NHS
Blood and Transplant

ANNUAL REPORT ON INTESTINE TRANSPLANTATION

REPORT FOR 2021/2022
(1 APRIL 2012 – 31 MARCH 2022)

SEPTEMBER 2022

PRODUCED IN COLLABORATION WITH NHS ENGLAND

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EXECUTIVE SUMMARY

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This report presents key figures about intestine transplantation in the UK. The period covered is 10 years of transplant data, from 1 April 2012 to 31 March 2022. The report presents information on patients on the transplant list, number of transplants, demographic characteristics of donors and transplant recipients, and patient survival after first intestine transplant; both on a national and a centre-specific basis. The results on post-transplant survival should be regarded as guidance only due to the limited number of transplants performed.

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

Key findings

- On 31 March 2022, there were 14 patients on the UK active intestine **transplant list**, the same number as compared to the end of the previous year. Of those patients registered onto the transplant list in a recent two year period (1 April 2018 – 31 March 2020), 63% had received a transplant two years post-registration, while 12% died on the list, 10% were removed due to a deteriorating condition and 15% were still waiting at time of data analysis.

- Overall **median waiting time** to intestine transplant for registrations between 1 April 2018 and 31 March 2021 was 182 days, or 6 months. This was calculated for adults and paediatrics combined.

- There were 198 intestine **transplants** performed in the UK over the 10 year period covered by this report. Of all transplants, 25% were in paediatric recipients while 75% were in adult recipients. A small proportion of these were re-transplants while the rest were primary transplants.

- In the last financial year, 2021/2022, a record high 27 intestine **transplants** were performed, a 56% increase from 2020/2021. By age group, 20 adult transplants were performed, and 7 paediatric transplants were performed.

- The national rates of **survival** (unadjusted) after first intestine transplantation for **adult patients** were estimated at 95%, 88%, and 73% at 90 days, one and five years post-transplant, respectively for those who did not receive the liver and 87%, 71%, and 52% at 90 days, one and five years post-transplant, respectively for those who did receive the liver. There was evidence of better survival in those not receiving the liver at 1- and 5- year post-transplant.

- The national rates of **survival** after first intestine transplantation for **paediatric patients** (unadjusted) were estimated at 100% and 100% at 90 days and one year post-transplant, respectively, for those who did not receive the liver and at 92% and 81% 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 2021/2022, NHS Blood and Transplant.*

INTRODUCTION

INTRODUCTION

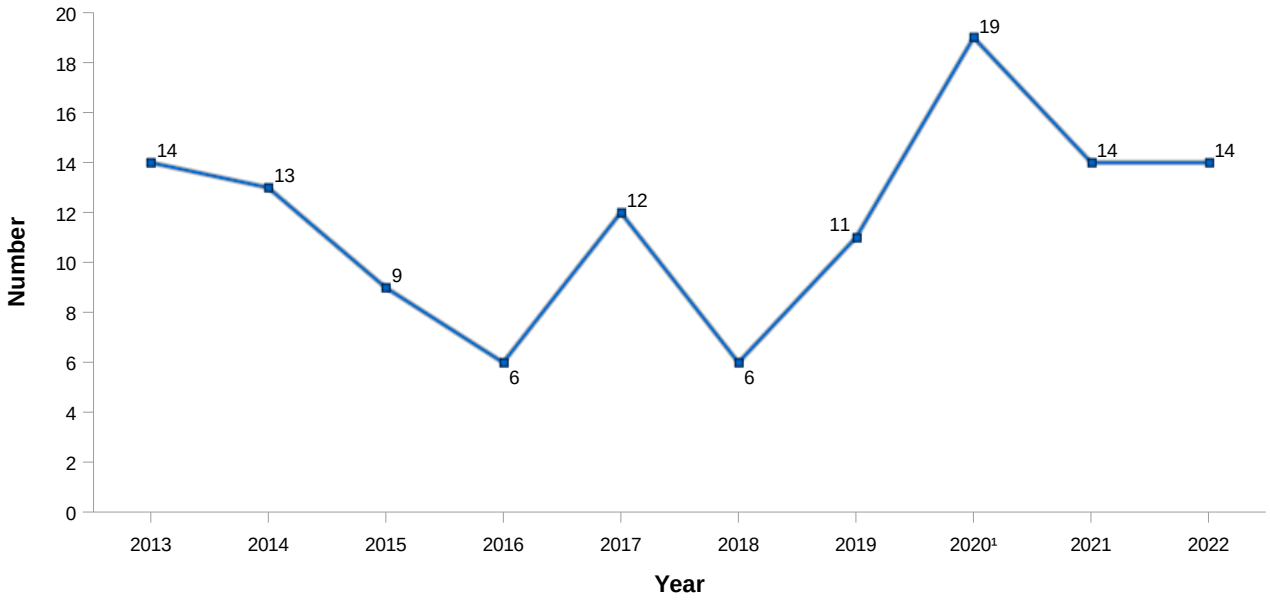
This report presents information on the UK transplant list, transplant activity and transplant outcomes between 1 April 2012 and 31 March 2022, for all four designated centres performing intestine transplantation in the UK. Data were obtained from the UK Transplant Registry, at NHS Blood and Transplant, 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 2012 and 2021. The number of patients waiting for a transplant has increased in recent years, with a peak of 19 patients in 2020, and 14 in 2022.

Figure 2.1 Patients on the active intestine transplant list at 31 March



¹ Waiting list as at 29 February 2020

Figure 2.2 shows the number of adults and paediatrics on the active transplant list at 31 March 2022 by centre. In total, there were ten adults and four paediatrics across centres. Ten-year trends of the number of adults and paediatrics on the active transplant list by transplant centre are shown later in the report, in **Figure 3.2** and **Figure 7.2**, respectively.

Figure 2.2 Patients on the active intestine transplant list at 31 March 2022, by centre

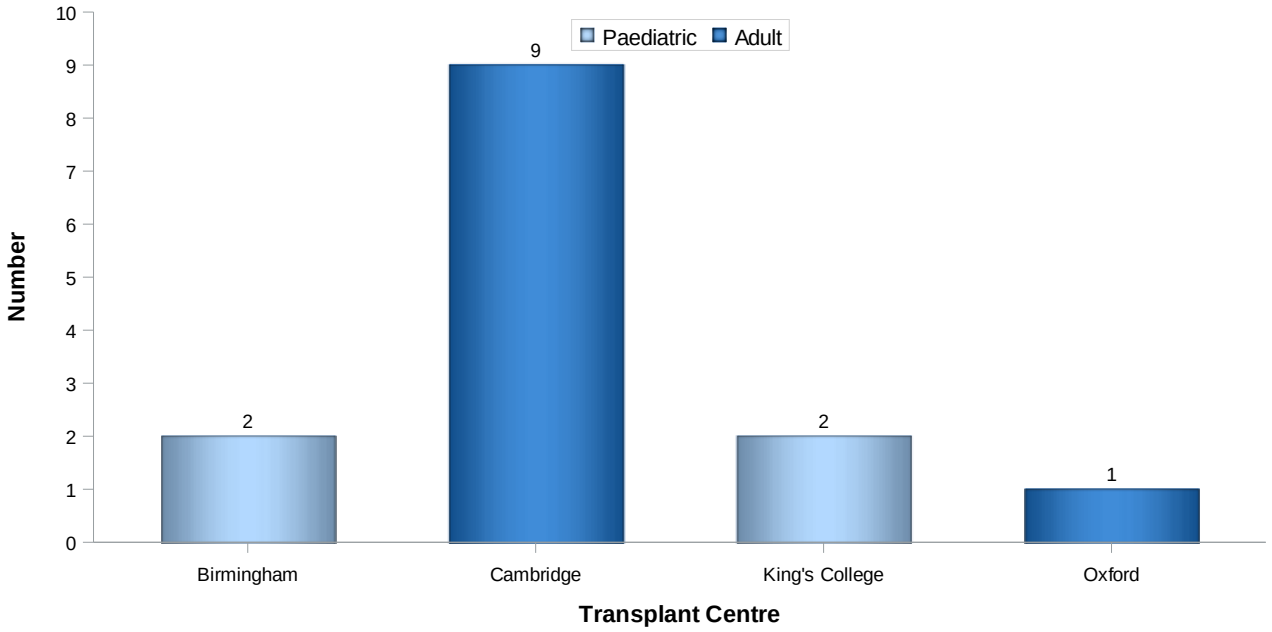


Figure 2.3 shows the number of registrations made onto the active intestine transplant list each year in the last 10 years. The number of registrations has fluctuated over the decade, with highs and lows at different time points, and an increase to 34 in 2021/2022.

Figure 2.3 Number of registrations onto the active intestine transplant list, 1 April 2012 - 31 March 2022

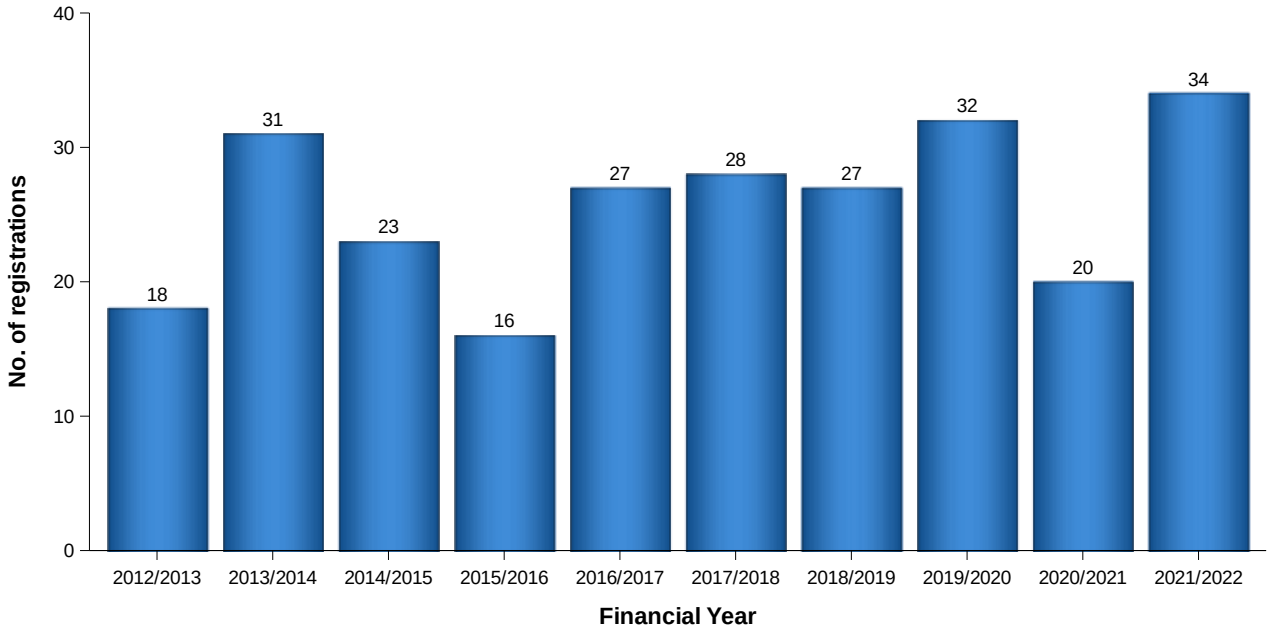
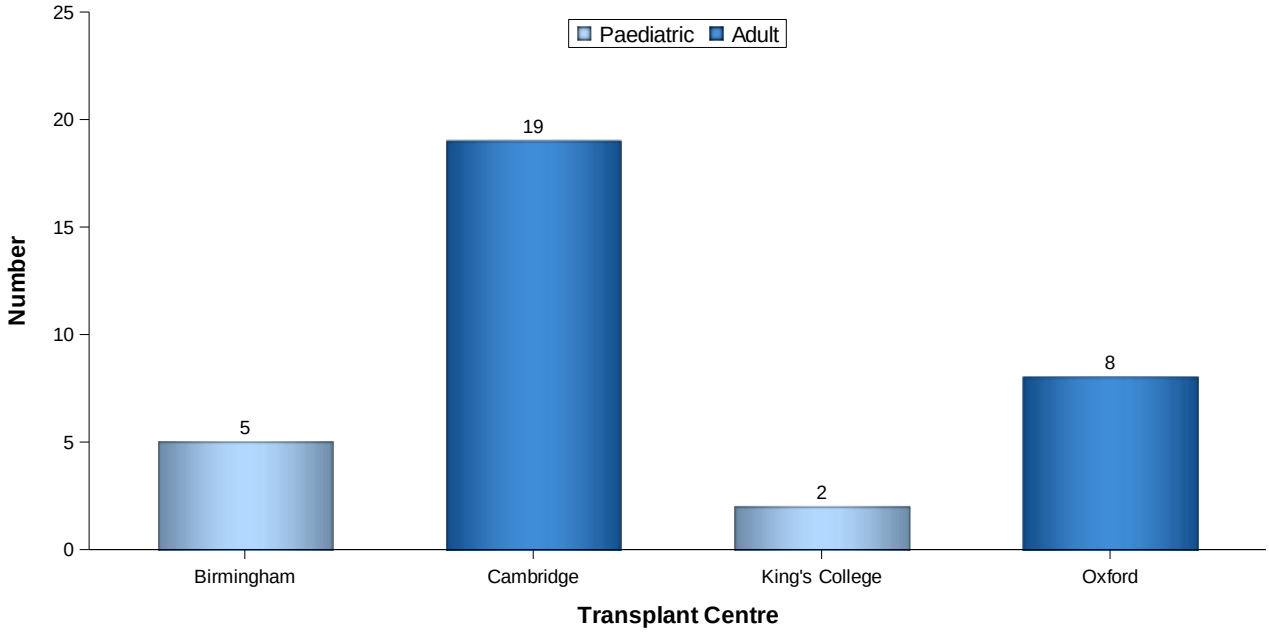


Figure 2.4 shows the number of registrations onto the active intestine transplant list in 2021/2022 by centre. In total, there were 27 adult registrations and 7 paediatric registrations.

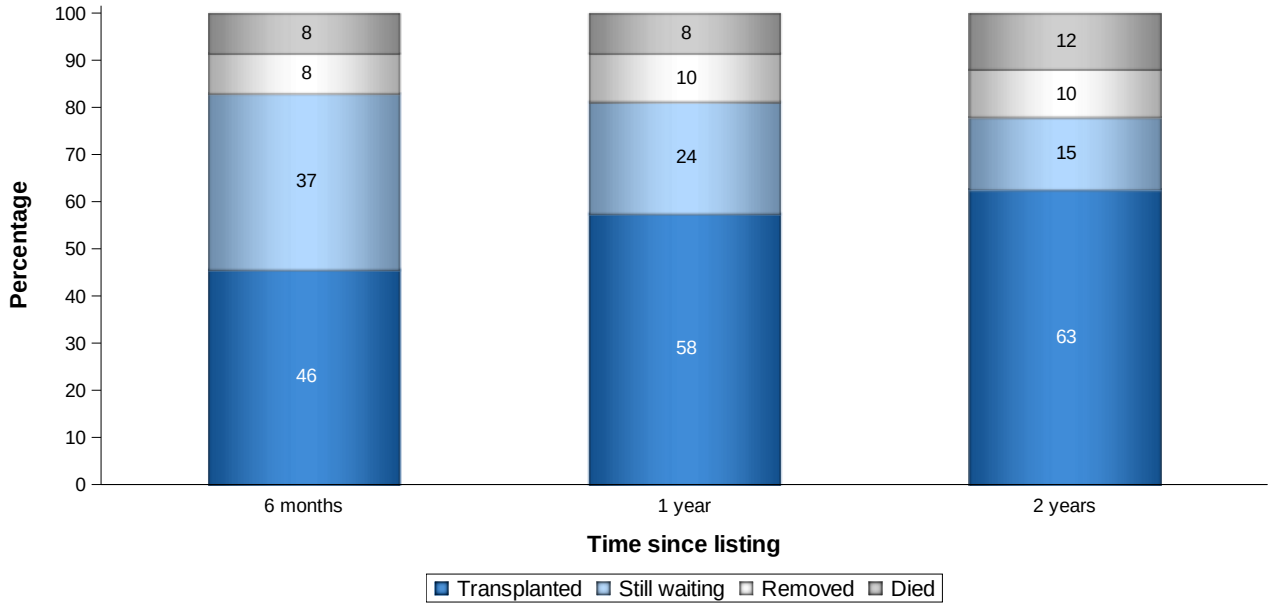
Figure 2.4 Registrations onto the active intestine transplant list, 1 April 2021 - 31 March 2022, by centre



2.1.1 Post-registration outcomes, 1 April 2018 – 31 March 2020

The registration outcomes of patients listed between 1 April 2018 and 31 March 2020 for an elective intestine transplant are summarised in **Figure 2.5**. This shows the proportion of patients transplanted, still waiting or dying (includes those removed due to deteriorating condition) while waiting six months, one year and two years after joining the transplant list. At two years post-registration 63% of patients had received a transplant, 12% had died on the list, 15% were still waiting, and 10% had been removed.

Figure 2.5 Post-registration outcome for 59 elective registrations for an intestine transplant made in the UK, 1 April 2018 - 31 March 2020



2.1.2 Median waiting time to transplant, 1 April 2018 – 31 March 2021

Table 2.1 shows median waiting time to elective intestine transplant by registration type for adults and paediatrics, combined, registered between 1 April 2018 and 31 March 2021. Overall, on average, patients waited 182 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 2018 - 31 March 2021

Registration type	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Liver containing	35	250	138 – 362
Non liver containing	38	100	70 – 130
TOTAL	**73**	**182**	**107 – 257**

Note: any periods of suspension from the list are included in the calculation of median waiting times

2.2 Transplants

Figure 2.6 shows the number of intestine transplants performed each year in the last 10 years. Currently in the UK, intestine transplants are performed from donors after brain death (DBD), however, there has been one transplant in 2017/2018 performed using a living donor. The total number of transplants over the decade was 198, with annual figures fluctuating between 12 and 27. In 2021/2022, there were a record high of 27 transplants performed.

Figure 2.6 Total number of intestine transplants, 1 April 2012 - 31 March 2022

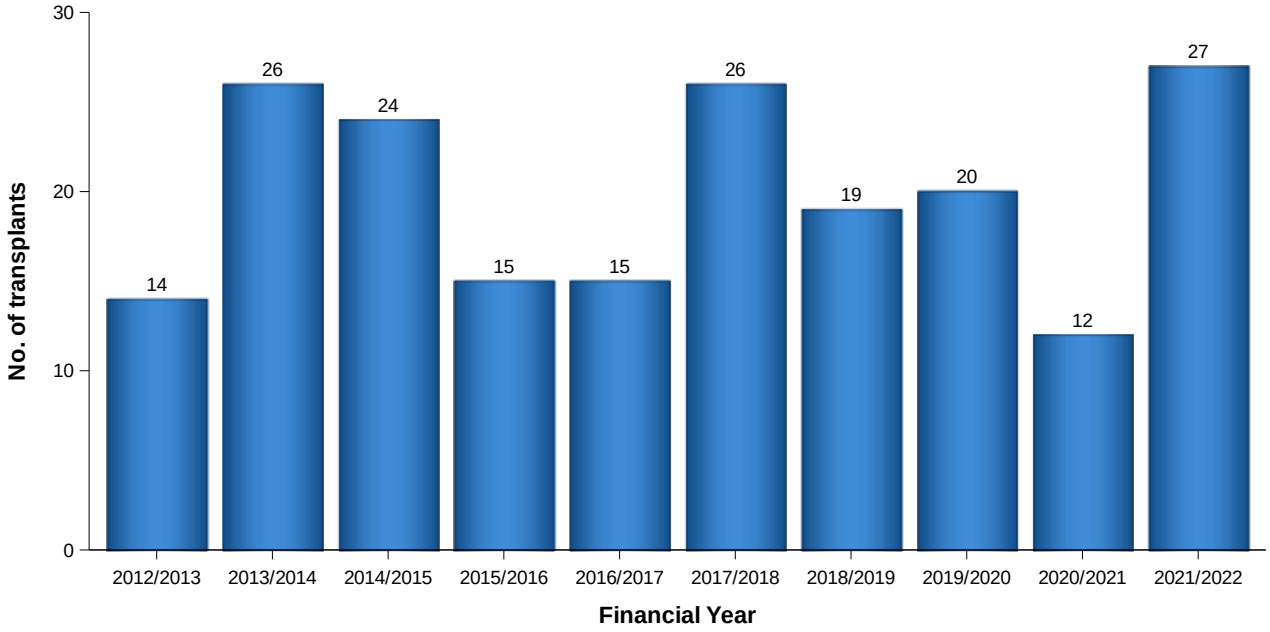
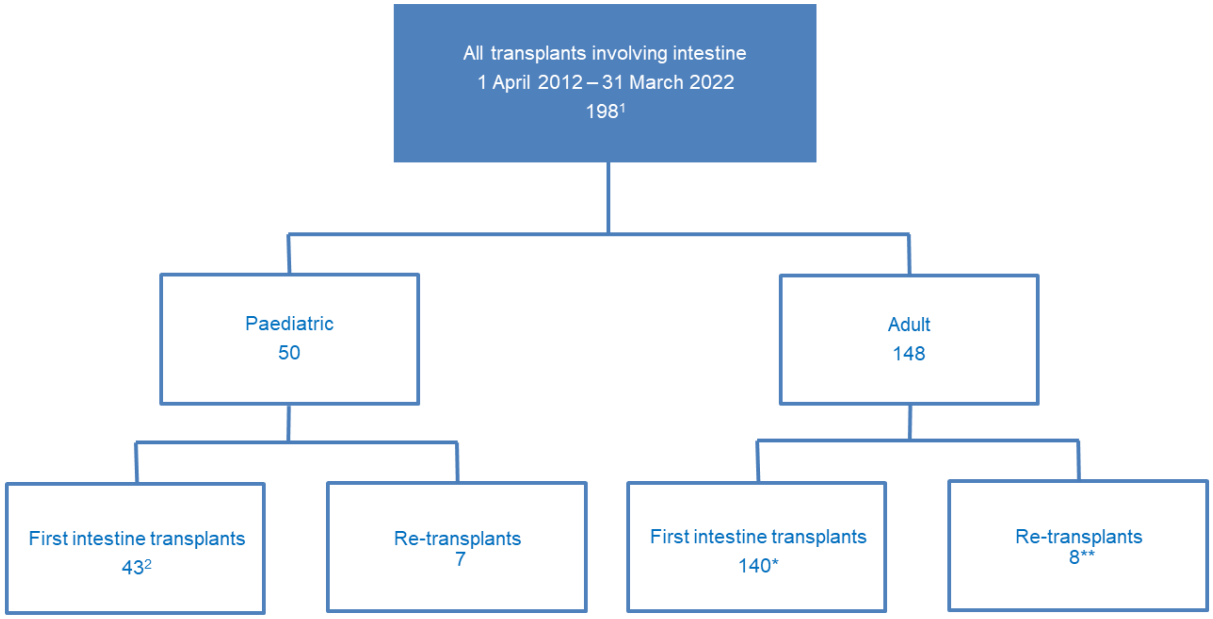


Figure 2.7 details the 198 intestine transplants performed in the UK in the 10 year period. Of these, 50 (25%) were in paediatrics and 148 (75%) were in adults. Most of both paediatric and adult transplants were in first time recipients.

Figure 2.7 UK intestine transplants, 1 April 2012 to 31 March 2022



[1] Excludes one abdominal wall only transplant (October 2016)
[2] Includes one living donor liver and bowel transplant (June 2017)

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

2.3 Geographical variation in registration and transplant rates

Figure 2.8 shows rates of registration to the intestinal transplant list per million population (pmp) between 1 April 2012 and 31 March 2022 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 2012 – 31 March 2022

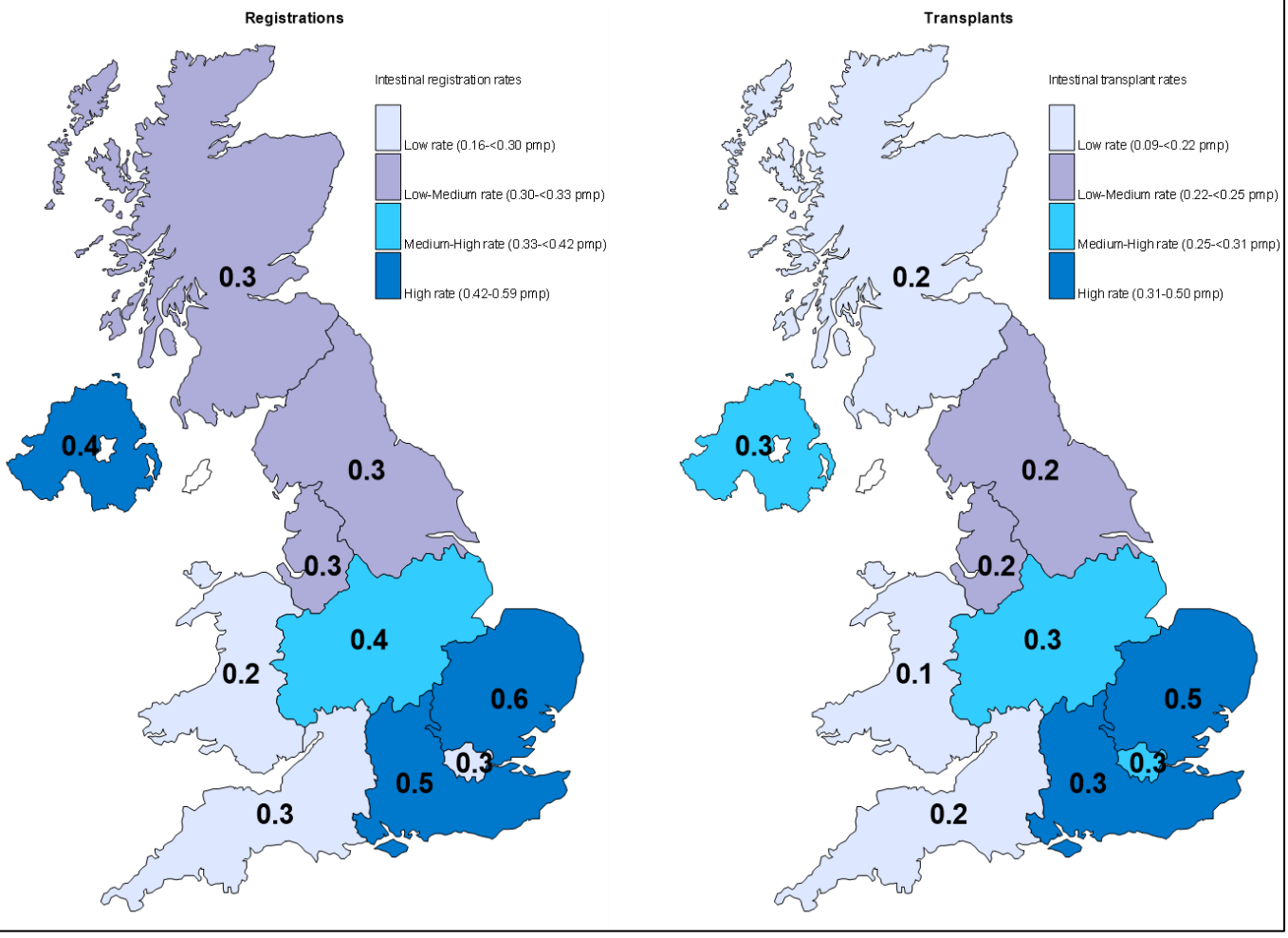


Table 2.2 Intestinal registration and transplant rates per million population (pmp) in the UK, 1 April 2012 - 31 March 2022, by Country/NHS region

Country/ NHS region	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire	2.8	(0.3)	2.0	(0.2)
North West	2.2	(0.3)	1.7	(0.2)
Midlands	3.8	(0.4)	3.3	(0.3)
East of England	3.9	(0.6)	3.3	(0.5)
London	2.5	(0.3)	2.3	(0.3)
South East	4.1	(0.5)	2.9	(0.3)
South West	1.7	(0.3)	0.9	(0.2)
England	**21.0**	**(0.4)**	**16.4**	**(0.3)**
Isle of Man	**0.0**	**(0.0)**	**0.0**	**(0.0)**
Channel Islands	**0.0**	**(0.0)**	**0.0**	**(0.0)**
Wales	**0.5**	**(0.2)**	**0.3**	**(0.1)**
Scotland	**1.8**	**(0.3)**	**1.2**	**(0.2)**
Northern Ireland	**0.8**	**(0.4)**	**0.5**	**(0.3)**
TOTAL	**24.4[1]**	**(0.4)**	**18.7[2]**	**(0.3)**

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

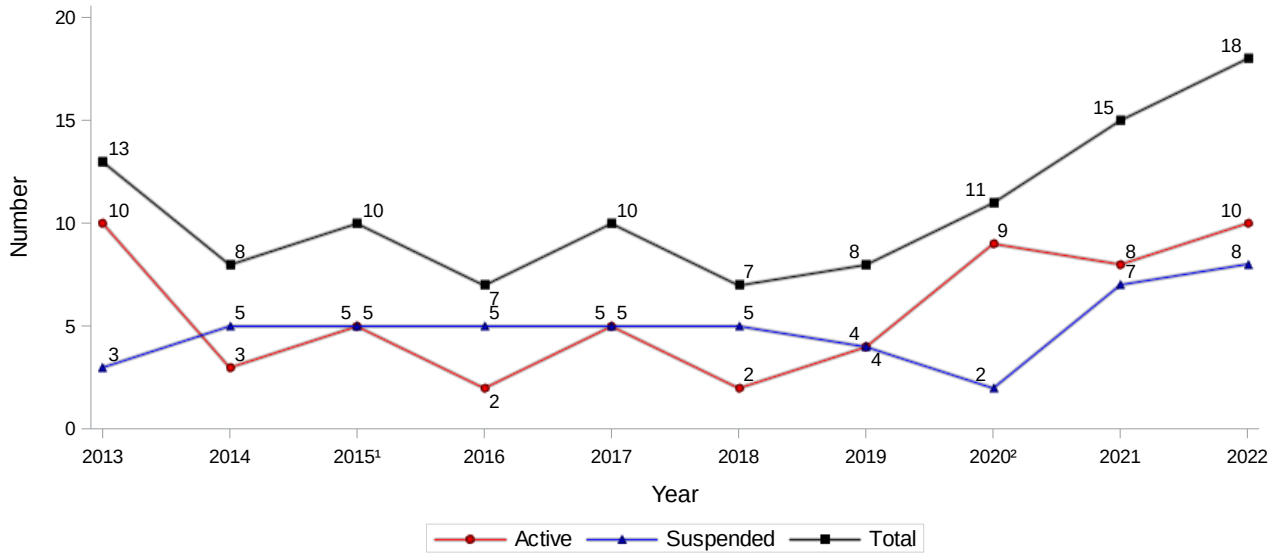
ADULT INTESTINE TRANSPLANTATION

3. Transplant list

3.1 Adult intestine transplant list as at 31 March, 2013 – 2022

Figure 3.1 shows the number of adults active or suspended on the intestine transplant list at 31 March of each year between 2013 and 2022. The number of adults on the active intestine transplant list remained low over most of the decade but has increased to 10 at 31 March 2022.

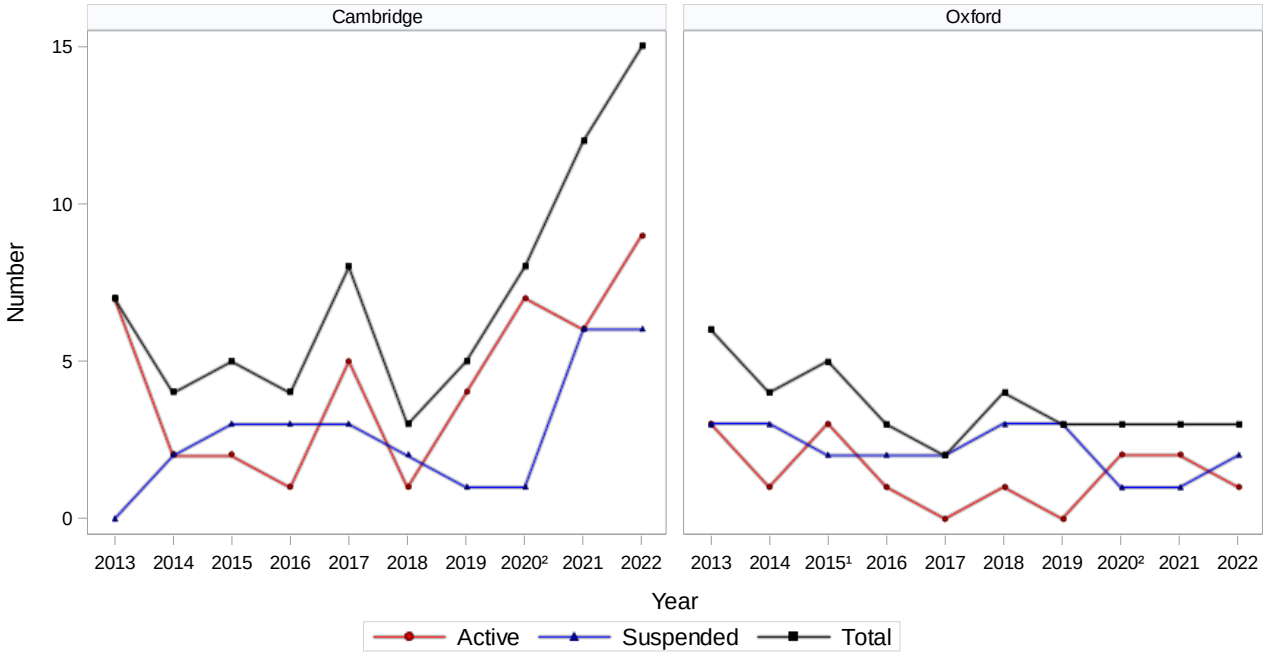
Figure 3.1 Adult patients on the intestine transplant list at 31 March, 2013 - 2022



¹ Excludes one patient at Oxford registered for abdominal wall only
² Waiting list as at 29 February 2020

Figure 3.2 shows the number of adults on the intestine transplant list at 31 March of each year between 2013 and 2022, at each transplant centre. Cambridge had generally more adults on the national active transplant list than Oxford.

Figure 3.2 Adult patients on the intestine transplant list at 31 March, by centre, 2013 - 2022



¹ Excludes one patient at Oxford registered for abdominal wall only
² Waiting list as at 29 February 2020

The demographic characteristics of 186 adult intestine transplant recipient registrations in the 10-year period are shown by centre and overall in **Table 3.1**. Nationally, 52% of patients were male and the median age was 45 years old. The most common known indication for transplantation was short bowel syndrome. The median recipient BMI was 22 kg/m^2. 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 2012 - 31 March 2022

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Number of registrations		129 (100)	57 (100)	**186 (100)**
Number of patients		121	55	**176**
Registration type	Elective	122 (95)	57 (100)	**179 (96)**
	Super-urgent	7 (5)	0 (0)	**7 (4)**
Transplant type required	Non liver containing	45 (35)	57 (100)	**102 (55)**
	Liver containing	84 (65)	0 (0)	**84 (45)**
Recipient sex	Male	61 (47)	35 (61)	**96 (52)**
	Female	68 (53)	22 (39)	**90 (48)**
Recipient ethnicity group	White	115 (89)	51 (89)	**166 (89)**
	BAME[1]	14 (11)	6 (11)	**20 (11)**
Indication group	Short bowel syndrome	41 (32)	22 (39)	**63 (34)**
	Motility disorders	7 (5)	3 (5)	**10 (5)**
	Primary mucosal disorders	1 (1)	0 (0)	**1 (1)**
	Tumour	12 (9)	18 (32)	**30 (16)**
	Liver disease	17 (13)	1 (2)	**18 (10)**
	Other/not reported	24 (19)	8 (14)	**32 (17)**
	Retransplant	11 (9)	3 (5)	**14 (8)**
	Mesenteric thrombosis	16 (12)	2 (4)	**18 (10)**
Patient location	Out-patient	60 (47)	36 (63)	**96 (52)**
	Ward	16 (12)	9 (16)	**25 (13)**
	ICU/HDU	6 (5)	0 (0)	**6 (3)**
	Not reported	47 (36)	12 (21)	**59 (32)**
Pre-transplant renal support	No	118 (91)	55 (96)	**173 (93)**
	Yes	11 (9)	2 (4)	**13 (7)**
Previous abdominal surgery	No	18 (14)	0 (0)	**18 (10)**
	Yes	103 (80)	57 (100)	**160 (86)**
	Not reported	8 (6)	0 (0)	**8 (4)**
Recipient blood group	O	51 (40)	25 (44)	**76 (41)**
	A	47 (36)	25 (44)	**72 (39)**
	B	22 (17)	6 (11)	**28 (15)**
	AB	9 (7)	1 (2)	**10 (5)**
Recipient age years	Median (IQR)	45 (33,54)	45 (34,52)	**45 (33,53)**
	Not reported	0	0	**0**
Recipient BMI kg/m^2	Median (IQR)	22 (20,27)	22 (20,24)	**22 (20,26)**
	Not reported	1	1	**2**

[1] Black, Asian and minority ethnic groups

4. Response to offers

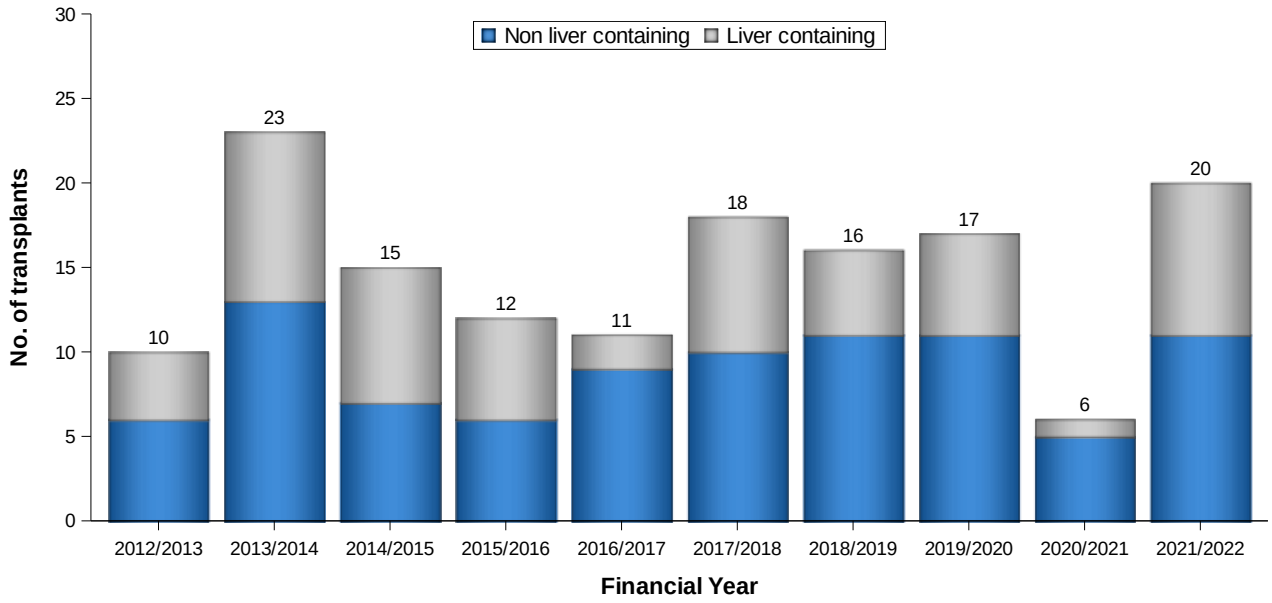
Potential DBD donors aged under 60 years and with a weight of less than 90 kg are considered for intestine donation. However, centres are highly selective when accepting donor organs which leads to high decline rates. Between 1 April 2021 and 31 March 2022, Cambridge received intestine offers from 113 donors and Oxford received intestine offers from 140. Their offer decline rates were 88% and 96%, respectively.

5. Transplants

5.1 Adult intestine transplants, 1 April 2012 – 31 March 2022

Figure 5.1 shows the number of adult intestine transplants performed in the last 10 years, by transplant type. The annual number of adult transplants reached a peak of 23 in 2013/2014, with 20 performed in the last financial year.

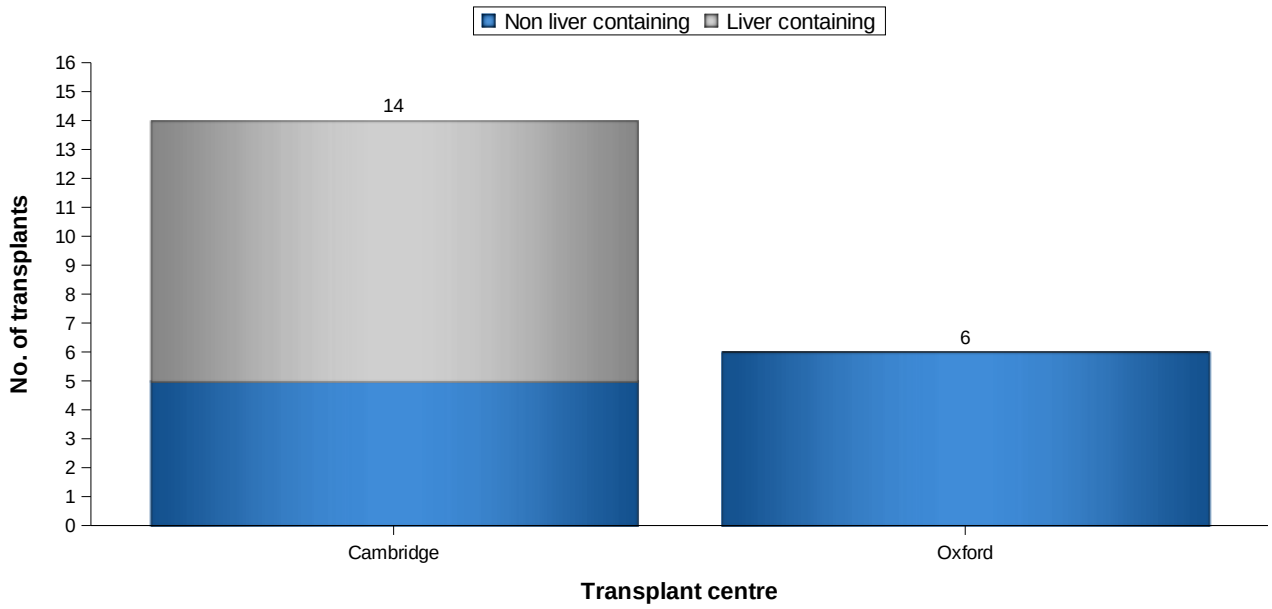
Figure 5.1 Adult intestine transplants in the UK, 1 April 2012 - 31 March 2022



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

Figure 5.2 shows the number of adult intestine transplants performed in 2021/2022, by centre and transplant type. Oxford performed six transplants last year. Cambridge performed nine transplants containing the liver, with the rest not including liver.

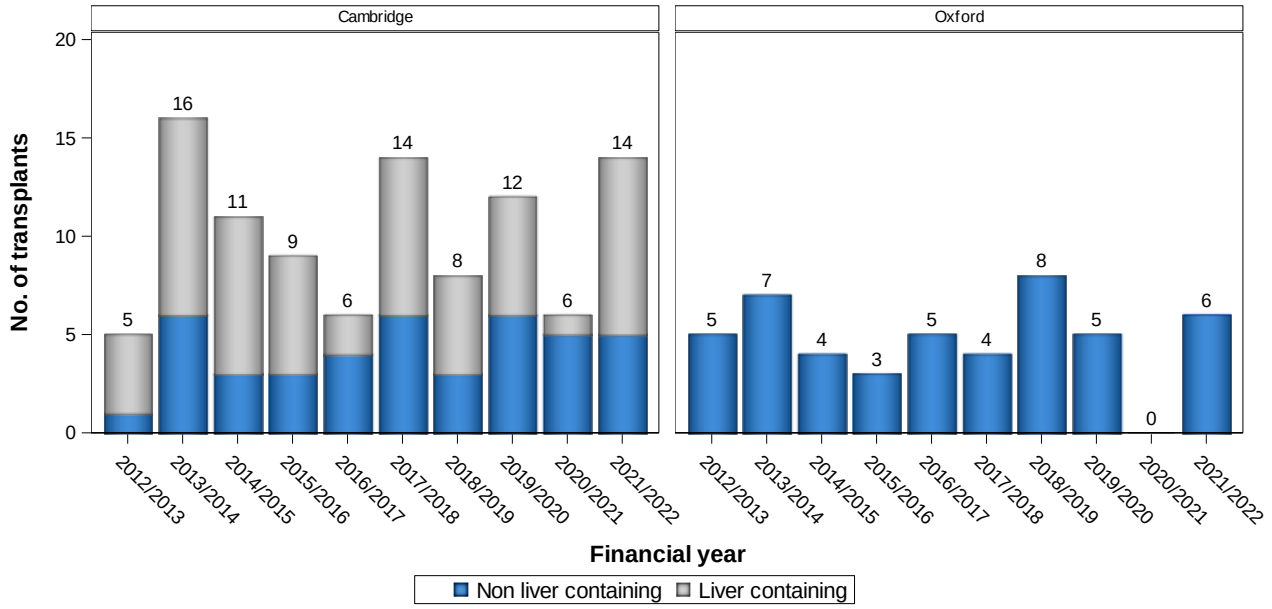
Figure 5.2 Adult intestine transplants in the UK by centre, 1 April 2021 - 31 March 2022



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

Figure 5.3 shows the number of adult intestine transplants performed in the last 10 years, by centre and type of transplant. Oxford performed their highest number of transplants over the decade in 2018/2019, while Cambridge performed their highest number in 2013/2014. Overall Cambridge performed 101 transplants (68%) and Oxford performed 47 (32%).

Figure 5.3 Adult intestine transplants by centre, 1 April 2012 - 31 March 2022



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

The demographic characteristics of 148 adult intestine transplant recipients in the 10 year period are shown by centre and overall in **Table 5.1**. Nationally, 54% 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. Seven of the transplants were in super-urgent patients, with the rest in elective recipients. For some characteristics, percentages may not add up to 100 due to rounding.

Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2012 - 31 March 2022

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Number of transplants		101 (100)	47 (100)	**148 (100)**
Urgency	Elective	94 (93)	47 (100)	**141 (95)**
	Super-urgent	7 (7)	0 (0)	**7 (5)**
Recipient sex	Male	48 (48)	32 (68)	**80 (54)**
	Female	53 (52)	15 (32)	**68 (46)**
Recipient ethnicity group	White	93 (92)	42 (89)	**135 (91)**
	BAME[1]	8 (8)	5 (11)	**13 (9)**
Indication group	Short bowel syndrome	40 (40)	21 (45)	**61 (41)**
	Motility disorders	8 (8)	3 (6)	**11 (7)**
	Tumour	13 (13)	16 (34)	**29 (20)**
	Liver disease	11 (11)	1 (2)	**12 (8)**
	Other/not reported	9 (9)	1 (2)	**10 (7)**
	Retransplant	6 (6)	3 (6)	**9 (6)**
	Mesenteric thrombosis	14 (14)	2 (4)	**16 (11)**
Patient location	Out-patient	59 (58)	34 (72)	**93 (63)**
	Ward	25 (25)	7 (15)	**32 (22)**
	ICU/HDU	12 (12)	0 (0)	**12 (8)**
	Not reported	5 (5)	6 (13)	**11 (7)**
Pre-transplant renal support	No	89 (88)	40 (85)	**129 (87)**
	Yes	7 (7)	1 (2)	**8 (5)**
	Not reported	5 (5)	6 (13)	**11 (7)**
Previous abdominal surgery	No	14 (14)	2 (4)	**16 (11)**
	Yes	78 (77)	39 (83)	**117 (79)**
	Not reported	9 (9)	6 (13)	**15 (10)**
Life style activity	Normal	3 (3)	4 (9)	**7 (5)**
	Restricted	18 (18)	5 (11)	**23 (16)**
	Self-care	33 (33)	24 (51)	**57 (39)**
	Confined	11 (11)	4 (9)	**15 (10)**
	Reliant	19 (19)	3 (6)	**22 (15)**
	Not reported	17 (17)	7 (15)	**24 (16)**
Restricted venous access at registration	No	63 (62)	32 (68)	**95 (64)**
	Yes	27 (27)	12 (26)	**39 (26)**
	Not reported	11 (11)	3 (6)	**14 (10)**
Recipient age years	Median (IQR)	45 (32,54)	45 (34,53)	**45 (34,54)**
	Not reported	0	0	**0**

Table 5.1 Demographic characteristics of adult intestine transplant recipients, 1 April 2012 - 31 March 2022

		Cambridge N (%)	Oxford N (%)	**TOTAL N (%)**
Recipient BMI kg/m^2	Median (IQR)	22 (20,26)	22 (20,24)	**22 (20,25)**
	Not reported	0	1	**1**
Serum bilirubin umol/l	Median (IQR)	18 (8,56)	9 (5,12)	**13 (7,28)**
	Not reported	6	6	**12**
Time on list days	Median (IQR)	56 (20,175)	51 (16,116)	**54 (18,145)**
	Not reported	0	0	**0**
Donor sex	Male	39 (39)	26 (55)	**65 (44)**
	Female	62 (61)	21 (45)	**83 (56)**
Donor ethnicity group	White	94 (93)	44 (94)	**138 (93)**
	BAME[1]	7 (7)	2 (4)	**9 (6)**
	Not reported	0 (0)	1 (2)	**1 (1)**
Donor cause of death group	Stroke	83 (82)	28 (60)	**111 (75)**
	Trauma	10 (10)	13 (28)	**23 (16)**
	Other	8 (8)	6 (13)	**14 (10)**
Donor history of diabetes	No	101 (100)	47 (100)	**148 (100)**
Donor age years	Median (IQR)	28 (18,42)	27 (20,39)	**28 (20,41)**
	Not reported	0	0	**0**
Donor BMI kg/m^2	Median (IQR)	22 (21,24)	22 (21,23)	**22 (21,24)**
	Not reported	0	0	**0**
Transplant type	Non liver containing	42 (42)	47 (100)	**89 (60)**
	Liver containing	59 (58)	-	**59 (40)**
ABO match	Identical	69 (68)	43 (91)	**112 (76)**
	Compatible	32 (32)	4 (9)	**36 (24)**
Cold ischaemic time (hours)	Median (IQR)	5 (4.3,5.5)	6.2 (5.6,7)	**5.3 (4.5,6)**
	Not reported	12	13	**25**

[1] Black, Asian and minority ethnic groups

5.2 Cold ischaemia time, 1 April 2012 – 31 March 2022

Figure 5.4 shows boxplots of the cold ischaemic times (CIT) of deceased donor organs used in adult intestine transplants over the last 10 years. This is the elapsed time from removal of the organs from the donor to removal from ice prior to implant. The line inside the box indicates the median value. The median CIT has generally remained stable over the decade and was 4.8 hours for 2021/2022.

Figure 5.4 Median cold ischaemia time in adult intestine transplants, 1 April 2012 - 31 March 2022

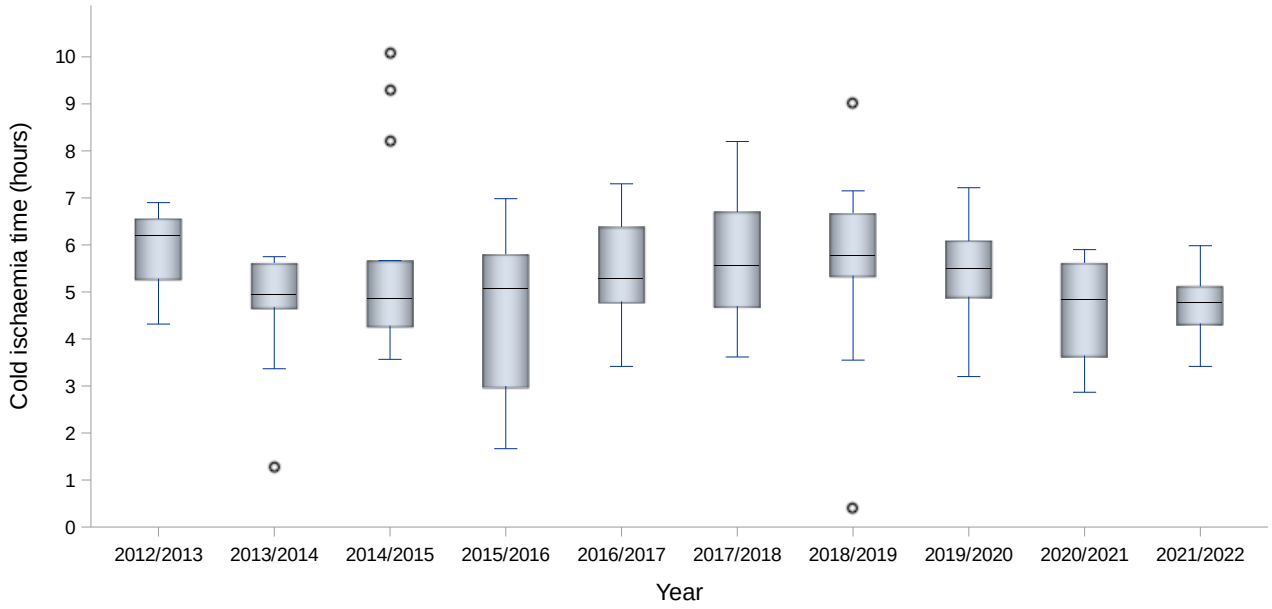
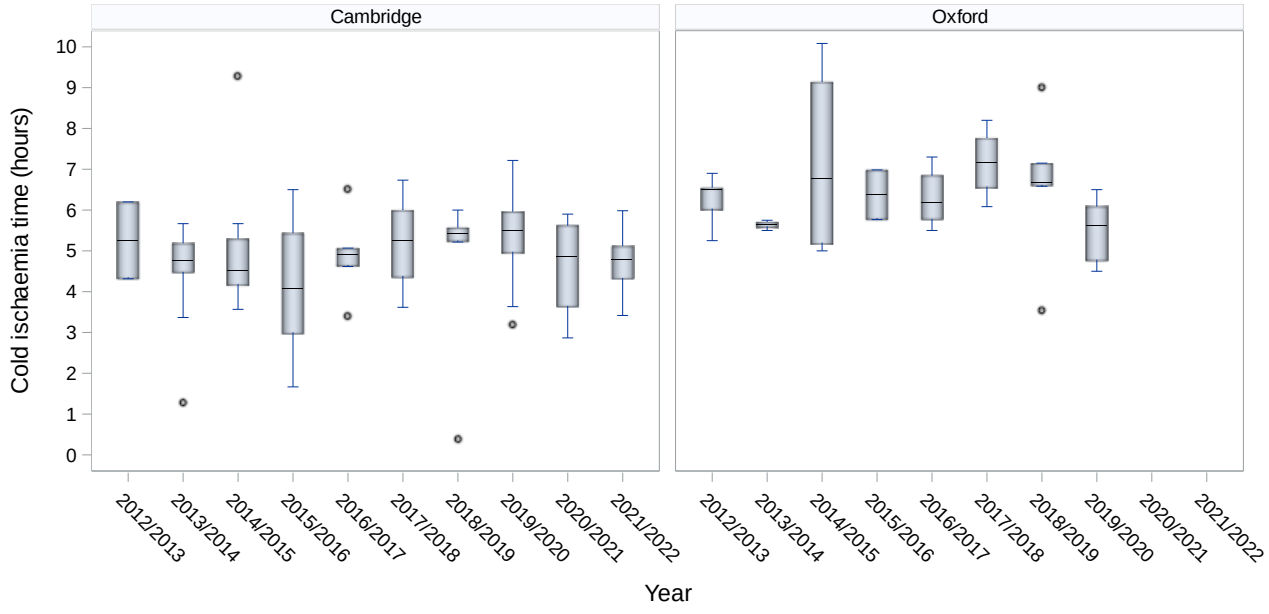


Figure 5.5 shows the median CITs in adult intestine transplants over the last 10 years for each transplant centre. Generally, CITs were longer for transplants performed by Oxford. All of these boxplots represent a small number of observations and, as shown in **Table 5.1**, a proportion of CITs have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

Figure 5.5 Median cold ischaemia time in all adult intestine transplants, 1 April 2012 - 31 March 2022



6. Post-transplant survival

This section presents patient survival post adult intestine transplantation for first intestine transplants between 1 April 2012 and 31 March 2022, by transplanting centre and transplant type. Of the 140 transplants of this kind in the time period, survival information was known in 134 cases. Due to small numbers, unadjusted survival rates only are presented, but these do not account for differences in the case mix at each centre and transplant type.

6.1 Survival by transplant type

Table 6.1 shows the 90-day patient survival rates for adult first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type. The 90-day survival rate for patients who received a liver was 87% and was 95% 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=0.09).

Table 6.1 90-day patient survival (%) for adult first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI) Unadjusted	
Cambridge			
Liver containing[1]	54	87.0	(74.7-93.6)
Non liver containing[2]	41	100.0	-
Oxford			
Non liver containing[2]	39	89.7	(74.9-96.0)
Total			
Liver containing[1]	**54**	**87.0**	**(74.7-93.6)**
Non liver containing[2]	**80**	**95.0**	**(87.2-98.1)**

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

One-year patient survival rates are shown in **Table 6.2**. At one year post-transplant, the survival rate for patients not receiving the liver was 88.2%, and was 70.7% for patients receiving the liver. There was 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=0.01).

Table 6.2	1-year patient survival (%) for adult first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type		
Transplant type	**Number of transplants**	**1-year survival (95% CI) Unadjusted**	
Cambridge			
Liver containing[1]	54	70.7	(56.1-81.2)
Non liver containing[2]	41	89.0	(73.4-95.7)
Oxford			
Non liver containing[2]	39	87.1	(71.7-94.4)
Total			
Liver containing[1]	**54**	**70.7**	**(56.1-81.2)**
Non liver containing[2]	**80**	**88.2**	**(78.6-93.7)**

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

Five-year patient survival rates are shown in **Table 6.3**. At five year post-transplant, the survival rate for patients not receiving the liver was 72.6%, and was 52.0% for patients receiving the liver. There was evidence of a significant difference in survival between those receiving the liver and those who did not at 5 years (log-rank p=0.01).

Table 6.3	5-year patient survival (%) for adult first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type		
Transplant type	**Number of transplants**	**5-year survival (95% CI) Unadjusted**	
Cambridge			
Liver containing[1]	54	52.0	(35.9-65.9)
Non liver containing[2]	41	81.8	(63.5-91.5)
Oxford			
Non liver containing[2]	39	63.4	(42.3-78.6)
Total			
Liver containing[1]	**54**	**52.0**	**(35.9-65.9)**
Non liver containing[2]	**80**	**72.6**	**(58.8-82.4)**

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

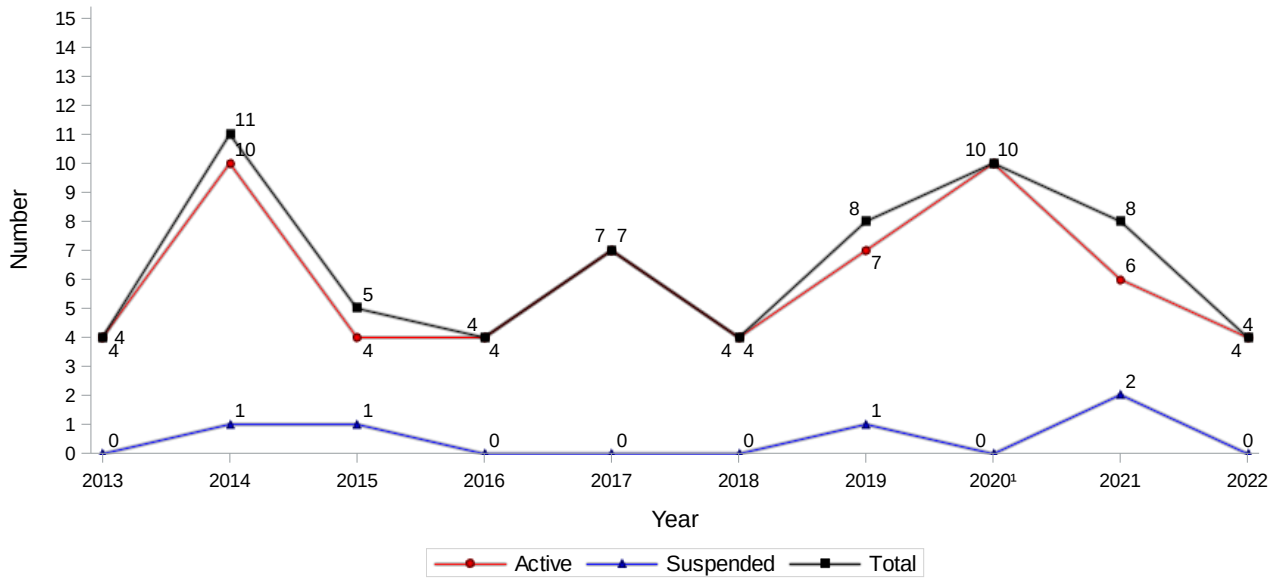
PAEDIATRIC INTESTINE TRANSPLANTATION

7. Transplant list

7.1 Paediatric intestine transplant list as at 31 March, 2013 – 2022

Figure 7.1 shows the number of paediatrics (aged<18 years) active and suspended on the intestine transplant list at 31 March of each year between 2013 and 2022. The number of paediatrics on the active transplant list ranged between 4 and 10 each year and was 4 on 31 March 2022.

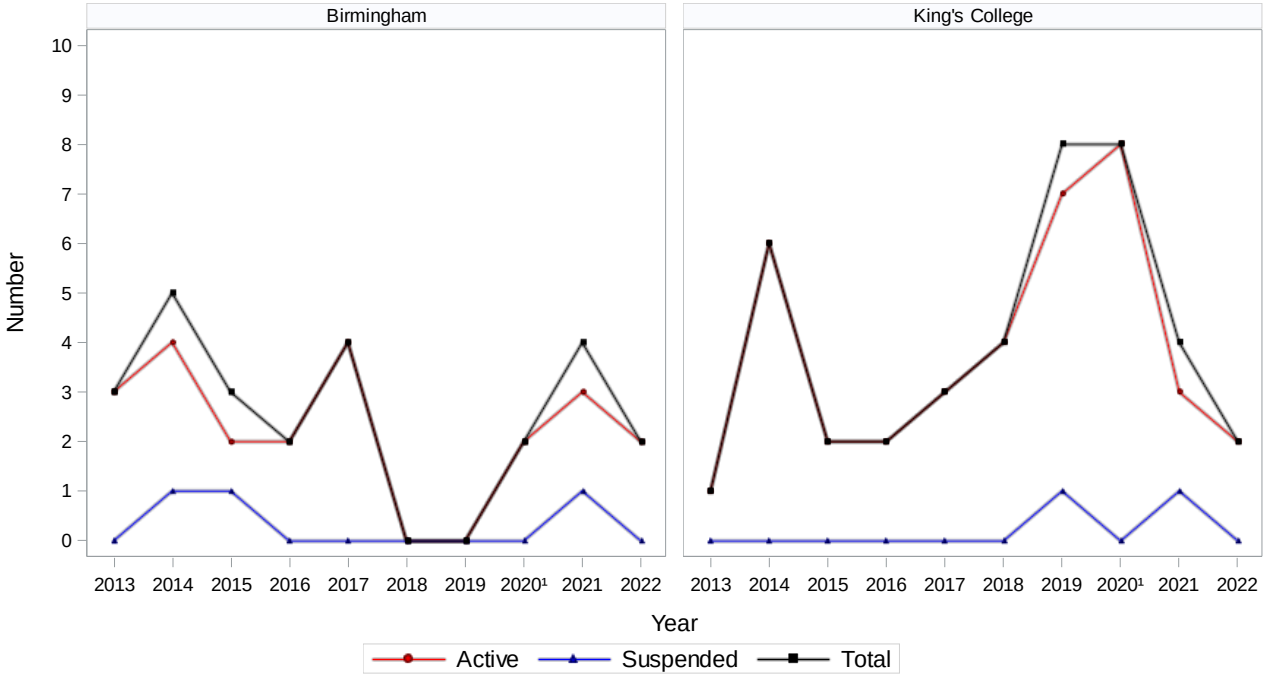
Figure 7.1 Paediatric patients on the intestine transplant list at 31 March, 2013 - 2022



¹ Waiting list as at 29 February 2020

Figure 7.2 shows the number of paediatrics on the intestine transplant list at 31 March of each year between 2013 and 2022, at each transplant centre. The number of paediatrics waiting at Birmingham has decreased over the decade while the numbers waiting at King's College Hospital had increased in recent years to 8 in 2020 before falling to 2 in the latest financial year.

Figure 7.2 Paediatric patients on the intestine transplant list at 31 March, by centre, 2013 - 2022



¹ Waiting list as at 29 February 2020

The demographic characteristics of 70 paediatric intestine transplant recipient registrations in the 10-year period are shown by centre and overall in **Table 7.1**. Nationally, 59% of patients were male and the median age was 3 years old. The most commonly known indication for transplantation was short bowel syndrome. The median recipient BMI was 16 kg/m^2. 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 2012 - 31 March 2022

		Birmingham N (%)	King's College Hospital N (%)	**TOTAL N (%)**
Number of registrations		36 (100)	34 (100)	**70 (100)**
Number of patients		34	29	**63**
Registration type	Elective	36 (100)	34 (100)	**70 (100)**
Transplant type required	Non liver containing	9 (25)	7 (21)	**16 (23)**
	Liver containing	27 (75)	27 (79)	**54 (77)**
Recipient sex	Male	23 (64)	18 (53)	**41 (59)**
	Female	13 (36)	16 (47)	**29 (41)**
Recipient ethnicity group	White	28 (78)	22 (65)	**50 (71)**
	BAME[1]	6 (17)	12 (35)	**18 (26)**
	Not reported	2 (6)	0 (0)	**2 (3)**
Indication group	Short bowel syndrome	20 (56)	13 (38)	**33 (47)**
	Motility disorders	8 (22)	8 (24)	**16 (23)**
	Primary mucosal disorders	4 (11)	1 (3)	**5 (7)**
	Other/not reported	2 (6)	4 (12)	**6 (9)**
	Retransplant	2 (6)	8 (24)	**10 (14)**
Patient location	Out-patient	19 (53)	17 (50)	**36 (51)**
	Ward	5 (14)	7 (21)	**12 (17)**
	ICU/HDU	0 (0)	2 (6)	**2 (3)**
	Not reported	12 (33)	8 (24)	**20 (29)**
Pre-transplant renal support	No	36 (100)	33 (97)	**69 (99)**
	Yes	0 (0)	1 (3)	**1 (1)**
Previous abdominal surgery	No	5 (14)	2 (6)	**7 (10)**
	Yes	31 (86)	32 (94)	**63 (90)**
Recipient blood group	O	16 (44)	12 (35)	**28 (40)**
	A	16 (44)	17 (50)	**33 (47)**
	B	3 (8)	3 (9)	**6 (9)**
	AB	1 (3)	2 (6)	**3 (4)**
Recipient age years	Median (IQR)	3 (1,6)	4 (2,6)	**3 (1,6)**
	Not reported	0	0	**0**
Recipient BMI kg/m^2	Median (IQR)	16 (15,18)	17 (16,19)	**16 (16,19)**
	Not reported	0	0	**0**

[1] Black, Asian and minority ethnic groups

8. Response to offers

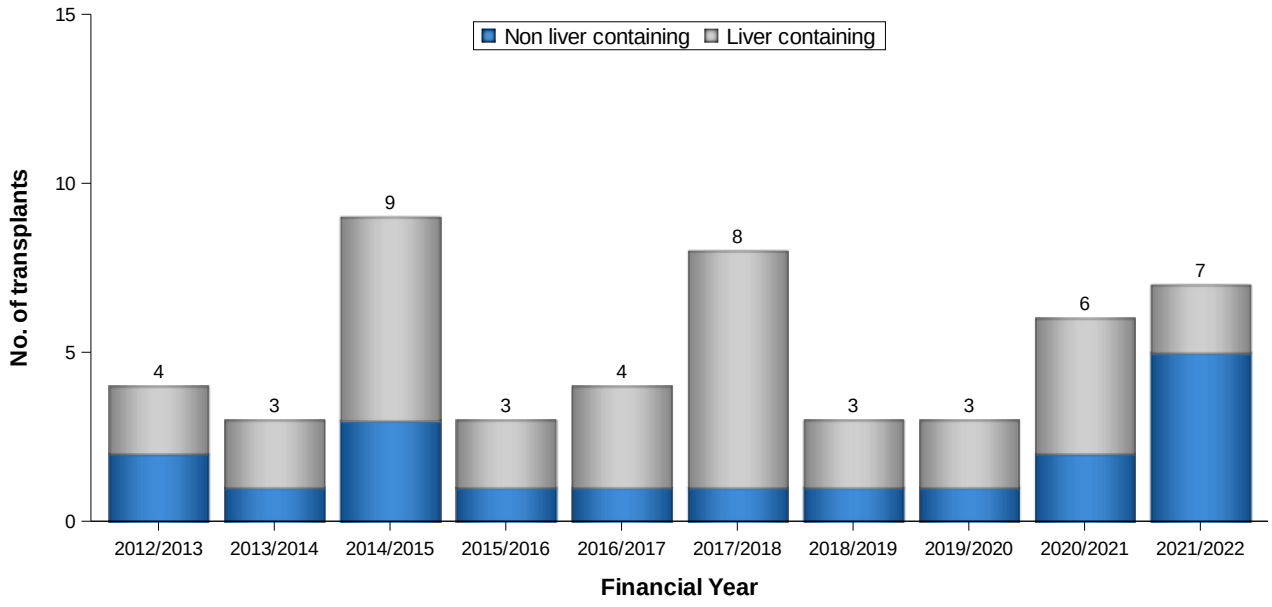
Between 1 April 2021 and 31 March 2022, Birmingham and King's College Hospital received offers from 31 and 7 donors, respectively, for intestine transplant patients at their centres. Their offer decline rates were 87% and 57% respectively. These rates are high to some extent because centres are very selective, particularly about the size of the donor.

9. Transplants

9.1 Paediatric intestine transplants, 1 April 2012 – 31 March 2022

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 7 performed in 2021/2022. In 2017/2018, a living liver and bowel transplant was performed by King's College Hospital. This transplant is included in the numbers presented in this section.

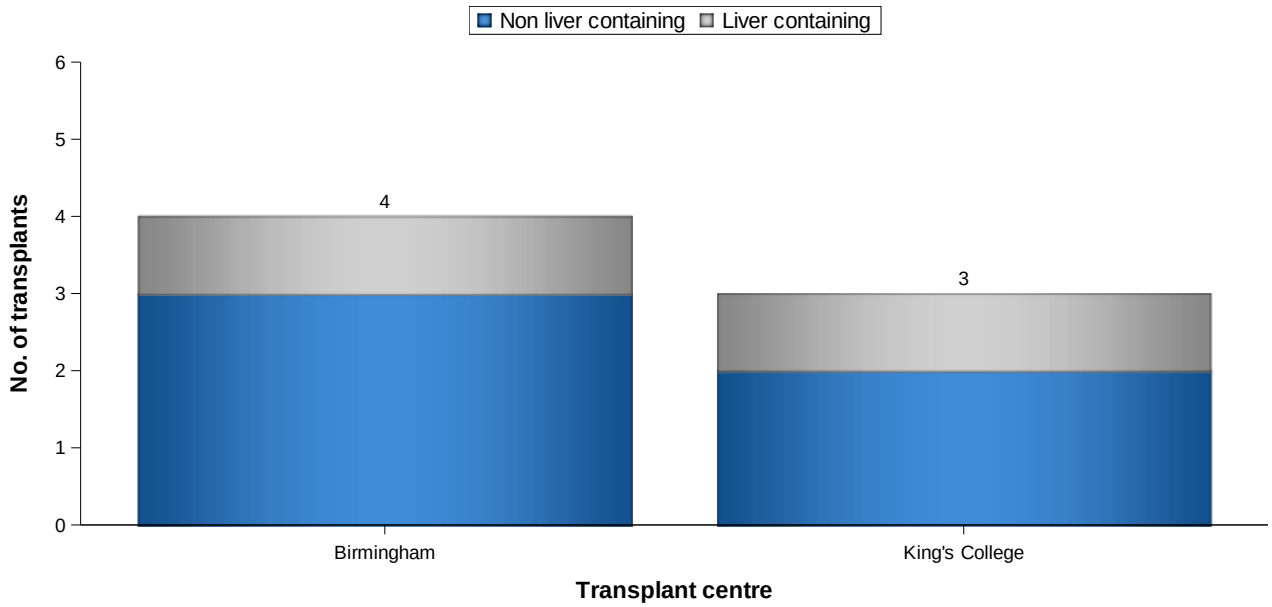
Figure 9.1 Paediatric intestine transplants in the UK, 1 April 2012 - 31 March 2022



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

Figure 9.2 shows the number of paediatric intestine transplants performed in 2021/2022, by centre and transplant type. Birmingham performed four transplants, and King's College hospital performed three transplants. Five of the transplants were non liver containing and two included the liver.

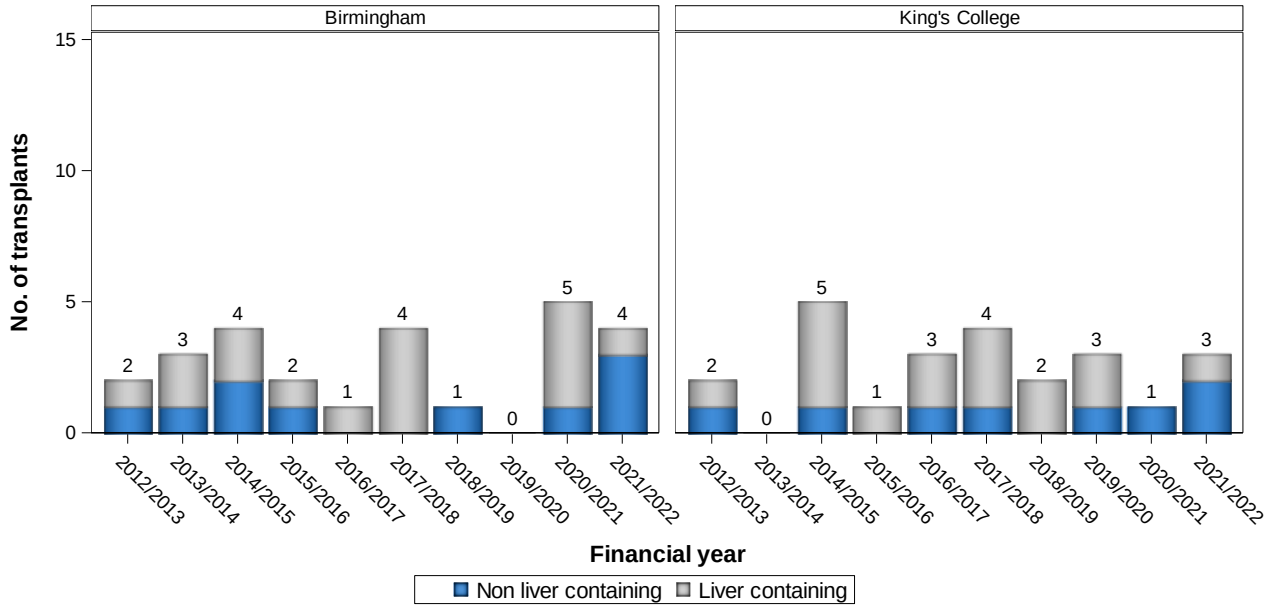
Figure 9.2 Paediatric intestine transplants in the UK by centre, 1 April 2021 - 31 March 2022



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

Figure 9.3 shows the number of paediatric intestine transplants performed in the last 10 years, by centre and type of transplant. There is a decreasing trend in the number of transplants performed by King's College Hospital, and overall they performed 24 (48%) of transplants compared with 26 (52%) by Birmingham.

Figure 9.3 Paediatric intestine transplants by centre, 1 April 2012 - 31 March 2022



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

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, 56% of recipients were male and the median recipient age was 5 years old, while the median age of donors was 5 years old. The most common indication for transplantation was short bowel syndrome. All transplants were performed in elective recipients. For some characteristics, percentages may not add up to 100 due to rounding.

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2012 - 31 March 2022

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Number of transplants		26 (100)	24 (100)	**50 (100)**
Urgency	Elective	26 (100)	24 (100)	**50 (100)**
Recipient sex	Male	16 (62)	12 (50)	**28 (56)**
	Female	10 (38)	12 (50)	**22 (44)**
Recipient ethnicity group	White	17 (65)	14 (58)	**31 (62)**
	BAME[1]	7 (27)	10 (42)	**17 (34)**
	Not reported	2 (8)	0 (0)	**2 (4)**
Indication group	Short bowel syndrome	15 (58)	6 (25)	**21 (42)**
	Motility disorders	4 (15)	7 (29)	**11 (22)**
	Primary mucosal disorders	3 (12)	2 (8)	**5 (10)**
	Liver disease	1 (4)	0 (0)	**1 (2)**
	Other/not reported	1 (4)	3 (13)	**4 (8)**
	Retransplant	2 (8)	6 (25)	**8 (16)**
Patient location	Out-patient	18 (69)	16 (67)	**34 (68)**
	Ward	5 (19)	4 (17)	**9 (18)**
	ICU/HDU	0 (0)	3 (13)	**3 (6)**
	Not reported	3 (12)	1 (4)	**4 (8)**
Pre-transplant renal support	No	22 (85)	23 (96)	**45 (90)**
	Yes	1 (4)	0 (0)	**1 (2)**
	Not reported	3 (12)	1 (4)	**4 (8)**
Previous abdominal surgery	No	5 (19)	2 (8)	**7 (14)**
	Yes	18 (69)	21 (88)	**39 (78)**
	Not reported	3 (12)	1 (4)	**4 (8)**
Life style activity	Restricted	8 (31)	7 (29)	**15 (30)**
	Reliant	0 (0)	4 (17)	**4 (8)**
	Aged fiver years or less	14 (54)	12 (50)	**26 (52)**
	Not reported	4 (15)	1 (4)	**5 (10)**
Restricted venous access at registration	No	14 (54)	14 (58)	**28 (56)**
	Yes	12 (46)	10 (42)	**22 (44)**
Recipient age years	Median (IQR)	4 (1,7)	5 (4,8)	**5 (2,7)**
	Not reported	0	0	**0**
Recipient BMI kg/m^2	Median (IQR)	16 (16,17)	16 (15,18)	**16 (15,18)**
	Not reported	0	0	**0**

Table 9.1 Demographic characteristics of paediatric elective intestine transplant recipients, 1 April 2012 - 31 March 2022

		Birmingham N (%)	King's College N (%)	**TOTAL N (%)**
Serum bilirubin umol/l	Median (IQR)	13 (8,158)	10 (7,34)	**10 (8,47)**
	Not reported	3	1	**4**
Time on list days	Median (IQR)	153 (57,231)	295 (161,663)	**188 (77,330)**
	Not reported	0	1	**1**
Donor sex	Male	14 (54)	13 (54)	**27 (54)**
	Female	12 (46)	11 (46)	**23 (46)**
Donor ethnicity group	White	19 (73)	17 (71)	**36 (72)**
	BAME[1]	3 (12)	3 (13)	**6 (12)**
	Not reported	4 (15)	4 (17)	**8 (16)**
Donor cause of death group	Stroke	19 (73)	16 (67)	**35 (70)**
	Trauma	4 (15)	1 (4)	**5 (10)**
	Other	3 (12)	6 (25)	**9 (18)**
	Living	0 (0)	1 (4)	**1 (2)**
Donor history of diabetes	No	23 (88)	20 (83)	**43 (86)**
	Not reported	3 (12)	4 (17)	**7 (14)**
Donor age years	Median (IQR)	7 (2,11)	3 (1,9)	**5 (1,10)**
	Not reported	0	0	**0**
Donor BMI kg/m^2	Median (IQR)	17 (15,19)	16 (14,17)	**16 (15,19)**
	Not reported	0	1	**1**
Transplant type	Non liver containing	10 (38)	8 (33)	**18 (36)**
	Liver containing	16 (62)	16 (67)	**32 (64)**
ABO match	Identical	21 (81)	18 (75)	**39 (78)**
	Compatible	5 (19)	6 (25)	**11 (22)**
Cold ischaemic time hours	Median (IQR)	5.5 (4.4,6.3)	8 (6.9,9)	**6.5 (5.3,8)**
	Not reported	3	4	**7**

[1] Black, Asian and minority ethnic groups

9.2 Cold ischaemia time, 1 April 2012 – 31 March 2022

Figure 9.4 shows boxplots of the CITs of deceased donor organs used in paediatric intestine transplants over the last 10 years. This is the elapsed time from removal of the organs from the donor to removal from ice prior to implant. The line inside the box indicates the median value. The median CIT in paediatric transplants has remained fairly stable over time and was 7.0 hours in 2021/2022.

Figure 9.4 Median cold ischaemia time in paediatric intestine transplants, 1 April 2012 - 31 March 2022

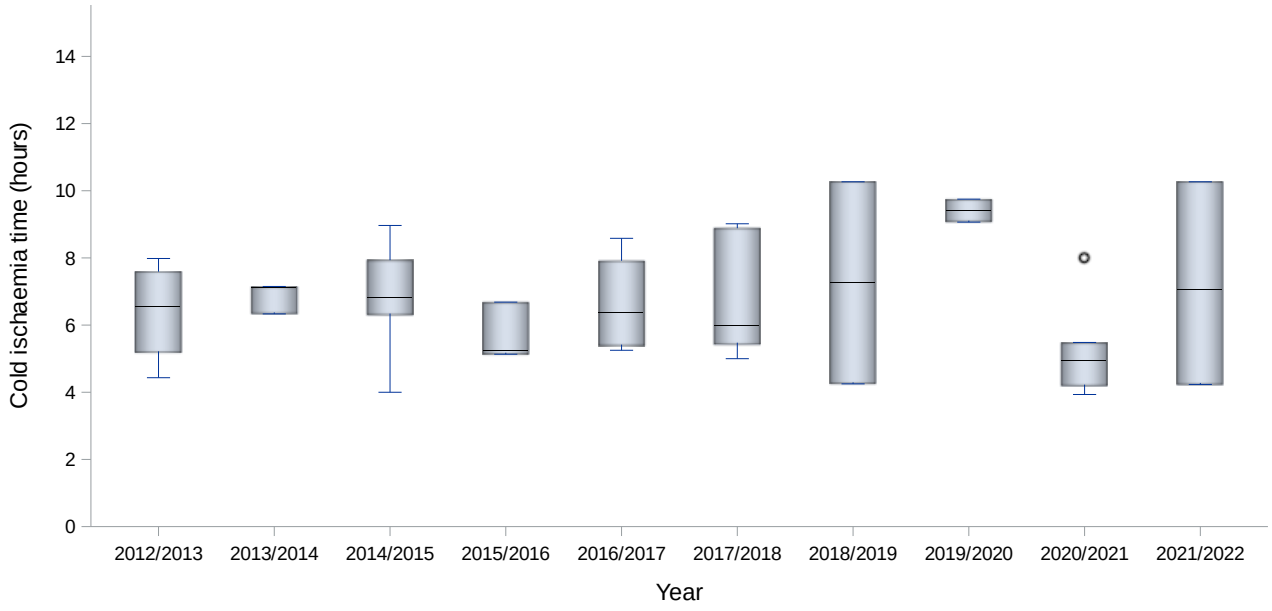
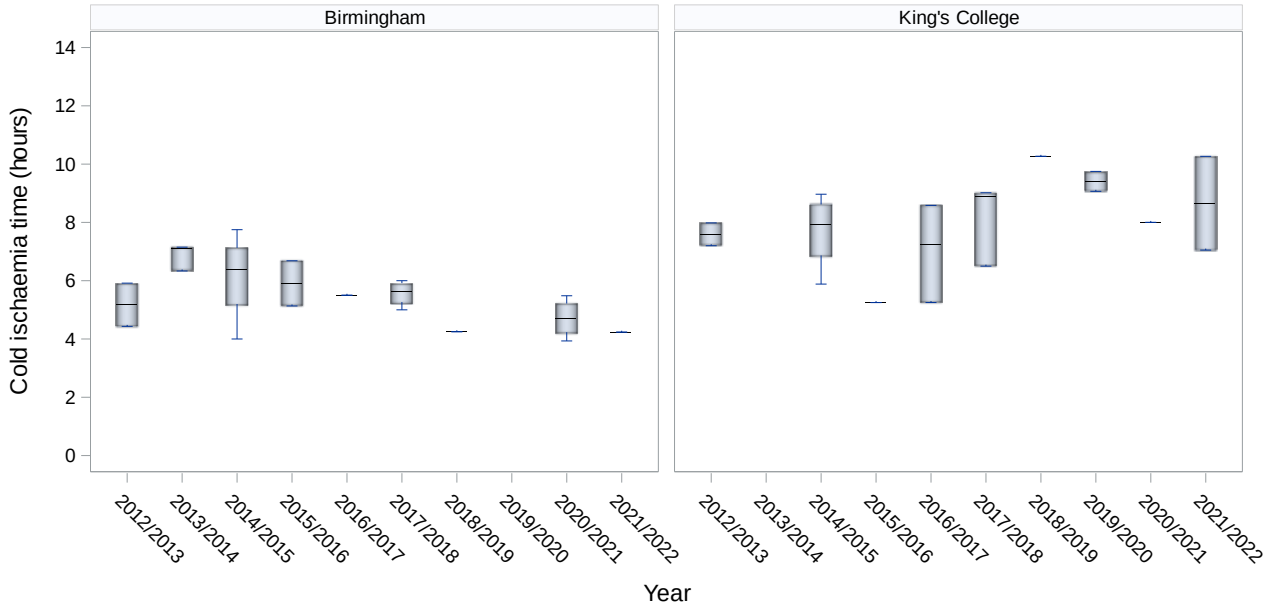


Figure 9.5 shows the median CITs in paediatric intestine transplants by centre over the last 10 years for deceased donors. There is a decreasing trend in CIT for Birmingham, and CITs seem to be generally greater at King's College than at Birmingham. All of these boxplots represent a small number of observations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

Figure 9.5 Median cold ischaemia time in all paediatric intestine transplants, 1 April 2012 - 31 March 2022



10. Post-transplant survival

This section presents patient survival post paediatric intestine transplantation for first intestine transplants between 1 April 2012 and 31 March 2022, by transplanting centre and transplant type. Of the 43 transplants of this kind in the time period, survival information was known for all transplants. Due to small numbers, unadjusted survival rates only are presented, which means that these do not account for differences in the case mix at each centre and transplant type.

10.1 Survival by transplant type

Table 10.1 shows the 90-day unadjusted patient survival rates for paediatric first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type. The 90-day survival rate for patients who received a liver was 92.4% 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=0.27).

Table 10.1 90-day patient survival (%) for paediatric first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type

Transplant type	Number of transplants	90-day survival (95% CI) Unadjusted	
Birmingham			
Liver containing[1]	14	85.7	(53.9-96.2)
Non liver containing[2]	10	100.0	-
King's College Hospital			
Liver containing[1]	13	100.0	-
Non liver containing[2]	6[3]	-	-
Total			
Liver containing[1]	**27**	**92.4**	**(73.0-98.1)**
Non liver containing[2]	**16**	**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 80.5% 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=0.08).

Table 10.2 1-year patient survival (%) for paediatric first intestine transplants between 1 April 2012 and 31 March 2022, by transplant type

Transplant type	Number of transplants	1-year survival (95% CI) Unadjusted	
Birmingham			
Liver containing[1]	14	70.7	(39.4-87.9)
Non liver containing[2]	10	100.0	-
King's College Hospital			
Liver containing[1]	13	91.7	(53.9-98.8)
Non liver containing[2]	6[3]	-	-
Total			
Liver containing[1]	**27**	**80.5**	**(59.2-91.4)**
Non liver containing[2]	**16**	**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 2021

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 2021 and 31 December 2021, for recipients being followed up by each centre, and the percentage of forms that had been returned at time of analysis (29 July 2022). Annual follow-up forms are broken down into those issued at one year post-transplant and "lifetime follow-up", which is two years or longer. There are a number of forms missing for this period for adult transplants. 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, 1 January 2021 to 31 December 2021

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	13	77	0	-	0	-	54	100
Oxford	4	0	0	-	0	-	25	0
Total	**17**	**59**	**0**	**-**	**0**	**-**	**79**	**68**

Table 11.2 Form return rates by follow-up centre, 1 January 2021 to 31 December 2021

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	4	25	0	-	0	-	24	100
Cambridge	0	-	0	-	0	-	5	80
King's College Hospital	3	67	0	-	0	-	13	85
Oxford	0	-	0	-	0	-	9	33
Total	**7**	**43**	**0**	**-**	**0**	**-**	**51**	**82**

APPENDIX

A1: Number of patients analysed

Data were obtained from the UK Transplant Registry for the 10-year time period, 1 April 2012 to 31 March 2022. NHS Group 2 transplants have been included in all analyses (except Section 2.3 Geographical variation in registration and transplant rates), while liver-only transplants because of intestine failure have been excluded. Three transplants performed at Cambridge between 2007 and 2013 that included a short length of donor jejunum for recipient anatomical reasons but not because of intestine failure have been excluded. Additionally, one transplant at Oxford, in 2016, involving the abdominal wall only where the patient was registered using the Intestinal Failure Transplant Recipient Registration form has also been excluded. 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 2012 to 31 March 2022

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Cambridge	94	7	90	5
Oxford	47	0	45	0
TOTAL	**141**	**7**	**135**	**5**

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 2012 to 31 March 2022

Centre	All transplants		First-time transplants	
	Elective	Super-urgent	Elective	Super-urgent
Birmingham	26	0	24	0
King's College Hospital	24	0	19	0
TOTAL	**50**	**0**	**43**	**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 2012 and 31 March 2022 were extracted from the UK Transplant Registry on 12 July 2022 (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-2020 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No NHS region age- or sex-specific standardisation of rates was performed.

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

Transplant rates

Transplant rates pmp were obtained as the number of intestinal transplants on NHS group 1 recipients from deceased donors between 1 April 2012 and 31 March 2022 (numerator), divided by the mid-2020 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 2012 and 31 March 2022 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 2018 and 31 March 2021 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, 29 July 2022, were censored at that time.

Unadjusted survival rates

Unadjusted patient survival rates were estimated using Kaplan-Meier methods. Patient survival rates are based on the number of patients transplanted and the number and timing of those that die within the post-transplant period of interest. Patients can be included in this method of analysis irrespective of the length of follow-up recorded. If a patient is alive at the end of the follow-up, then information about the survival of the patient is censored at the time of analysis. Death, irrespective of whether the graft is still functioning or not, is classed as an event.

Offer decline rates

Donor intestine offer decline rates were calculated for each intestine transplant centre. The denominator was equal to the number of intestines offered to them from UK DBD donors who met the criteria for intestine donation and whose family granted consent for intestine donation. The numerator was equal to the number of intestines each centre declined. Therefore, if a centre received two offers from the same donor for two of their patients and declined it for both, this counts as one offer and one decline; if they accepted it for one of these patients it counts as one offer and one acceptance. The general criteria for intestine donation is donor age less than 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 2021 to 31 March 2022.

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.

Cold ischaemic time (CIT)
The length of time that elapses between the chilling of the intestine after its blood supply has been cut off in the donor and its grafting into the recipient is called cold ischaemic time. Generally, the shorter this time, the better the long-term survival of the recipient.

Confidence interval (CI)
When an estimate of a quantity such as a survival rate is obtained from data, the value of the estimate depends on the set of patients whose data were used. If, by chance, data from a different set of patients had been used, the value of the estimate may have been different. There is therefore some uncertainty linked with any estimate. A confidence interval is a range of values whose width gives an indication of the uncertainty or precision of an estimate. The number of transplants or patients analysed influences the width of a confidence interval. Smaller data sets tend to lead to wider confidence intervals compared to larger data sets. Estimates from larger data sets are therefore more precise than those from smaller data sets. Confidence intervals are calculated with a stated probability, usually 95%.

Confidence limit
The upper and lower bounds of a confidence interval.

Donor after brain death (DBD)
Donation after Brainstem Death (DBD) 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.

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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