



**Blood and Transplant**

**ANNUAL REPORT ON  
INTESTINE TRANSPLANTATION**

**REPORT FOR 2019/2020  
(1 APRIL 2010 – 31 MARCH 2020)**

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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 2010 to 31 March 2020. 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.

**The COVID-19 pandemic has led to unprecedented challenges for UK transplantation. Concerns about the ability to care for transplant recipients, lack of access to resource because it is being used for patients in the pandemic, and the risk versus benefit for immunosuppressed transplant recipients, have resulted in a major reduction in the number of organ transplants undertaken.**

**Waiting list figures at the 31 March 2020 do not accurately reflect the need for an organ transplant due to the COVID-19 pandemic. Different practices have been established across the UK and across organ groups with regards to waiting list management. Due to this, a snapshot of the waiting list at 29 February 2020 has been used to better reflect activity near the end of the 2019/2020 financial year, where appropriate.**

## Key findings

- On 29 February 2020, there were 19 patients on the UK active intestine **transplant list**, which represents a 73% increase compared to the end of the previous year. Of those patients registered onto the transplant list in a recent two year period (1 April 2016 – 31 March 2018), 80% had received a transplant two years post-registration, while 9% died on the list, 6% were removed and 6% were still waiting at time of data analysis.
- Overall **median waiting time** to intestine transplant for registrations between 1 April 2016 and 31 March 2019 was 98 days, or 3.2 months. This was calculated for adult and paediatric patients combined.
- There were 198 intestine **transplants** performed in the UK over the 10 year period covered by this report. Of all transplants 28% were in paediatric recipients while 72% were in adult recipients. A small proportion of these 28% and 72% were re-transplants while the rest were primary transplants.
- In the last financial year, 2019/2020, 20 intestine **transplants** were performed, a 5% increase from 2018/2019. By age group, 17 adult transplants were performed, which was 5% more than 2018/2019, and 3 paediatric transplants were performed, which was the same as 2018/2019.
- The national rates of **survival** ([unadjusted](#)) after first intestine transplantation for **adult patients** were estimated at 95%, 88%, and 72% at 90 days, one and five years post-transplant, respectively for those who did not receive the liver and 89%, 74%, and 39% at 90 days, one and five years post-transplant, respectively for those who did receive the liver. There was evidence of better survival in those not receiving the liver at 1- and 5- year post-transplant.
- The national rates of **survival** after first intestine transplantation for **paediatric patients** ([unadjusted](#)) were estimated at 100% and 91% at 90 days and one year post-transplant, respectively, for those who did not receive the liver and at 92% and 83% at 90 days and one year post-transplant, respectively, for those who did receive the liver. Survival estimates at 5-years are not presented due to the small number of transplants.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Intestine Transplantation 2019/2020, NHS Blood and Transplant.*

# **INTRODUCTION**



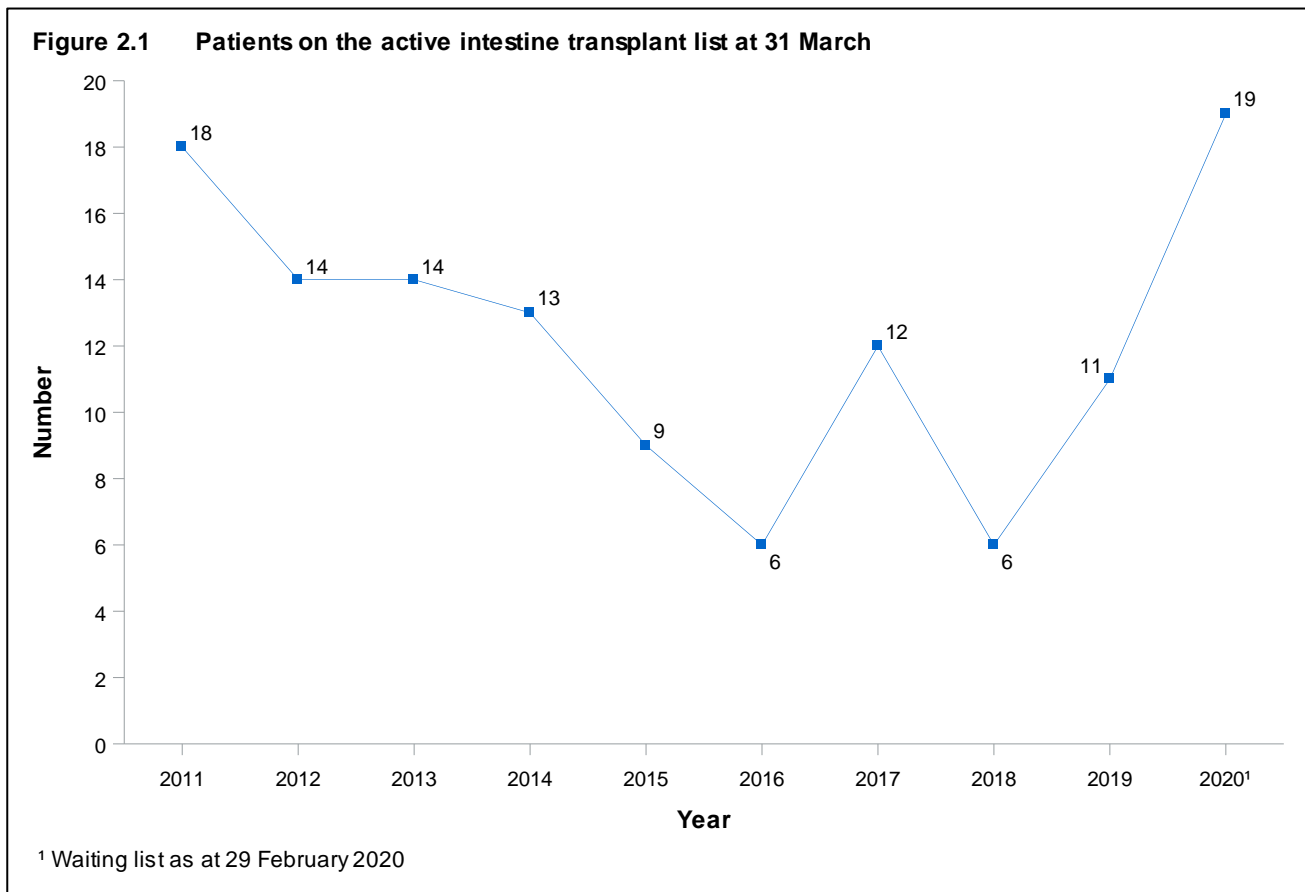
# INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2010 and 31 March 2020, 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.

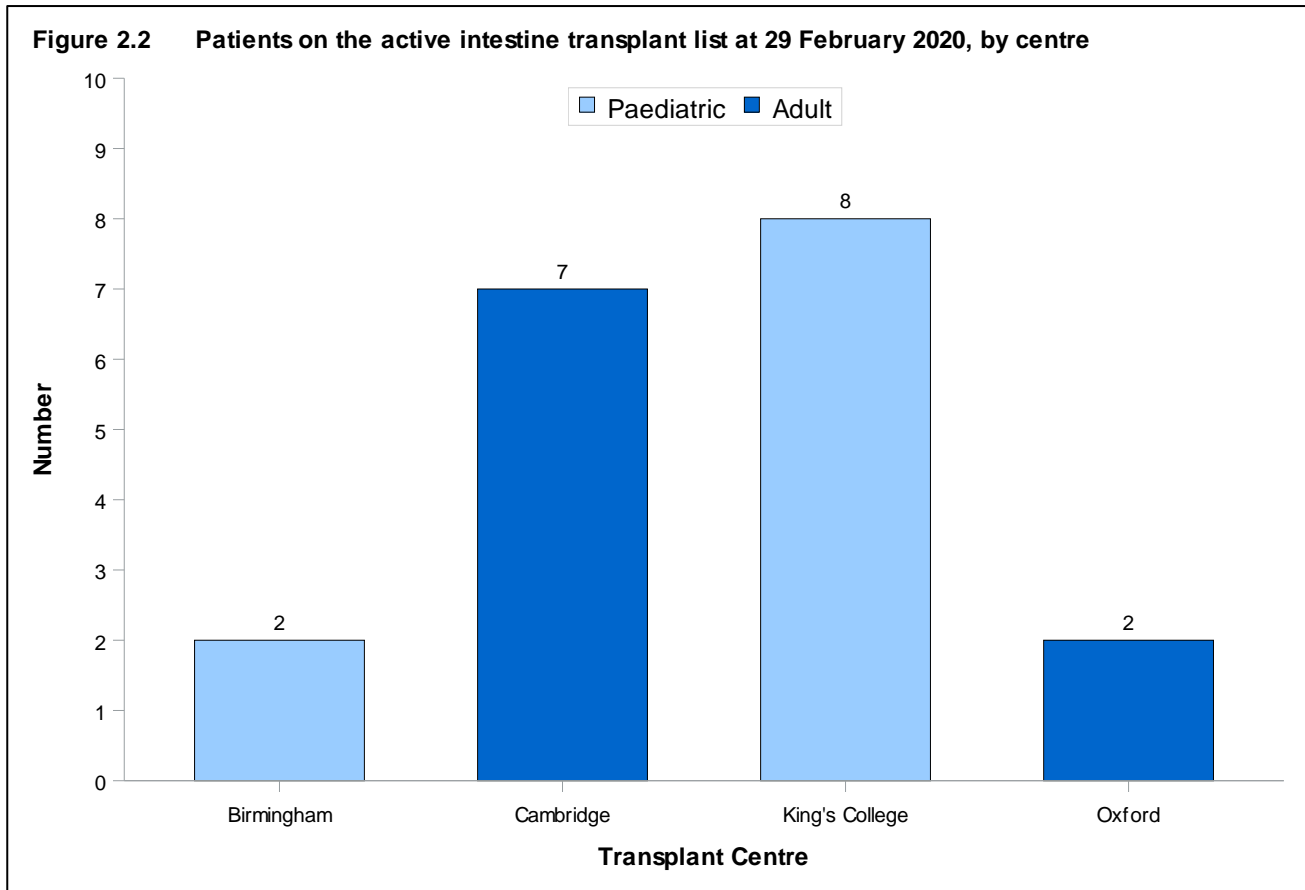
## 2.1 Transplant list

**Figure 2.1** shows the total number of patients on the intestine [active transplant list](#) at 31 March of each year between 2011 and 2020. The number of patients waiting for a transplant has increased in recent years, with a peak of 19 patients on 29 February 2020.



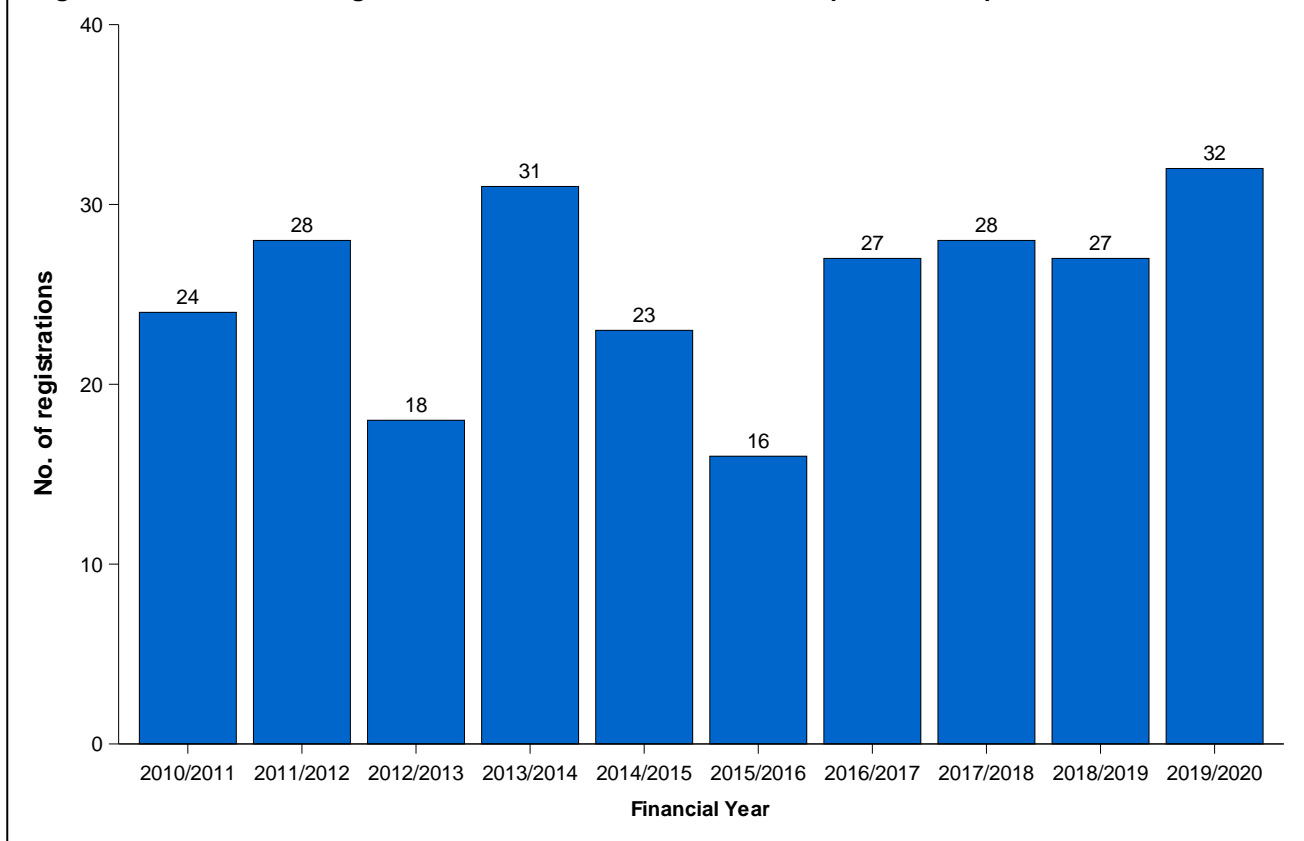


**Figure 2.2** shows the number of adult and paediatric patients on the [active transplant list](#) at 29 February 2020 by centre. In total, there were nine adult and ten paediatric patients across centres. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown later in the report, in **Figure 3.2** and **Figure 7.2**, respectively.

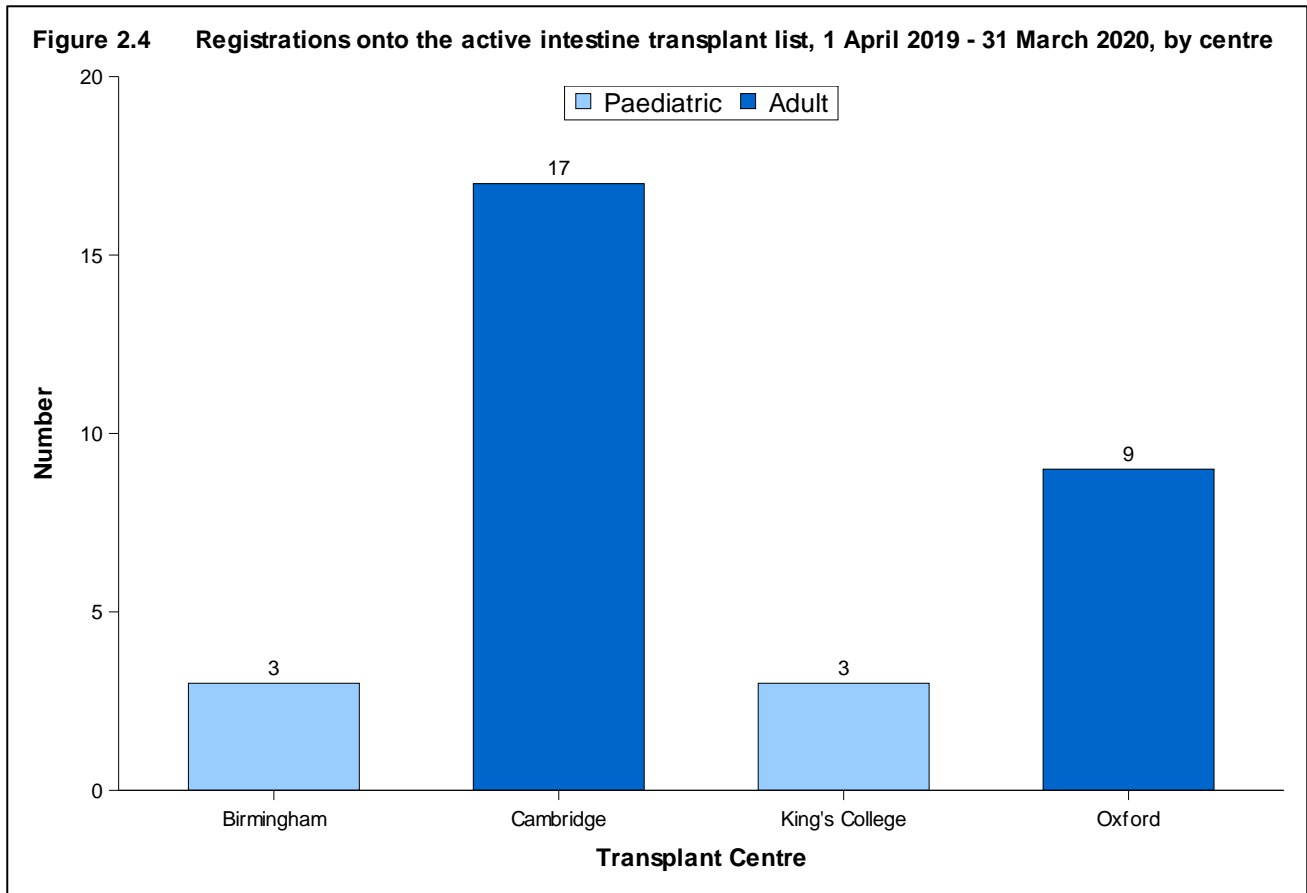


**Figure 2.3** shows the number of registrations made onto the active intestine transplant list each year in the last 10 years. The number of registrations has remained reasonably stable over the decade, but has increased slightly to 32 registrations in 2019/2020.

**Figure 2.3** Number of registrations onto the active intestine transplant list, 1 April 2010 - 31 March 2020

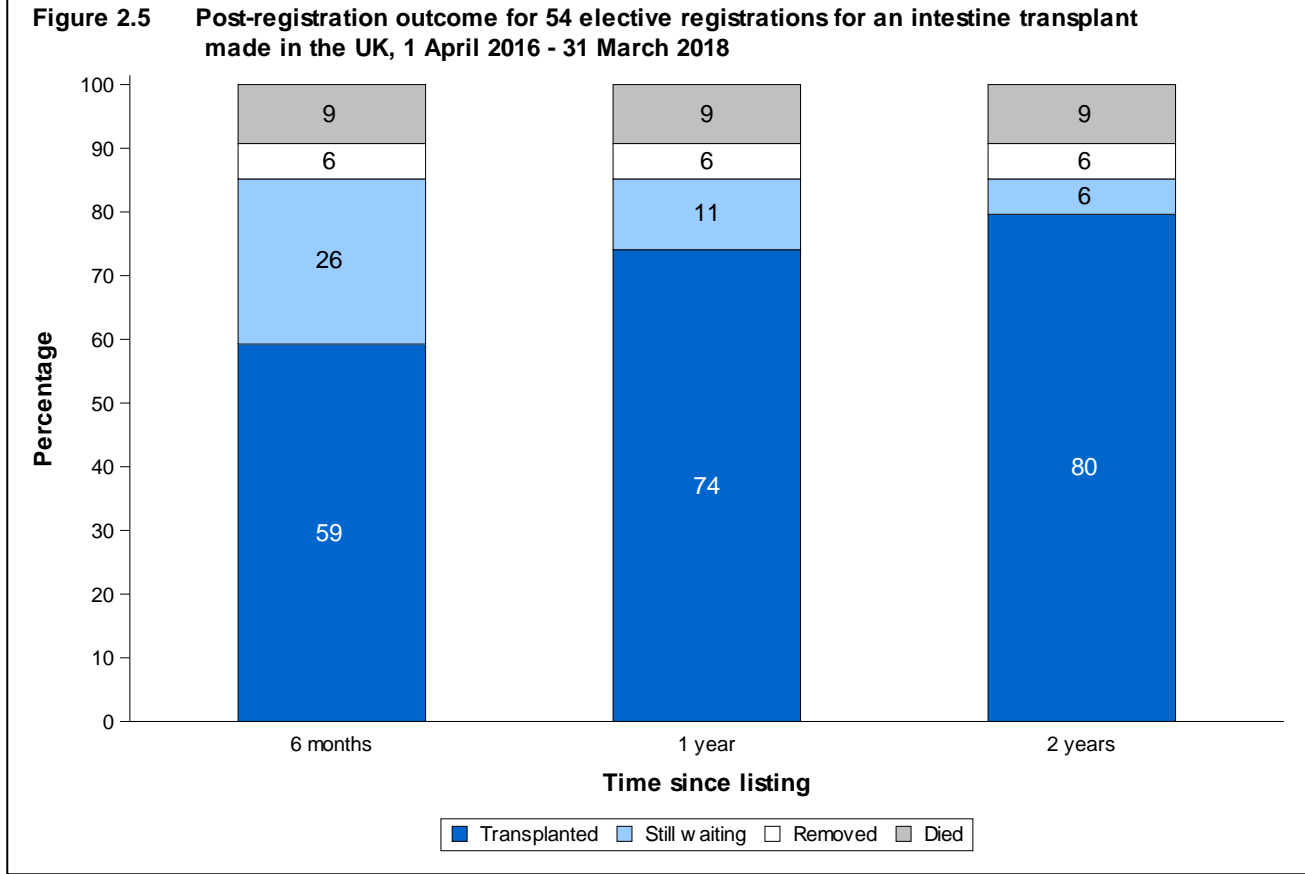


**Figure 2.4** shows the number of registrations onto the active intestine transplant list in 2019/2020 by centre. In total, there were 26 adult registrations and 6 paediatric registrations.



### 2.1.1 Post-registration outcomes, 1 April 2016 – 31 March 2018

The registration outcomes of patients listed between 1 April 2016 and 31 March 2018 for an elective intestine transplant are summarised in **Figure 2.5**. 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 80% of patients had received a transplant, 9% had died on the list, 6% were still waiting, and 6% had been removed.



### 2.1.2 Median waiting time to transplant, 1 April 2016 – 31 March 2019

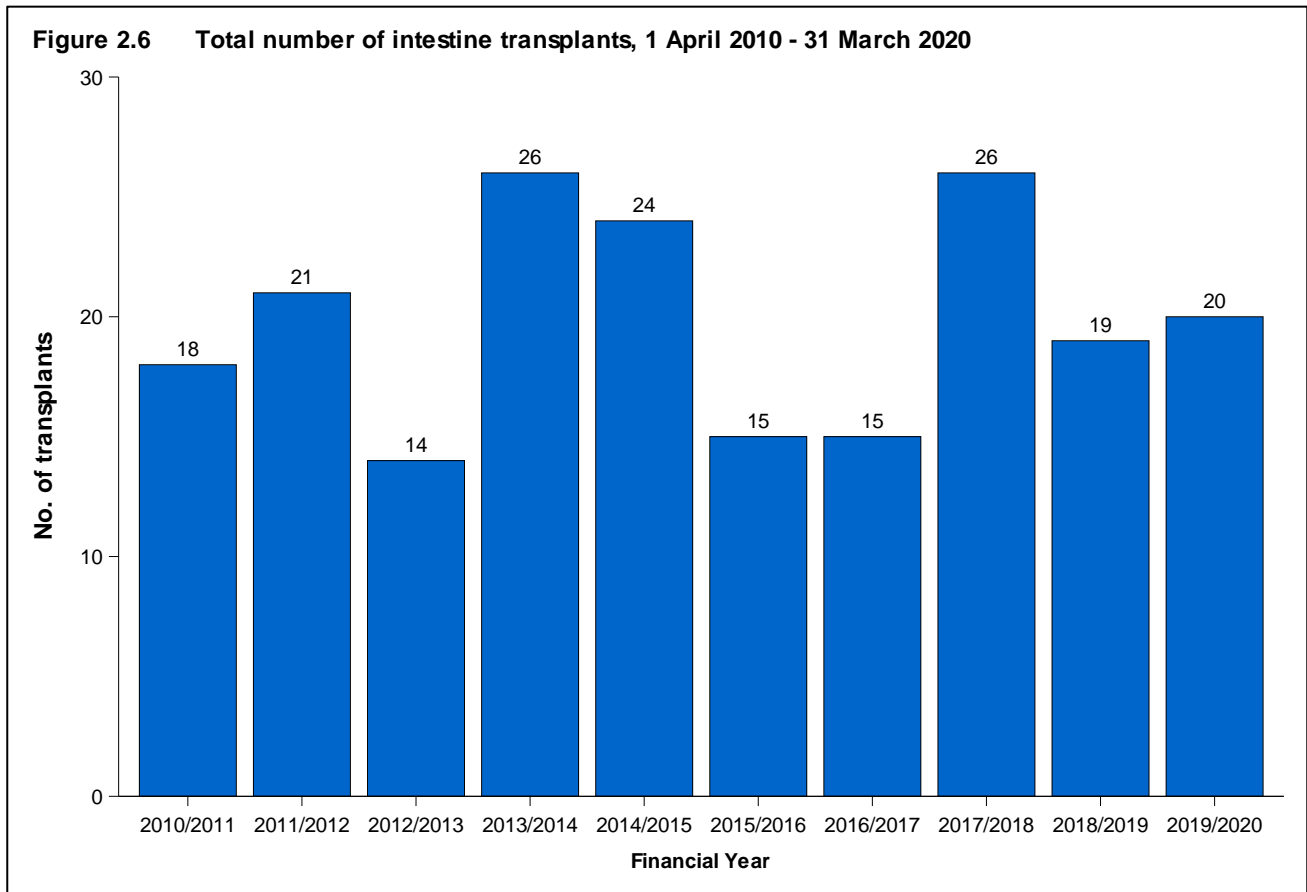
Table 2.1 shows [median waiting time](#) to [elective](#) intestine transplant by registration type for adult and paediatric patients, combined, registered between 1 April 2016 and 31 March 2019. Overall, on average, patients waited 98 days (approximately three months) for a transplant.

<b>Table 2.1 Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2016 - 31 March 2019</b>			
Registration type	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Intestine only <sup>1</sup>	14	139	0 – 284
Liver, intestine and pancreas <sup>1</sup>	35	190	136 – 244
Intestine and pancreas <sup>1</sup>	24	51	19 – 83
<b>TOTAL</b>	<b>73</b>	<b>98</b>	<b>57 – 139</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

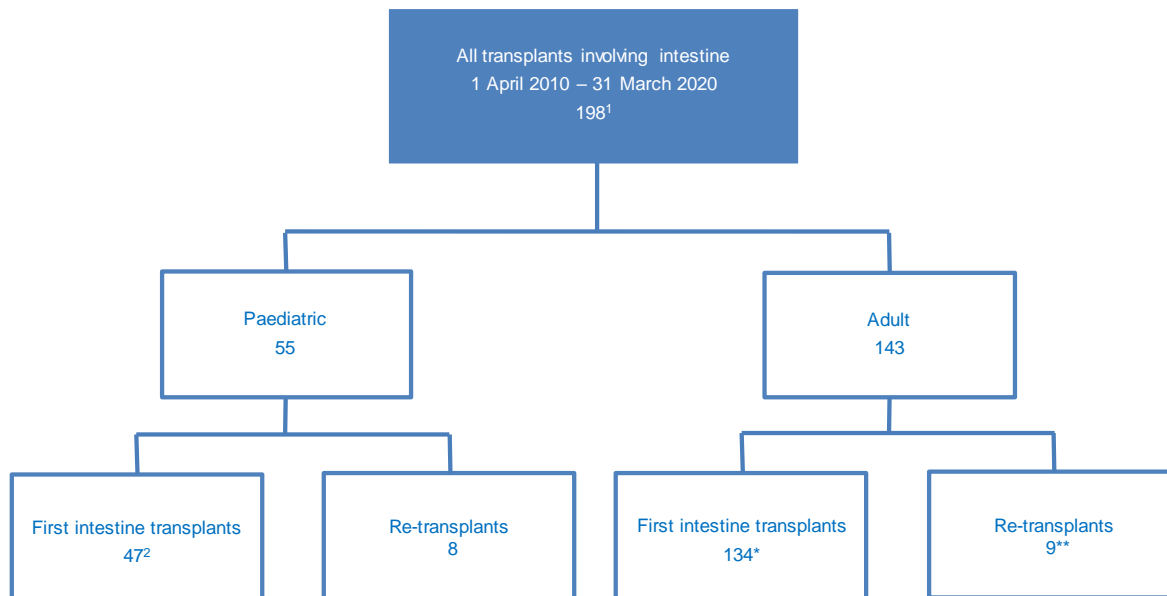
## 2.2 Transplants

**Figure 2.6** 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 198, with annual figures fluctuating between 14 and 26. In 2019/2020, there were 20 transplants performed.



**Figure 2.7** details the 198 intestine transplants performed in the UK in the 10 year period. Of these, 55 (28%) were in paediatric patients and 143 (72%) were in adult patients. Most of both paediatric and adult transplants were in first time recipients.

**Figure 2.7 UK intestine transplants, 1 April 2010 to 31 March 2020**



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

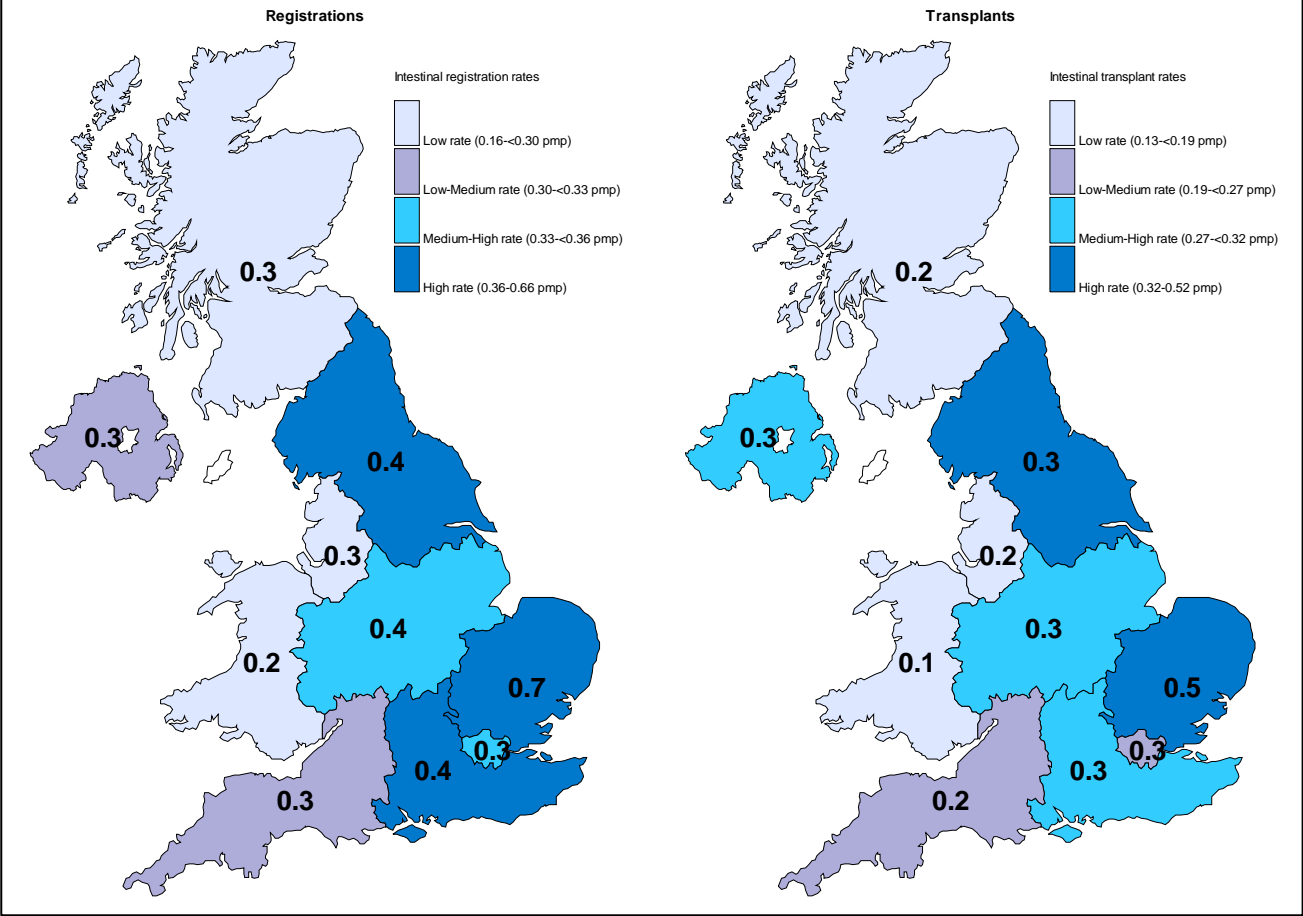
\* Five of these transplants were super-urgent  
\*\* Two of these transplants were super-urgent

## 2.3 Geographical variation in registration and transplant rates

**Figure 2.6** shows the mean annual rate of registration to the intestine transplant list per million population based on registrations between 1 April 2010 and 31 March 2020 compared with the annual average intestine transplant rates pmp for the same time period, by recipient country/NHS region of residence. **Table 2.2** shows the breakdown of these numbers by recipient country/NHS region 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 than a random effect for the different NHS regions in England only. Only first registrations and transplants in this period were considered. The larger the SCV the greater the evidence of a high level of systematic variation between areas. Registration and transplant rates yielded an SCV of 0 (p-value >0.999) and 0 (p-value >0.999), respectively. The p-value shows the probability that an SCV of this size (or higher) would be observed by chance if only random variation existed and therefore there is no evidence of geographical variation beyond what would be expected at random. No adjustment has been made for area-specific demographic characteristics that may impact the rates of registration to the transplant list and transplantation such as age and sex. Therefore, these results should be interpreted with caution.

**Figure 2.8 Comparison of mean annual intestine registration rates (pmp) with mean annual transplant rates (pmp) by recipient country/NHS region of residence, 1 April 2010 – 31 March 2020**





**Table 2.2 Intestinal registration and transplant rates per million population (pmp) in the UK, 1 April 2010 – 31 March 2020, by Country/NHS region**

<b>Country/ NHS region</b>	<b>Registrations (pmp)</b>		<b>Transplants (pmp)</b>	
North East and Yorkshire	3.3	(0.4)	2.8	(0.3)
North West	2.1	(0.3)	1.3	(0.2)
Midlands	3.7	(0.4)	2.9	(0.3)
East of England	4.3	(0.7)	3.4	(0.5)
London	3	(0.3)	2.3	(0.3)
South East	3.2	(0.4)	2.5	(0.3)
South West	1.8	(0.3)	1.2	(0.2)
<b>England</b>	<b>21.4</b>	<b>(0.4)</b>	<b>16.4</b>	<b>(0.3)</b>
<b>Isle of Man</b>	<b>0</b>	<b>(0.0)</b>	<b>0</b>	<b>(0.0)</b>
<b>Channel Islands</b>	<b>0</b>	<b>(0.0)</b>	<b>0</b>	<b>(0.0)</b>
<b>Wales</b>	<b>0.5</b>	<b>(0.2)</b>	<b>0.4</b>	<b>(0.1)</b>
<b>Scotland</b>	<b>1.4</b>	<b>(0.3)</b>	<b>0.9</b>	<b>(0.2)</b>
<b>Northern Ireland</b>	<b>0.6</b>	<b>(0.3)</b>	<b>0.6</b>	<b>(0.3)</b>
<b>TOTAL</b>	<b>24.2<sup>1</sup></b>	<b>(0.4)</b>	<b>18.7<sup>2</sup></b>	<b>(0.3)</b>

<sup>1</sup> Registrations include 3 recipients whose postcode was unknown and excludes 3 recipients who reside in the Republic of Ireland and 6 recipients who reside overseas

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

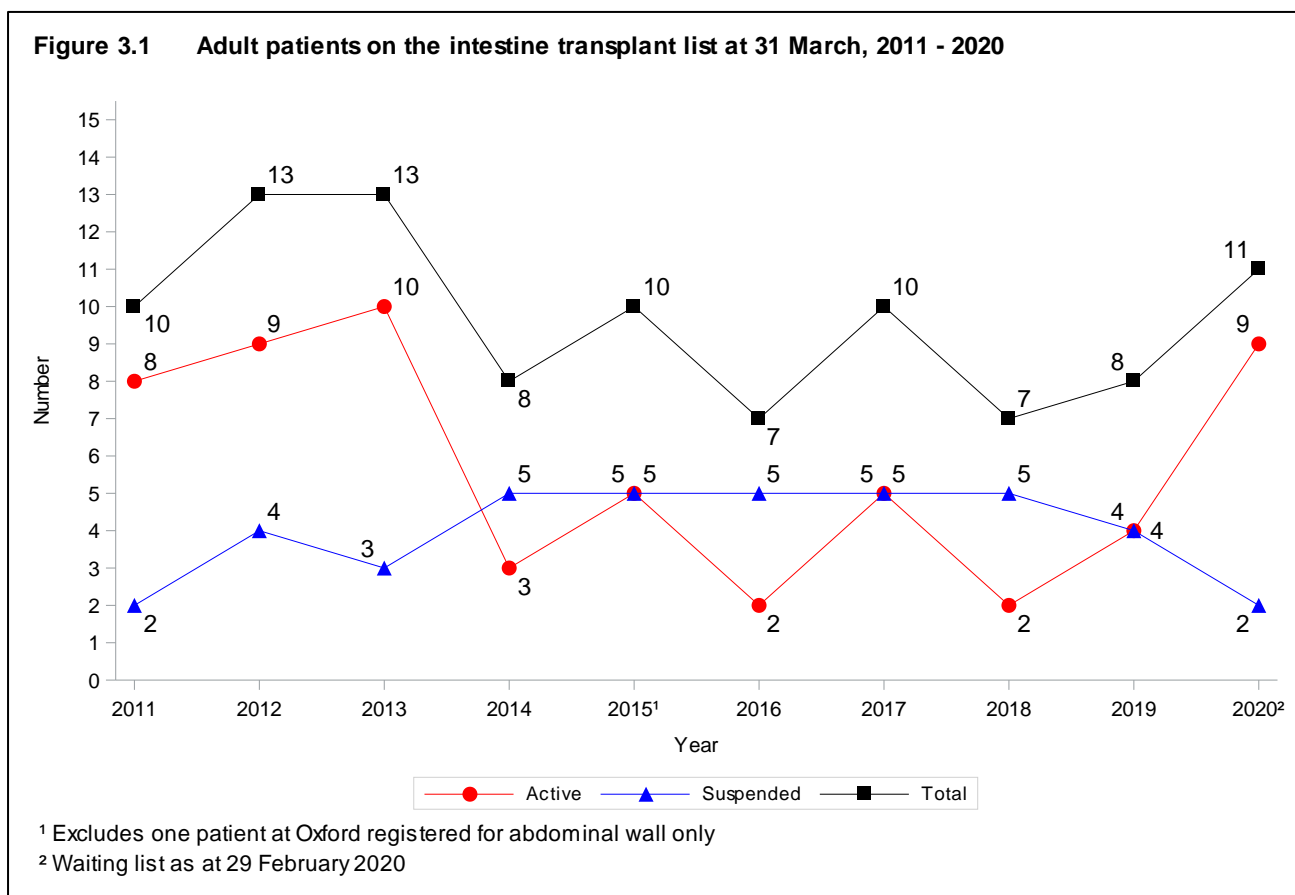
# **ADULT INTESTINE TRANSPLANTATION**



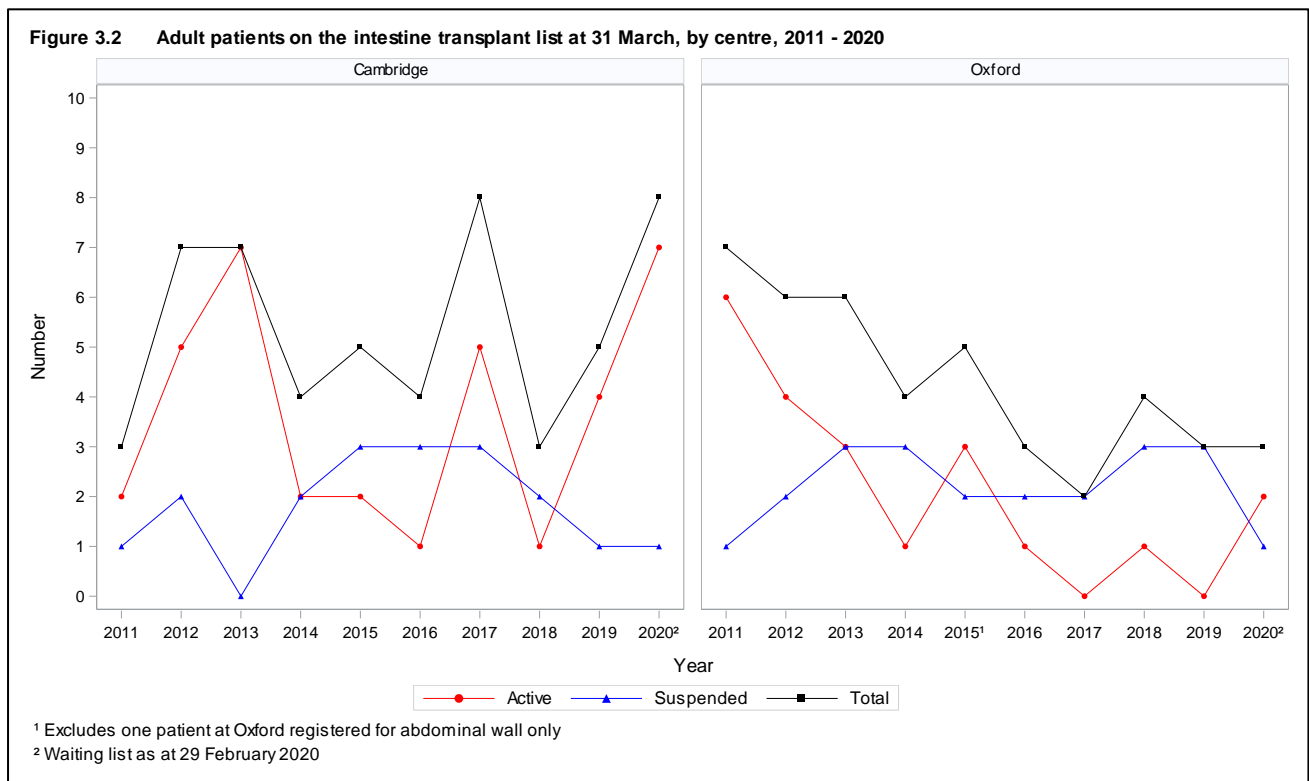
### 3. Transplant list

#### 3.1 Adult intestine transplant list as at 31 March, 2011 – 2020

Figure 3.1 shows the number of adult patients active or suspended on the intestine transplant list at 31 March of each year between 2011 and 2020. The number of patients on the [active intestine transplant list](#) remained low over most of the decade but has increased to 9 at 29 February 2020.



**Figure 3.2** shows the number of adult patients on the intestine transplant list at 31 March of each year between 2011 and 2020, at each transplant centre. Cambridge had generally more adult patients on the national [active transplant list](#) than Oxford.



The demographic characteristics of 173 adult intestine transplant recipient registrations in the 10 year period are shown by centre and overall in **Table 3.1**. Nationally, 53% 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 22 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 2010 - 31 March 2020**

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of registrations		117 (100)	56 (100)	<b>173 (100)</b>
Number of patients		105	54	<b>159</b>
Registration type	Elective	110 (94)	56 (100)	<b>166 (96)</b>
	Super-urgent	7 (6)	0 (0)	<b>7 (4)</b>
Transplant type required	Intestine only	1 (1)	28 (50)	<b>29 (17)</b>
	Including liver	78 (67)	-	<b>78 (45)</b>
	Not including liver	38 (32)	28 (50)	<b>66 (38)</b>
Recipient sex	Male	57 (49)	35 (63)	<b>92 (53)</b>
	Female	60 (51)	21 (38)	<b>81 (47)</b>
Recipient ethnicity group	White	106 (91)	52 (93)	<b>158 (91)</b>
	Other	11 (9)	4 (7)	<b>15 (9)</b>
Indication group	Short bowel syndrome	44 (38)	21 (38)	<b>65 (38)</b>
	Motility disorders	8 (7)	5 (9)	<b>13 (8)</b>
	Tumour	11 (9)	20 (36)	<b>31 (18)</b>
	Liver disease	15 (13)	1 (2)	<b>16 (9)</b>
	Other/not reported	15 (13)	6 (11)	<b>21 (12)</b>
	Retransplant	8 (7)	2 (4)	<b>10 (6)</b>
	Mesenteric thrombosis	16 (14)	1 (2)	<b>17 (10)</b>
Pre-transplant renal support	No	106 (91)	54 (96)	<b>160 (93)</b>
	Yes	11 (9)	2 (4)	<b>13 (8)</b>
Previous abdominal surgery	No	18 (15)	0 (0)	<b>18 (10)</b>
	Yes	92 (79)	56 (100)	<b>148 (86)</b>
	Not reported	7 (6)	0 (0)	<b>7 (4)</b>
Recipient blood group	O	48 (41)	28 (50)	<b>76 (44)</b>
	A	44 (38)	21 (38)	<b>65 (38)</b>
	B	18 (15)	5 (9)	<b>23 (13)</b>
	AB	7 (6)	2 (4)	<b>9 (5)</b>
Recipient age (years)	Median (IQR)	44 (33,54)	40 (34,52)	<b>43 (33,53)</b>
	Not reported	0	0	<b>0</b>
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (20,26)	22 (20,25)	<b>22 (20,25)</b>
	Not reported	2	1	<b>3</b>

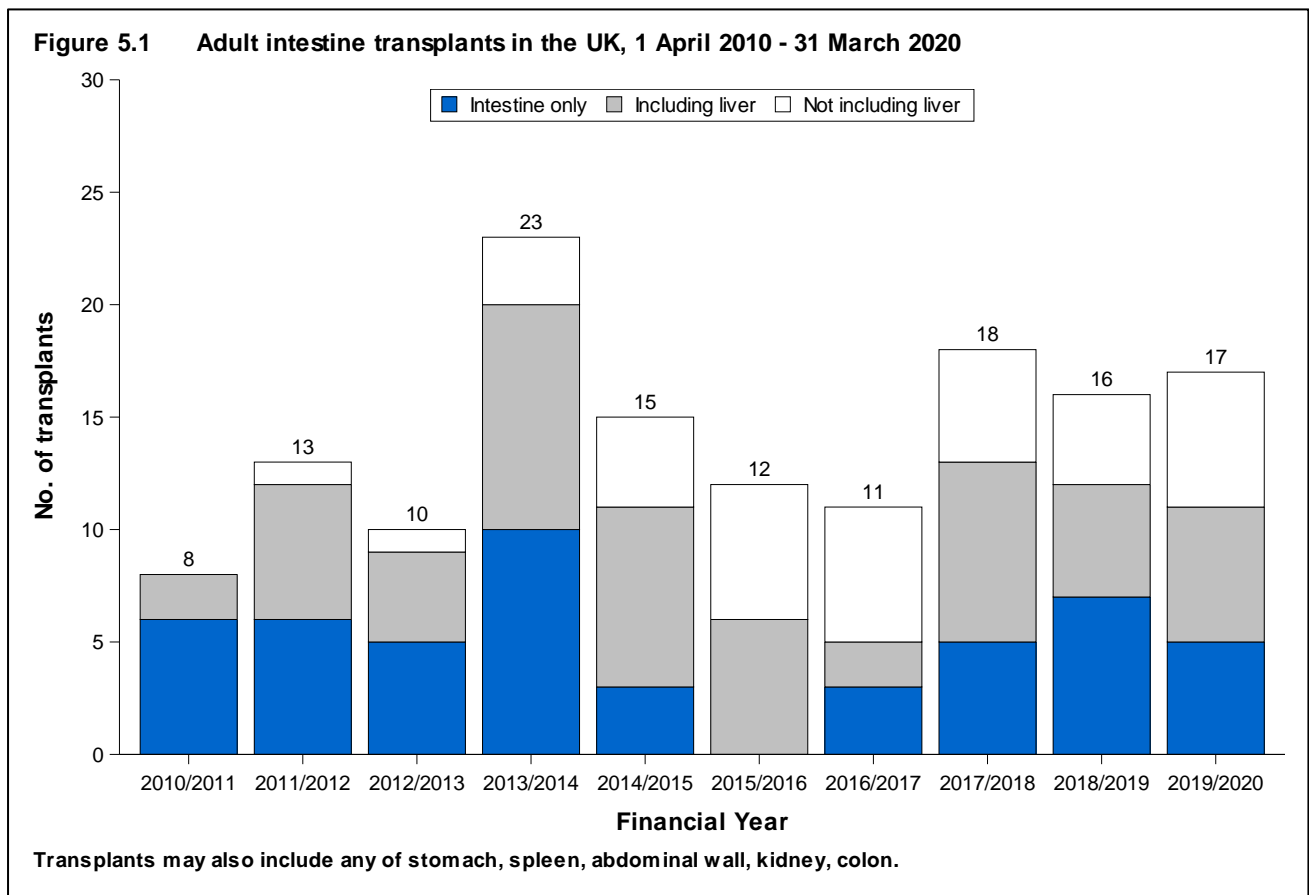
#### 4. Response to offers

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 2019 and 31 March 2020, Cambridge received intestine offers from 120 donors and Oxford received intestine offers from 67. Their [offer decline rates](#) were 90% and 93%, respectively.

#### 5. Transplants

##### 5.1 Adult intestine transplants, 1 April 2010 – 31 March 2020

**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 reached a peak of 23 in 2013/2014 before falling, but increased slightly to 17 in the last financial year.



**Figure 5.2** shows the number of adult intestine transplants performed in 2019/2020, by centre and [transplant type](#). Cambridge performed 12 of the 17 transplants last year. Half of transplants performed at Cambridge included the liver while all performed at Oxford were categorised as intestine only.

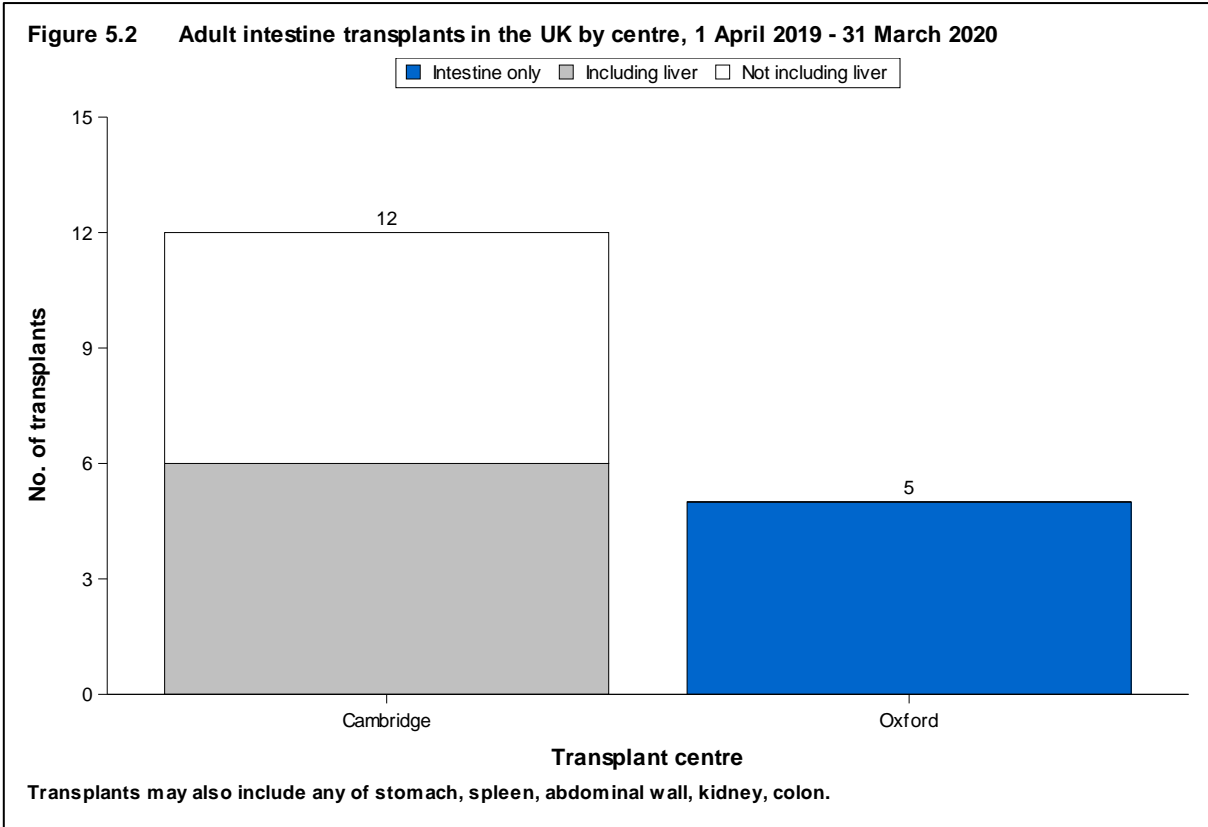
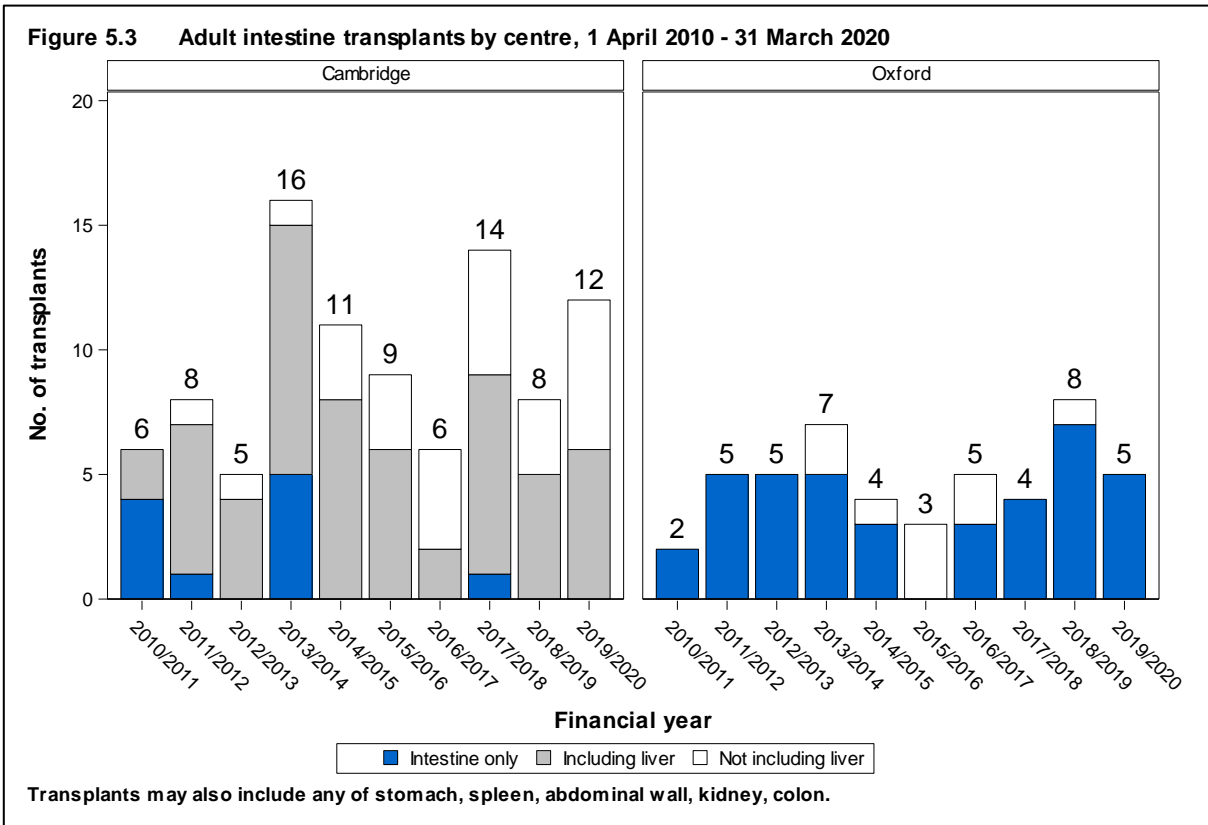


Figure 5.3 shows the number of adult intestine transplants performed in the last 10 years, by centre and [type of transplant](#). Oxford performed their highest number of transplants over the decade in 2018/2019, while Cambridge performed their highest number in 2013/2014. Overall Cambridge performed 95 transplants (66%) and Oxford performed 48 (34%).



The demographic characteristics of 143 adult intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 5.1**. Nationally, 55% of recipients were male and the [median](#) age of recipients was 45 years old, while the median age of donors was 31 years old. The most common indication for transplantation was short bowel syndrome. Seven of the transplants were in super-urgent patients, with the rest in [elective](#) recipients. For some characteristics, percentages may not add up to 100 due to rounding.

<b>Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2010 - 31 March 2020</b>				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of transplants		95 (100)	48 (100)	<b>143 (100)</b>
Urgency	Elective	88 (93)	48 (100)	<b>136 (95)</b>
	Super-urgent	7 (7)	0 (0)	<b>7 (5)</b>
Recipient sex	Male	48 (51)	30 (63)	<b>78 (55)</b>
	Female	47 (49)	18 (38)	<b>65 (46)</b>
Recipient ethnicity group	White	87 (92)	44 (92)	<b>131 (92)</b>
	Other	8 (8)	4 (8)	<b>12 (8)</b>
Indication group	Short bowel syndrome	42 (44)	21 (44)	<b>63 (44)</b>
	Motility disorders	7 (7)	4 (8)	<b>11 (8)</b>
	Tumour	10 (11)	18 (38)	<b>28 (20)</b>
	Liver disease	10 (11)	1 (2)	<b>11 (8)</b>
	Other/not reported	7 (7)	1 (2)	<b>8 (6)</b>
	Retransplant	5 (5)	2 (4)	<b>7 (5)</b>
	Mesenteric thrombosis	14 (15)	1 (2)	<b>15 (11)</b>
Patient location	Out-patient	55 (58)	41 (85)	<b>96 (67)</b>
	Ward	23 (24)	7 (15)	<b>30 (21)</b>
	ICU/HDU	12 (13)	0 (0)	<b>12 (8)</b>
	Not reported	5 (5)	0 (0)	<b>5 (4)</b>
Pre-transplant renal support	No	83 (87)	47 (98)	<b>130 (91)</b>
	Yes	7 (7)	1 (2)	<b>8 (6)</b>
	Not reported	5 (5)	0 (0)	<b>5 (4)</b>
Previous abdominal surgery	No	14 (15)	2 (4)	<b>16 (11)</b>
	Yes	73 (77)	46 (96)	<b>119 (83)</b>
	Not reported	8 (8)	0 (0)	<b>8 (6)</b>
Life style activity	Normal	1 (1)	4 (8)	<b>5 (4)</b>
	Restricted	19 (20)	6 (13)	<b>25 (18)</b>
	Self-care	33 (35)	29 (60)	<b>62 (43)</b>
	Confined	11 (12)	5 (10)	<b>16 (11)</b>
	Reliant	18 (19)	3 (6)	<b>21 (15)</b>
	Not reported	13 (14)	1 (2)	<b>14 (10)</b>
Restricted venous access at registration	No	63 (66)	31 (65)	<b>94 (66)</b>
	Yes	24 (25)	15 (31)	<b>39 (27)</b>
	Not reported	8 (8)	2 (4)	<b>10 (7)</b>
Recipient age (years)	Median (IQR)	46 (33,54)	41 (34,52)	<b>45 (34,54)</b>

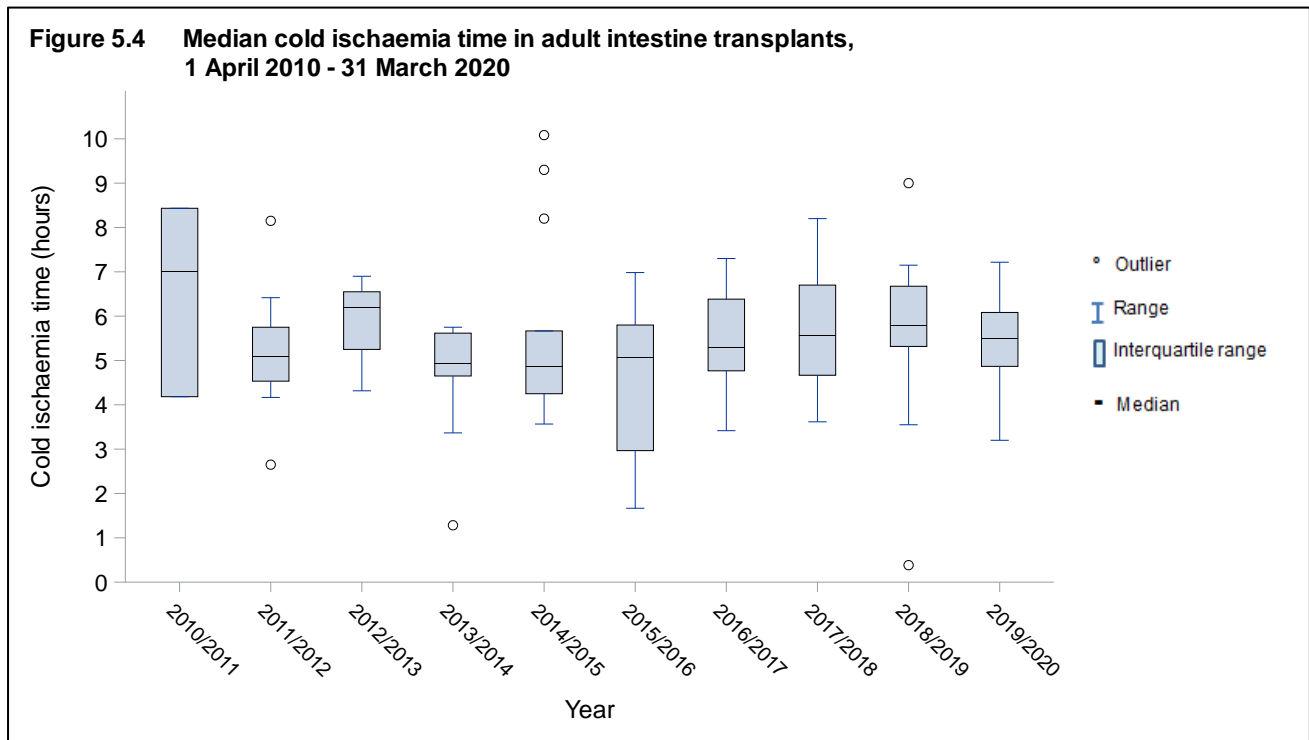


**Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2010 - 31 March 2020**

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (20,24)	22 (20,24)	<b>22 (20,24)</b>
	Not reported	1	1	<b>2</b>
Serum bilirubin (umol/l)	Median (IQR)	20 (11,62)	10 (5,12)	<b>13 (8,29)</b>
	Not reported	6	0	<b>6</b>
Time on list (days)	Median (IQR)	48 (17,142)	43 (17,113)	<b>48 (17,119)</b>
Donor sex	Male	36 (38)	25 (52)	<b>61 (43)</b>
	Female	59 (62)	23 (48)	<b>82 (57)</b>
Donor ethnicity group	White	88 (93)	45 (94)	<b>133 (93)</b>
	Other	7 (7)	2 (4)	<b>9 (6)</b>
	Not reported	0 (0)	1 (2)	<b>1 (1)</b>
Donor cause of death group	Stroke	76 (80)	28 (58)	<b>104 (73)</b>
	Trauma	12 (13)	15 (31)	<b>27 (19)</b>
	Other	7 (7)	5 (10)	<b>12 (8)</b>
Donor history of diabetes	No	95 (100)	48 (100)	<b>143 (100)</b>
Donor age (years)	Median (IQR)	32 (20,41)	28 (21,39)	<b>31 (20,41)</b>
Donor BMI (kg/m <sup>2</sup> )	Median (IQR)	22 (20,24)	22 (21,23)	<b>22 (21,24)</b>
Transplant type	Intestine only	11 (12)	39 (81)	<b>50 (35)</b>
	Including liver	57 (60)	-	<b>57 (40)</b>
	Not including liver	27 (28)	9 (19)	<b>36 (25)</b>
ABO match	Identical	65 (68)	45 (94)	<b>110 (77)</b>
	Compatible	30 (32)	3 (6)	<b>33 (23)</b>
Cold ischaemic time (hours)	Median (IQR)	4.9 (4.2,5.6)	6.2 (5.6,7.0)	<b>5.4 (4.6,6.2)</b>
	Not reported	12	7	<b>19</b>

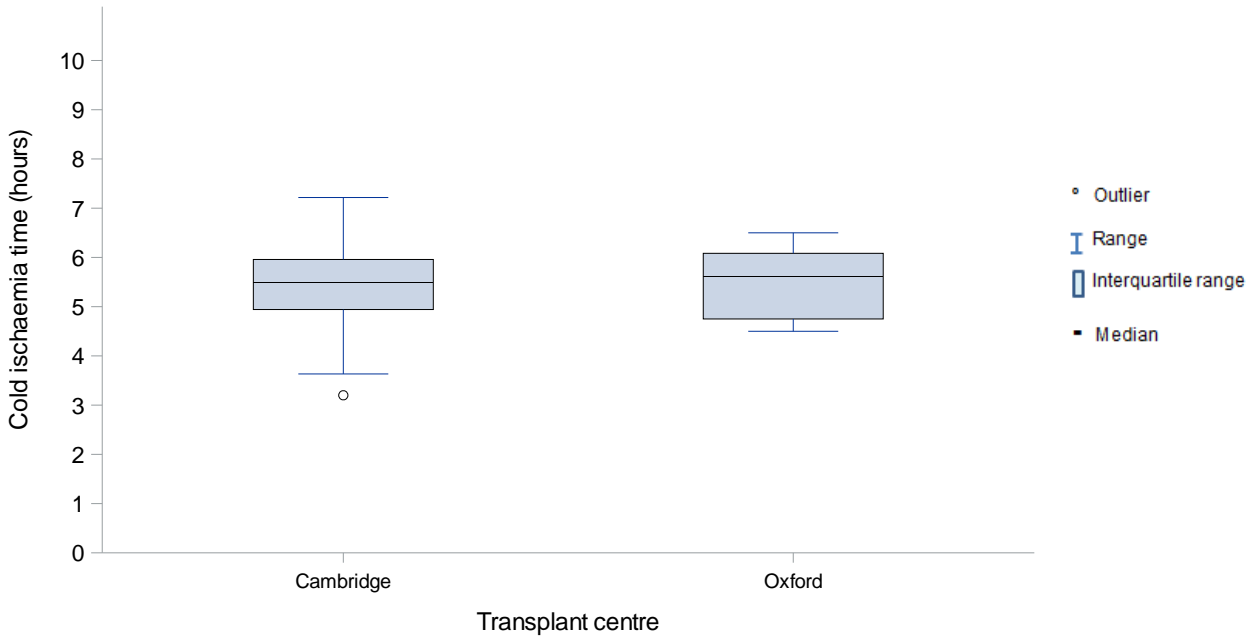
## 5.2 Cold ischaemia time, 1 April 2010 – 31 March 2020

**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 generally decreased in the decade, from 7.0 hours in 2010/2011 to 5.5 hours in 2018/2019.

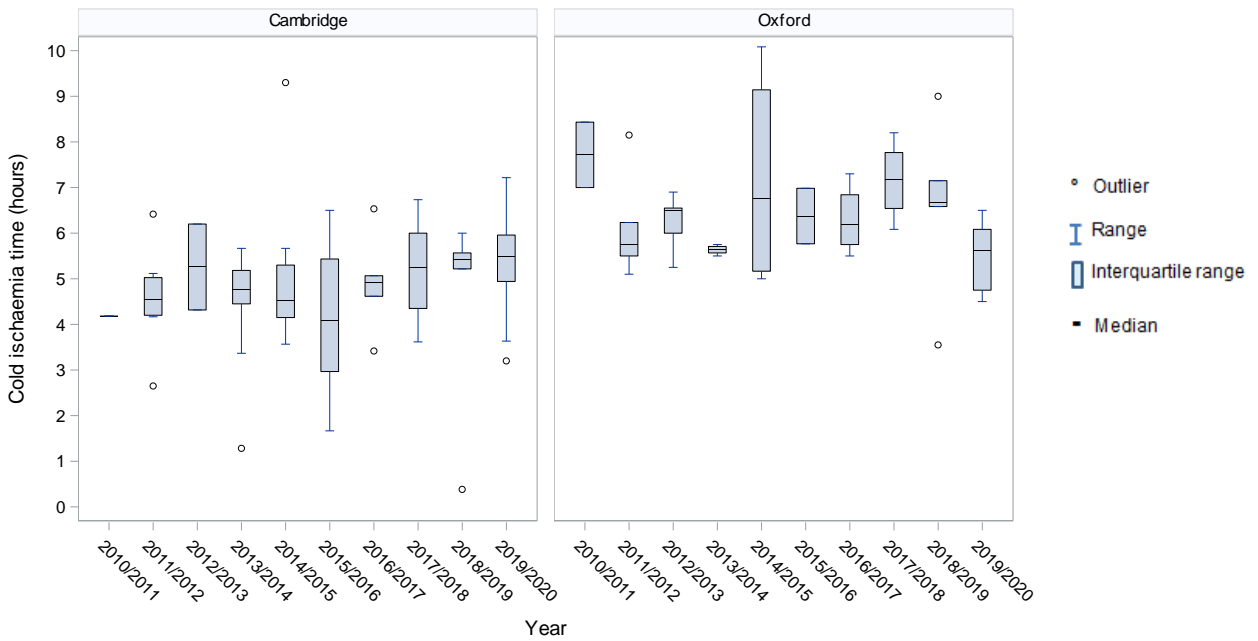


**Figure 5.5** shows the median CITs in adult intestine transplants in 2019/2020 for each transplant centre, while **Figure 5.6** shows the same data but over the last 10 years. Generally, CITs were longer for transplants performed by Oxford. All of these boxplots represent a small number of observations 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 2019 - 31 March 2020**



**Figure 5.6 Median cold ischaemia time in all adult intestine transplants, 1 April 2010 - 31 March 2020**



## 6. Post-transplant survival

This section presents patient survival post adult intestine transplantation for first intestine transplants between 1 April 2010 and 31 March 2020. Of the 134 transplants of this kind in the time period, survival information was known in all cases. Due to small numbers, [unadjusted survival rates](#) only are presented, but these do not account for differences in the [case mix](#) at each centre and transplant type.

### 6.1 Survival by transplant type

**Table 6.1** shows the 90-day [patient survival rates](#) for adult first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type. The 90-day survival rate for patients who received a liver was 88.5% and was 95.1% for patients not receiving the liver. There was no evidence of a significant difference in survival between those receiving the liver and those who did not at 90 days (log-rank  $p=0.15$ ).

<b>Table 6.1 90-day patient survival (%) for adult first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type</b>			
<b>Transplant type</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI) <a href="#">Unadjusted</a></b>	
<b>Cambridge</b>			
Including liver	52	88.5	(76.1-94.6)
Not including liver <sup>1</sup>	36	100.0	-
<b>Oxford</b>			
Not including liver <sup>1</sup>	46	91.3	(78.3-96.6)
<b>Total</b>			
<b>Including liver</b>	<b>52</b>	<b>88.5</b>	<b>(76.1-94.6)</b>
<b>Not including liver<sup>1</sup></b>	<b>82</b>	<b>95.1</b>	<b>(87.5-98.1)</b>
<sup>1</sup> Includes intestine only			

One-year [patient survival rates](#) are shown in **Table 6.2**. At one year post-transplant, the survival rate for patients not receiving the liver was 88.1%, and was 73.9% for patients receiving the liver. There was evidence of a moderate significant difference in survival between those receiving the liver and those who did not at 1 year post-transplant (log-rank  $p=0.03$ ).

<b>Table 6.2 1-year patient survival (%) for adult first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type</b>			
<b>Transplant type</b>	<b>Number of transplants</b>	<b>1-year survival (95% CI) <u>Unadjusted</u></b>	
<b>Cambridge</b>			
Including liver	52	73.9	(59.3-84.0)
Not including liver <sup>1</sup>	36	87.3	(69.6-95.0)
<b>Oxford</b>			
Not including liver <sup>1</sup>	46	88.8	(75.1-95.2)
<b>Total</b>			
<b>Including liver</b>	<b>52</b>	<b>73.9</b>	<b>(59.3-84.0)</b>
<b>Not including liver<sup>1</sup></b>	<b>82</b>	<b>88.1</b>	<b>(78.3-93.6)</b>
<sup>1</sup> Includes intestine only			

Five-year [patient survival rates](#) are shown in **Table 6.3**. At five year post-transplant, the survival rate for patients not receiving the liver was 71.8%, and was 39.3% for patients receiving the liver. There was evidence of a strong significant difference in survival between those receiving the liver and those who did not at 5 years (log-rank p=0.002).

<b>Table 6.3 5-year patient survival (%) for adult first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type</b>			
<b>Transplant type</b>	<b>Number of transplants</b>	<b>5-year survival (95% CI) <u>Unadjusted</u></b>	
<b>Cambridge</b>			
Including liver	52	39.3	(22.2-56.0)
Not including liver <sup>1</sup>	36	79.1	(58.8-90.2)
<b>Oxford</b>			
Not including liver <sup>1</sup>	46	65.8	(44.9-80.4)
<b>Total</b>			
<b>Including liver</b>	<b>52</b>	<b>39.3</b>	<b>(22.2-56.0)</b>
<b>Not including liver<sup>1</sup></b>	<b>82</b>	<b>71.8</b>	<b>(57.7-82.0)</b>
<sup>1</sup> Includes intestine only			

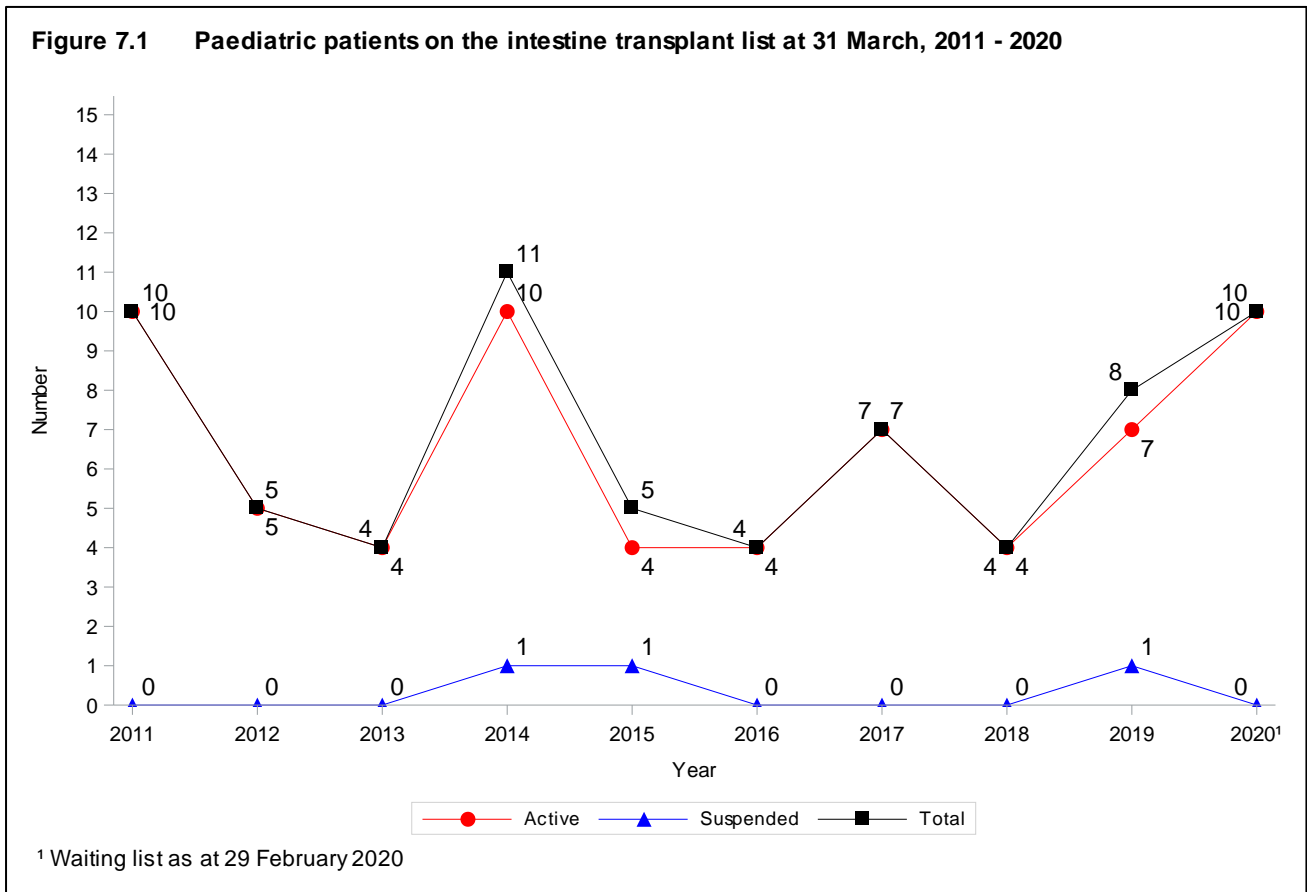
# **PAEDIATRIC INTESTINE TRANSPLANTATION**



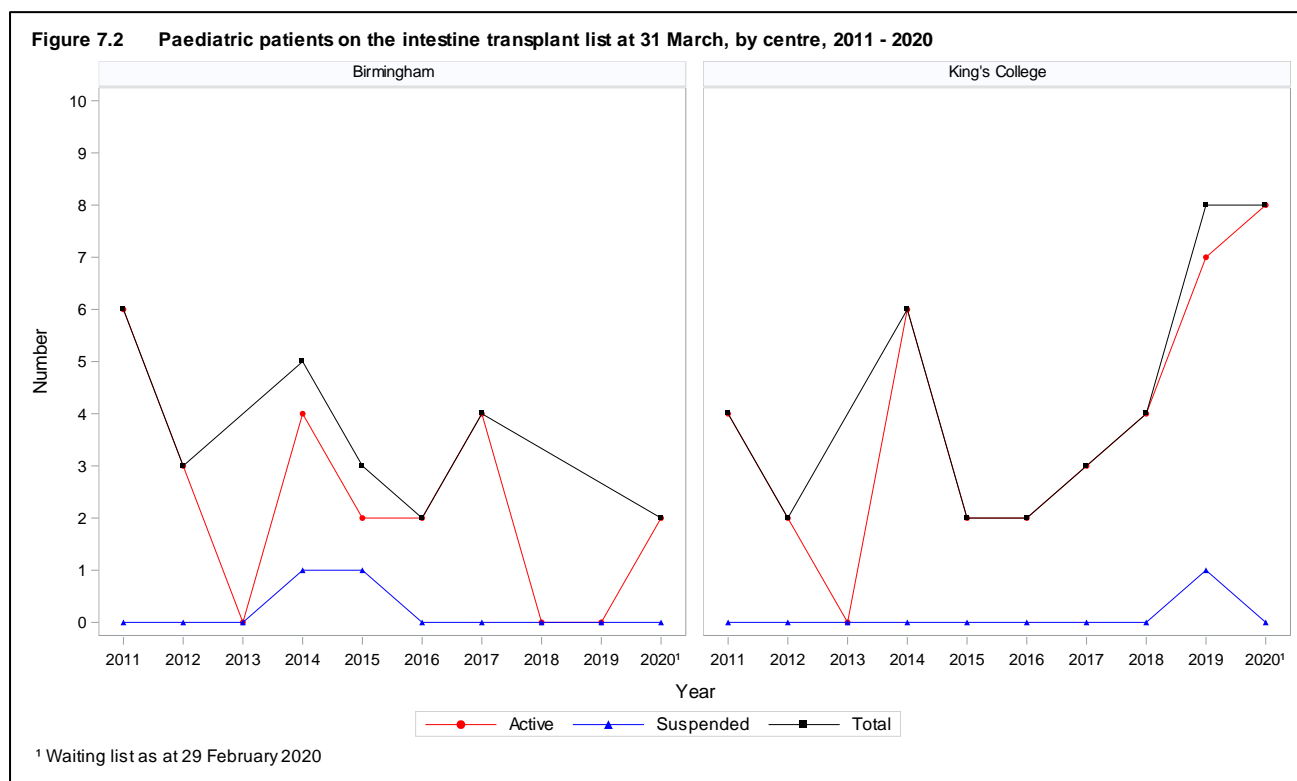
## 7. Transplant list

### 7.1 Paediatric intestine transplant list as at 31 March, 2011 – 2020

**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 2011 and 2020. The number of patients on the [active transplant list](#) ranged between 4 and 10 each year and was 10 on 29 February 2020.



**Figure 7.2** shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2011 and 2020, at each transplant centre. The number of patients waiting at Birmingham has decreased over the decade while the numbers waiting at King's College Hospital has increased in recent years.



The demographic characteristics of 81 paediatric intestine transplant recipient registrations in the 10-year period are shown by centre and overall in **Table 7.1**. Nationally, 57% of patients were male and the [median](#) age was 3 years old. The most commonly 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 2010 - 31 March 2020**

		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		43 (100)	38 (100)	<b>81 (100)</b>
Number of patients		40	33	<b>73</b>
Registration type	Elective	43 (100)	38 (100)	<b>81 (100)</b>
Transplant type required	Intestine only	10 (23)	11 (29)	<b>21 (26)</b>
	Including liver	29 (67)	26 (68)	<b>55 (68)</b>
	Not including liver	4 (9)	1 (3)	<b>5 (6)</b>
Recipient sex	Male	26 (60)	20 (53)	<b>46 (57)</b>
	Female	17 (40)	18 (47)	<b>35 (43)</b>
Recipient ethnicity group	White	37 (86)	25 (66)	<b>62 (77)</b>
	Other	6 (14)	13 (34)	<b>19 (24)</b>
Indication group	Short bowel syndrome	24 (56)	15 (39)	<b>39 (48)</b>
	Motility disorders	6 (14)	10 (26)	<b>16 (20)</b>
	Primary mucosal disorders	6 (14)	3 (8)	<b>9 (11)</b>
	Other/not reported	1 (2)	3 (8)	<b>4 (5)</b>
	Retransplant	6 (14)	7 (18)	<b>13 (16)</b>
Pre-transplant renal support	No	41 (95)	37 (97)	<b>78 (96)</b>
	Yes	1 (2)	1 (3)	<b>2 (3)</b>
	Not reported	1 (2)	0 (0)	<b>1 (1)</b>
Previous abdominal surgery	No	7 (16)	3 (8)	<b>10 (12)</b>
	Yes	36 (84)	35 (92)	<b>71 (88)</b>
Recipient blood group	O	20 (47)	10 (26)	<b>30 (37)</b>
	A	17 (40)	23 (61)	<b>40 (49)</b>
	B	5 (12)	4 (11)	<b>9 (11)</b>
	AB	1 (2)	1 (3)	<b>2 (3)</b>
Recipient age (years)	Median (IQR)	3 (0,6)	4 (2,6)	<b>3 (1,6)</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	0	0	<b>0</b>

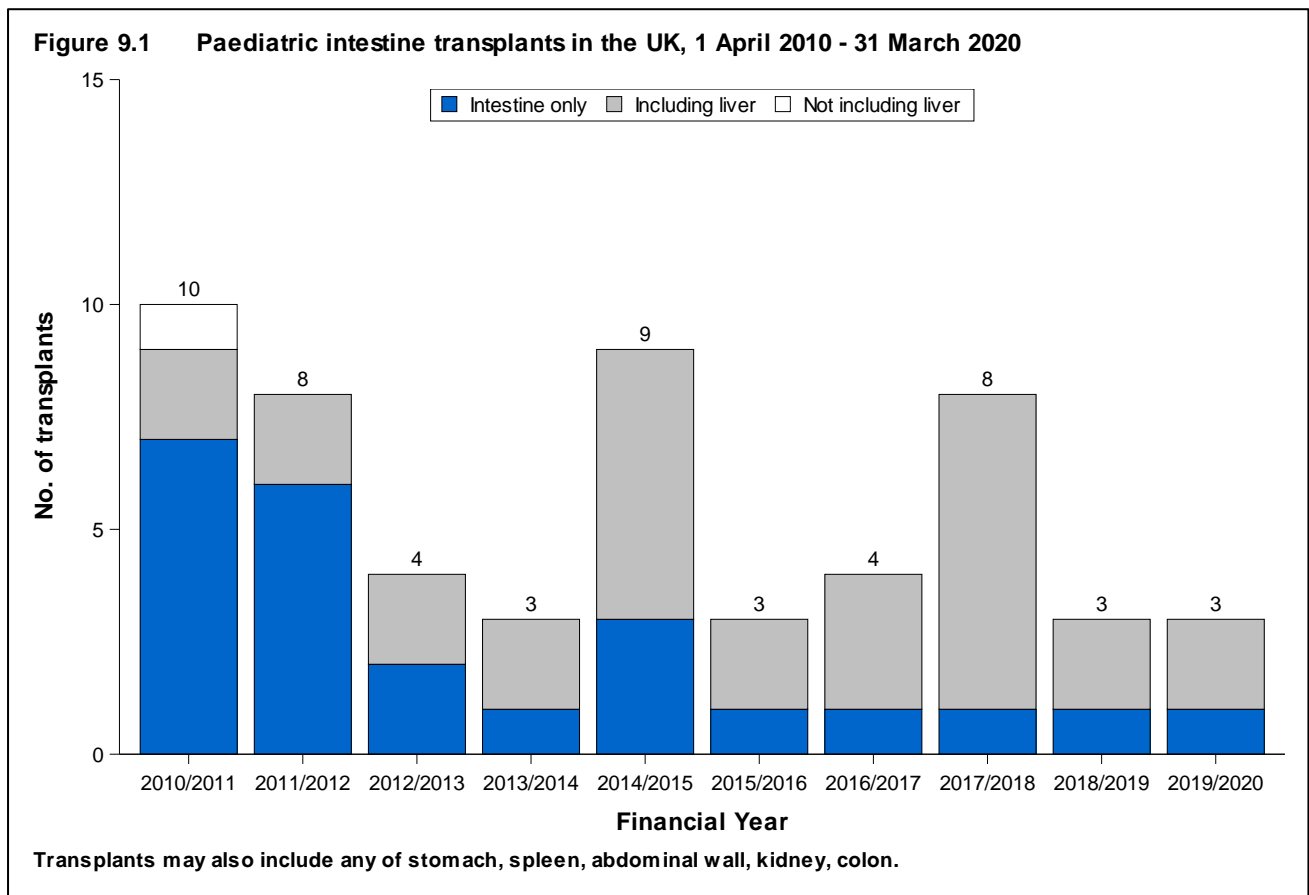
## 8. Response to offers

Between 1 April 2019 and 31 March 2020 Birmingham and King's College Hospital received offers from 6 and 13 donors, respectively, for intestine transplant patients at their centres. Their [offer decline rates](#) were 100% and 77% respectively. These rates are very high to some extent because centres are very selective, particularly about the size of the donor.

## 9. Transplants

### 9.1 Paediatric intestine transplants, 1 April 2010 – 31 March 2020

**Figure 9.1** shows the number of paediatric intestine transplants performed in the last 10 years, by [transplant type](#). The number of paediatric transplants has fallen over the period, with a peak of 10 in 2010/2011 to 3 in 2019/2020. 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 2019/2020, by centre and [transplant type](#). Birmingham performed no transplants, and King's College Hospital performed three transplants, two of which included the liver.

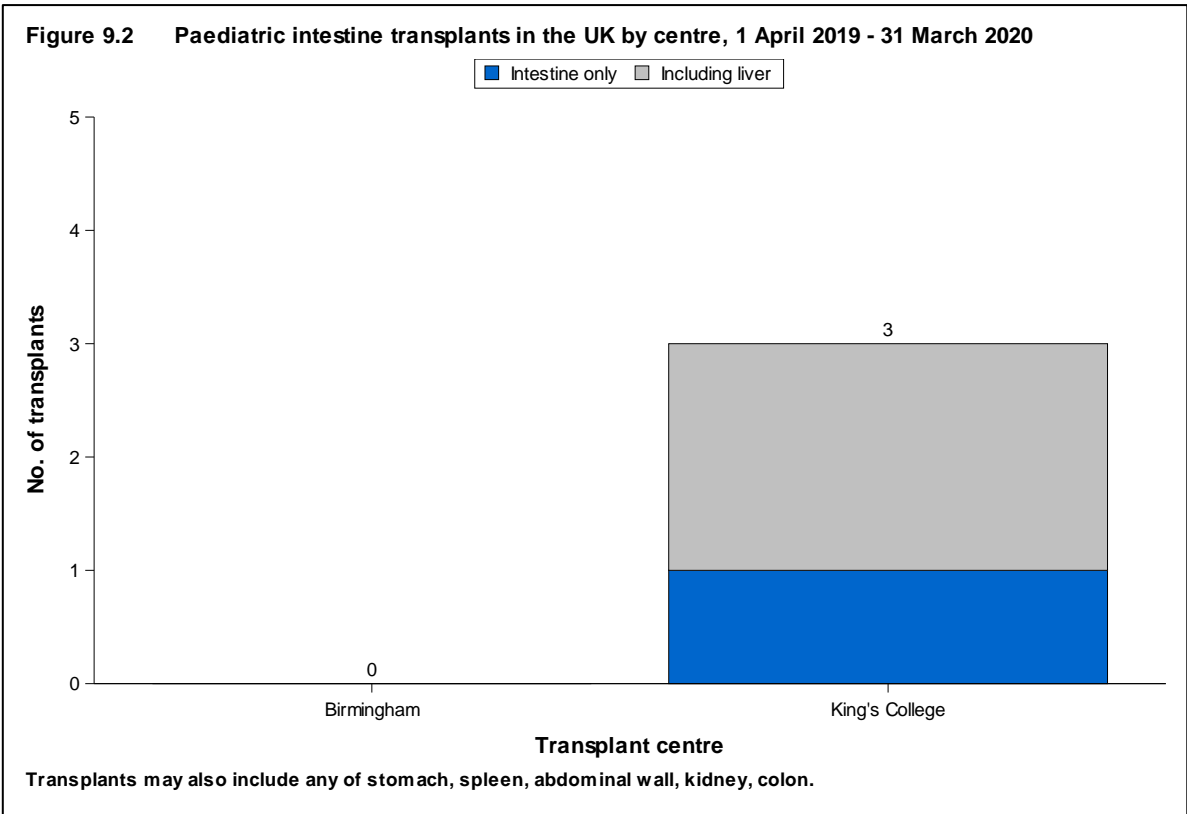
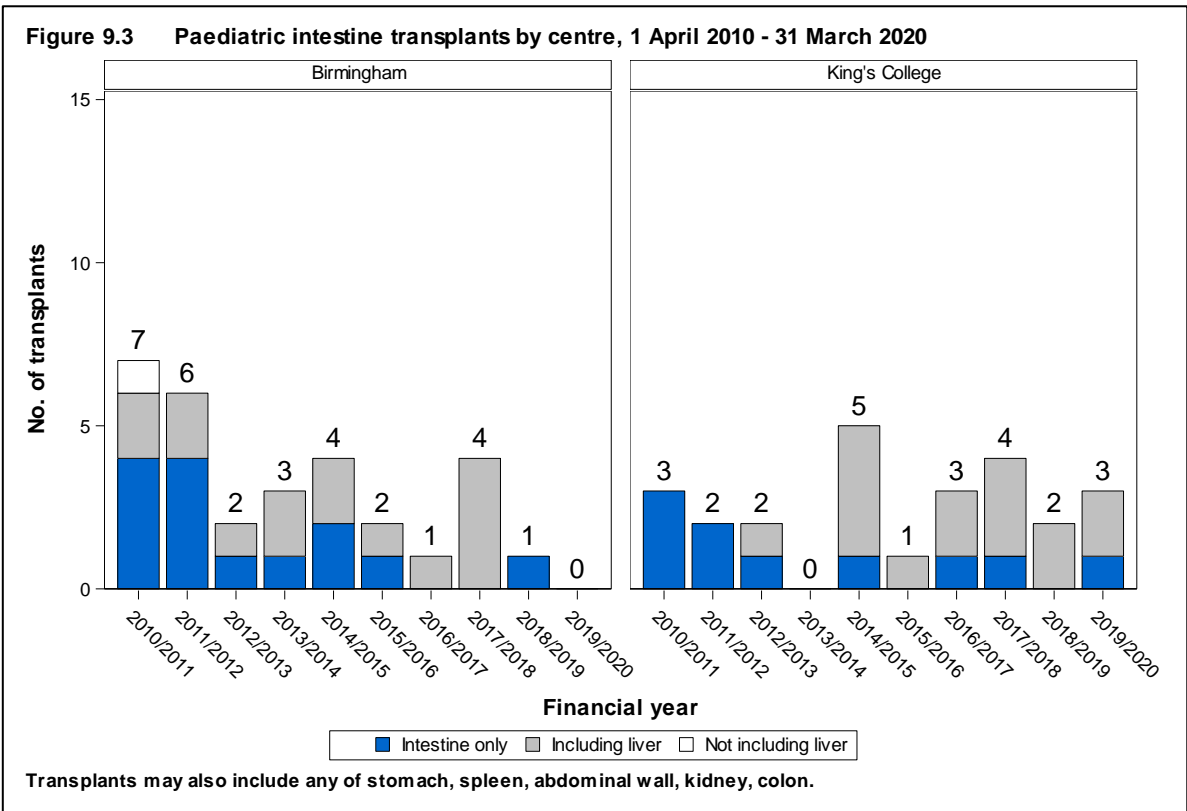


Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and [type of transplant](#). There is a decreasing trend in the number of transplants performed by Birmingham, but overall they performed 30 (55%) of transplants compared with 25 (45%) by King's College Hospital.



The demographic characteristics of 55 paediatric intestine transplant recipients in the 10-year period are shown by centre and overall in **Table 9.1**. Nationally, 53% of recipients were male and the [median](#) recipient age was 4 years old, while the median age of donors was 5 years old. The most common indication for transplantation was short bowel syndrome. All transplants were performed in [elective](#) recipients. For some characteristics, percentages may not add up to 100 due to rounding.

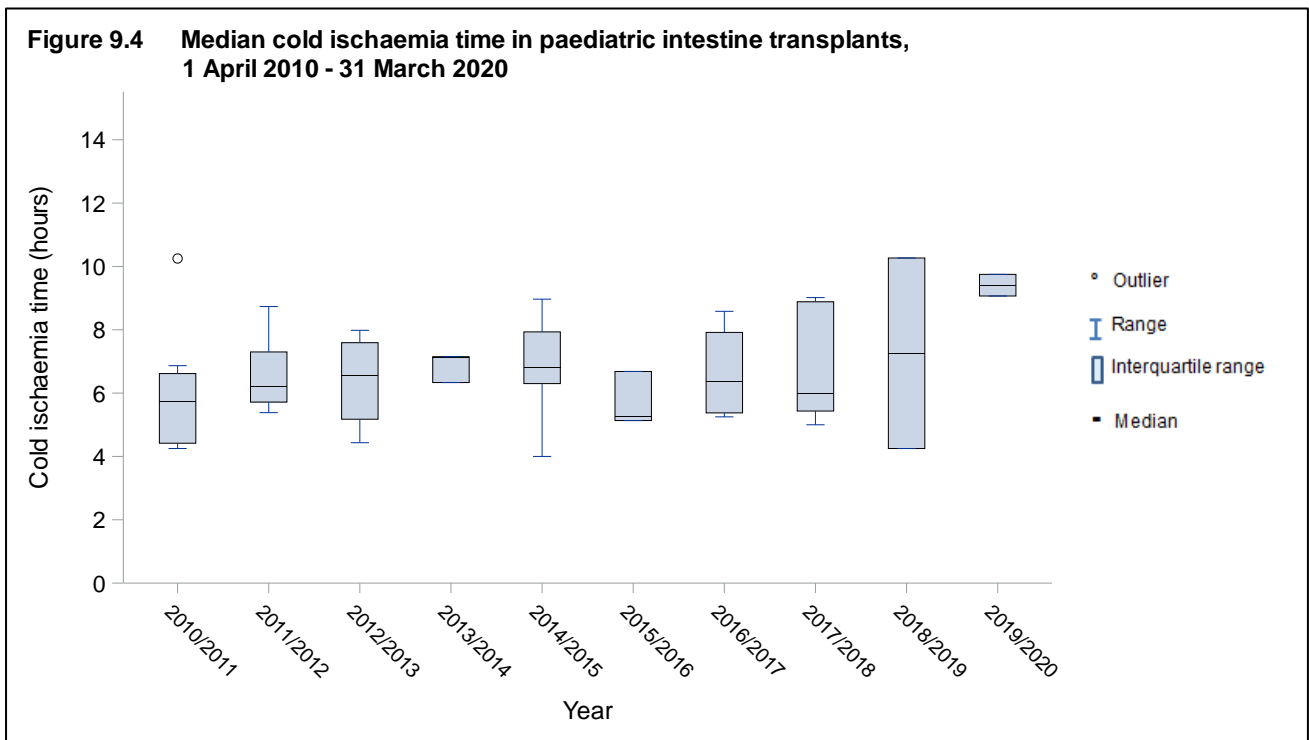
<b>Table 9.1 Demographic characteristics of paediatric intestine transplant recipients, 1 April 2010 - 31 March 2020</b>				
		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		30 (100)	25 (100)	<b>55 (100)</b>
Urgency	Elective	30 (100)	25 (100)	<b>55 (100)</b>
Recipient sex	Male	16 (53)	13 (52)	<b>29 (53)</b>
	Female	14 (47)	12 (48)	<b>26 (47)</b>
Recipient ethnicity group	White	23 (77)	18 (72)	<b>41 (75)</b>
	Other	7 (23)	7 (28)	<b>14 (26)</b>
Indication group	Short bowel syndrome	19 (63)	8 (32)	<b>27 (49)</b>
	Motility disorders	2 (7)	7 (28)	<b>9 (16)</b>
	Primary mucosal disorders	5 (17)	2 (8)	<b>7 (13)</b>
	Liver disease	1 (3)	0 (0)	<b>1 (2)</b>
	Other/not reported	0 (0)	2 (8)	<b>2 (4)</b>
	Retransplant	3 (10)	6 (24)	<b>9 (16)</b>
Patient location	Out-patient	26 (87)	18 (72)	<b>44 (80)</b>
	Ward	4 (13)	4 (16)	<b>8 (15)</b>
	ICU/HDU	0 (0)	3 (12)	<b>3 (6)</b>
Pre-transplant renal support	No	29 (97)	25 (100)	<b>54 (98)</b>
	Yes	1 (3)	0 (0)	<b>1 (2)</b>
Previous abdominal surgery	No	7 (23)	2 (8)	<b>9 (16)</b>
	Yes	23 (77)	23 (92)	<b>46 (84)</b>
Life style activity	Normal	1 (3)	1 (4)	<b>2 (4)</b>
	Restricted	7 (23)	7 (28)	<b>14 (26)</b>
	Reliant	0 (0)	3 (12)	<b>3 (6)</b>
	Aged five years or less	19 (63)	14 (56)	<b>33 (60)</b>
	Not reported	3 (10)	0 (0)	<b>3 (6)</b>
Restricted venous access at registration	No	13 (43)	14 (56)	<b>27 (49)</b>
	Yes	16 (53)	10 (40)	<b>26 (47)</b>
	Not reported	1 (3)	1 (4)	<b>2 (4)</b>
Recipient age (years)	Median (IQR)	4 (1,6)	5 (4,7)	<b>4 (2,7)</b>
	Not reported	0	0	<b>0</b>

<b>Table 9.1 Demographic characteristics of paediatric intestine transplant recipients, 1 April 2010 - 31 March 2020</b>				
		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Recipient BMI (kg/m <sup>2</sup> )	Median (IQR)	16 (16,17)	17 (16,19)	<b>17 (16,18)</b>
	Not reported	0	0	<b>0</b>
Serum bilirubin (umol/l)	Median (IQR)	9 (7,63)	10 (7,20)	<b>10 (7,29)</b>
	Not reported	2	0	<b>2</b>
Time on list (days)	Median (IQR)	192 (134,260)	204 (130,425)	<b>193 (134,356)</b>
Donor sex	Male	13 (43)	15 (60)	<b>28 (51)</b>
	Female	17 (57)	10 (40)	<b>27 (49)</b>
Donor ethnicity group	White	22 (73)	19 (76)	<b>41 (75)</b>
	Other	4 (13)	2 (8)	<b>6 (11)</b>
	Not reported	4 (13)	4 (16)	<b>8 (15)</b>
Donor cause of death group	Stroke	18 (60)	16 (64)	<b>34 (62)</b>
	Trauma	6 (20)	3 (12)	<b>9 (16)</b>
	Other	6 (20)	5 (20)	<b>11 (20)</b>
	Living	0 (0)	1 (4)	<b>1 (2)</b>
Donor history of diabetes	No	24 (80)	21 (84)	<b>45 (82)</b>
	Yes	1 (3)	0 (0)	<b>1 (2)</b>
	Not reported	5 (17)	4 (16)	<b>9 (16)</b>
Donor age (years)	Median (IQR)	7 (2,13)	3 (1,6)	<b>5 (1,10)</b>
Donor BMI (kg/m <sup>2</sup> )	Median (IQR)	16 (15,19)	15 (13,17)	<b>16 (14,18)</b>
	Not reported	0	1	<b>1</b>
Transplant type	Intestine only	14 (47)	10 (40)	<b>24 (44)</b>
	Including liver	15 (50)	15 (60)	<b>30 (55)</b>
	Not including liver	1 (3)	0 (0)	<b>1 (2)</b>
ABO match	Identical	23 (77)	19 (76)	<b>42 (76)</b>
	Compatible	7 (23)	6 (24)	<b>13 (24)</b>
Cold ischaemic time (hours)	Median (IQR)	6.0 (5.1,6.5)	8.3 (6.7,9.0)	<b>6.4 (5.4,7.8)</b>
	Not reported	1	5	<b>6</b>

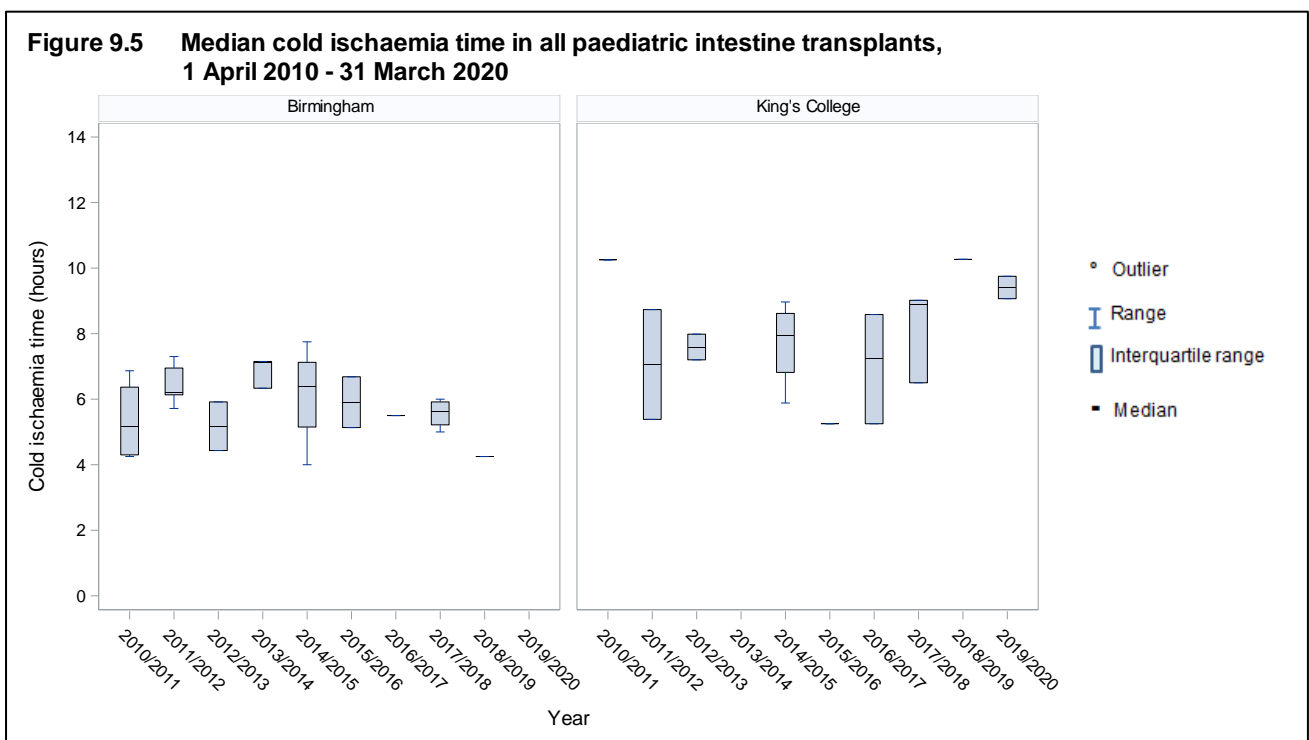
## 9.2 Cold ischaemia time, 1 April 2010 – 31 March 2020

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 increased over the time period from 5.8 hours in 2010/2011 to 9.4 hours in 2019/2020. However, note that the

2019/2020 estimate is based on only three transplant cases at King's College Hospital and should be interpreted with caution.



**Figure 9.5** shows the median CITs in paediatric intestine transplants by centre over the last 10 years for deceased donors. 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 patient survival post paediatric intestine transplantation for first intestine transplants between 1 April 2010 and 31 March 2020. Of the 47 transplants of this kind in the time period, survival information was known for 46 transplants. Due to small numbers, [unadjusted survival rates](#) only are presented, which means that these do not account for differences in the [case mix](#) at each centre and transplant type.

### 10.1 Survival by transplant type

**Table 10.1** shows the 90-day [unadjusted patient survival rates](#) for paediatric first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type. The 90-day survival rate for patients who received a liver was 91.7% and was 100% for patients not receiving the liver. There was no evidence of a significant difference in survival between those receiving the liver and those who did not at 90 days (log-rank  $p=0.18$ ).

<b>Table 10.1 90-day patient survival (%) for paediatric first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type</b>			
<b>Transplant type</b>	<b>Number of transplants</b>	<b>90-day survival (95% CI) <a href="#">Unadjusted</a></b>	
<b>Birmingham</b>			
Including liver	13	84.6	(51.2-95.9)
Not including liver <sup>1</sup>	14	100.0	-
<b>King's College Hospital</b>			
Including liver	11	100.0	-
Not including liver <sup>1</sup>	8 <sup>2</sup>	-	-
<b>Total</b>			
<b>Including liver</b>	<b>24</b>	<b>91.7</b>	<b>(70.6-97.8)</b>
<b>Not including liver<sup>1</sup></b>	<b>22</b>	<b>100.0</b>	<b>-</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.			

One-year [patient survival rates](#) are shown in **Table 10.2**. At one year post-transplant, the survival rate for patients not receiving the liver was 90.5%, and was 83.3% for patients receiving the liver. There was no evidence of a significant difference in survival between those receiving the liver and those who did not at 1 year (log-rank  $p=0.45$ ).

<b>Table 10.2 1-year patient survival (%) for paediatric first intestine transplants between 1 April 2010 and 31 March 2020, by transplant type</b>			
<b>Transplant type</b>	<b>Number of transplants</b>	<b>1-year survival (95% CI) <u>Unadjusted</u></b>	
<b>Birmingham</b>			
Including liver	13	76.9	(44.2-91.9)
Not including liver <sup>1</sup>	14	92.9	(59.1-99.0)
<b>King's College Hospital</b>			
Including liver	11	90.9	(50.8-98.7)
Not including liver <sup>1</sup>	8 <sup>2</sup>	-	-
<b>Total</b>			
<b>Including liver</b>	<b>24</b>	<b>83.3</b>	<b>(61.5-93.4)</b>
<b>Not including liver<sup>1</sup></b>	<b>22</b>	<b>90.5</b>	<b>(67.0-97.5)</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.			

Five-year [patient survival rates](#) are not presented due to the small number of patients in the paediatric section of this report who are still being followed up after one year, which is exacerbated by the break down of survival rates by transplant type.



# FORM RETURN RATES



## 11.1 Form return rates, 1 January – 31 December 2019

Form return rates are reported by follow-up centre in **Table 11.1** for adult transplants and **Table 11.2** for paediatric transplants. 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 2019 and 31 December 2019, for patients being followed up by each centre, and the percentage of forms that had been returned at time of analysis (30 June 2020). 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 paediatric transplants. Note that some paediatric transplant patients are followed up at Cambridge and Oxford.

**Table 11.1 Form return rates by follow-up centre for adult transplants, 1 January 2019 to 31 December 2019**

Follow-up 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	12	100	12	100	11	100	36	100
Oxford	4	100	6	100	9	100	20	100
<b>Total</b>	<b>16</b>	<b>100</b>	<b>18</b>	<b>100</b>	<b>20</b>	<b>100</b>	<b>56</b>	<b>100</b>

**Table 11.2 Form return rates by follow-up centre for paediatric transplants, 1 January 2019 to 31 December 2019**

Follow-up 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	0	-	1	100	2	100	27	100
Cambridge	0	-	0	-	0	-	4	75
King's College Hospital	2	100	2	50	1	100	10	100
Oxford	0	-	0	-	0	-	6	67
<b>Total</b>	<b>2</b>	<b>100</b>	<b>3</b>	<b>67</b>	<b>3</b>	<b>100</b>	<b>47</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 2010 to 31 March 2020. NHS Group 2 transplants have been included in all analyses (except Section 2.3 Geographical variation in registration and transplant rates), 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 2010 to 31 March 2020</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	88	7	83	5
Oxford	48	0	46	0
<b>TOTAL</b>	<b>136</b>	<b>7</b>	<b>129</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 2010 to 31 March 2020</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	30	0	27	0
King's College Hospital	25	0	20	0
<b>TOTAL</b>	<b>55</b>	<b>0</b>	<b>47</b>	<b>0</b>

## **Geographical variation analysis**

### **Registration rates**

All NHS group 1 patients who were registered onto the intestinal transplant lists with an active status between 1 April 2010 and 31 March 2020 were extracted from the UK Transplant Registry on 3 July 2020. This was then divided by 10 to give the average number of registrations per year (numerator). Patients were assigned to NHS regions in England using their postcode of residence, as reported at registration. The number of registrations per million population (pmp) by NHS region was obtained using mid-2018 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No NHS region age- or sex-specific standardisation of rates was performed.

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

### **Transplant rates**

Transplant rates pmp were obtained as the annual average number of intestinal transplants on NHS group 1 recipients from donors between 1 April 2010 and 31 March 2020 (numerator), divided by the mid-2018 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 2010 and 31 March 2020 were included. If a patient was re-registered during the time period, only the first registration was considered. If a patient underwent more than one intestinal transplant in the time period, only the first transplant was considered.

## A2: Methods

### Waiting time to transplant

Waiting time was calculated from date of registration to date of transplant, for [elective](#) patients registered between 1 April 2016 and 31 March 2019 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, 26 June 2020, 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 2019 to 31 March 2020.

### Geographical variation analysis

For a given individual who is a resident in a given NHS region, 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.

A one-sided p-value for the hypothesis that the SCV is greater than zero versus the null hypothesis that the SCV is equal to zero was derived using a parametric bootstrap where data were simulated from the Poisson distribution that would be consistent with the null hypothesis (multiplicative rate factor is equal to one in all areas and  $\sigma^2$  equal to zero). The observed SCV was then compared against this simulated data to calculate the probability that an SCV of at least this size would be observed due to chance if the null hypothesis were true.

10,000 bootstrap samples of size 7 (number of areas) were simulated, where the registration/transplant count in each area was drawn from a Poisson distribution with its expected value being the area-specific expected count (the rate of transplants/registrations in the total population multiplied by the population of the area) . The SCV was then calculated in each of the 10,000 samples and a bootstrap p-value for the SCV in the observed data was estimated as:

$$P_{boot} = \frac{1 + \#\{SCV_{sim} \geq SCV_{obs}\}}{10000 + 1}$$

where  $\#\{SCV_{sim} \geq SCV_{obs}\}$  is the number of SCV values in the simulated datasets which are greater than or equal to the SCV in the observed data. This follows the simulation method given in Ibanez et al., BMC Health Services Research, 2009, 9:60. No adjustment was made for area-specific demographic characteristics that may impact the rates of registration to the transplant list and transplantation such as age and sex.

### **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)**

Donation after Brainstem Death (DBD) means donation which takes place following the diagnosis of death using neurological criteria.

### **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 is 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 recipients.

*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.

Prepared by:

Statistics and Clinical Studies, NHS Blood and Transplant

Rachel Hogg  
Dr Elisa Allen

