



Blood and Transplant

**ANNUAL REPORT ON
INTESTINE TRANSPLANTATION**

**REPORT FOR 2023/2024
(1 APRIL 2014 – 31 MARCH 2024)**

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EXECUTIVE SUMMARY



EXECUTIVE SUMMARY

This report presents key figures about intestine transplantation in the UK. The period reported covers 10 years of transplant data, from 1 April 2014 to 31 March 2024. 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 unadjusted results on post-transplant survival should be regarded as guidance only due to the limited number of transplants performed.

Key findings

- On 31 March 2024, there were 13 patients on the UK active intestine **transplant list**, three more than the end of the previous year.
- Of those patients registered onto the transplant list in a recent two year period (1 April 2020 – 31 March 2022), 72% had received a transplant two years post-registration, while 7% died on the list (or were removed due to condition deteriorating), 9% were removed and 11% were still waiting at time of data analysis.
- **Median total waiting time** to elective intestine transplant between 1 April 2020 and 31 March 2023 was 172 days for **adult registrations** and 138 days for **paediatric registrations**.
- There were 205 intestine **transplants** performed in the UK over the 10 year period covered by this report. Of all transplants, 75% were in adult recipients while 25% were in paediatric recipients. A small proportion of these were re-transplants while the rest were primary transplants.
- In the last financial year, 2023/2024, 22 intestine **transplants** were performed, a small decrease of three from 2022/2023. Of the 22 transplants, 17 (77%) were in adult recipients and 5 (23%) were in paediatric recipients.
- The national rates of **survival** ([unadjusted](#)) after first intestine transplantation for **adult patients** were estimated at 97%, 86%, and 69% at 90 days, one and five years post-transplant, respectively for those **who did not receive the liver** and 91%, 77%, and 60% at 90 days, one and five years post-transplant, respectively for those **who did receive the liver**. There was no significant difference in survival rates between those receiving and those not receiving the liver. Please note these survival rates are unadjusted and include registrations due to malignancy.
- The national rates of **survival** after first intestine transplantation for **paediatric patients** ([unadjusted](#)) were estimated at 100% at both 90 days and one year post-transplant for those **who did not receive the liver** and at 93% and 85% 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 2023/2024, NHS Blood and Transplant.*

INTRODUCTION



INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2014 and 31 March 2024, for all four designated centres performing intestine transplantation in the UK. Data were obtained from the UK Transplant Registry, at NHS Blood and Transplant, which holds information relating to donors, recipients and outcomes for all intestine transplants performed in the UK.

The report is divided into two main sections; one for adult recipients (aged ≥ 18 years) and one for paediatric recipients (aged < 18 years). Cambridge and Oxford are *adult* transplant centres, whereas Birmingham and King’s College Hospital are *paediatric* transplant centres. 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 2015 and 2024. The number of patients waiting for a transplant has decreased in recent years, with a peak of 18 patients in 2020 compared to 13 in 2024.

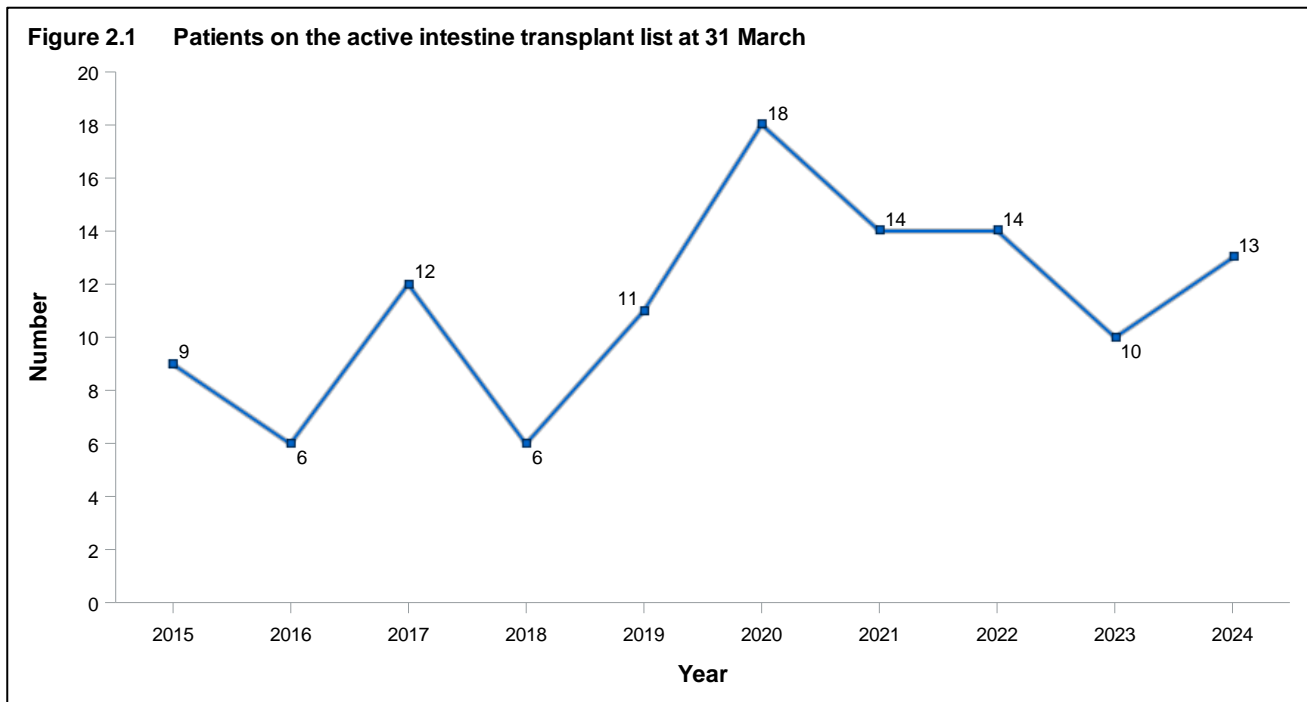


Figure 2.2 shows the number of adult and paediatric patients on the [active transplant list](#) on 31 March 2024, by centre. In total, there were five adults and eight paediatric patients on the active transplant list. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown later in the report, in **Figure 3.2** and **Figure 7.2**, respectively.

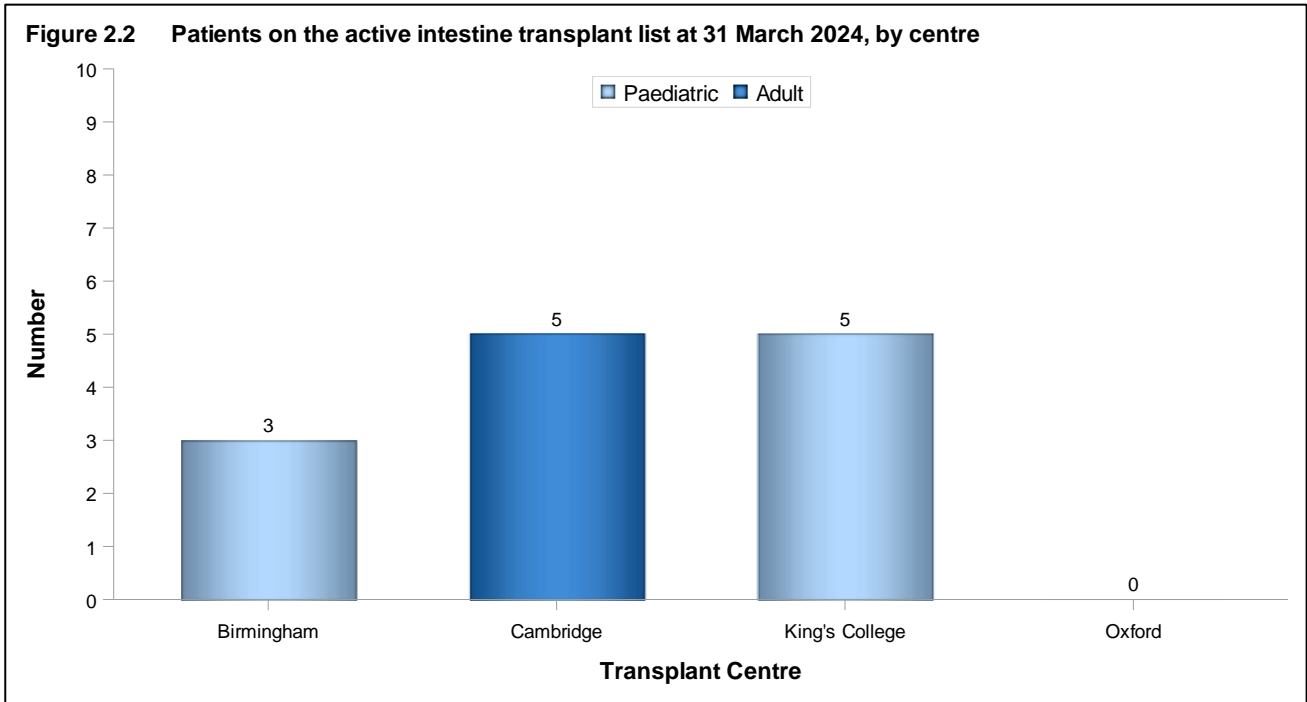


Figure 2.3 shows the number of registrations made onto the active intestine transplant list each year in the last 10 years. The number of registrations has fluctuated over the decade, with 31 registrations in 2023/2024.

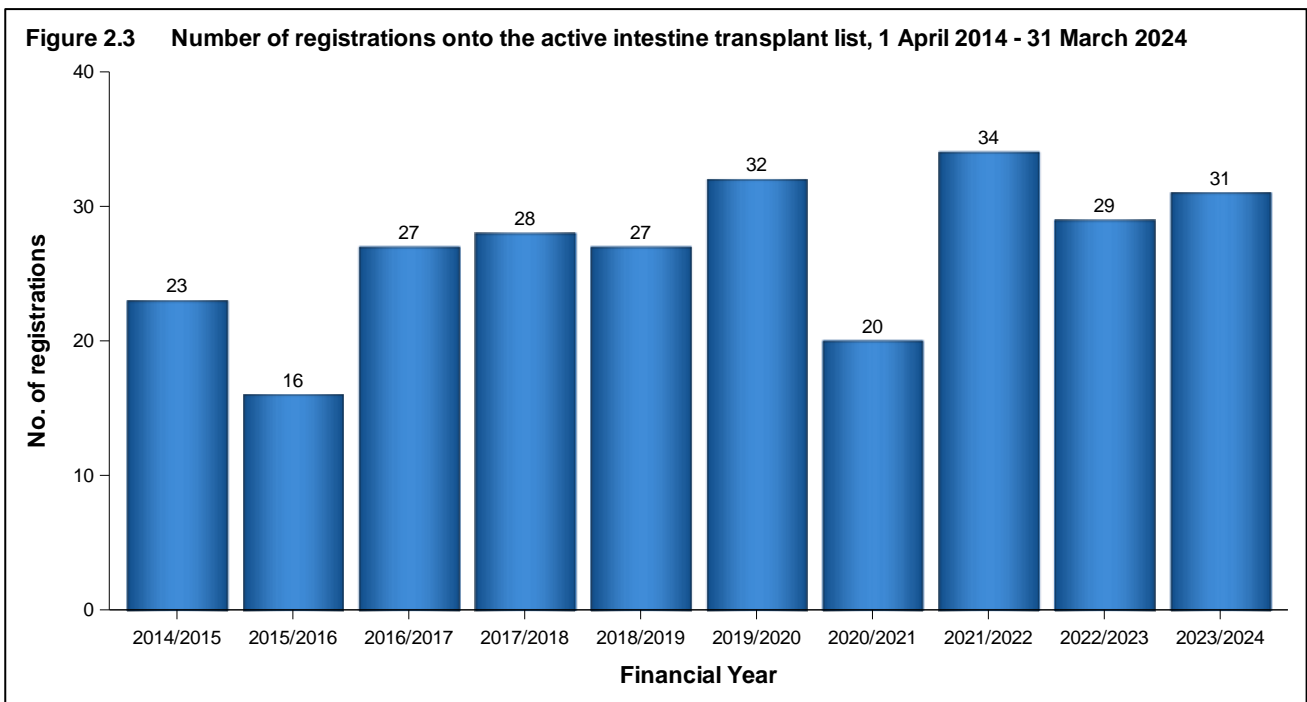
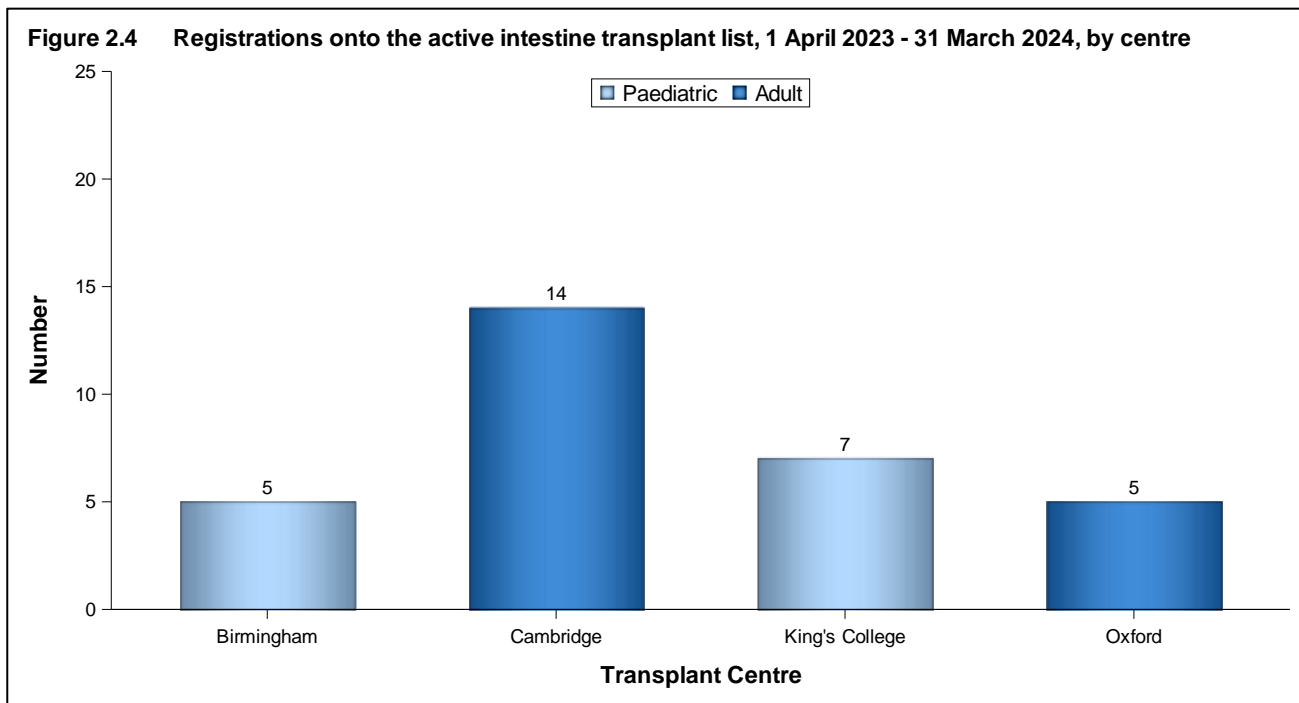
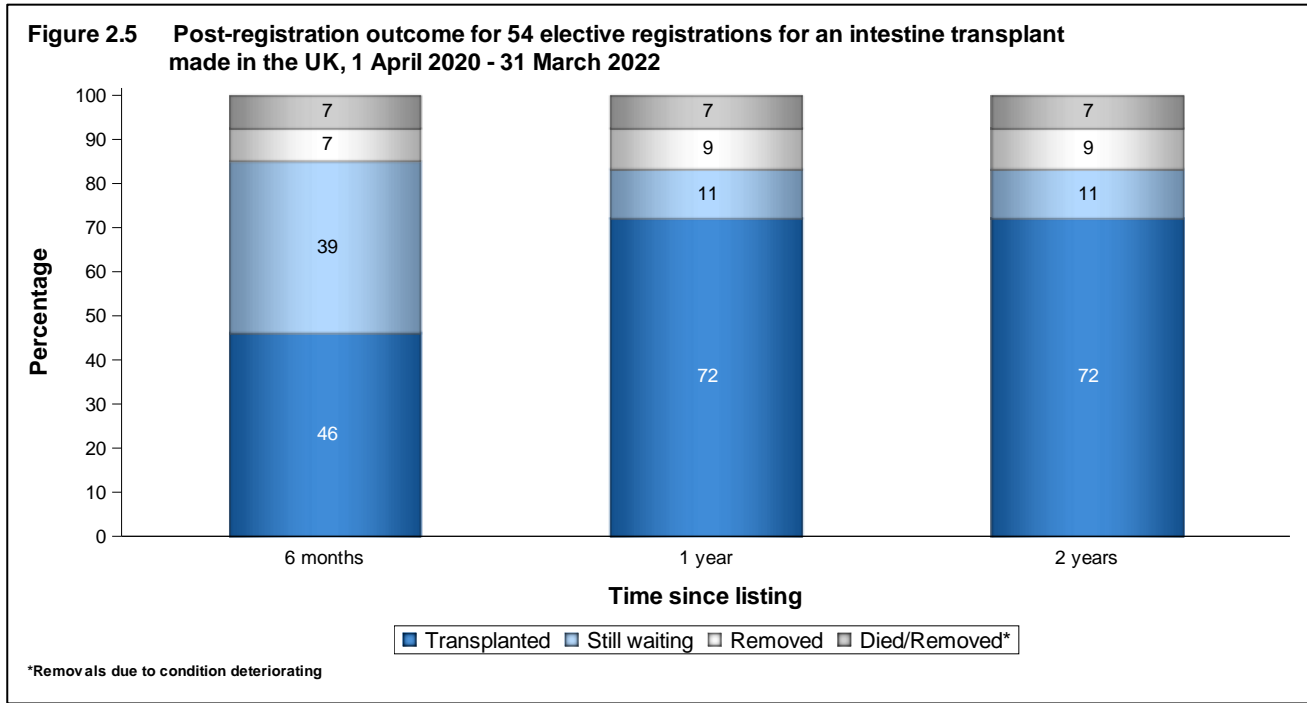


Figure 2.4 shows the number of registrations onto the active intestine transplant list in 2023/2024, by centre. There were 19 adult registrations and 12 paediatric registrations.



2.1.1 Post-registration outcomes, 1 April 2020 – 31 March 2022

The registration outcomes of patients listed between 1 April 2020 and 31 March 2022 for an elective intestine transplant are summarised in **Figure 2.5**. This shows the proportion of patients transplanted or still waiting six months, one year and two years after joining the transplant list. At two years post-registration 72% of patients had received a transplant and 11% were still waiting.



2.1.2 Median waiting time to transplant, 1 April 2020 – 31 March 2023

Table 2.1 shows [median waiting time](#) to [elective](#) intestine transplant by registration type for adult and paediatric patients, combined, registered between 1 April 2020 and 31 March 2023. Overall, on average, patients waited a total of 172 days (approximately six months) for a transplant.

Table 2.1 Median waiting time to elective intestine transplant in the UK, for patients registered 1 April 2020 - 31 March 2023					
Registration type	Number of patients registered	Total waiting time (days)¹		Active waiting time (days)	
		Median	95% Confidence interval	Median	95% Confidence interval
Liver containing	38	158	11 – 305	143	56 – 230
Non liver containing	36	172	55 – 289	144	77 - 211
TOTAL	74	172	90 – 254	144	85 - 203

¹ Periods of suspension from the list are included in the calculation of total 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 have been two transplants, one in 2017/2018 and one in 2023/2024, performed using living donors. The total number of transplants over the decade was 206, with annual figures fluctuating between 12 and 27. In 2023/24, 23 transplants were performed, a slight decrease from the previous year.

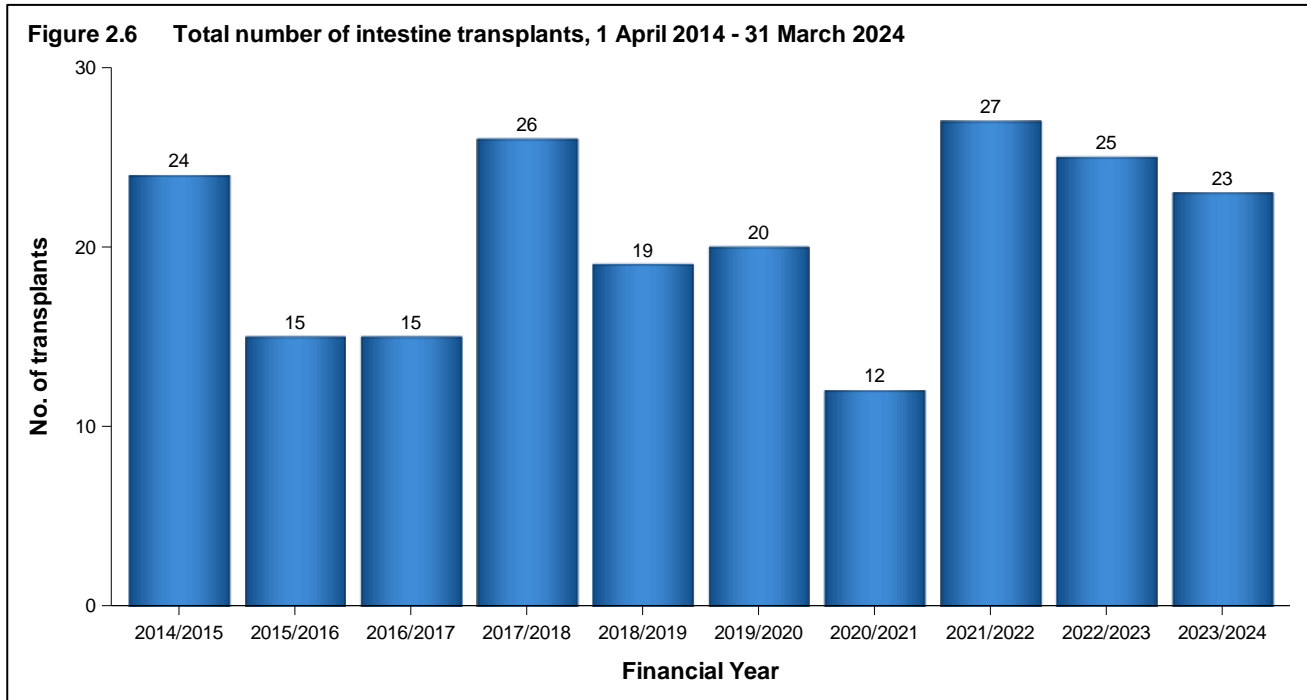
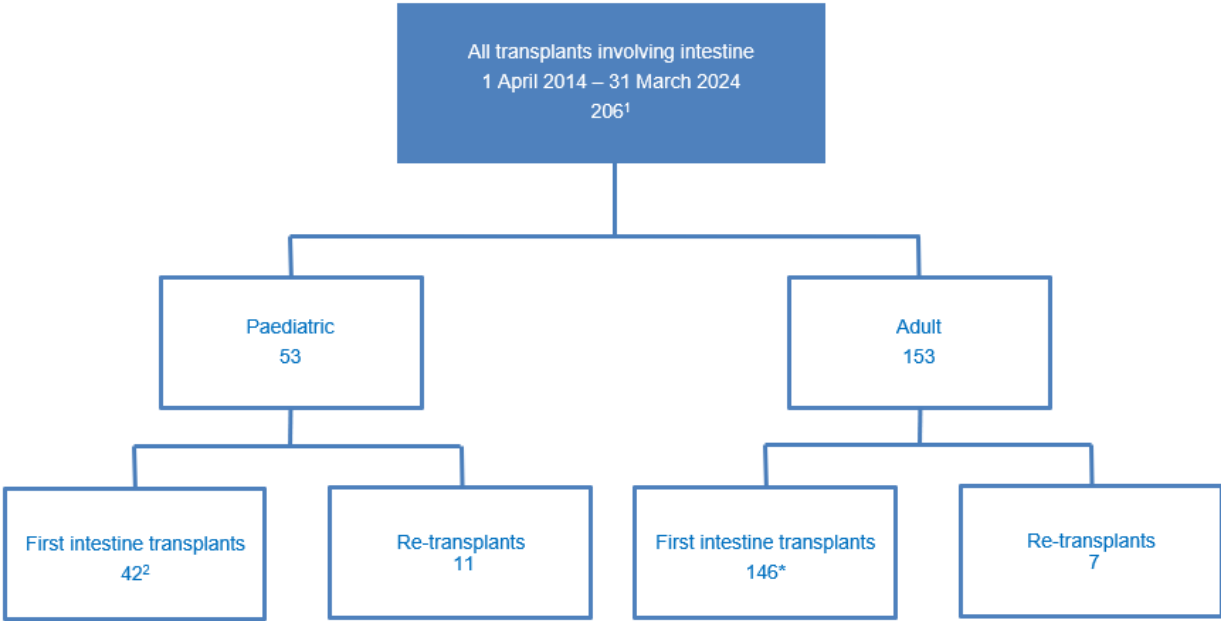


Figure 2.7 details the 206 intestine transplants performed in the UK in the 10 year period. Of these, 53 (26%) were in paediatric recipients and 153 (74%) were in adult recipients. Most of both paediatric and adult transplants were in first time recipients.

Figure 2.7 UK intestine transplants, 1 April 2014 to 31 March 2024



¹ Excludes one known abdominal wall only transplant (October 2016)
² Includes one living donor liver and bowel transplant (June 2017)
and one living donor bowel-only transplant (September 2023)

* Three of these transplants were super-urgent

2.3 Geographical variation in registration and transplant rates

Figure 2.8 shows rates of registration to the intestinal transplant list per million population (pmp) between 1 April 2014 and 31 March 2024 compared with intestinal 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 coefficient component of variation (SCV) was used to identify if the variation is more (or less) 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, 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 2014 – 31 March 2024

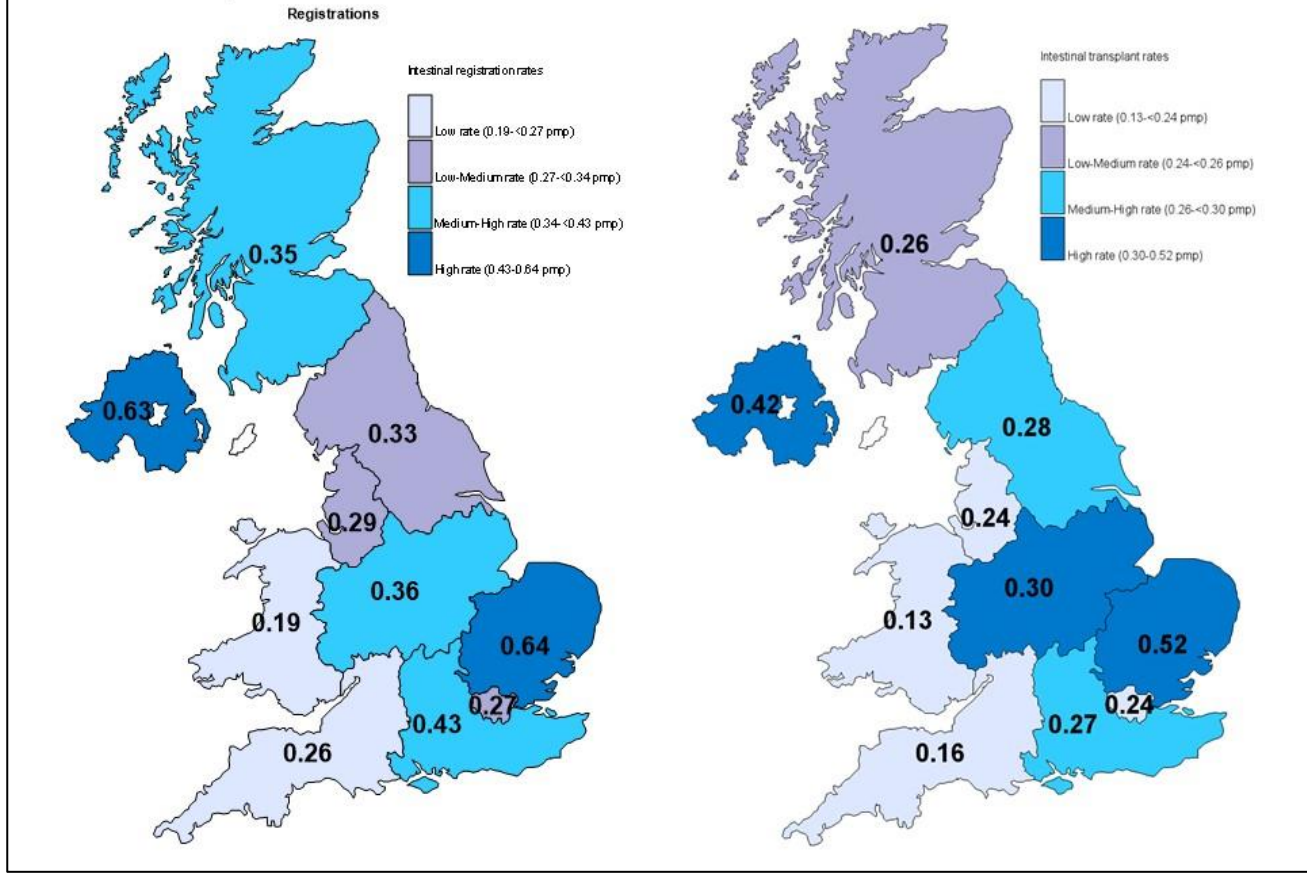
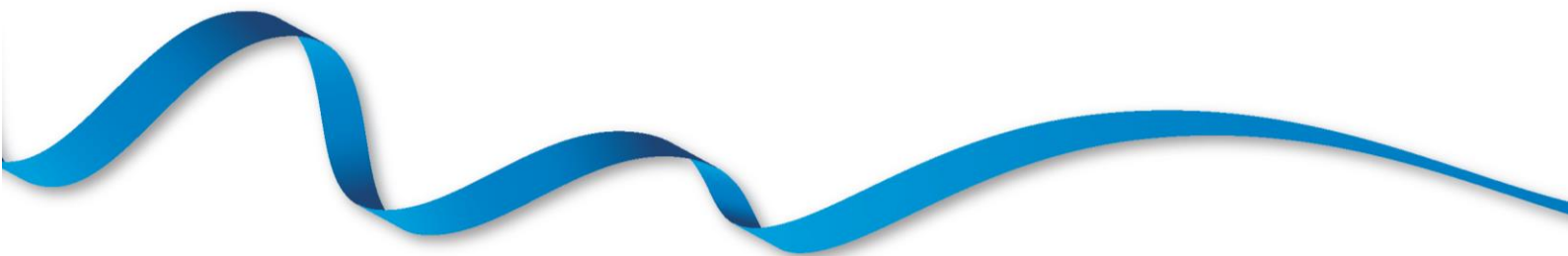


Table 2.2 Intestinal registration and transplant rates per million population (pmp) in the UK, 1 April 2014 - 31 March 2024, by country/NHS region				
Country/ NHS region	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire	2.7	(0.33)	2.3	(0.28)
North West	2.2	(0.29)	1.8	(0.24)
Midlands	4.0	(0.36)	3.3	(0.30)
East of England	4.1	(0.64)	3.3	(0.52)
London	2.4	(0.27)	2.1	(0.24)
South East	4.0	(0.43)	2.5	(0.27)
South West	1.5	(0.26)	0.9	(0.16)
England	20.9	(0.37)	16.2	(0.28)
Isle of Man	0.0	(0.0)	0.0	(0.0)
Channel Islands	0.0	(0.0)	0.0	(0.0)
Wales	0.6	(0.19)	0.4	(0.13)
Scotland	1.9	(0.35)	1.4	(0.26)
Northern Ireland	1.2	(0.63)	0.8	(0.42)
TOTAL	24.9¹	(0.37)	19.1²	(0.28)

¹ Registrations include 3 recipients whose postcode was unknown and excludes 5 recipients who reside in the Republic of Ireland and 5 recipients who reside overseas

² Transplants include 3 recipients whose postcode was unknown and excludes 4 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, 2015 – 2024

Figure 3.1 shows the number of adults active or suspended on the intestine transplant list at 31 March of each year between 2015 and 2024. The number of adults on the [active intestine transplant list](#) remained low over most of the decade with 5 adults active at 31 March 2024.

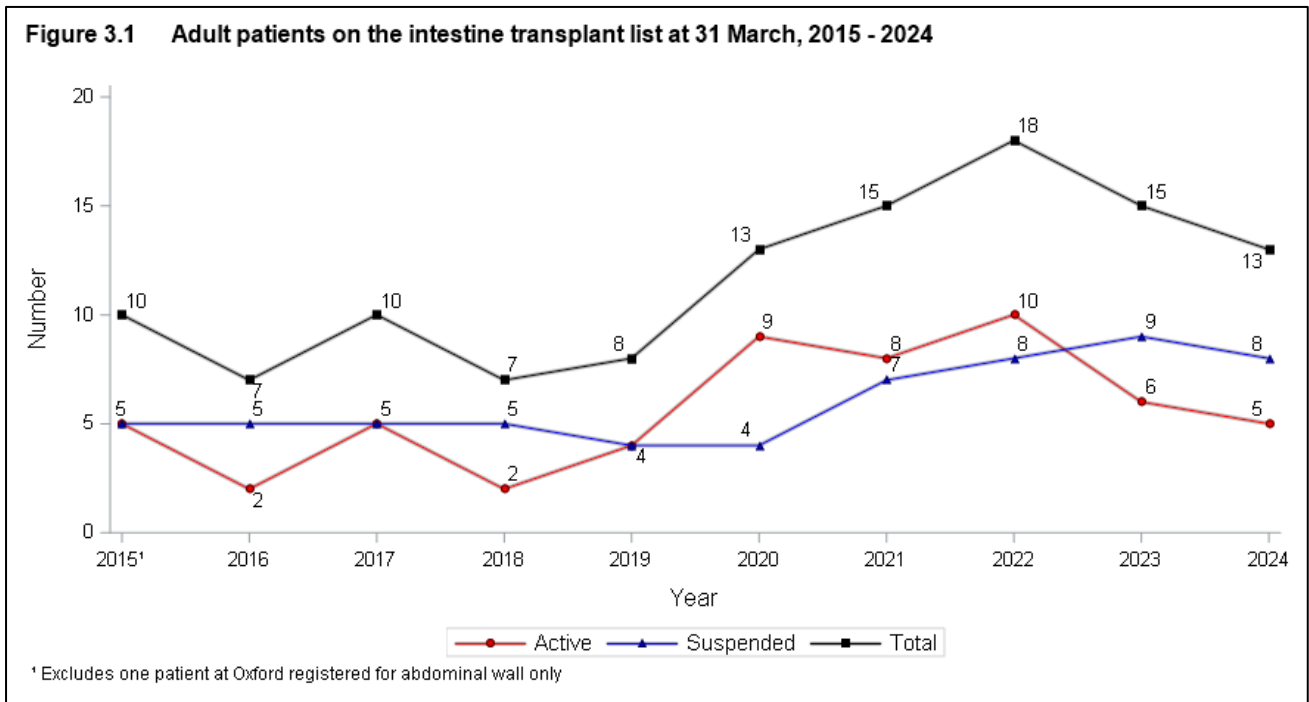
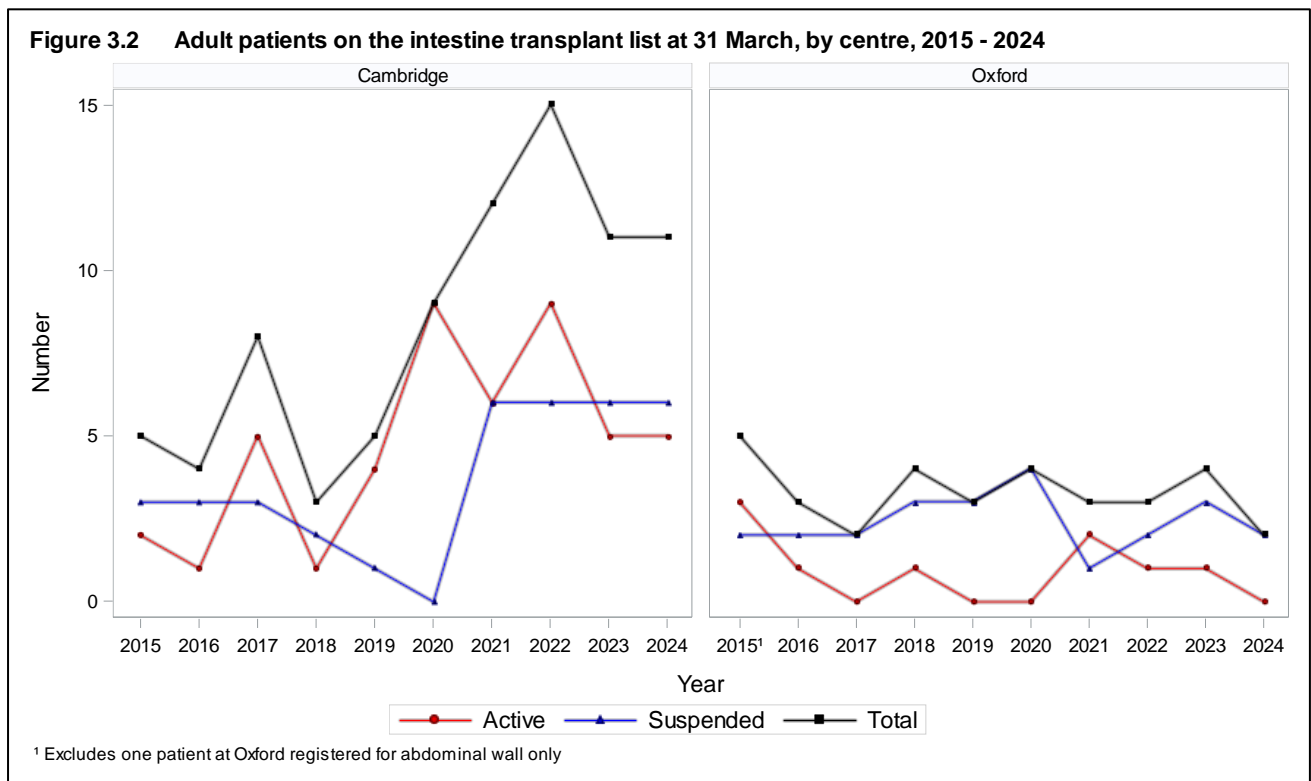


Figure 3.2 shows the number of adults on the intestine transplant list at 31 March of each year between 2015 and 2024, at each transplant centre. Cambridge had generally more adults on the national [active transplant list](#) than Oxford.



The demographic characteristics of 193 adult intestine transplant recipient registrations in the 10-year period are shown by centre and overall in **Table 3.1**. Nationally, 51% of registrations 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/m². 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 2014 - 31 March 2024

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of registrations		136	57	193
Number of patients		132 (100)	56 (100)	188 (100)
Registration type	Elective	132 (97)	57 (100)	189 (98)
	Super-urgent	4 (3)	0	4 (2)
Transplant type required	Non liver containing	59 (43)	57 (100)	116 (60)
	Liver containing	77 (57)	0	77 (40)
Recipient sex	Male	66 (49)	33 (58)	99 (51)
	Female	70 (51)	24 (42)	94 (49)
Recipient ethnicity group	White	121 (89)	52 (91)	173 (90)
	Other	15 (11)	5 (9)	20 (10)
Indication group	Short bowel syndrome	44 (33)	16 (28)	60 (31)
	Motility disorders	7 (5)	2 (4)	9 (5)
	Primary mucosal disorders	1 (1)	0	1 (1)
	Tumour	16 (12)	20 (35)	36 (19)
	Liver disease	12 (9)	0	12 (6)
	Other/not reported	31 (23)	13 (23)	44 (23)
	Retransplant	10 (7)	4 (7)	14 (7)
	Mesenteric thrombosis	13 (10)	2 (4)	15 (8)
Patient location	Out-patient	71 (52)	32 (56)	103 (53)
	Ward	15 (11)	7 (12)	22 (11)
	ICU/HDU	4 (3)	0	4 (2)
	Not reported	46 (34)	18 (32)	64 (33)
Pre-transplant renal support	No	127 (93)	55 (96)	182 (94)
	Yes	8 (6)	2 (4)	10 (5)
	Not reported	1 (1)	0	1 (1)
Previous abdominal surgery	No	18 (13)	0	18 (9)
	Yes	113 (83)	57 (100)	170 (88)
	Not reported	5 (4)	0	5 (3)
Recipient blood group	O	57 (42)	24 (42)	81 (42)
	A	48 (35)	26 (46)	74 (38)
	B	21 (15)	5 (9)	26 (14)
	AB	10 (7)	2 (4)	12 (6)
Recipient age years	Median (IQR)	43 (32,53)	48 (35,55)	45 (33,53)
Recipient BMI kg/m2	Median (IQR)	22 (20,26)	21 (20,24)	22 (20,26)
	Not reported	1	0	1

An indication of registration outcomes for adult elective patients registered on the intestine transplant list in the UK between 1 April 2020 and 31 March 2022 is summarised in **Figure 3.3**.

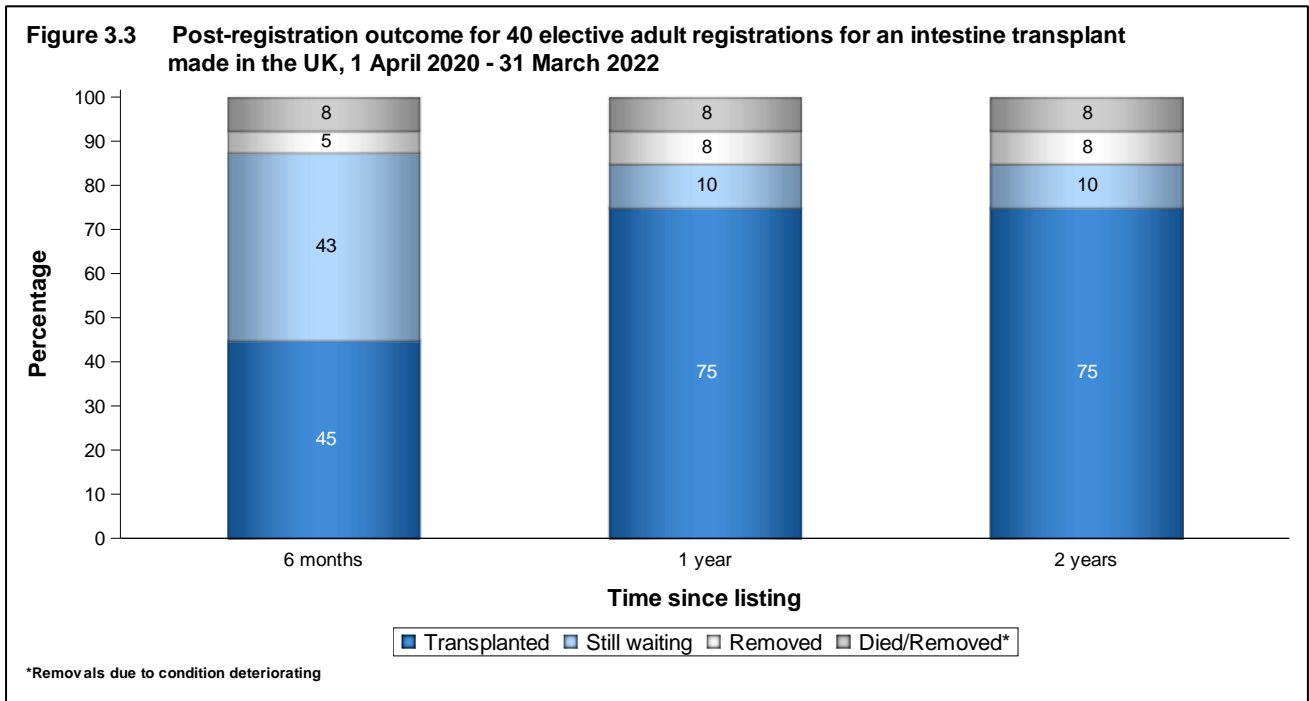


Figure 3.4 shows the proportion of patients transplanted, removed, died while waiting, or still waiting on the list at 6 months after joining the list, by transplant centre. 48% of registrations at Cambridge received a transplant within 6 months of listing compared to 33% at Oxford. Note there were 9 registrations at Oxford between 1 April 2020 and 31 March 2022.

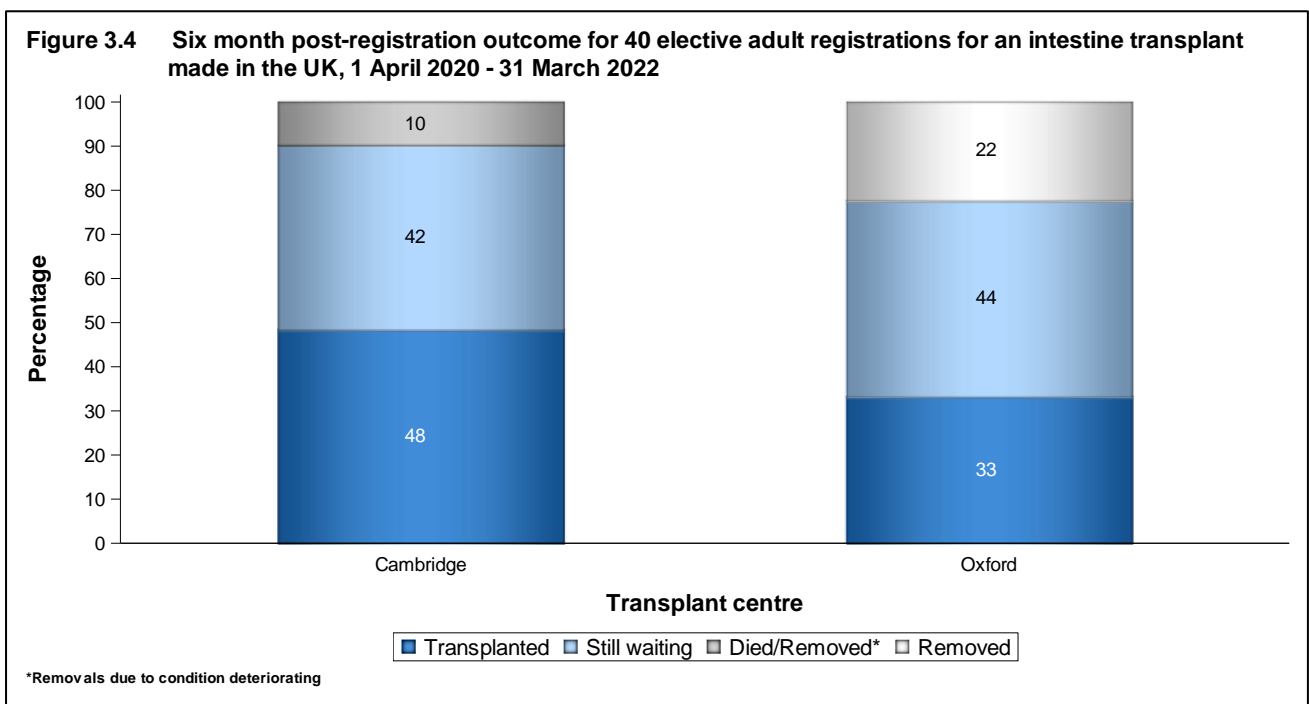


Table 3.2 shows [median waiting time](#) to [elective](#) intestine transplant by registration type for adult patients, registered between 1 April 2020 and 31 March 2023. The national UK median total waiting time to transplant for adult elective patients is 172 days.

Table 3.2 Median total waiting time to elective intestine transplant in the UK, for adults registered 1 April 2020 - 31 March 2023					
Registration type	Number of patients registered	Total waiting time (days)¹		Active waiting time (days)	
		Median	95% Confidence interval	Median	95% Confidence interval
Liver containing	24	158	35 – 281	143	67 – 219
Non liver containing	30	172	55 – 289	160	94 - 226
TOTAL	54	172	80 – 264	144	87 - 201

¹ Periods of suspension from the list are included in the calculation of total median waiting times

4. Response to offers

Potential [DBD](#) donors aged under 60 years and with a weight of less than 90 kg are considered for intestine donation. However, centres are highly selective when accepting donor organs which leads to high decline rates. Between 1 April 2023 and 31 March 2024, Cambridge received 161 intestine offers from 109 donors and Oxford received 83 intestine offers from 63 donors. Their [donor offer decline rates](#) were 89% and 92%, respectively.

Table 4.1 Offer decline rates for each centre, 1 April 2023 - 31 March 2024				
Centre	Offers	%Decline	Donors	%Decline
Cambridge	161	92	109	89
Oxford	83	94	63	92
TOTAL	244	93	172	90

5. Transplants

5.1 Adult intestine transplants, 1 April 2014 – 31 March 2024

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 21 in 2022/2023, with 17 performed in the last financial year.

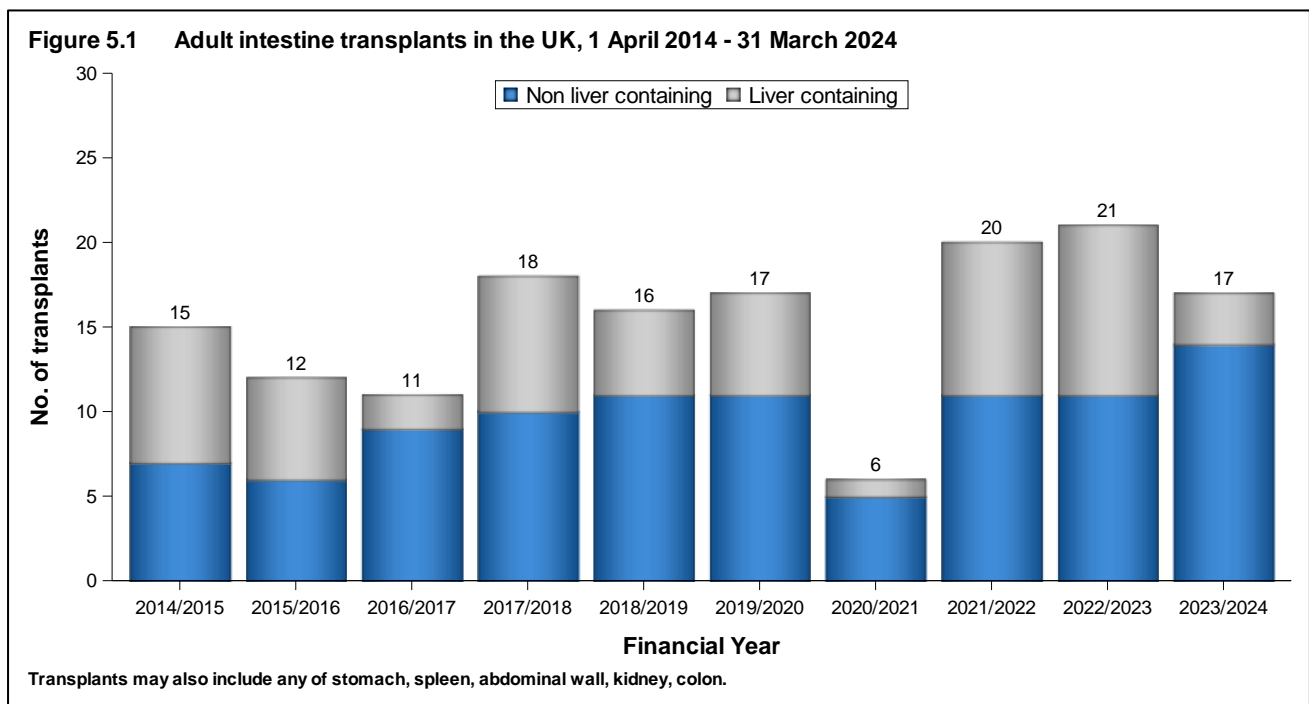


Figure 5.2 shows the number of adult intestine transplants performed in 2023/2024, by centre and [transplant type](#). Oxford performed five transplants in the last financial year. Cambridge performed three transplants containing a liver, with the remaining nine not including a liver.

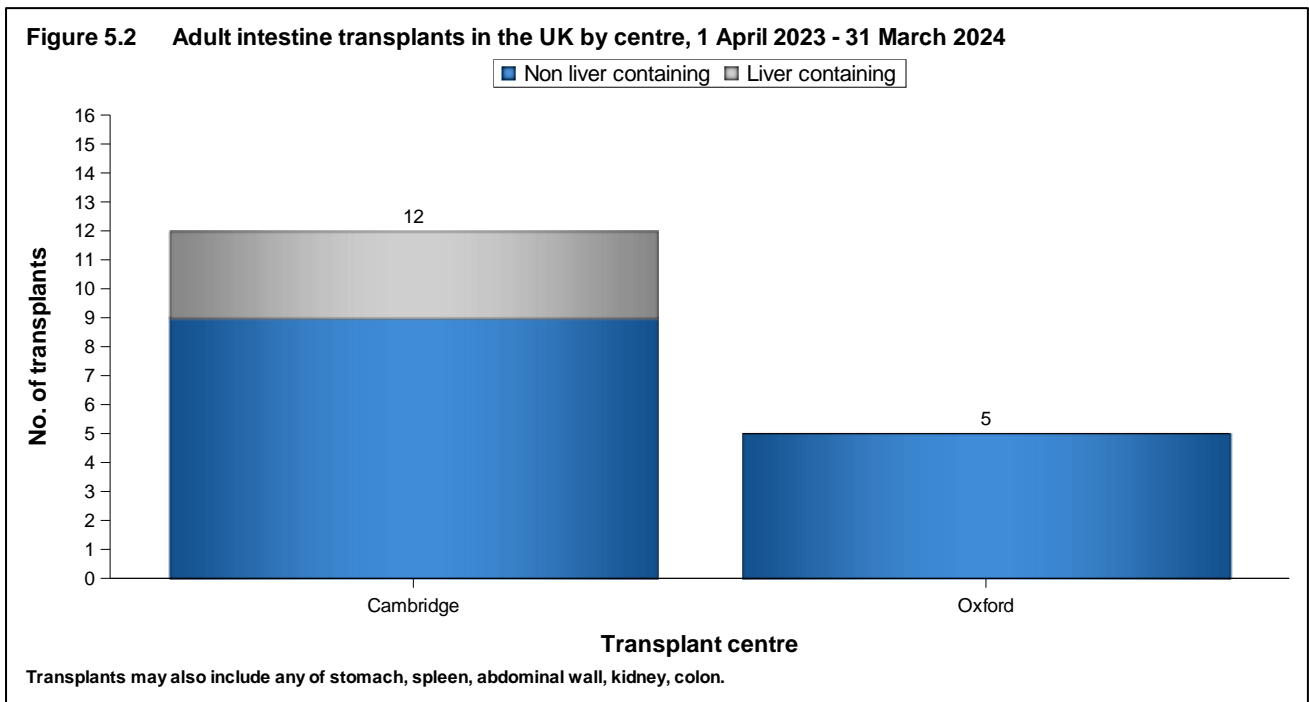
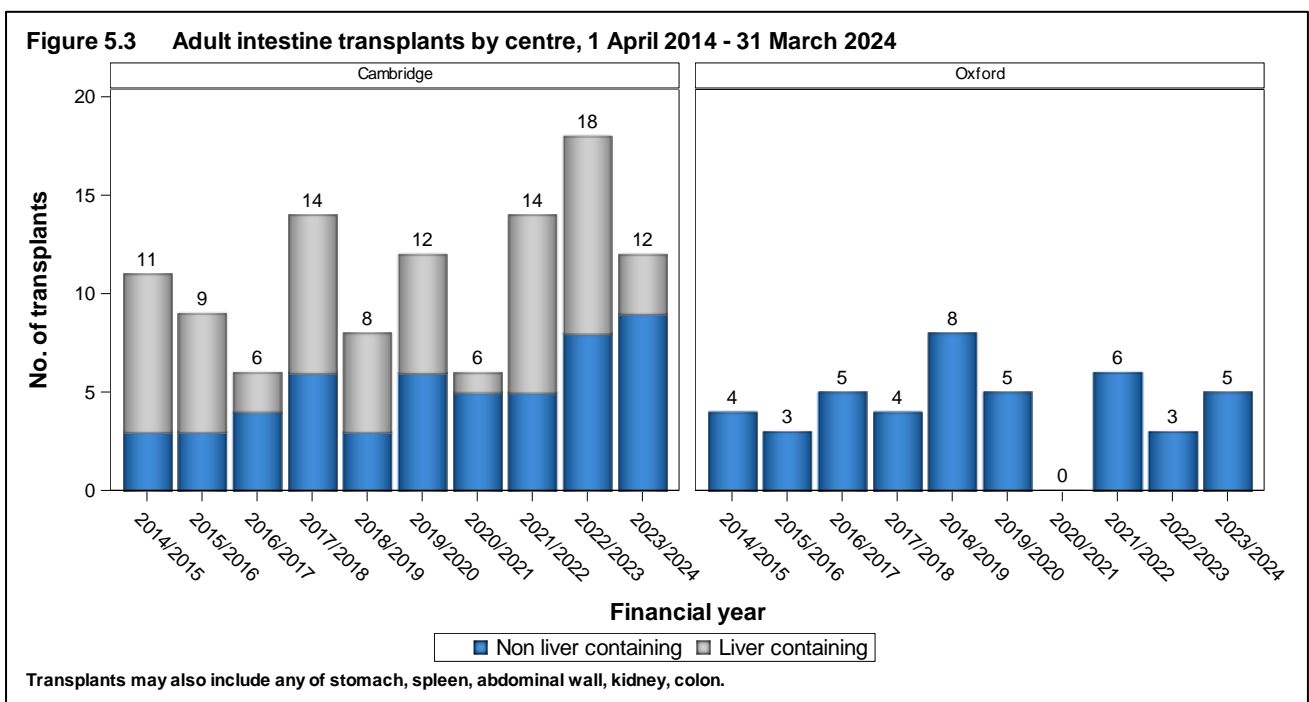


Figure 5.3 shows the number of adult intestine transplants performed in the last 10 years, by centre and [type of transplant](#). Oxford performed their highest number of transplants over the decade in 2018/2019, while Cambridge performed their highest number in 2022/2023. Overall Cambridge performed 110 transplants (72%) and Oxford performed 43 (28%).



The demographic characteristics of 153 adult 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 of recipients was 45 years old, while the median age of donors was 28 years old. The most common indication for transplantation was short bowel syndrome. Three 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.

Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2014 - 31 March 2024				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of transplants		110	43	153 (100)
Urgency	Elective	107 (97)	43 (100)	150 (98)
	Super-urgent	3 (3)	0	3 (2)
Recipient sex	Male	58 (53)	29 (67)	87 (57)
	Female	52 (47)	14 (33)	66 (43)
Recipient ethnicity group	White	99 (90)	39 (91)	138 (90)
	Other	11 (10)	4 (9)	15 (10)
Indication group	Short bowel syndrome	43 (39)	16 (37)	59 (39)
	Motility disorders	7 (6)	1 (2)	8 (5)
	Tumour	16 (15)	18 (42)	34 (22)
	Liver disease	10 (9)	0	10 (7)
	Other/not reported	14 (13)	2 (5)	16 (11)
	Retransplant	8 (7)	4 (9)	12 (8)
	Mesenteric thrombosis	12 (11)	2 (5)	14 (9)
Patient location	Out-patient	61 (55)	36 (84)	97 (63)
	Ward	28 (25)	6 (14)	34 (22)
	ICU/HDU	8 (7)	0	8 (5)
	Not reported	13 (12)	1 (2)	14 (9)
Pre-transplant renal support	No	89 (81)	41 (95)	130 (85)
	Yes	7 (6)	1 (2)	8 (5)
	Not reported	14 (13)	1 (2)	15 (10)
Previous abdominal surgery	No	15 (14)	1 (2)	16 (11)
	Yes	78 (71)	41 (95)	119 (78)
	Not reported	17 (15)	1 (2)	18 (12)
Lifestyle activity	Normal	6 (5)	1 (2)	7 (5)
	Restricted	23 (21)	6 (14)	29 (19)
	Self-care	30 (27)	28 (65)	58 (38)
	Confined	12 (11)	2 (5)	14 (9)
	Reliant	14 (13)	3 (7)	17 (11)
	Not reported	25 (23)	3 (7)	28 (18)
Restricted venous access at registration	No	67 (61)	28 (65)	95 (62)
	Yes	35 (32)	12 (28)	47 (31)
	Not reported	8 (7)	3 (7)	11 (7)
Recipient age years	Median (IQR)	43 (32,53)	48 (36,56)	45 (34,54)

Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2014 - 31 March 2024

		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Recipient BMI kg/m2	Median (IQR)	23 (20,26)	22 (21,23)	22 (20,25)
Serum bilirubin umol/l	Non liver containing (N)	52	43	95
	Median (IQR)	11 (7,18)	10 (6,16)	10 (6,16)
	Not reported	8	1	9
	Liver containing (N)	58	0	58
	Median (IQR)	35 (15,119)	-	35 (15,119)
	Not reported	6	0	6
	Overall (N)	110	43	153
	Median (IQR)	18 (10,55)	10 (6,16)	14 (7,37)
	Not reported	14	1	15
Total time on list days	Median (IQR)	70 (26,182)	61 (17,116)	68 (25,160)
Donor sex	Male	42 (38)	20 (47)	62 (41)
	Female	68 (62)	23 (53)	91 (60)
Donor ethnicity group	White	100 (91)	41 (95)	141 (92)
	Other	9 (8)	1 (2)	10 (7)
	Not reported	1 (1)	1 (2)	2 (1)
Donor cause of death group	Stroke	93 (85)	31 (72)	124 (81)
	Trauma	8 (7)	6 (14)	14 (9)
	Other	9 (8)	6 (14)	15 (10)
Donor history of diabetes	No	110 (100)	43 (100)	153 (100)
Donor age years	Median (IQR)	26 (18,41)	33 (20,41)	28 (19,41)
Donor BMI kg/m2	Median (IQR)	22 (20,24)	23 (21,23)	22 (21,24)
Transplant type	Non liver containing	52 (47)	43 (100)	95 (62)
	Liver containing	58 (53)	0	58 (38)
ABO match	Identical	74 (67)	37 (86)	111 (73)
	Compatible	36 (33)	6 (14)	42 (28)
Total preservation time hours	Median (IQR)	5 (4.2,5.5)	6.4 (5.6,7.2)	5.4 (4.6,6.1)
	Not reported	15	0	15

5.2 Total preservation time, 1 April 2014 – 31 March 2024

Figure 5.4 shows [boxplots](#) of the [total preservation time](#) 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 its transplantation into the recipient. The line inside the box indicates the [median](#) value. The median total preservation time has generally remained stable over the decade and was 5.2 hours for 2023/2024.

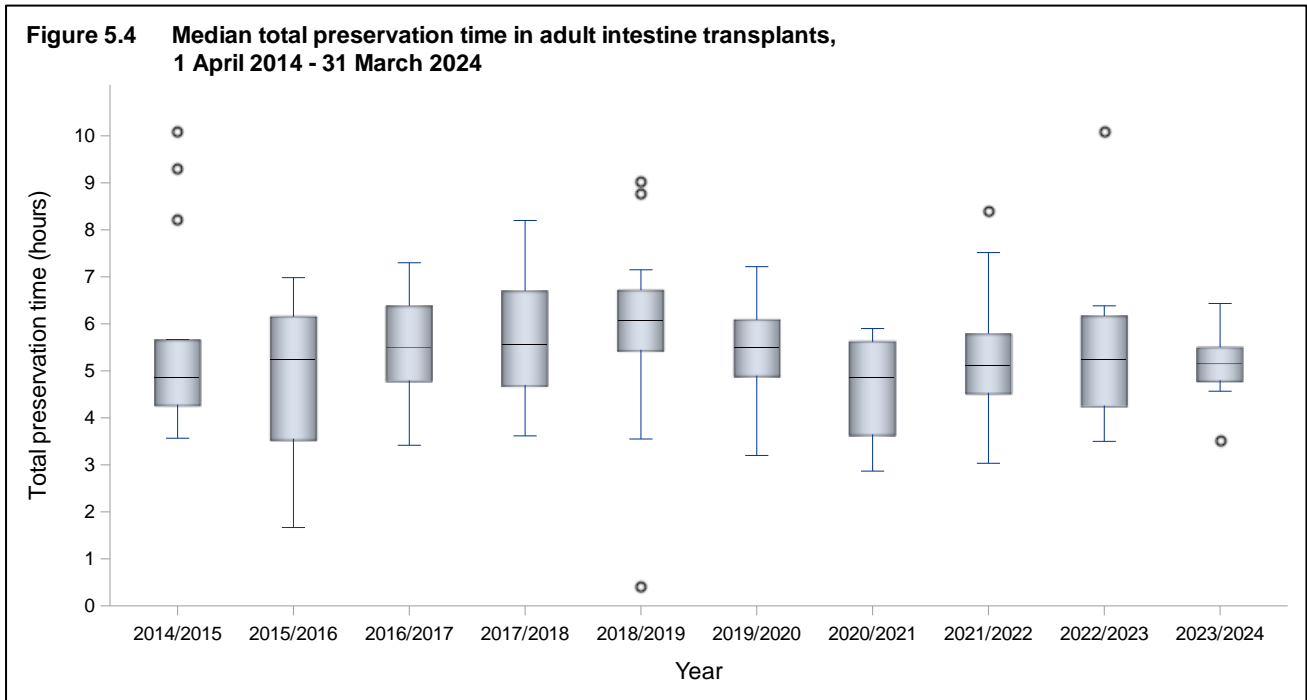
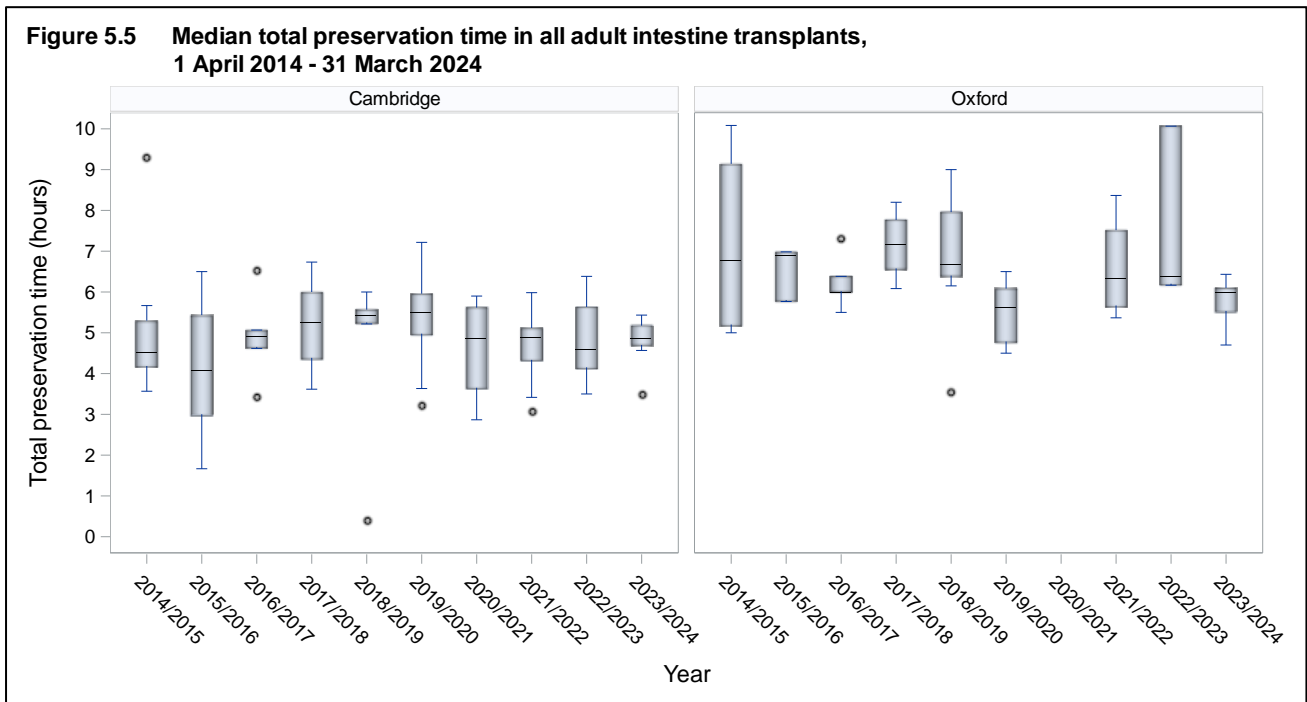


Figure 5.5 shows the median total preservation times in adult intestine transplants over the last 10 years for each transplant centre. Generally, total preservation times were longer for transplants performed by Oxford. All of these boxplots represent a small number of observations and as shown in **Table 5.1**, a proportion of total preservation times have not been reported.

The total preservation time used is cold ischaemia time as reported on the intestinal transplant record form and may include periods of machine perfusion; no adjustment has been made for this.



6. Post-transplant survival

This section presents patient survival after first adult intestine transplantation performed between 1 April 2014 and 31 March 2024, by transplanting centre and transplant type. Of the 146 transplants of this kind in the time period, survival information was known in 145 cases. Due to small numbers, [unadjusted survival rates](#) only are presented and the estimates below do not account for differences in the [case mix](#) at each centre.

Table 6.1 shows the 90-day [patient survival rates](#) by transplant type. 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 $p=0.12$).

Table 6.2 shows the 90-day patient survival rates by indication (malignancy versus non-malignant) for recipients who did not receive a liver containing transplant.

Table 6.1 Unadjusted 90-day patient survival (%) for adult first intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	90-day survival (95% CI)	
		<u>Unadjusted</u>	
Cambridge			
Liver containing ¹	54	90.7	(79.2-96.0)
Non liver containing ²	52	100.0	-
Oxford			
Non liver containing ²	39	92.3	(78.0-97.5)
Total			
Liver containing¹	54	90.7	(79.2-96.0)
Non liver containing²	91	96.7	(90.1-98.9)
¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants			
² Includes intestine only, bowel & pancreas, modified multivisceral transplants			

Table 6.2 Unadjusted 90-day patient survival (%) for adult first NON-LIVER CONTAINING intestine transplants between 1 April 2014 and 31 March 2024, by indication			
Transplant type	Number of transplants	90-day survival (95% CI)	
		<u>Unadjusted</u>	
Cambridge			
Malignant indication ¹	1	-	-
Non-malignant indication	51	100.0	-
Oxford			
Malignant indication	17	94.1	(65.0-99.1)
Non-malignant indication	22	90.9	(68.3-97.6)
Overall			
Malignant indication	18	94.4	(66.6-99.2)
Non-malignant indication	73	97.3	(89.5-99.3)
Overall	91	96.7	(90.1-98.9)
¹ 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 6.3**. At one year post-transplant, the survival rate for patients not receiving the liver was 86.4%, and was 76.9% 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 post-transplant (log-rank p=0.13). **Table 6.4** shows the one-year patient survival rates by indication (malignancy versus non-malignant) for recipients who did not receive a liver containing transplant.

Table 6.3 Unadjusted one-year patient survival (%) for adult first intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	1-year survival (95% CI) <u>Unadjusted</u>	
Cambridge			
Liver containing ¹	54	76.9	(62.9-86.2)
Non liver containing ²	52	88.4	(74.3-95.0)
Oxford			
Non liver containing ²	39	83.6	(67.0-92.3)
Total			
Liver containing¹	54	76.9	(62.9-86.2)
Non liver containing²	91	86.4	(74.3-90.5)

¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants
² Includes intestine only, bowel & pancreas, modified multivisceral transplants

Table 6.4 Unadjusted one-year patient survival (%) for adult first NON-LIVER CONTAINING intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	5-year survival (95% CI) <u>Unadjusted</u>	
Cambridge			
Malignant indication ¹	1	-	-
Non-malignant indication	51	88.9	(75.3-95.2)
Oxford			
Malignant indication	17	81.1	(51.9-93.5)
Non-malignant indication	22	86.1	(62.9-95.3)
Overall			
Malignant indication	18	82.2	(54.3-93.9)
Non-malignant indication	73	88.2	(77.7-93.9)
Overall	91	86.4	(74.3-90.5)

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

Five-year [patient survival rates](#) are shown in **Table 6.5**. At five year post-transplant, the survival rate for patients not receiving the liver was 68.5%, and was 59.5% for patients receiving the liver. There was some evidence of a significant difference in survival between those receiving the liver and those who did not at 5 years (log-rank p=0.10). **Table 6.6** shows the breakdown of survival rates by registrations due to malignancy, for recipients not receiving the liver.

Table 6.5 Unadjusted five-year patient survival (%) for adult first intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	5-year survival (95% CI) <u>Unadjusted</u>	
Cambridge			
Liver containing ¹	54	59.5	(43.6-72.4)
Non liver containing ²	52	82.1	(65.6-91.1)
Oxford			
Non liver containing ²	39	53.3	(39.1-70.7)
Total			
Liver containing¹	54	59.5	(43.6-72.4)
Non liver containing²	91	68.5	(54.5-78.9)

¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants
² Includes intestine only, bowel & pancreas, modified multivisceral transplants

Table 6.6 Unadjusted five-year patient survival (%) for adult first NON-LIVER CONTAINING intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	5-year survival (95% CI) <u>Unadjusted</u>	
Cambridge			
Malignant indication ¹	1	-	-
Non-malignant indication	51	82.5	(66.4-91.4)
Oxford			
Malignant indication	17	39.8	(14.0-64.9)
Non-malignant indication	22	70.7	(41.1-87.3)
Overall			
Malignant indication	18	44.4	(18.2-68.0)
Non-malignant indication	73	78.9	(65.2-87.7)
Overall	91	68.5	(54.5-78.9)

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

PAEDIATRIC INTESTINE TRANSPLANTATION



7. Transplant list

7.1 Paediatric intestine transplant list as at 31 March, 2015 – 2024

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 2015 and 2024. The number of paediatric patients on the [active transplant list](#) ranged between 4 and 9 each year and was 8 on 31 March 2024.

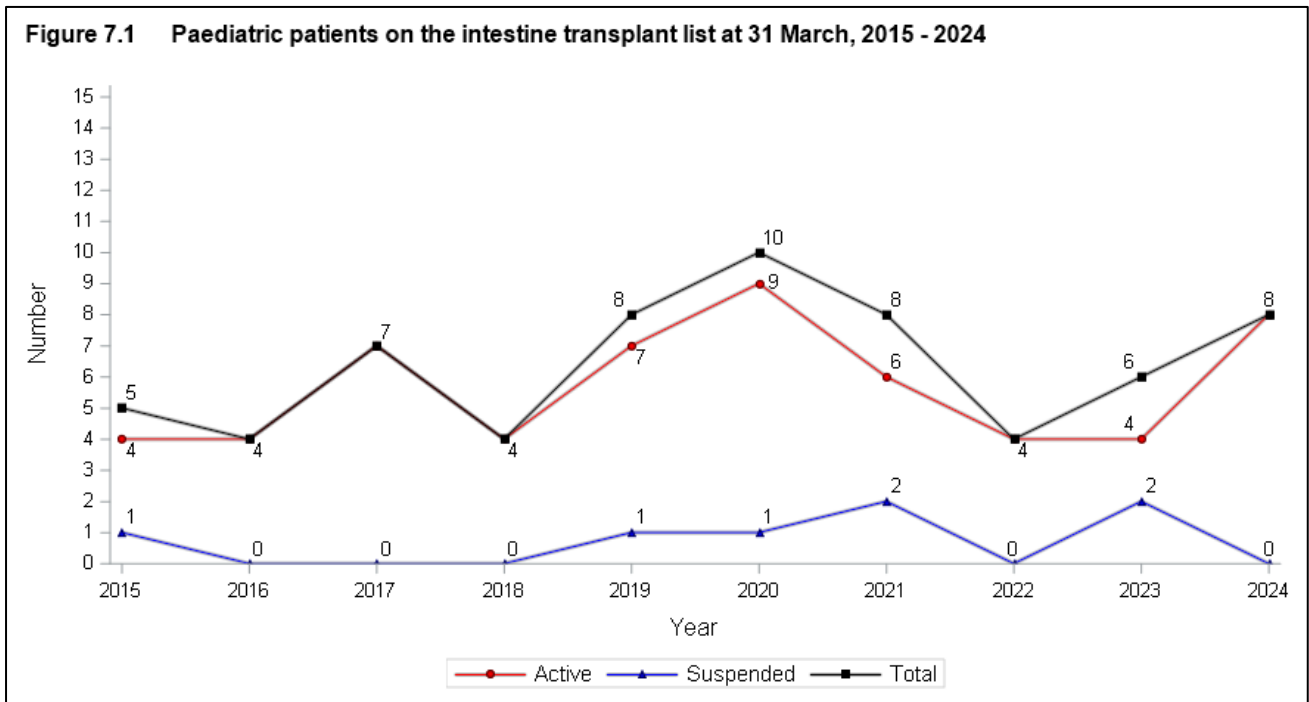
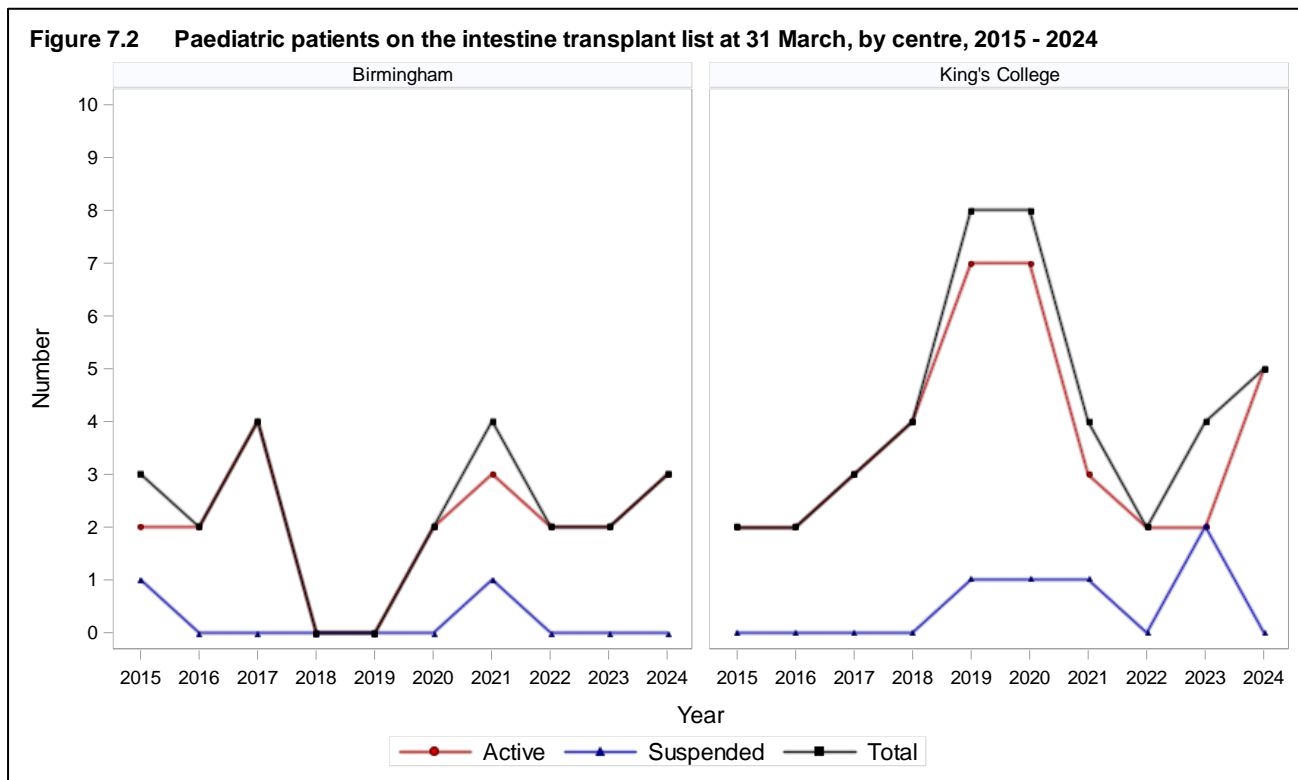


Figure 7.2 shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2015 and 2024, at each transplant centre. The number of paediatric patients on the active transplant list at Birmingham decreased to 0 in 2018 and 2019 then increased, with 3 patients active in 2024; while the number active at King's College Hospital increased to 7 in 2019 and 2020 before decreasing, with 5 patients active in 2024.



The demographic characteristics of 74 paediatric intestine transplant recipient registrations in the 10-year period are shown by centre and overall in **Table 7.1**. Nationally, 58% of registrations 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 16 kg/m². 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 2014 - 31 March 2024

		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		34	40	74 (100)
Number of patients		33 (100)	34 (100)	67 (100)
Registration type	Elective	34 (100)	40 (100)	74 (100)
Transplant type required	Non liver containing	8 (24)	9 (23)	17 (23)
	Liver containing	26 (76)	31 (78)	57 (77)
Recipient sex	Male	21 (62)	22 (55)	43 (58)
	Female	13 (38)	18 (45)	31 (42)
Recipient ethnicity group	White	27 (79)	28 (70)	55 (74)
	Other	5 (15)	12 (30)	17 (23)
	Not reported	2 (6)	0	2 (3)
Indication group	Short bowel syndrome	16 (47)	17 (43)	33 (45)
	Motility disorders	7 (21)	8 (20)	15 (20)
	Primary mucosal disorders	3 (9)	2 (5)	5 (7)
	Tumour	1 (3)	1 (3)	2 (3)
	Other/not reported	5 (15)	4 (10)	9 (12)
	Retransplant	2 (6)	8 (20)	10 (14)
Patient location	Out-patient	20 (59)	21 (53)	41 (55)
	Ward	4 (12)	8 (20)	12 (16)
	ICU/HDU	0	2 (5)	2 (3)
	Not reported	10 (29)	9 (23)	19 (26)
Pre-transplant renal support	No	34 (100)	39 (98)	73 (99)
	Yes	0	1 (3)	1 (1)
Previous abdominal surgery	No	6 (18)	3 (8)	9 (12)
	Yes	28 (82)	37 (93)	65 (88)
Recipient blood group	O	19 (56)	12 (30)	31 (42)
	A	10 (29)	21 (53)	31 (42)
	B	1 (3)	5 (13)	6 (8)
	AB	4 (12)	2 (5)	6 (8)
Recipient age (years)	Median (IQR)	4 (2,8)	3 (1,5)	3 (1,6)
Recipient BMI (kg/m ²)	Median (IQR)	16 (15,19)	16 (16,19)	16 (16,19)

An indication of registration outcomes for paediatric elective patients registered on the intestine transplant list in the UK between 1 April 2020 and 31 March 2022 is summarised in **Figure 7.3**. The proportion of paediatric patients transplanted within six month of listing is 50%.

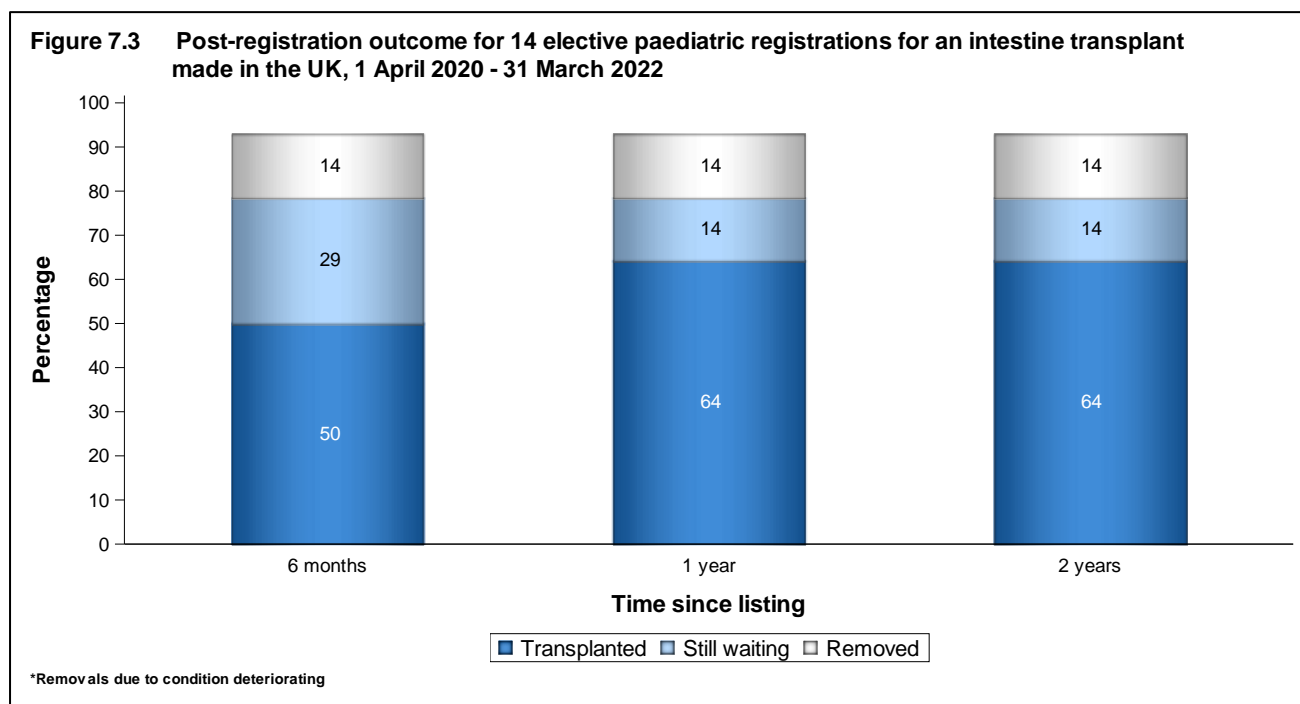


Table 7.2 shows [median waiting time](#) to [elective](#) intestine transplant by registration type for paediatric patients, registered between 1 April 2020 and 31 March 2023. The national UK median total waiting time to transplant for paediatric elective patients is 138 days.

Table 7.2 Median waiting time to elective intestine transplant in the UK, for paediatric patients registered 1 April 2020 - 31 March 2023					
Registration type	Number of patients registered	Total waiting time (days) ¹		Active waiting time (days)	
		Median	95% Confidence interval	Median	95% Confidence interval
Liver containing	14	946	8 – 1884	903	12 – 17940
Non liver containing	6	252	65 – 439	252	65 - 439
TOTAL	20	138	0 – 376	118	0 - 364

¹ Periods of suspension from the list are included in the calculation of total median waiting times

8. Response to offers

Between 1 April 2023 and 31 March 2024, Birmingham and King’s College Hospital received offers from 61 and 11 donors, respectively, for intestine transplant patients at their centres. Their [donor offer decline rates](#) were 97% and 73% respectively. These rates are high to some extent because centres are very selective, particularly about the size of the donor.

Centre	Offers	%Decline	Donors	%Decline
Birmingham	63	97	61	97
King’s College	12	75	11	73
TOTAL	75	93	72	93

9. Transplants

9.1 Paediatric intestine transplants, 1 April 2014 – 31 March 2024

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 fluctuated over the period, with 5 performed in 2023/2024. In 2017/2018, a living liver and bowel transplant was performed by King’s College Hospital and in 2023/2024, a living bowel-only transplant was performed by King’s College Hospital. These transplants are included in the numbers presented in this section.

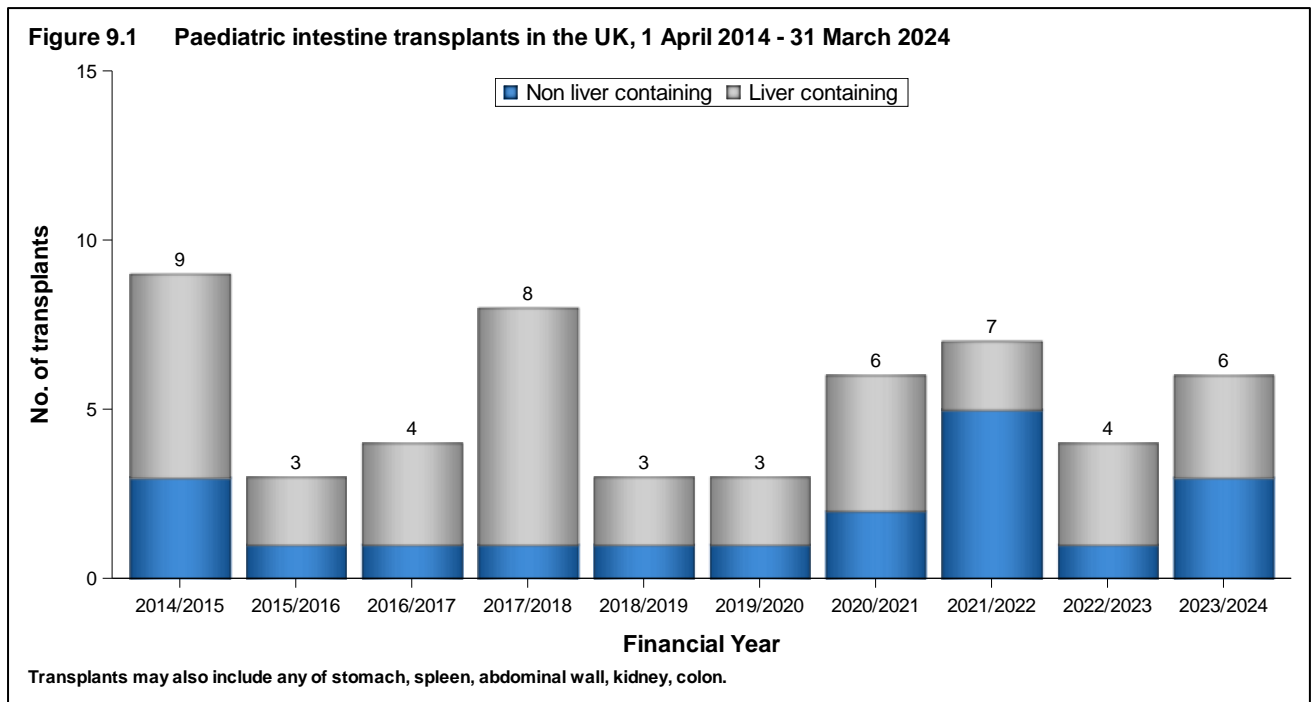


Figure 9.2 shows the number of paediatric intestine transplants performed in 2023/2024, by centre and [transplant type](#). Birmingham performed two transplants and King's College Hospital performed four transplants, including one living donor transplant. Three of the transplants were non liver containing and three included the liver.

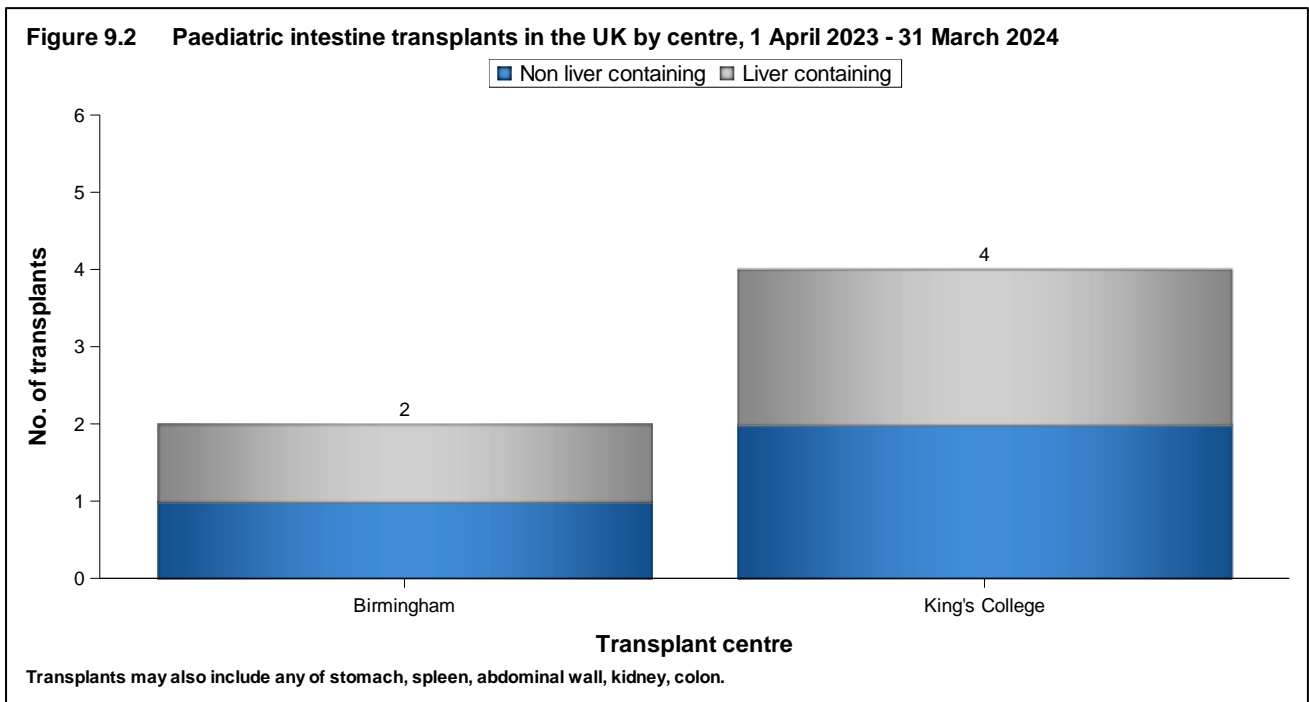
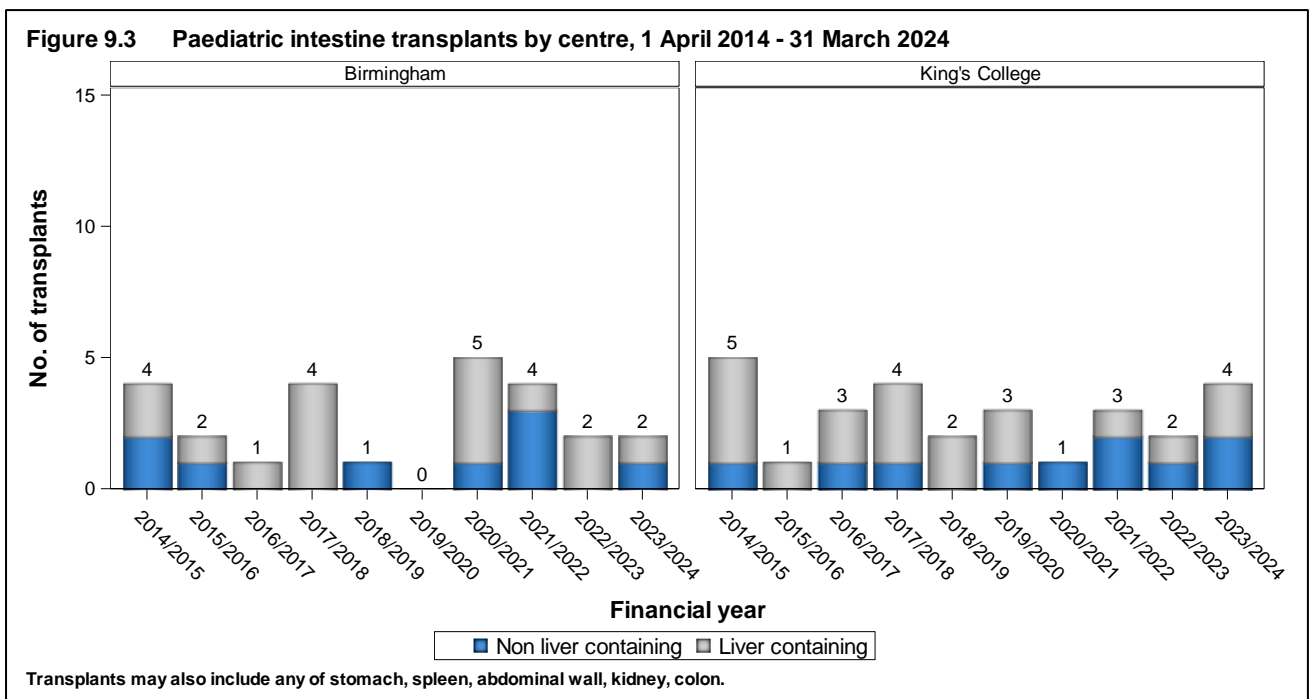


Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and [type of transplant](#). The number of transplants performed by King's College Hospital fluctuated in the last 10 years, and overall they performed 28 (53%) of transplants, whilst the number of transplants performed by Birmingham fluctuates with 25 (47%) of transplants performed overall.



The demographic characteristics of 53 paediatric intestine transplant recipients in the 10-year period are shown by centre and overall in **Table 9.1**. Nationally, 62% of recipients were male and the [median](#) recipient age was 5 years old, while the median age of donors was 7 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.

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2014 - 31 March 2024				
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		25	28	53 (100)
Transplant type	Non liver containing	9 (36)	10 (36)	19 (36)
	Liver containing	16 (64)	18 (64)	34 (64)
Recipient sex	Male	16 (64)	17 (61)	33 (62)
	Female	9 (36)	11 (39)	20 (38)
Recipient ethnicity group	White	17 (68)	18 (64)	35 (66)
	Other	6 (24)	10 (36)	16 (30)
	Not reported	2 (8)	0	2 (4)
Indication group	Short bowel syndrome	12 (48)	6 (21)	18 (34)
	Motility disorders	4 (16)	7 (25)	11 (21)
	Primary mucosal disorders	3 (12)	1 (4)	4 (8)
	Tumour	1 (4)	1 (4)	2 (4)
	Other/not reported	3 (12)	6 (21)	9 (17)
	Retransplant	2 (8)	7 (25)	9 (17)
Patient location	Out-patient	20 (80)	14 (50)	34 (64)
	Ward	4 (16)	4 (14)	8 (15)
	ICU/HDU	1 (4)	3 (11)	4 (8)
	Not reported	0	7 (25)	7 (13)
Pre-transplant renal support	No	24 (96)	21 (75)	45 (85)
	Yes	1 (4)	0	1 (2)
	Not reported	0	7 (25)	7 (13)
Previous abdominal surgery	No	9 (36)	1 (4)	10 (19)
	Yes	16 (64)	20 (71)	36 (68)
	Not reported	0	7 (25)	7 (13)
Lifestyle activity	Normal	1 (4)	0	1 (2)
	Restricted	9 (36)	7 (25)	16 (30)
	Self-care	2 (8)	0	2 (4)
	Confined	0	4 (14)	4 (8)
	Reliant	12 (48)	10 (36)	22 (42)
	Not reported	1 (4)	7 (25)	8 (15)
Restricted venous access at registration	No	15 (60)	16 (57)	31 (59)
	Yes	10 (40)	11 (39)	21 (40)
	Not reported	0	1 (4)	1 (2)

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2014 - 31 March 2024

		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Recipient age years	Median (IQR)	6 (2,9)	5 (4,8)	5 (3,9)
Recipient BMI kg/m ²	Median (IQR)	16 (16,18)	16 (15,18)	16 (15,18)
	Not reported	0	1	1
Serum bilirubin umol/l	Non liver containing (N reported)	7	6	13
	Median (IQR)	9 (8,17)	14 (9,20)	9 (8,18)
	Not reported	2	4	6
	Liver containing (N reported)	16	15	31
	Median (IQR)	10 (6,101)	10 (9,34)	10 (7,41)
	Not reported	0	3	3
	Overall (N reported)	23	21	44
	Median (IQR)	9 (7,41)	10 (9,34)	10 (8,38)
	Not reported	2	7	9
Total time on list days ¹	Median (IQR)	87 (42,221)	247 (134,632)	179 (58,333)
Donor sex	Male	15 (60)	14 (50)	29 (55)
	Female	10 (40)	14 (50)	24 (45)
Donor ethnicity group	White	20 (80)	18 (64)	38 (72)
	Other	2 (8)	3 (11)	5 (9)
	Not reported	3 (12)	7 (25)	10 (19)
Donor cause of death group	Stroke	20 (80)	18 (64)	38 (72)
	Trauma	3 (12)	1 (4)	4 (8)
	Other	2 (8)	7 (25)	9 (17)
	Living	0	2 (7)	2 (4)
Donor history of diabetes	No	24 (96)	22 (79)	46 (87)
	Not reported	1 (4)	6 (21)	7 (13)
Donor age years	Median (IQR)	8 (5,17)	5 (2,13)	7 (2,14)
Donor BMI kg/m ²	Median (IQR)	18 (15,19)	15 (14,17)	16 (15,19)
		0	2	2
ABO match	Identical	20 (80)	21 (75)	41 (77)
	Compatible	5 (20)	7 (25)	12 (23)
Total preservation time hours	Median (IQR)	5.2 (4.2,6)	8.3 (6.8,9)	6 (5,7.9)
	Not reported	0	10	10

¹ Excludes living donor transplants

9.2 Total preservation time, 1 April 2014 – 31 March 2024

Figure 9.4 shows [boxplots](#) of the [total preservation times](#) 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 total preservation time in paediatric transplants has remained fairly stable over time and was 6.1 hours in 2023/2024.

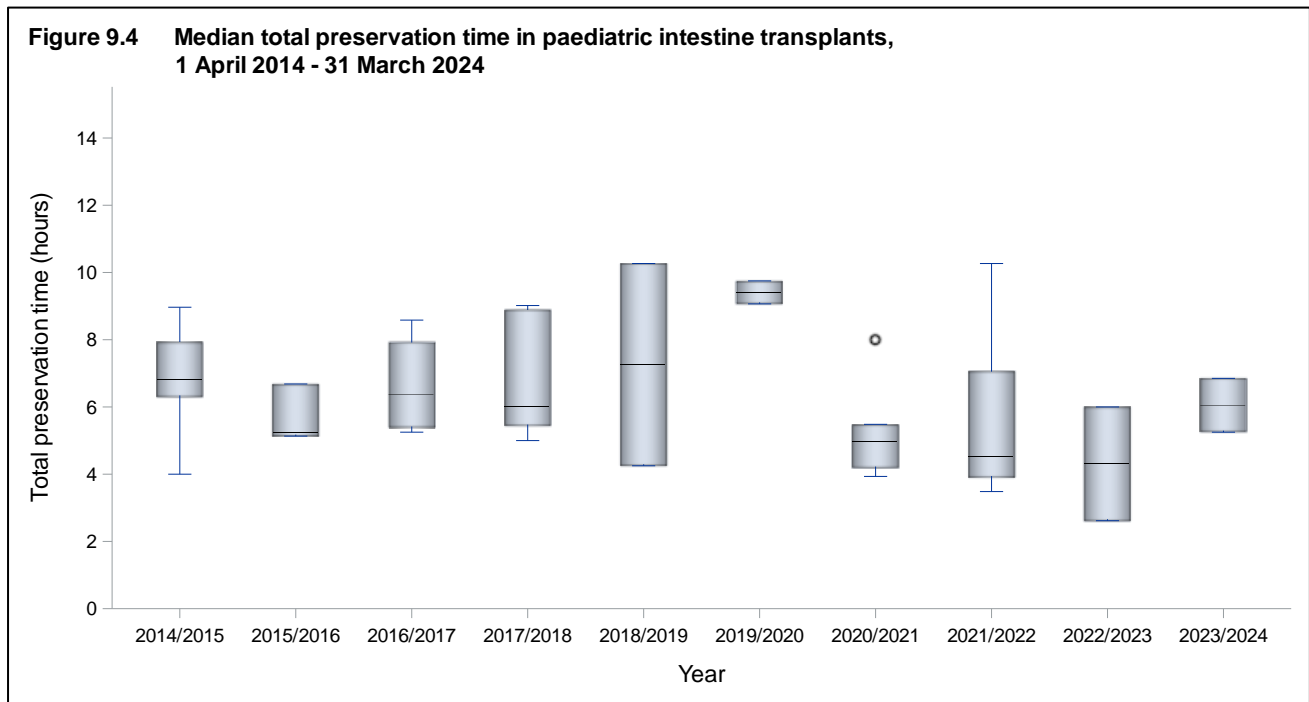
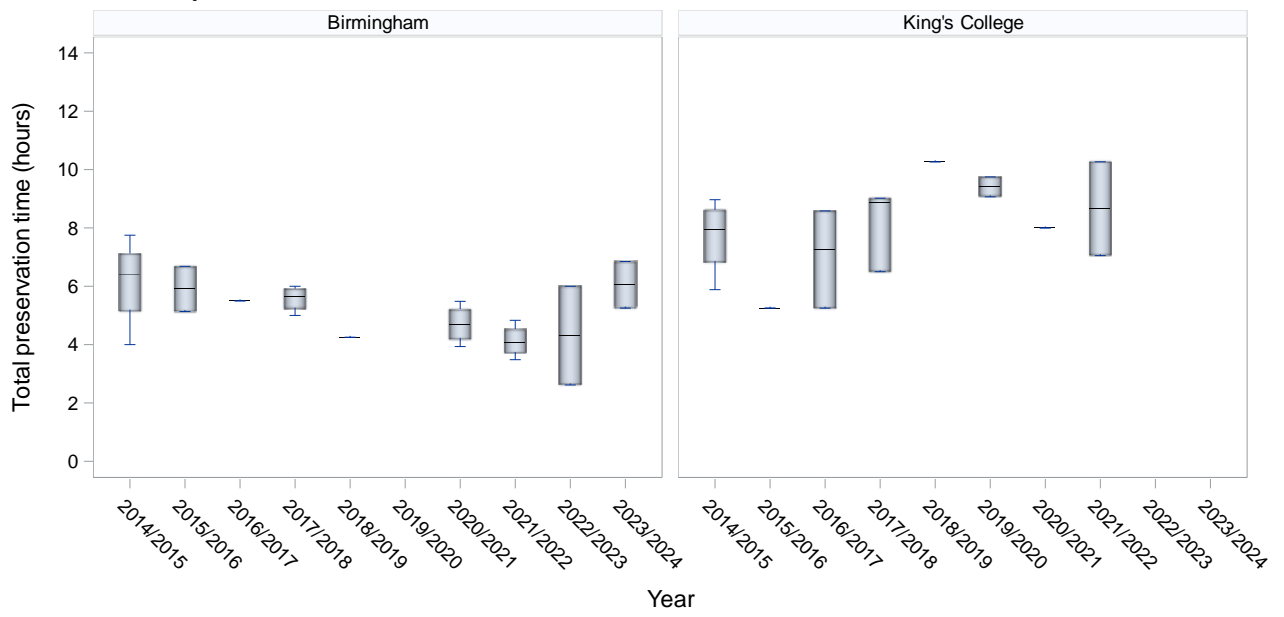


Figure 9.5 shows the median total preservation times in paediatric intestine transplants by centre over the last 10 years for deceased donors. There was a decreasing trend in total preservation time for Birmingham up to 2022/23, and total preservation times seem to be generally greater at King's College than at Birmingham. All of these boxplots represent a small number of observations and, as shown in **Table 9.1**, a proportion of total preservation times have not been reported.

Figure 9.5 Median total preservation time in all paediatric intestine transplants, 1 April 2014 - 31 March 2024



10. Post-transplant survival

This section presents patient survival post paediatric intestine transplantation for first intestine transplants between 1 April 2014 and 31 March 2024, by transplanting centre and transplant type. Of the 42 transplants of this kind in the time period, survival information was known in 41 cases. 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](#) by transplant type. The 90-day survival rate for patients who received a liver was 92.6% 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 $p=0.29$).

Table 10.1 90-day patient survival (%) for paediatric first intestine transplants between 1 April 2014 and 31 March 2024, by transplant type			
Transplant type	Number of transplants	90-day survival (95% CI) <u>Unadjusted</u>	
Birmingham			
Liver containing ¹	13	84.6	(51.2-95.9)
Non liver containing ²	9 ³	-	-
King's College Hospital			
Liver containing ¹	14	100.0	-
Non liver containing ²	6 ³	-	-
Total			
Liver containing¹	27	92.6	(73.5-98.1)
Non liver containing²	15	100.0	-
¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants			
² Includes intestine only, bowel & pancreas, modified multivisceral transplants			
³ 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 100.0%, and was 84.7% 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=0.13).

Table 10.2 1-year patient survival (%) for paediatric first intestine transplants between 1 April 2013 and 31 March 2023, by transplant type			
Transplant type	Number of transplants	1-year survival (95% CI) <u>Unadjusted</u>	
Birmingham			
Liver containing ¹	13	76.2	(42.7-91.7)
Non liver containing ²	9 ³	-	-
King's College Hospital			
Liver containing ¹	14	92.3	(56.6-98.9)
Non liver containing ²	6 ³	-	-
Total			
Liver containing¹	27	84.7	(64.2-94.0)
Non liver containing²	15	100.0	-
¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants			
² Includes intestine only, bowel & pancreas, modified multivisceral transplants			
³ 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 2023

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 2023 and 31 December 2023, for recipients being followed up by each centre, and the percentage of forms that had been returned at time of analysis (1 September 2024). 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. Note that some paediatric transplant patients have transitioned to be followed up at Cambridge and Oxford, both of which are adult transplant centres.

Table 11.1 Form return rates by follow-up centre for adult transplants, 1 January 2023 to 31 December 2023								
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	11	27	14	100	15	100	60	100
Oxford	5	100	5	100	2	100	26	100
Total	16	50	19	100	17	100	86	100

Table 11.2 Form return rates by follow-up centre for paediatric transplants, 1 January 2023 to 31 December 2023								
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	2	100	3	100	2	100	26	100
Cambridge	0	-	0	-	0	-	6	100
King's College	2	0	1	100	2	100	16	88
Oxford	0	-	0	-	0	-	14	86
Total	4	50	4	100	4	100	62	94

APPENDIX



A1: Number of patients analysed

Data were obtained from the UK Transplant Registry for the 10-year time period, 1 April 2014 to 31 March 2024. 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. 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 been excluded. Those 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.

Table A1 Number of adult intestine transplants, by transplant centre and urgency status, 1 April 2014 to 31 March 2024				
Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Cambridge	107	3	103	3
Oxford	43	0	40	0
TOTAL	150	3	143	3

Table A2 shows the number of paediatric transplants including the intestine in the 10-year period by centre and urgency status. The left hand columns show the total number of transplants (including re-transplants) and the right hand columns shows first-time transplants only.

Table A2 Number of paediatric intestine transplants, by transplant centre and urgency status, 1 April 2014 to 31 March 2024				
Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Birmingham	25	0	22	0
King's College Hospital	28	0	20	0
TOTAL	53	0	42	0

Geographical variation analysis

Registration rates

All NHS group 1 patients who were registered onto the intestinal transplant lists with an active status between 1 April 2014 and 31 March 2024 were extracted from the UK Transplant Registry on 10 July 2024 (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-2022 population estimates based on the Office for National Statistics (ONS) 2021 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 number of intestinal transplants on NHS group 1 recipients from deceased donors between 1 April 2014 and 31 March 2024 (numerator), divided by the mid-2022 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 2014 and 31 March 2024 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 2020 and 31 March 2023 for an intestine transplant. Any periods of suspension were included in the calculation. Registrations for a re-transplant were included too. [Kaplan-Meier](#) methods were used to calculate median waiting times, where patients who were removed or died on the transplant list were censored at the date of event. Patients who were still active on the transplant list at time of analysis, 9 July 2024, 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.

Donor 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 60 years and weight less than 90 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 2023 to 31 March 2024.

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 σ^2 . If the factor is one for all areas, then area differences are fully explained by the area-specific Poisson rate. If the factor varies with a nonzero variance, σ^2 , then we conclude that there are unexplained area differences.

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

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 σ^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.

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) is a type of donation that 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.

Total preservation time

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 total preservation time. Generally, the shorter this time, the better the long-term survival of the recipient.

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 two groups:

Liver containing. 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.

Non liver containing. 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. This also 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.

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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