)	<b>7 (10)</b>
Previous abdominal surgery	No	8 (17)	1 (4)	<b>9 (13)</b>
	Yes	36 (75)	19 (83)	<b>55 (78)</b>
	Not reported	4 (8)	3 (13)	<b>7 (10)</b>
Life style activity	Normal	1 (2)	1 (4)	<b>2 (3)</b>
	Restricted	8 (17)	6 (26)	<b>14 (20)</b>
	Self-care	3 (6)	0	<b>3 (4)</b>
	Reliant	1 (2)	3 (13)	<b>4 (6)</b>
	Aged five years or less	27 (56)	10 (43)	<b>37 (52)</b>
	Not reported	8 (17)	3 (13)	<b>11 (16)</b>
Restricted venous access at registration	No	16 (33)	13 (57)	<b>29 (41)</b>
	Yes	24 (50)	8 (35)	<b>32 (45)</b>
	Not reported	8 (17)	2 (9)	<b>10 (14)</b>
Recipient age (years)	Median (IQR)	3 (1,6)	5 (3,8)	<b>4 (1,7)</b>
	Not reported	0	0	<b>0</b>

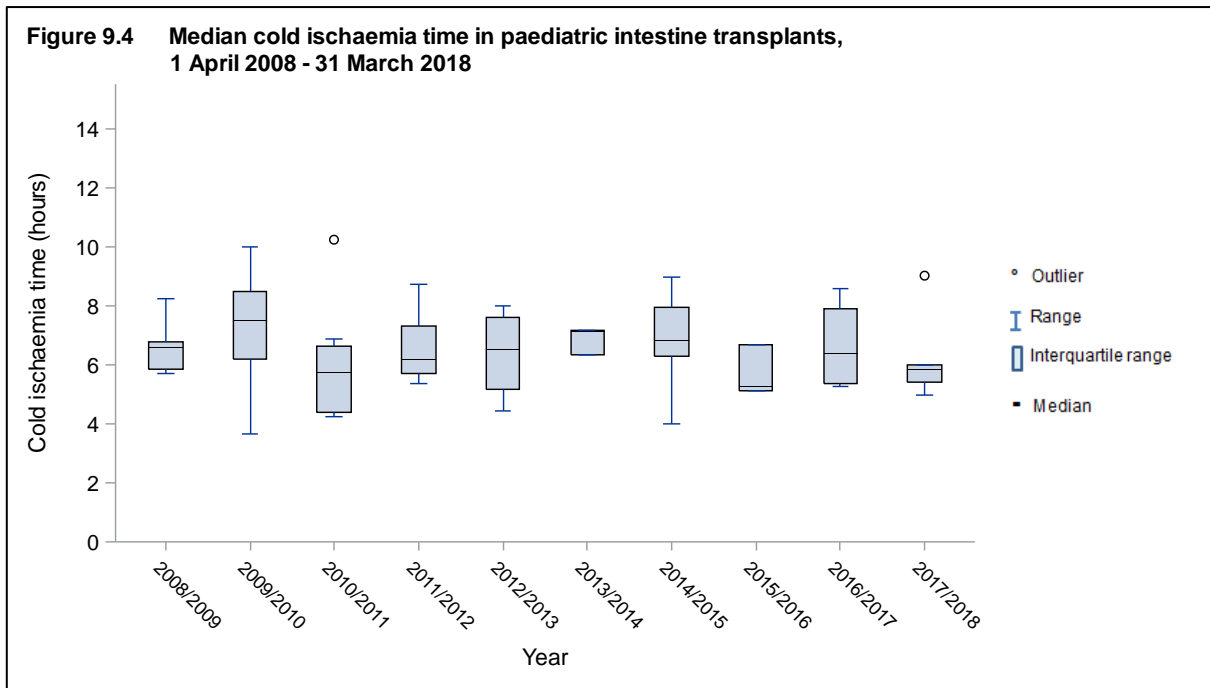


**Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2008 - 31 March 2018**

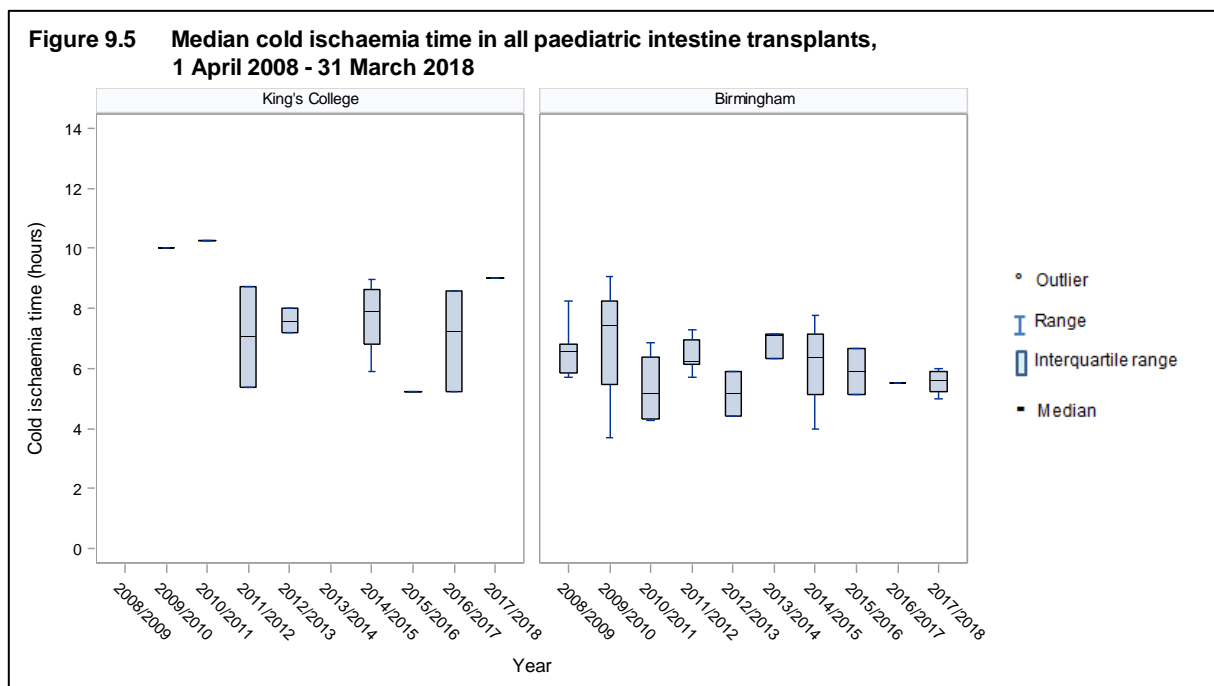
		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	17 (16,19)	18 (16,19)	<b>18 (16,19)</b>
	Not reported	39	3	<b>42</b>
Serum bilirubin (umol/l)	Median (IQR)	12 (8,84)	10 (6,19)	<b>10 (7,44)</b>
	Not reported	7	3	<b>10</b>
Time on list (days)	Median (IQR)	181 (59,254)	178 (77,321)	<b>181 (64,278)</b>
Donor sex	Male	24 (50)	15 (65)	<b>39 (55)</b>
	Female	24 (50)	8 (35)	<b>32 (45)</b>
Donor ethnicity group	White	37 (77)	16 (70)	<b>53 (75)</b>
	Other	6 (13)	2 (9)	<b>8 (11)</b>
	Not reported	5 (10)	5 (22)	<b>10 (14)</b>
Donor cause of death group	Stroke	25 (52)	13 (57)	<b>38 (54)</b>
	Trauma	10 (21)	3 (13)	<b>13 (18)</b>
	Other	13 (27)	6 (26)	<b>19 (27)</b>
	Living	0	1 (4)	<b>1 (1)</b>
Donor history of diabetes	No	40 (83)	18 (78)	<b>58 (82)</b>
	Yes	1 (2)	0	<b>1 (1)</b>
	Not reported	7 (15)	5 (22)	<b>12 (17)</b>
Donor age (years)	Median (IQR)	5 (2,13)	4 (0,8)	<b>5 (2,11)</b>
Donor BMI (kg/m <sup>2</sup> )	Median (IQR)	16 (15,19)	15 (13,19)	<b>16 (14,19)</b>
	Not reported	0	1	<b>1</b>
Transplant type	Intestine only	19 (40)	10 (43)	<b>29 (41)</b>
	Including liver	25 (52)	12 (52)	<b>37 (52)</b>
	Not including liver	4 (8)	1 (4)	<b>5 (7)</b>
ABO match	Identical	40 (83)	20 (87)	<b>60 (85)</b>
	Compatible	8 (17)	3 (13)	<b>11 (16)</b>
Cold ischaemic time (hours)	Median (IQR)	6.3 (5.4,7)	8 (6.4,8.9)	<b>6.4 (5.5,7.5)</b>
	Not reported	6	7	<b>13</b>

## 9.2 Cold ischaemia time, 1 April 2008 – 31 March 2018

Figure 9.4 shows [boxplots](#) of the [CITs](#) of deceased donor organs used in paediatric intestine transplants over the last 10 years. This is the elapsed time from removal of the organs from the donor to removal from ice prior to implant. 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 5.3 and 7.5 hours.



**Figure 9.5** shows the median CITs in paediatric intestine transplants by centre over the last 10 years for deceased donors. Note that prior to 2009/2010 King's College Hospital did not perform any intestine transplants which means there are no boxplots presented for the first year. There is a decreasing trend in CIT for Birmingham. 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

This section presents survival post paediatric intestine transplantation. Due to small numbers, [unadjusted survival rates](#) are presented, but these do not account for differences in the [case mix](#) at each centre and transplant type.

### 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 2008 and 31 March 2018, overall and by centre. There were 63 transplants of this kind in the time period and survival information was known in 60 cases; of these, 95% of patients were alive 90 days post-transplant.

<b>Table 10.1 Unadjusted 90-day patient survival (%) paediatric elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI)</b>	
Birmingham	41	92.7	(79.0-97.6)
King's College Hospital	19	100.0	-
<b>TOTAL</b>	<b>60</b>	<b>95.0</b>	<b>(85.3-98.4)</b>

Unadjusted one- and five-year patient survival rates are shown in **Table 10.2** and **Table 10.3**, respectively. One year post-transplant, 86.2% of transplanted patients are alive while, five years post-transplant, the survival rate is 58.7%. Note that the number of transplants at King's College Hospital is small and survival rates for this centre must be taken only as a guide.

<b>Table 10.2 Unadjusted one-year patient survival (%) paediatric elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>1-year survival (95% CI)</b>	
Birmingham	41	82.9	(67.5-91.5)
King's College Hospital	19	93.8	(63.2-99.1)
<b>TOTAL</b>	<b>60</b>	<b>86.2</b>	<b>(74.3-92.9)</b>

<b>Table 10.3 Unadjusted five-year patient survival (%) paediatric elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant centre</b>			
<b>Centre</b>	<b>Number of transplants</b>	<b>5-year survival (95% CI)</b>	
Birmingham	41	53.4	(36.3-67.8)
King's College Hospital	19	72.5	(42.1-88.8)
<b>TOTAL</b>	<b>60</b>	<b>58.7</b>	<b>(44.0-70.7)</b>

## 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 small numbers, the intestine only group has been included with the not including liver group and these survival rates must be taken only as a guide.

<b>Table 10.4 Unadjusted patient survival (%) for paediatric elective first intestine transplants between 1 April 2008 and 31 March 2018, by transplant type</b>							
<b>Transplant type</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI)</b>		<b>1-year survival (95% CI)</b>		<b>5-year survival (95% CI)</b>	
<b>Birmingham</b>							
Including liver	19	84.2	(58.7-94.6)	73.7	(47.9-88.1)	35.1	(14.8-56.3)
Not including liver <sup>1</sup>	22	100.0	-	90.9	(68.3-97.6)	69.2	(43.0-85.2)
<b>King's College Hospital</b>							
Including liver	10	100.0	-	100.0	-	50.0	(11.1-80.4)
Not including liver <sup>1</sup>	9 <sup>2</sup>	-	-	-	-	-	-
<b>TOTAL</b>	<b>60</b>	<b>95.0</b>	<b>(85.3-98.4)</b>	<b>86.2</b>	<b>(74.3-92.9)</b>	<b>58.7</b>	<b>(44.0-70.7)</b>

<sup>1</sup> Includes intestine only  
<sup>2</sup> Survival rates for transplant types with less than 10 transplants are not presented due to small numbers.

# FORM RETURN RATES



## 11.1 Form return rates, 1 January – 31 December 2017

Form return rates are reported in **Table 11.1** for all centres. The forms included are the intestine transplant record form and the three month and annual intestine transplant follow-up forms that are reported to the UK Transplant Registry database. The tables show the number of forms issued between 1 January 2017 and 31 December 2017, for patients at each centre, and the percentage of forms that had been returned at time of analysis (8 June 2018). 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. There are a number of forms missing for this period for all centres.

<b>Table 11.1 Form return rates, by age group and transplant centre, for forms issued between 1 January 2017 and 31 December 2017</b>									
Age group	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
Adult	Cambridge	8	100	7	100	9	100	33	97
	Oxford	6	100	6	100	4	100	16	94
	<b>Total</b>	<b>14</b>	<b>100</b>	<b>13</b>	<b>100</b>	<b>13</b>	<b>100</b>	<b>49</b>	<b>96</b>
Paediatric	Birmingham	2	100	1	0	1	100	38	95
	King's College Hospital	3	33	4	100	3	100	10	80
	<b>Total</b>	<b>5</b>	<b>60</b>	<b>5</b>	<b>80</b>	<b>4</b>	<b>100</b>	<b>48</b>	<b>92</b>
<b>TOTAL</b>		<b>19</b>	<b>89</b>	<b>18</b>	<b>94</b>	<b>17</b>	<b>100</b>	<b>97</b>	<b>94</b>

# APPENDIX



## A1: Number of patients analysed

Data were obtained from the UK Transplant Registry for the 10 year time period, 1 April 2008 to 31 March 2018. NHS Group 2 transplants have been included while liver-only transplants because of intestine 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 intestine failure have been excluded. Additionally, one transplant at Oxford in 2016 involving the abdominal wall only where the patient was registered using the Intestinal Failure Transplant Recipient Registration form has also been excluded. Patients who are registered for an intestine transplant but receive a liver only transplant are included in the transplant list activity but are excluded in the transplant activity and post-transplant survival sections.

**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.

<b>Table A1 Number of adult intestine transplants, by transplant centre and urgency status, 1 April 2008 to 31 March 2018</b>				
<b>Centre</b>	<b>All transplants</b>		<b>First-time transplants</b>	
	<b>Elective</b>	<b>Super-urgent</b>	<b>Elective</b>	<b>Super-urgent</b>
Cambridge	77	7	72	5
Oxford	41	0	40	0
<b>TOTAL</b>	<b>118</b>	<b>7</b>	<b>112</b>	<b>5</b>

**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.

<b>Table A2 Number of paediatric intestine transplants, by transplant centre and urgency status, 1 April 2008 to 31 March 2018</b>				
<b>Centre</b>	<b>All transplants</b>		<b>First-time transplants</b>	
	<b>Elective</b>	<b>Super-urgent</b>	<b>Elective</b>	<b>Super-urgent</b>
Birmingham	48	0	44	0
King's College Hospital	23	0	19	0
<b>TOTAL</b>	<b>71</b>	<b>0</b>	<b>63</b>	<b>0</b>



## **Geographical variation analysis**

### **Registration rates**

All NHS group 1 patients who were registered onto the intestine transplant lists with an active status between 1 April 2008 and 31 March 2018 were extracted from the UK Transplant Registry on 6 June 2018. 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-2016 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 intestine transplants on NHS group 1 recipients from donors based on transplants between 1 April 2008 and 31 March 2018 (numerator), divided by the mid-2016 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 2008 and 31 March 2018 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 intestine 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 2014 and 31 March 2017 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, 8 June 2018, 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 2017 to 31 March 2018.

### 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  $\sigma^2$ . 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,  $\sigma^2$ , 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  $\sigma^2$ . 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 intestine 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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