

ANNUAL REPORT ON INTESTINE TRANSPLANTATION

REPORT FOR 2024/2025 (1 APRIL 2015 – 31 MARCH 2025)

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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 2015 to 31 March 2025. 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 2025, there were 8 patients on the UK active intestine **transplant list**, five less than the end of the previous year.
- Of those patients registered onto the transplant list in a recent two year period (1 April 2021 31 March 2023), 62% had received a transplant two years post-registration, while 11% died on the list (or were removed due to condition deteriorating), 10% were removed and 16% were still waiting at time of data analysis.
- Median total waiting time to elective intestine transplant between 1 April 2021 and 31 March 2024 was 133 days for adult registrations and 250 days for paediatric registrations.
- There were 199 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, 2024/2025, 17 intestine **transplants** were performed, a decrease of six from 2023/2024. Of the 17 transplants, 11 (65%) were in adult recipients and 6 (35%) were in paediatric recipients.
- The national rates of survival (unadjusted) after first intestine transplantation for adult patients were estimated at 97%, 86%, and 68% at 90 days, one and five years post-transplant, respectively, for those who did not receive the liver and 92%, 78%, and 52% 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 at 90 days and one year post-transplant but there was a significant difference in survival rates at five years post-transplant. 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** (<u>unadjusted</u>) were estimated at 100%, 100% and 76% at 90 days, one and five years post-transplant, respectively, for those **who did not receive the liver** and at 92%, 80% and 63 % at 90 days, one and five years post-transplant, respectively, for those **who did receive the liver**.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Intestine Transplantation 2024/2025, NHS Blood and Transplant.*

INTRODUCTION

INTRODUCTION

This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2015 and 31 March 2025, 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. Data were extracted on 10 July 2025.

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 <u>patient survival rates</u> 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 <u>active transplant list</u> at 31 March of each year between 2016 and 2025. The number of patients waiting for a transplant has decreased in recent years, with a peak of 18 patients in 2020 compared to 8 in 2025.

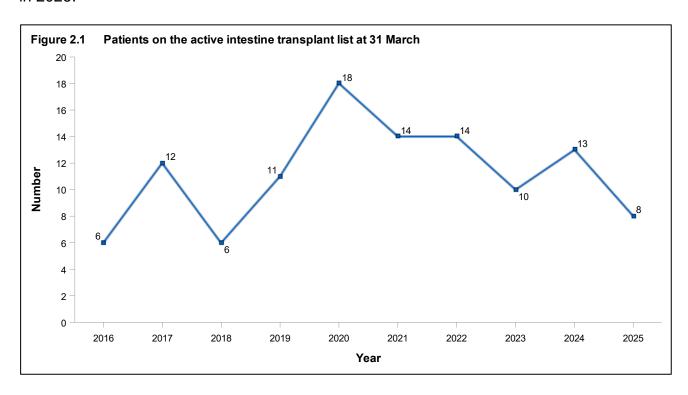


Figure 2.2 shows the number of adult and paediatric patients on the <u>active transplant list</u> on 31 March 2025, by centre. In total, there were six adults and two paediatric patients on the active transplant list. Ten-year trends of the number of adult and paediatric patients on the active transplant list by transplant centre are shown later in the report, in **Figure 3.2** and **Figure 7.2**, respectively.

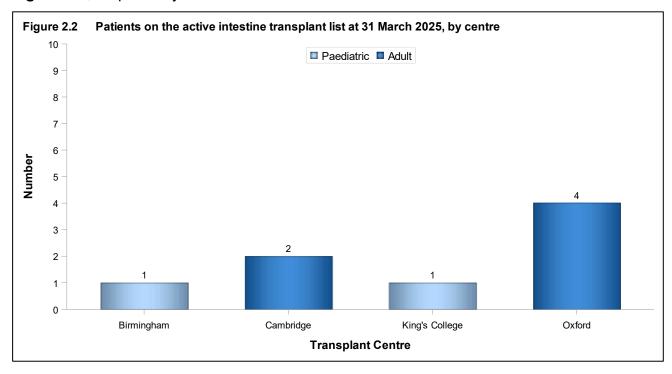


Figure 2.3 shows the number of registrations made onto the active intestine transplant list each year in the last 10 years. The number of registrations has fluctuated over the decade, with 25 registrations in 2024/2025.

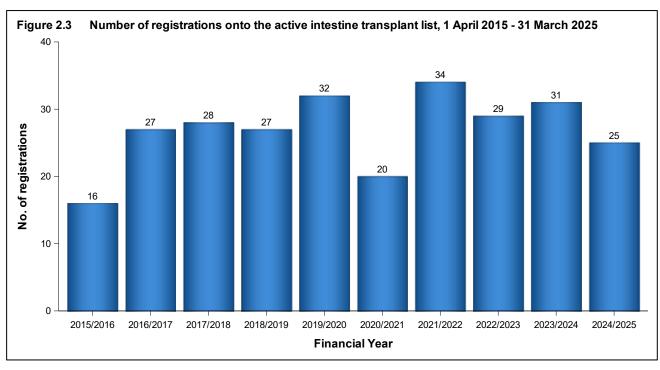
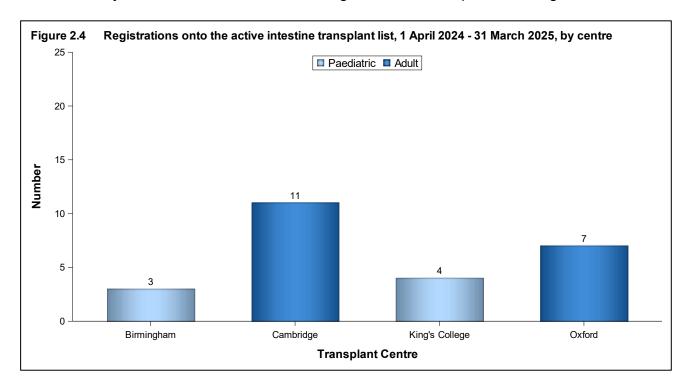
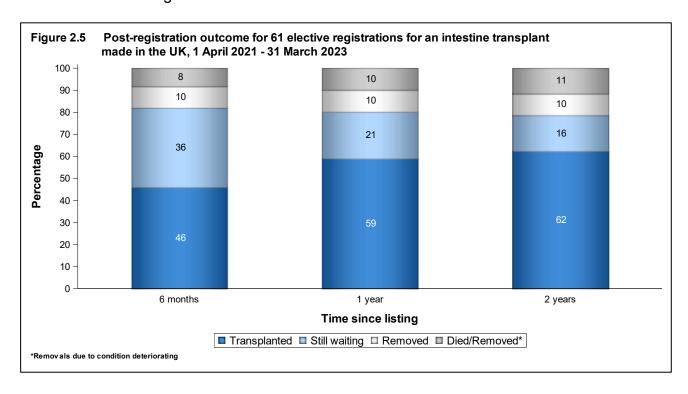


Figure 2.4 shows the number of registrations onto the active intestine transplant list in 2024/2025, by centre. There were 18 adult registrations and 7 paediatric registrations.



2.1.1 Post-registration outcomes, 1 April 2021 – 31 March 2023

The registration outcomes of patients listed between 1 April 2021 and 31 March 2023 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 62% of patients had received a transplant and 16% were still waiting.



2.1.2 Median waiting time to transplant, 1 April 2021 – 31 March 2024

Table 2.1 shows median waiting time to elective intestine transplant by registration type for adult and paediatric patients, combined, registered between 1 April 2021 and 31 March 2024. Patients who received a living donor transplant were excluded. A small proportion of patients requiring a liver containing graft are removed from the intestinal transplant waiting list to receive a liver transplant without the small bowel; the liver transplant is counted as receiving a transplant. Overall, on average, patients waited a total of 144 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 2021 - 31 March 2024					
Registration type	Number of patients	Total wa	aiting time (days) ¹	Active w	aiting time (days)
	registered	Median	95% Confidence interval	Median	95% Confidence interval
Liver containing ²	38	158	89 – 227	147	50 – 244
Non liver containing	49	144	97 – 191	131	87 – 175
TOTAL	87	144	113 – 175	136	97 - 175

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

² Patients who received a liver only transplant are classed as transplanted

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 (<u>DBD</u>), 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 199, with annual figures fluctuating between 12 and 27. In 2024/25, 17 transplants were performed, a decrease from the previous year.

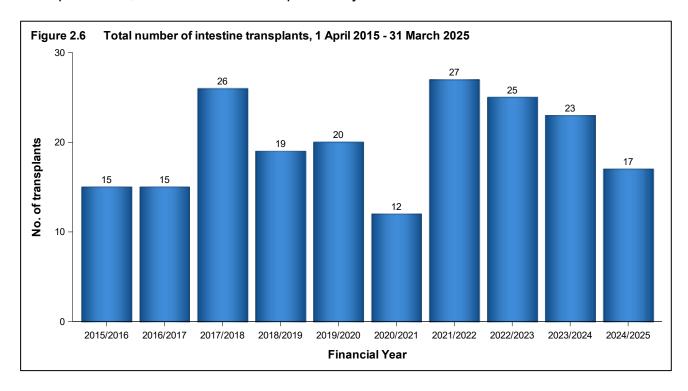
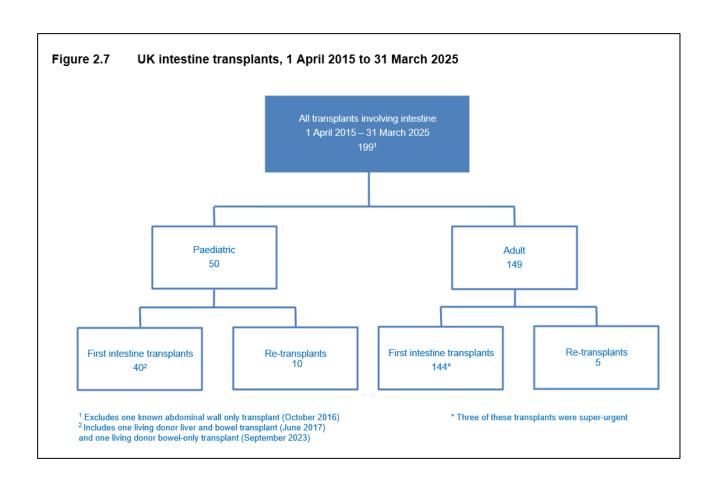


Figure 2.7 details the 199 intestine transplants performed in the UK in the 10 year period. Of these, 50 (25%) were in paediatric recipients and 149 (75%) were in adult recipients. Most of both paediatric and adult transplants were in first time recipients.



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 2015 and 31 March 2025 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 inevitable 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.

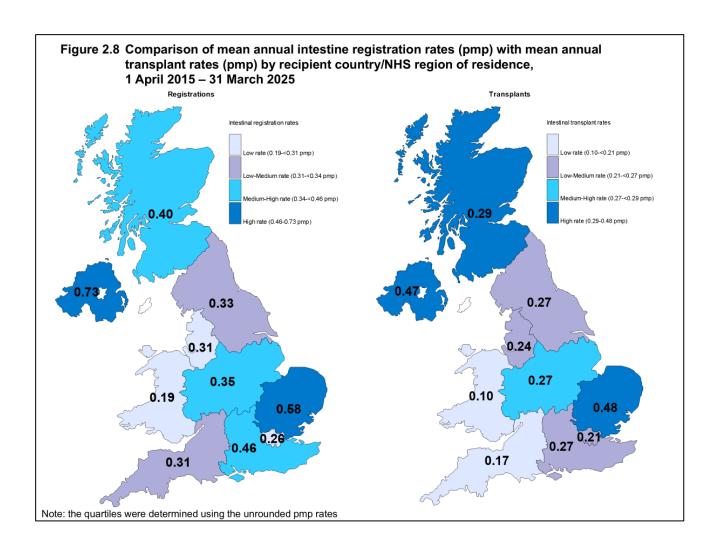


Table 2.2 Intestinal registration and transplant rates per million population (pmp) in the UK, 1 April 2015 - 31 March 2025, by country/NHS region

Country/ NHS region	Registration	ons (pmp)	Transpla	nts (pmp)
North East and Yorkshire North West Midlands East of England London South East South West	2.7 2.3 3.8 3.7 2.3 4.3	(0.3) (0.3) (0.4) (0.6) (0.3) (0.5) (0.3)	2.2 1.8 3.0 3.1 1.9 2.5 1.0	(0.3) (0.2) (0.3) (0.5) (0.2) (0.3) (0.2)
England Isle of Man Channel Islands	20.9 0 0	(0.4) (0.0) (0.0)	15.5 0 0	(0.3) (0.0) (0.0)
Wales	0.6	(0.3)	0.3	(0.1)
Scotland	2.2	(0.4)	1.6	(0.3)
Northern Ireland	1.4	(0.7)	0.9	(0.5)
TOTAL	25.4 ¹	(0.4)	18.6 ²	(0.3)

¹ Registrations include 3 recipients whose postcode was unknown and excludes 5 recipients who reside in the Republic of Ireland and 4 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 3 recipients who reside overseas

ADULT INTESTINE TRANSPLANTATION

3. Transplant list

3.1 Adult intestine transplant list as at 31 March, 2016 – 2025

Figure 3.1 shows the number of adults active or suspended on the intestine transplant list at 31 March of each year between 2016 and 2025. The number of adults on the <u>active</u> intestine transplant list remained low over most of the decade with 6 adults active at 31 March 2025.

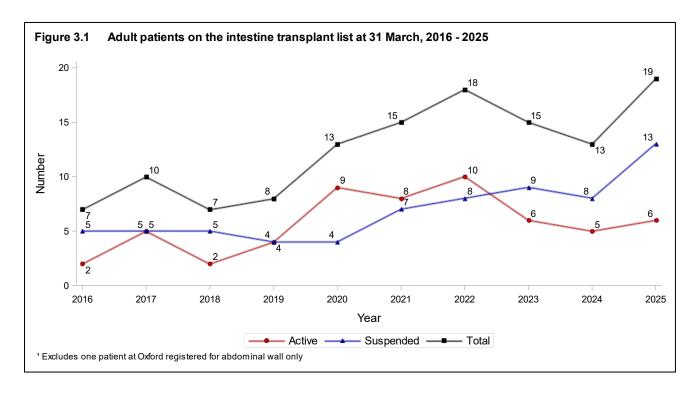
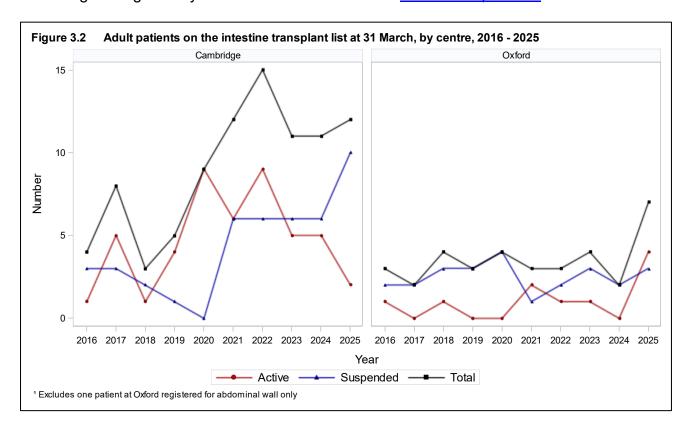


Figure 3.2 shows the number of adults on the intestine transplant list at 31 March of each year between 2016 and 2025, at each transplant centre.

Cambridge had generally more adults on the national <u>active transplant list</u> 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 <u>median</u> age was 45 years old. The most common known indication for transplantation was short bowel syndrome (29%). 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 2015 - 31 March 2025				
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of registrations		135	58	193 (100)
Number of patients		132 (100)	57 (100)	189 (100)
Registration type	Elective	131 (97)	58 (100)	189 (98)
	Super-urgent	4 (3)	0	4 (2)
Transplant type required	Non liver containing	62 (46)	58 (100)	120 (62)
	Liver containing	73 (54)	0	73 (38)
Recipient sex	Male	66 (49)	33 (57)	99 (51)
	Female	69 (51)	25 (43)	94 (49)
Recipient ethnicity group	White	120 (89)	53 (91)	173 (90)
	Other	15 (11)	5 (9)	20 (10)
Indication group	Short bowel syndrome Motility disorders Primary mucosal disorders Tumour Liver disease Other/not reported Retransplant Mesenteric thrombosis	39 (29) 6 (5) 2 (2) 19 (14) 11 (8) 35 (26) 11 (8) 10 (8)	17 (29) 1 (2) 0 18 (31) 0 17 (29) 3 (5) 2 (3)	56 (29) 7 (4) 2 (1) 37 (19) 11 (6) 52 (27) 14 (7) 12 (6)
Patient location	Out-patient	69 (51)	35 (60)	104 (54)
	Ward	15 (11)	6 (10)	21 (11)
	ICU/HDU	4 (3)	0	4 (2)
	Not reported	47 (35)	17 (29)	64 (33)
Pre-transplant renal support	No	126 (93)	56 (97)	182 (94)
	Yes	8 (6)	2 (3)	10 (5)
	Not reported	1 (1)	0	1 (1)
Previous abdominal surgery	No	14 (10)	0	14 (7)
	Yes	116 (86)	58 (100)	174 (90)
	Not reported	5 (4)	0	5 (3)
Recipient blood group	O	57 (42)	23 (40)	80 (42)
	A	48 (36)	29 (50)	77 (40)
	B	21 (16)	4 (7)	25 (13)
	AB	9 (7)	2 (3)	11 (6)
Recipient age (years)	Median (IQR)	43 (33,53)	50 (39,56)	45 (34,54)
Recipient BMI (kg/m²)	Median (IQR)	22 (20,26)	22 (21,25)	22 (20,26)

An indication of registration outcomes for adult elective patients registered on the intestine transplant list in the UK between 1 April 2021 and 31 March 2023 is summarised in **Figure 3.3**.

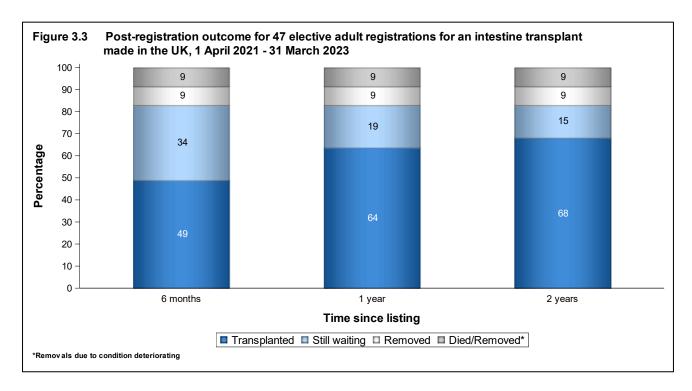


Figure 3.4 shows the proportion of patients transplanted, removed, died while waiting, or still waiting on the list at 6 months after joining the list, by transplant centre. 52% of registrations at Cambridge received a transplant within 6 months of listing compared to 43% at Oxford. Note there were 14 registrations at Oxford between 1 April 2021 and 31 March 2023.

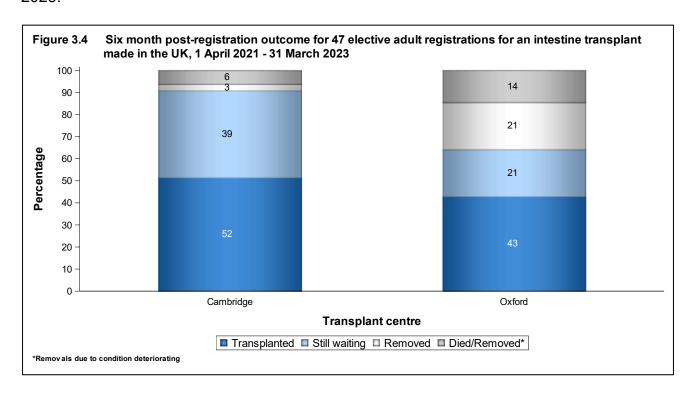


Table 3.2 shows <u>median waiting time</u> to <u>elective</u> intestine transplant by registration type for adult patients, registered between 1 April 2021 and 31 March 2024. Registrations ending in a living donor transplant are excluded. The national UK median total waiting time to transplant for adult elective patients is 133 days.

Table 3.2 Median total waiting time to elective intestine transplant in the UK, for adults registered 1 April 2021 - 31 March 2024					
Registration type Number of Total waiting time (days) ¹ Active waiting time (days patients					aiting time (days)
	registered	Median	95% Confidence interval	Median	95% Confidence interval
Liver containing Non liver containing	21 44	102 144	18 – 186 87 - 201	85 136	0 - 174 85 - 187
TOTAL 65 133 91 – 175 122 77 - 147					

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

4. Response to offers

Potential <u>DBD</u> 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 2024 and 31 March 2025, Cambridge received 105 intestine offers from 79 donors and Oxford received 33 intestine offers from 33 donors. Their <u>donor offer decline rates</u> were 87% and 97%, respectively.

Table 4.1	able 4.1 Offer decline rates for each centre, 1 April 2024 - 31 March 2025						
Centre	Offers	%Decline	Donors	%Decline			
Cambridge	105	90	79	87			
Oxford	33	97	33	97			
TOTAL	138	92	112	90			

5. Transplants

5.1 Adult intestine transplants, 1 April 2015 – 31 March 2025

Figure 5.1 shows the number of adult intestine transplants performed in the last 10 years, by <u>transplant type</u>. The annual number of adult transplants has decreased to 11 in 2024/2025.

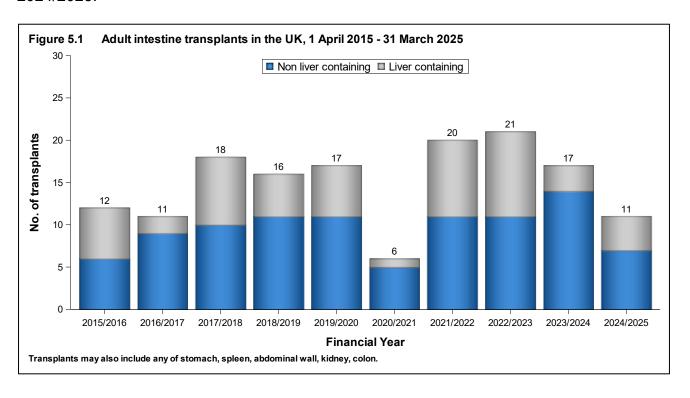


Figure 5.2 shows the number of adult intestine transplants performed in 2024/2025, by centre and <u>transplant type</u>. Oxford performed one transplants in the last financial year. Cambridge performed ten adult intestinal transplants (four liver containing and six non liver containing grafts).

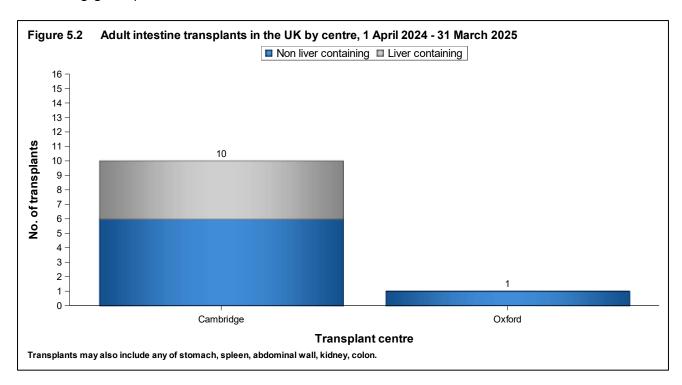
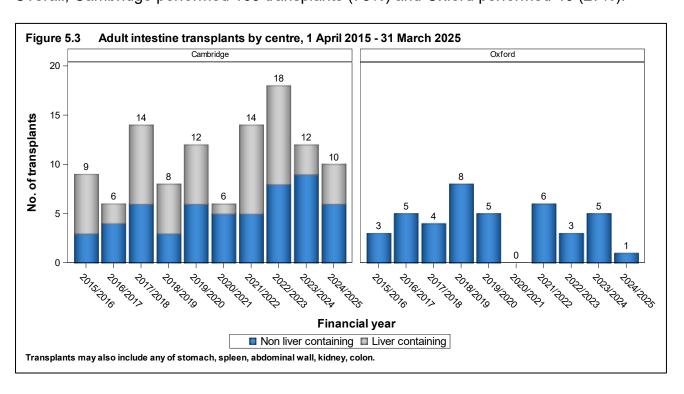


Figure 5.3 shows the number of adult intestine transplants performed in the last 10 years, by centre and type of transplant. Oxford performed their highest number of transplants over the decade in 2018/2019, while Cambridge performed their highest number in 2022/2023. Overall, Cambridge performed 109 transplants (73%) and Oxford performed 40 (27%).



The demographic characteristics of 149 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 <u>median</u> age of recipients was 45 years old, while the median age of donors was 29 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 <u>elective</u> recipients. For some characteristics, percentages may not add up to 100 due to rounding.

	ic characteristics of adult inte 5 - 31 March 2025	stine transplant reci	pients,	
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)
Number of transplants		109	40	149 (100)
Transplant type	Non liver containing	55 (50)	40 (100)	95 (64)
	Liver containing	54 (50)	0	54 (36)
Urgency	Elective	106 (97)	40 (100)	146 (98)
	Super-urgent	3 (3)	0	3 (2)
Recipient sex	Male	55 (50)	27 (68)	82 (55)
	Female	54 (50)	13 (33)	67 (45)
Recipient ethnicity group	White	97 (89)	36 (90)	133 (89)
	Other	12 (11)	4 (10)	16 (11)
Indication group	Short bowel syndrome Motility disorders Tumour Liver disease Other/not reported Retransplant Mesenteric thrombosis	40 (37) 7 (6) 19 (17) 10 (9) 15 (14) 9 (8) 9 (8)	16 (40) 1 (3) 16 (40) 0 2 (5) 3 (8) 2 (5)	56 (38) 8 (5) 35 (24) 10 (7) 17 (11) 12 (8) 11 (7)
Patient location	Out-patient	72 (66)	36 (90)	108 (73)
	Ward	27 (25)	3 (8)	30 (20)
	ICU/HDU	7 (6)	0	7 (5)
	Not reported	3 (3)	1 (3)	4 (3)
Pre-transplant renal support	No	97 (89)	38 (95)	135 (91)
	Yes	8 (7)	1 (3)	9 (6)
	Not reported	4 (4)	1 (3)	5 (3)
Previous abdominal surgery	No	11 (10)	1 (3)	12 (8)
	Yes	90 (83)	38 (95)	128 (86)
	Not reported	8 (7)	1 (3)	9 (6)
Lifestyle activity	Normal Restricted Self-care Confined Reliant Not reported	10 (9) 27 (25) 34 (31) 10 (9) 10 (9) 18 (17)	0 6 (15) 29 (73) 1 (3) 1 (3) 3 (8)	10 (7) 33 (22) 63 (42) 11 (7) 11 (7) 21 (14)
Restricted venous access at registration	No	63 (58)	26 (65)	89 (60)
	Yes	38 (35)	11 (28)	49 (33)
	Not reported	8 (7)	3 (8)	11 (7)

Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2015 - 31 March 2025					
		Cambridge N (%)	Oxford N (%)	TOTAL N (%)	
Recipient age (years)	Median (IQR)	43 (33,54)	52 (41,57)	45 (34,55)	
Recipient BMI (kg/m2)	Median (IQR)	23 (20,26)	22 (21,24)	22 (20,26)	
Serum bilirubin (umol/l)	Non liver containing (N) Median (IQR) Not reported	55 11 (6,17) 3	40 10 (6,17) 1	95 10 (6,17) 4	
	Liver containing (N) Median (IQR) Not reported	54 27 (14,119) 1	0 0 0	54 27 (14,119) 1	
	Overall (N) Median (IQR) Not reported	109 15 (8,32) 4	40 10 (6,17) 1	149 14 (7,30) 5	
Total time on list (days)	Median (IQR)	71 (28,183)	60 (18,115)	65 (28,167)	
Donor sex	Male Female	43 (39) 66 (61)	19 (48) 21 (53)	62 (42) 87 (58)	
Donor ethnicity group	White Other Not reported	99 (91) 9 (8) 1 (1)	38 (95) 1 (3) 1 (3)	137 (92) 10 (7) 2 (1)	
Donor cause of death group	Stroke Trauma Other	92 (84) 7 (6) 10 (9)	30 (75) 4 (10) 6 (15)	122 (82) 11 (7) 16 (11)	
Donor history of diabetes	No	109 (100)	40 (100)	149 (100)	
Donor age (years)	Median (IQR)	26 (17,42)	34 (22,41)	29 (18,41)	
Donor BMI (kg/m2)	Median (IQR)	22 (20,23)	22 (21,23)	22 (20,23)	
ABO match	Identical Compatible	74 (68) 35 (32)	34 (85) 6 (15)	108 (73) 41 (28)	
Total preservation time (hours)	Median (IQR) Not reported	5.1 (4.4,5.6) 5	6.3 (5.7,7)	5.4 (4.7,6.1) 5	

5.2 Total preservation time, 1 April 2015 – 31 March 2025

Figure 5.4 shows <u>boxplots</u> of the <u>total preservation time</u> 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 <u>median</u> value. The median total preservation time has generally remained stable over the decade and was 5.5 hours for 2024/2025.

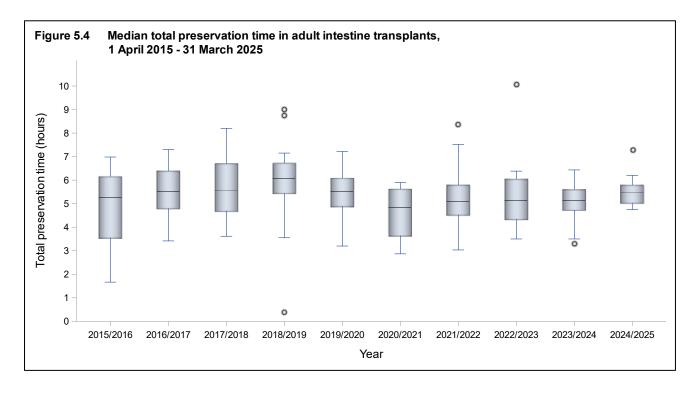
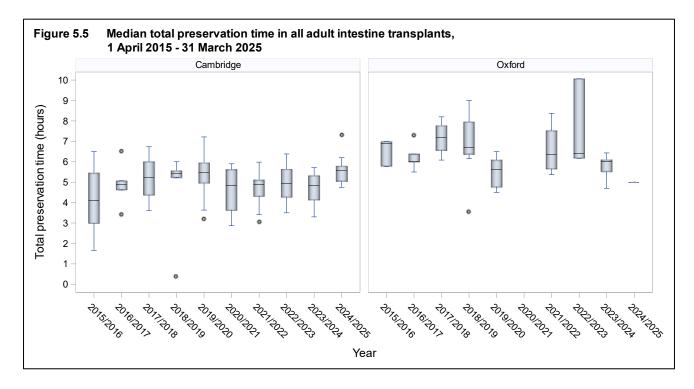


Figure 5.5 shows the median total preservation times in adult intestine transplants over the last 10 years for each transplant centre. Generally, total preservation times were longer for transplants performed by Oxford. All of these boxplots represent a small number of observations and as shown in **Table 5.1**, a number 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.



6. Post-transplant survival

This section presents patient survival after first adult intestine transplantation performed between 1 April 2015 and 31 March 2025, by transplanting centre and transplant type. Of the 144 transplants of this kind in the time period, survival information was known for all cases. Due to small numbers, <u>unadjusted</u> <u>survival rates</u> only are presented and the estimates below do not account for differences in the <u>case mix</u> at each centre.

Table 6.1 shows the 90-day <u>patient survival rates</u> 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=0.21).

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.

	0-day patient surviva oril 2015 and 31 Marc		st intestine transplants llant type	
Transplant type	Number of transplants	•	survival (95% CI) Jnadjusted	
Cambridge Liver containing ¹ Non liver containing ²	51 55	92.2 100.0	(80.4-97.0)	
Oxford Non liver containing ²	38	92.1	(77.5-97.4)	
Total Liver containing ¹ Non liver containing ²	51 93	92.2 96.8	(80.4-97.0) (90.3-98.9)	
Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants Includes intestine only, bowel & pancreas, modified multivisceral transplants				

	l 90-day patient survival (%) for ansplants between 1 April 2015				
Indication	Number of transplants 90-day survival (95% CI)				
Cambridge		<u> </u>	<u>Jnadjusted</u>		
Malignant indication ¹	1	-	-		
Non-malignant indication	54	100.0	-		
Oxford					
Malignant indication	18	88.9	(62.4-97.1)		
Non-malignant indication	20	95.0	(69.5-99.3)		
Overall					
Malignant indication	19	89.5	(64.1-97.3)		
Non-malignant indication	74	98.6	(90.8-99.8)		
Overall	93 96.8 (90.3-98.9)				
¹ Survival rates for transplant types with less than 10 transplants are not presented due to small numbers.					

One-year <u>patient survival rates</u> are shown in **Table 6.3**. At one year post-transplant, the survival rate for patients not receiving the liver was 85.5%, and was 78.1% 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 one-year post-transplant (log-rank p=0.23). **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 2015 and 31 March 2025, by transplant type Transplant type Number of 1-year survival (95% CI) transplants **Unadjusted** Cambridge Liver containing¹ 78.1 51 (63.9-87.2)Non liver containing² 55 88.3 (75.9 - 94.6)Oxford Non liver containing² 38 81.3 (64.7-90.6)Liver containing¹ 51 78.1 (63.9-87.2)Non liver containing² 93 85.5 (76.3-91.3)¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants ² Includes intestine only, bowel & pancreas, modified multivisceral transplants

	year patient survival (%) for ants between 1 April 2015 a			
Indication	Number of transplants	•	survival (95% CI) <u>Unadjusted</u>	
Cambridge				
Malignant indication ¹	1	-	-	
Non-malignant indication	54	88.1	(75.4-94.5)	
Oxford				
Malignant indication	18	72.2	(45.6-87.4)	
Non-malignant indication	20	89.7	(64.8-97.3)	
Overall				
Malignant indication	19	73.7	(47.9-88.1)	
Non-malignant indication	74	88.6	(78.5-94.1)	
Overall	93	85.5	(76.3-91.3)	
¹ Survival rates for transplant types with less than 10 transplants are not presented due to small numbers.				

Five-year <u>patient survival rates</u> are shown in **Table 6.5**. At five year post-transplant, the survival rate for patients not receiving the liver was 68.4%, and was 51.9% for patients receiving the liver. There was a significant difference in survival between those receiving the liver and those who did not at 5 years (log-rank p=0.03). **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 2015 and 31 March 2025, by transplant type Transplant type Number of 5-year survival (95% CI) transplants **Unadjusted** Cambridge Liver containing¹ 51 51.9 (35.2-66.2)Non liver containing² 55 81.8 (66.0-90.7)Oxford Non liver containing² 52.2 (31.6-69.4)38 Total 51 51.9 Liver containing¹ (35.2-66.2)Non liver containing² 93 (55.0-78.5)68.4 ¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants ² Includes intestine only, bowel & pancreas, modified multivisceral transplants

	ear patient survival (%) for nts between 1 April 2015 a			
Indication	Number of transplants	_	survival (95% CI) <u>Unadjusted</u>	
Cambridge				
Malignant indication ¹	1	-	-	
Non-malignant indication	54	81.3	(65.2-90.5)	
Oxford				
Malignant indication	18	35.5	(12.7-59.4)	
Non-malignant indication	20	73.1	(41.4-89.5)	
Overall				
Malignant indication	19	39.8	(16.4-62.5)	
Non-malignant indication	74	79.3	(65.6-88.0)	
Overall	93	68.4	(55.0-78.5)	
¹ Survival 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, 2016 – 2025

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 2016 and 2025. The number of paediatric patients on the <u>active transplant list</u> ranged between 2 and 9 each year and was 2 on 31 March 2025.

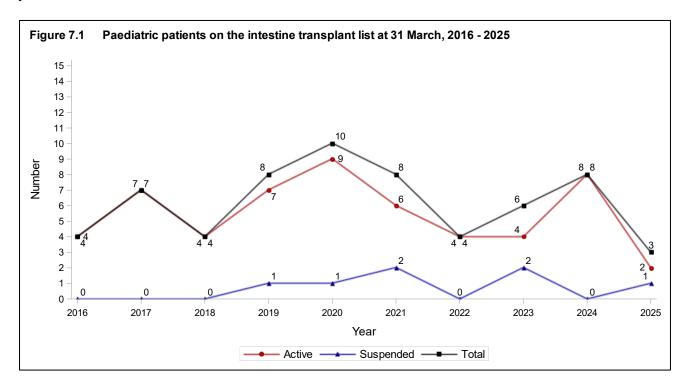
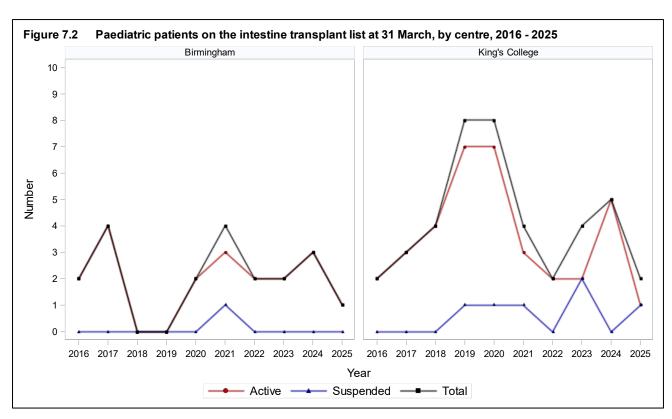


Figure 7.2 shows the number of paediatric patients on the intestine transplant list at 31 March of each year between 2016 and 2025, at each transplant centre. The number of paediatric patients on the active transplant list at 31 March 2025 was two with one patient at Birmingham and one at King's college.



The demographic characteristics of 76 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 <u>median</u> 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 2015 - 31 March 2025				
		Birmingham	King's College Hospital	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		33	43	76 (100)
Number of patients		31 (100)	36 (100)	67 (100)
Registration type	Elective	33 (100)	43 (100)	76 (100)
Transplant type required	Non liver containing	7 (21)	9 (21)	16 (21)
	Liver containing	26 (79)	34 (79)	60 (79)
Recipient sex	Male	20 (61)	24 (56)	44 (58)
	Female	13 (39)	19 (44)	32 (42)
Recipient ethnicity group	White	27 (82)	30 (70)	57 (75)
	Other	4 (12)	13 (30)	17 (22)
	Not reported	2 (6)	0	2 (3)
Indication group	Short bowel syndrome	17 (52)	17 (40)	34 (45)
	Motility disorders	7 (21)	9 (21)	16 (21)
	Primary mucosal disorders	1 (3)	2 (5)	3 (4)
	Tumour	3 (9)	1 (2)	4 (5)
	Other/not reported	4 (12)	5 (12)	9 (12)
	Retransplant	1 (3)	9 (21)	10 (13)
Patient location	Out-patient	19 (58)	18 (42)	37 (49)
	Ward	3 (9)	10 (23)	13 (17)
	ICU/HDU	1 (3)	2 (5)	3 (4)
	Not reported	10 (30)	13 (30)	23 (30)
Pre-transplant renal support	No	33 (100)	42 (98)	75 (99)
	Yes	0	1 (2)	1 (1)
Previous abdominal surgery	No	4 (12)	3 (7)	7 (9)
	Yes	29 (88)	40 (93)	69 (91)
Recipient blood group	O	17 (52)	15 (35)	32 (42)
	A	11 (33)	21 (49)	32 (42)
	B	1 (3)	5 (12)	6 (8)
	AB	4 (12)	2 (5)	6 (8)
Recipient age (years)	Median (IQR)	4 (2,9)	3 (1,5)	3 (2,7)
Recipient BMI (kg/m²)	Median (IQR)	16 (15,19)	16 (16,19)	16 (15,19)

An indication of registration outcomes for paediatric elective patients registered on the intestine transplant list in the UK between 1 April 2021 and 31 March 2023 is summarised in **Figure 7.3**. The proportion of paediatric patients transplanted within six month of listing is 36%.

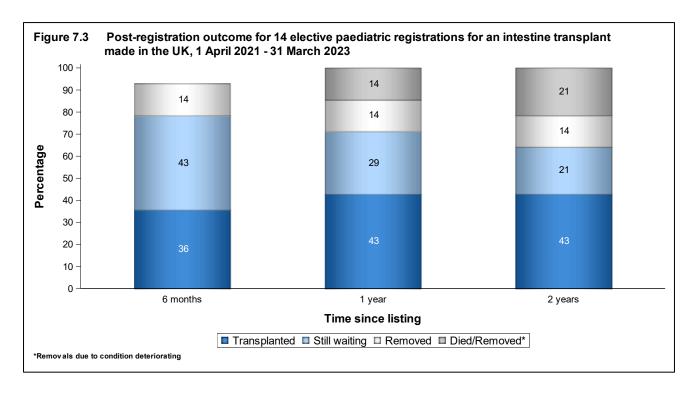


Table 7.2 shows median waiting time to elective intestine transplant by registration type for paediatric patients, registered between 1 April 2021 and 31 March 2024. A small proportion of patients requiring a liver are removed from the intestinal transplant waiting list to receive a liver transplant without the small bowel; the liver transplant is counted as receiving a transplant. Registrations ending in a living donor transplant are excluded. The national UK median total waiting time to transplant for paediatric elective patients is 250 days.

			stine transplant in the l April 2021 - 31 March 20				
Registration type	Number of patients	Total wa	aiting time (days)¹	Active w	ctive waiting time (days)		
	registered	Median	95% Confidence interval	Median	95% Confidence interval		
Liver containing	17	316	77 – 555	256	83 – 429		
Non liver containing	5	118	0 - 236	118	0 – 236		
TOTAL	22	250	69 - 431	250	87 - 413		

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

² Patients who received a liver only transplant are classed as transplanted

8. Response to offers

Between 1 April 2024 and 31 March 2025, Birmingham and King's College Hospital received offers from 26 and 9 donors, respectively, for intestine transplant patients at their centres. Their donor offer decline rates were 92% and 78% respectively. These rates are high to some extent because centres are very selective, particularly about the size of the donor.

Table 8.1 Offer decline rates for each centre, 1 April 2024 - 31 March 2025							
Centre	Offers	%Decline	Donors	%Decline			
Birmingham	26	92	26	92			
King's College	9	78	9	78			
TOTAL	35	89	35	89			

9. Transplants

9.1 Paediatric intestine transplants, 1 April 2015 – 31 March 2025

Figure 9.1 shows the number of paediatric intestine transplants performed in the last 10 years, by <u>transplant type</u>. The number of paediatric transplants has fluctuated over the period, with 6 performed in 2024/2025. 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.

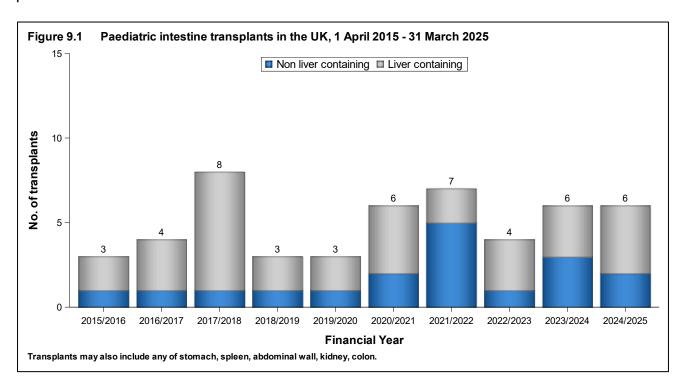


Figure 9.2 shows the number of paediatric intestine transplants performed in 2024/2025, by centre and <u>transplant type</u>. Both Birmingham and King's College Hospital performed three transplants. Two of the transplants were non liver containing and four included the liver.

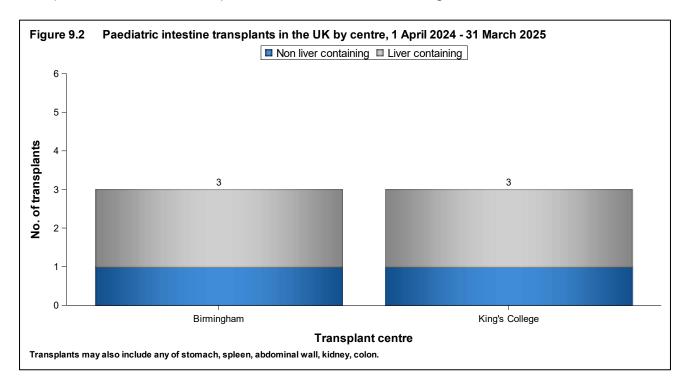
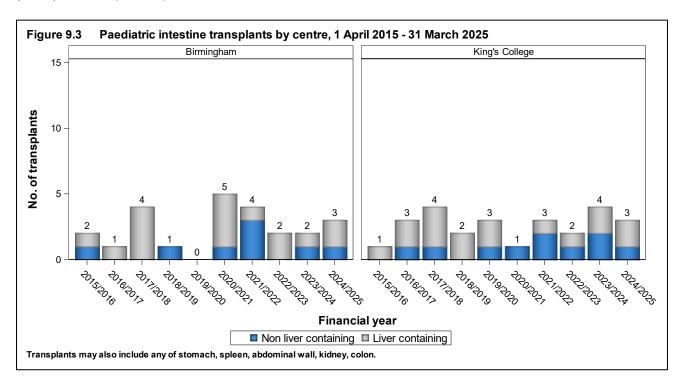


Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and <u>type of transplant</u>. The number of transplants performed by King's College Hospital fluctuated in the last 10 years, and overall they performed 26 (52%) of transplants, whilst the number of transplants performed by Birmingham fluctuates with 24 (48%) of transplants performed overall.



The demographic characteristics of 50 paediatric intestine transplant recipients in the 10-year period are shown by centre and overall in **Table 9.1**. Nationally, 60% of recipients were male and the <u>median</u> 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 <u>elective</u> recipients. For some characteristics, percentages may not add up to 100 due to rounding.

	emographic characteristics of paedia April 2015 - 31 March 2025	tric elective intestine tra	nsplant recipie	ents,
		Birmingham	King's College	TOTAL
		N (%)	N (%)	N (%)
Number of transp	plants	24	26	50 (100)
Transplant type	Non liver containing Liver containing	8 (33) 16 (67)	10 (38) 16 (62)	18 (36) 32 (64)
Recipient sex	Male Female	15 (63) 9 (38)	15 (58) 11 (42)	30 (60) 20 (40)
Recipient ethnicit group	ty White Other Not reported	17 (71) 5 (21) 2 (8)	18 (69) 8 (31) 0	35 (70) 13 (26) 2 (4)
Indication group	Short bowel syndrome Motility disorders Primary mucosal disorders Tumour Other/not reported Retransplant	10 (42) 4 (17) 3 (13) 3 (13) 3 (13) 1 (4)	6 (23) 6 (23) 2 (8) 1 (4) 4 (15) 7 (27)	16 (32) 10 (20) 5 (10) 4 (8) 7 (14) 8 (16)
Patient location	Out-patient Ward ICU/HDU Not reported	19 (79) 4 (17) 1 (4) 0	14 (54) 5 (19) 3 (12) 4 (15)	33 (66) 9 (18) 4 (8) 4 (8)
Pre-transplant re support	rnal No Yes Not reported	23 (96) 1 (4) 0	22 (85) 0 4 (15)	45 (90) 1 (2) 4 (8)
Previous abdomi surgery	inal No Yes Not reported	9 (38) 15 (63) 0	2 (8) 20 (77) 4 (15)	11 (22) 35 (70) 4 (8)
Lifestyle activity	Normal Restricted Self-care Confined Reliant Not reported	2 (8) 7 (29) 3 (13) 0 11 (46) 1 (4)	1 (4) 7 (27) 0 3 (12) 11 (42) 4 (15)	3 (6) 14 (28) 3 (6) 3 (6) 22 (44) 5 (10)
Restricted venou access at registra		16 (67) 8 (33) 0	15 (58) 10 (38) 1 (4)	31 (62) 18 (36) 1 (2)

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2015 - 31 March 2025 Birmingham King's **TOTAL** College N (%) N (%) N (%) Recipient age (years) Median (IQR) 7 (2,10) 5 (3,9) 5 (3,9) Recipient BMI (kg/m2) Median (IQR) 16 (15,19) 17 (16,19) 17 (16,19) Not reported 0 Non liver containing (N) Serum bilirubin 8 10 18 (umol/l) Median (IQR) 12 (8,17) 9 (3,20) 9 (7,17) Not reported 5 Liver containing (N) 16 16 32 Median (IQR) 14 (7,215) 12 (9,34) 14 (9,47) Not reported 0 Overall (N) 24 26 50 Median (IQR) 14 (8,41) 10 (9,34) 12 (8,38) Not reported 6 Total time on list days1 Median (IQR) 149 (44,251) 247 (134,736) 185 (74,345) Donor sex Male 12 (46) 27 (54) 15 (63) Female 14 (54) 23 (46) 9 (38) White Donor ethnicity group 19 (79) 17 (65) 36 (72) Other 2 (8) 3 (12) 5 (10) Not reported 3 (13) 6 (23) 9 (18) Donor cause of death Stroke 19 (79) 17 (65) 36 (72) Trauma group 2 (8) 0 2 (4) Other 3 (13) 7 (27) 10 (20) Living 0 2 (4) 2 (8) Donor history of 23 (96) No 20 (77) 43 (86) diabetes Not reported 1 (4) 6 (23) 7 (14) Median (IQR) Donor age (years) 9 (4,17) 4 (2,36) 7 (2,22) Donor BMI (kg/m2) Median (IQR) 19 (15,20) 16 (15,19) 17 (15,20) 0 2 2 ABO match Identical 18 (75) 20 (77) 38 (76) Compatible 6 (25) 6 (23) 12 (24) Median (IQR) Total preservation time 5.2 (4.2,6) 6 (5.1,8.2) 8.2 (7.1,9.8) (hours) Not reported 0 7 ¹ Excludes living donor transplants

9.2 Total preservation time, 1 April 2015 – 31 March 2025

Figure 9.4 shows <u>boxplots</u> of the <u>total preservation times</u> 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 <u>median</u> value. The median total preservation time in paediatric transplants was 7.2 hours in 2024/2025.

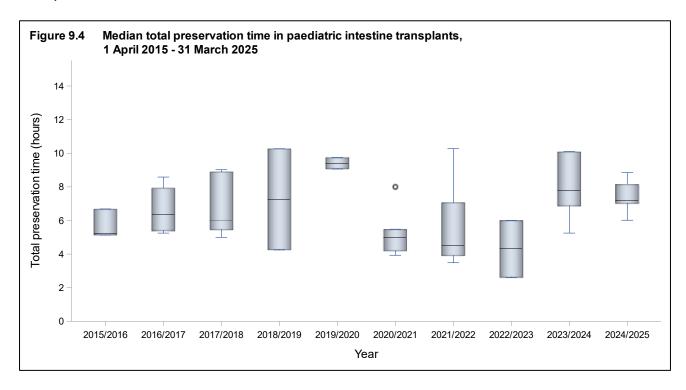
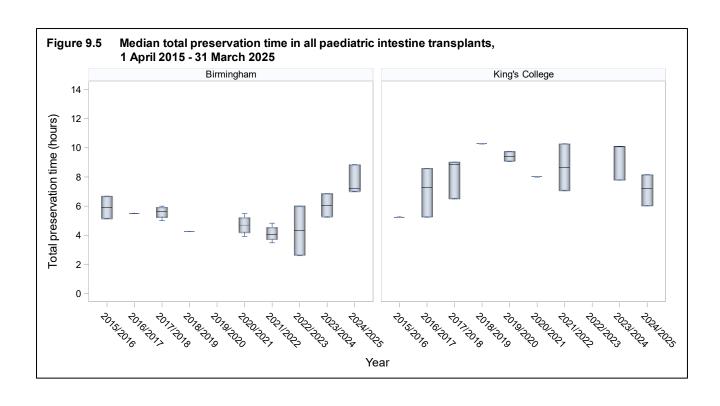


Figure 9.5 shows the median total preservation times in paediatric intestine transplants by centre over the last 10 years for deceased donors. There was a decreasing trend in total preservation time for Birmingham up to 2022/23, and total preservation times seem to be generally greater at King's College 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.



10. Post-transplant survival

This section presents patient survival post paediatric intestine transplantation for first intestine transplants between 1 April 2015 and 31 March 2025, by transplanting centre and transplant type. Of the 40 transplants of this kind in the time period, survival information was known for all cases. Due to small numbers, <u>unadjusted</u> <u>survival rates</u> are presented, which means that these do not account for differences in the <u>case mix</u> at each centre and transplant type.

10.1 Survival by transplant type

Table 10.1 shows the 90-day <u>unadjusted patient survival rates</u> by transplant type. The 90-day survival rate for patients who received a liver was 92.0% 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=0.28).

Table 10.1 90-day patient survival (%) for paediatric first intestine transplants between 1 April 2015 and 31 March 2025, by transplant type						
Transplant type	Number of transplants	•	vival (95% CI) <mark>djusted</mark>			
Birmingham Liver containing ¹ Non liver containing ²	14 8 ³	85.7 -	(53.9-96.2) -			
King's College Hospital Liver containing ¹ Non liver containing ²	11 7 ³	100.0	- -			
Total Liver containing ¹ Non liver containing ²	25 15	92.0 100.0	(71.6-97.9) -			

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 <u>patient survival rates</u> 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 80.0% 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=0.09).

Table 10.2 1-year patient survival (%) for paediatric first intestine transplants between 1 April 2015 and 31 March 2025, by transplant type						
Transplant type	Number of transplants	•	vival (95% CI) <u>djusted</u>			
Birmingham Liver containing ¹ Non liver containing ²	14 8 ³	78.6 -	(47.2-92.5) -			
King's College Hospital Liver containing ¹ Non liver containing ²	11 7 ³	81.8 -	(44.7-95.1) -			
Total Liver containing ¹ Non liver containing ²	25 15	80.0 100.0	(58.4-91.1) -			

¹ Includes liver, bowel & pancreas, multivisceral and liver & bowel transplants

Five-year <u>patient survival rates</u> are shown in **Table 10.3**. At five years post-transplant, the survival rate for patients not receiving the liver was 75.8% and was 62.7% 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 5 years (log-rank p=0.27).

Table 10.3 5-year patient survival (%) for paediatric first intestine transplants between 1 April 2015 and 31 March 2025, by transplant type						
Transplant type	Number of transplants		rvival (95% CI) I <mark>djusted</mark>			
Birmingham Liver containing ¹ Non liver containing ²	14 8 ³	68.8 -	(35.7-87.3)			
King's College Hospita Liver containing ¹ Non liver containing ²	al 11 7 ³	56.1 -	(19.5-81.5) -			
Total Liver containing ¹ Non liver containing ²	25 15	62.7 75.8	(37.7-79.9) (30.5-93.7)			

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.

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.

FORM RETURN RATES

11.1 Form return rates, 1 January – 31 December 2024

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 2024 and 31 December 2024, for recipients being followed up by each centre, and the percentage of forms that had been returned at time of analysis (23 July 2025). 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	le 11.1 Form return rates by follow-up centre for adult transplants, 1 January 2024 to 31 December 2024							
Follow-up centre	Transpla No. forms issued	ant record % returned	3 month No. forms issued	follow-up % returned	1 year f No. forms issued	follow-up % returned	Lifetime No. forms issued	follow-up % returned
Cambridge Oxford Total	15 1 16	100 100 100	13 3 16	100 100 100	10 4 14	100 100 100	64 24 88	100 100 100

Table 11.2 Form return rates by follow-up centre for paediatric transplants, 1 January 2024 to 31 December 2024								
Follow-up centre	Transpla No. forms issued	ant record % returned	3 month No. forms issued	follow-up % returned	1 year t No. forms issued	follow-up % returned	Lifetime No. forms issued	follow-up % returned
Birmingham Cambridge	2	100	2	100	2	100	23 11	100 91
King's College Hospital	4	100	6	100	2	100	13	100
Oxford	0	-	0	-	0	-	15	87
Total	6	100	8	100	4	100	62	95

APPENDIX

A1: Number of patients analysed

Data were obtained from the UK Transplant Registry for the 10-year time period, 1 April 2015 to 31 March 2025. 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 2015 to 31 March 2025						
Centre	All tra	nsplants	First-time	transplants		
	Elective	Super-urgent	Elective	Super-urgent		
Cambridge	106	3	103	3		
Oxford	40	0	38	0		
TOTAL	146	3	141	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 2015 to 31 March 2025						
Centre	All tra	ansplants Super-urgent	First-time Elective	transplants Super-urgent		
Birmingham	26	0	18	0		
King's College Hospital	24	0	22	0		
TOTAL	50	0	40	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 2015 and 31 March 2025 were extracted from the UK Transplant Registry on 10 June 2025 (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 2015 and 31 March 2025 (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 2015 and 31 March 2025 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 <u>elective</u> patients registered between 1 April 2021 and 31 March 2024 for an intestine transplant. Any periods of suspension were included in the calculation. Registrations for a re-transplant were included too. <u>Kaplan-Meier</u> 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. If the patient was removed and registered on the liver list on the date of removal, their waiting time is recorded as the time from intestinal registration to liver transplantation, as opposed to censored at the date of removal. Often patients receive a liver transplant on the date of removal from intestinal list. Patients who were still active on the transplant list at time of analysis, 17 July 2025, were censored at that time. Registrations ending in a living donor transplant are excluded.

Unadjusted survival rates

<u>Unadjusted</u> <u>patient survival</u> rates were estimated using <u>Kaplan-Meier</u> 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 <u>DBD</u> 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 2024 to 31 March 2025.

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:

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

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 <u>inter-quartile range</u>. The line inside the box indicates the <u>median</u> 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 brain 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 'superurgent' 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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