



Blood and Transplant

**ANNUAL REPORT ON CARDIOTHORACIC
ORGAN TRANSPLANTATION**

**REPORT FOR 2019/2020
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EXECUTIVE SUMMARY



1. Executive Summary

This report presents key figures and information about cardiothoracic organ transplantation in the UK. The period reported covers 10 years of heart and lung transplant data, from 1 April 2010 to 31 March 2020. The data include number of patients listed for a transplant, number of transplants performed and [survival rates](#) following heart and lung transplantation; both on a national and centre-specific basis.

Key findings

- In the last financial year, 2019/2020, 174 heart transplants were performed across the UK. This is an 5% decrease from the number performed in the previous year, 2018/2019. The number of lung transplants performed was 161, which was a 3% decrease from 2018/2019 and the lowest number over the past 10 years. These numbers, which are for adult and paediatric patients combined, represent 2.6 heart transplants per million population and 2.4 lung transplants per million population in the UK.
- On 31 March 2020, the national heart transplant list was particularly high, with 340 patients waiting for a heart transplant; 16% higher than on 31 March 2019 and 162% higher than a decade earlier. Of these, 26 adult patients and 16 paediatric patients were on the urgent heart only list and 1 adult was on the super-urgent list.
- On 18 May 2017, urgent and super-urgent lung allocation schemes were introduced in the UK. On 31 March 2020, there were 358 patients waiting for a lung or heart-lung transplant; 2% higher than on 31 March 2019 and 59% higher than a decade earlier. Of these, there were 5 adults on the heart-lung list, three adults and one paediatric patient on the urgent lung list and no patients on the super-urgent lung list at 31 March 2019.
- The national 30 day rate of **survival following adult heart transplantation** was 91.5%, which ranged from 87.8% to 94.4% across centres ([risk-adjusted](#)). The national 90 day survival rate was 87.3%, ranging from 80.8% to 91.4% across centres ([risk-adjusted](#)). The national 1 year survival rate was 83.2%, ranging from 77.1% to 86.7% across centres ([risk-adjusted](#)). The national 5 year survival rate was 69.9%, ranging from 59.6% to 78.3% across centres ([risk-adjusted](#)). At 5 years, there was some evidence of a significantly higher rate at Papworth in comparison to the national rate.
- The national 90 day rate of **survival following adult lung transplantation** was 90.9%, which ranged from 87.2% to 96.4% across centres ([risk-adjusted](#)), with evidence that the survival rate at Manchester was higher than the national average at this time period. The national 1 year survival rate was 82.6%, ranging from 74.3% to 87.4% across centres ([risk-adjusted](#)). The national 5 year survival rate was 55.3%, ranging from 32.1% to 59.6% across centres ([risk-adjusted](#)), with evidence to suggest a significantly lower rate at Birmingham compared with the national rate.
- The national rate of **survival following paediatric heart transplantation** was 95.9% at 30 days, 95.9% at 90 days, 93.4% at 1 year and 80.7% at 5 years. The [unadjusted](#) rates were similar between the two paediatric centres.
- The national rate of **survival following paediatric lung transplantation** was 90.3% at 90 days, 83.5% at 1 year, and 75.6% at 5 years. No comparisons were made across centres due to small numbers.

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

INTRODUCTION



2. Introduction

This report presents data on activity and outcomes of heart and lung transplant candidates and recipients between 1 April 2010 and 31 March 2020, for all centres performing heart and/or lung 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 cardiothoracic organ transplants performed in the UK.

Results are described separately for heart and lung activity and also for adult (aged 16 years or over) and paediatric patients (aged less than 16 years). There are seven cardiothoracic organ transplant centres in the UK; six in England and one in Scotland. Five of the seven centres specialise in adult transplantation, one in paediatric transplantation (Great Ormond Street Hospital) and one in both adult and paediatric transplantation (Newcastle). Any transplants carried out at Great Ormond Street Hospital in patients aged 16 or over are included in the paediatric sections, and any transplants carried out at adult only centres in patients less than 16 are included in the adult sections. Heart-lung block transplants are included in the lung analysis.

Patients requiring [multi-organ transplants](#) (other than heart-lung block transplants) are excluded from all analyses other than those presented in this Introduction section. In addition, partial lung transplants and patients receiving their second (or subsequent) graft are excluded from all survival analysis calculations (DCD heart transplants and heart-lung block transplants are considered separately).

Methods used are described in the [Appendix](#). The centre specific adult [survival rates](#) are adjusted for differences in [risk factors](#) between the centres. The risk models used are described in the [Appendix](#) and were developed in August 2015 in collaboration with the Cardiothoracic Advisory Group (CTAG) Clinical Audit Group.

In recent years changes have been introduced to the listing and allocation policies for lung transplantation; as of 18 May 2017, certain patients with the greatest clinical need can be registered urgently or super-urgently on the lung transplant list. Additionally, the year before, on 26 October 2016, a new super-urgent heart registration tier was introduced for adult candidates only.

2.1 Overview

Figure 2.1 shows the number of patients on the [active transplant lists](#) at financial year end between 2011 and 2020. The number of patients waiting for a lung transplant has generally increased year on year, reaching a peak of 378 in 2017, but has fallen to 358 in 2020, an increase of 2% on the previous year. The number of patients waiting for a heart transplant increased substantially over the decade, from 130 in 2011 to a peak of 340 in 2020, representing a 162% increase over the 10 years.

Figure 2.1 Number of patients on the national active heart and lung transplant lists at 31 March each year, 2011 to 2020

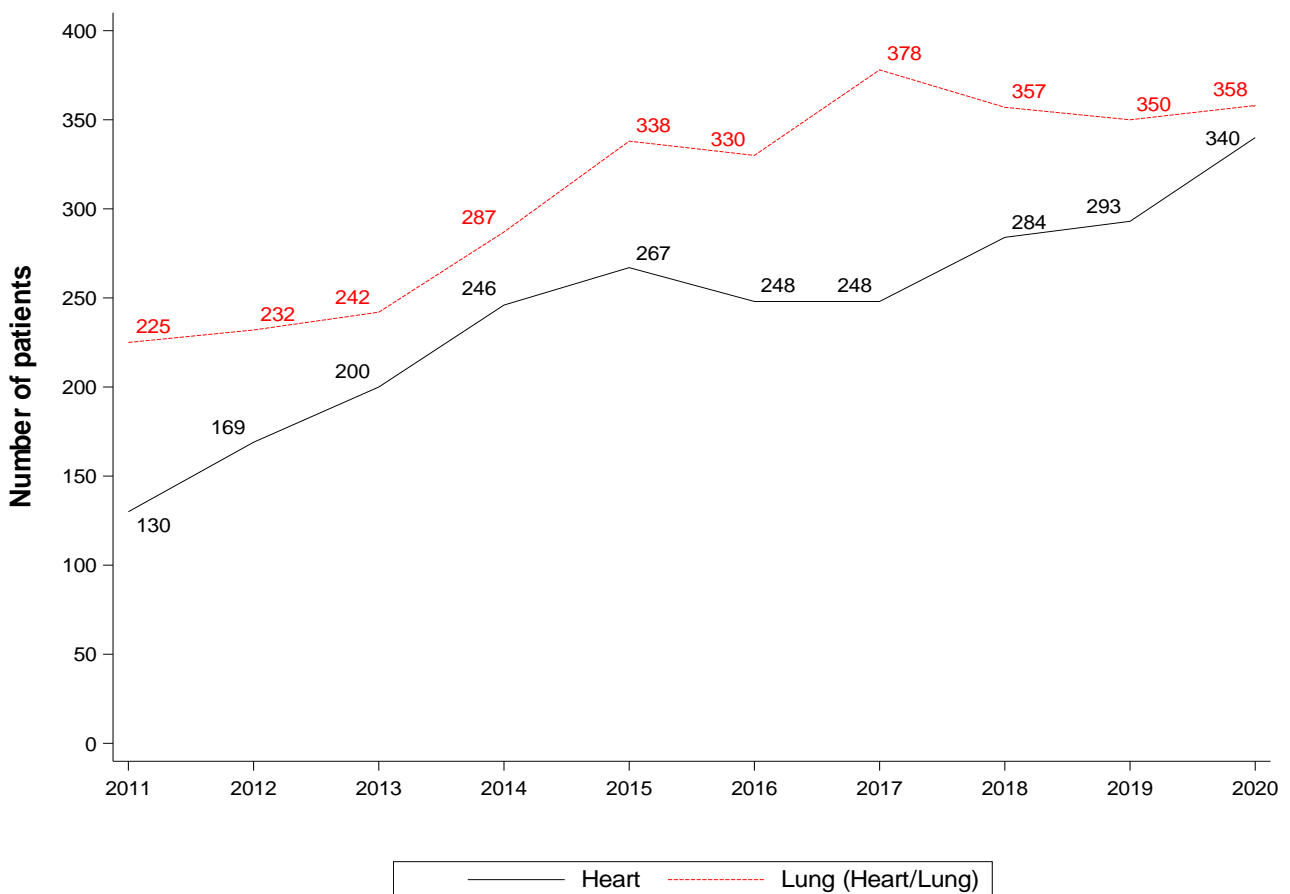


Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the [active transplant lists](#) at 31 March 2020 at each centre. In total, there were 659 adult and 39 paediatric patients waiting for a heart or lung transplant. Newcastle had the highest number of adult patients on both the heart and lung transplant lists. Note that Glasgow does not perform lung transplantation. Great Ormond Street Hospital had the highest number of paediatric patients on both the heart and lung transplant lists. These numbers include 6 patients waiting for a multi-organ transplant (1 heart and kidney, 3 heart and liver and 2 lung and liver). Compared with the previous year (see [Sections 3.1](#) and [15.1](#)), only Harefield saw a decrease in their heart waiting list figures whilst all other centres have seen an increase except Great Ormond Street which remained the same. With respect to the adult lung waiting list, Only Harefield and Manchester have seen a decrease, whilst all other centres saw a rise. For the paediatric lung waiting list, both Great Ormond Street Hospital and Newcastle saw a decrease (see [Sections 9.1](#) and [20.1](#)).

Figure 2.2 Number of adult patients on the active heart and lung transplant lists at 31 March 2020, by centre

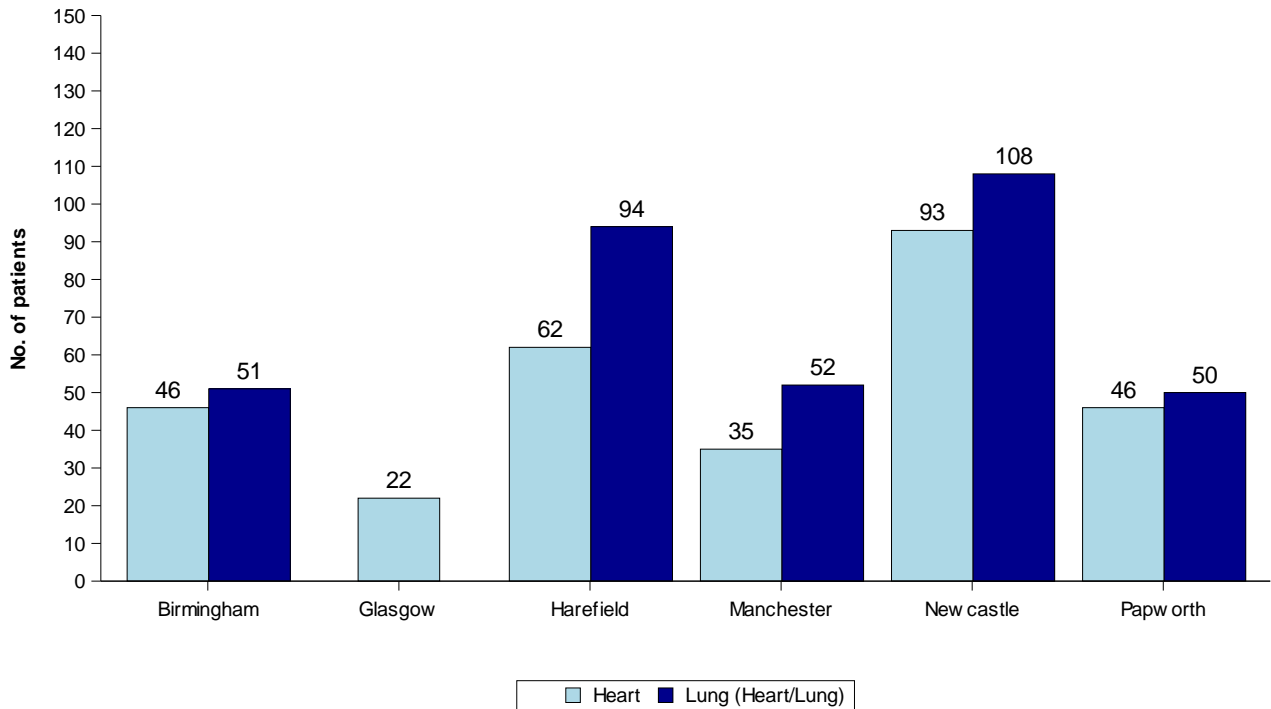


Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists at 31 March 2020, by centre

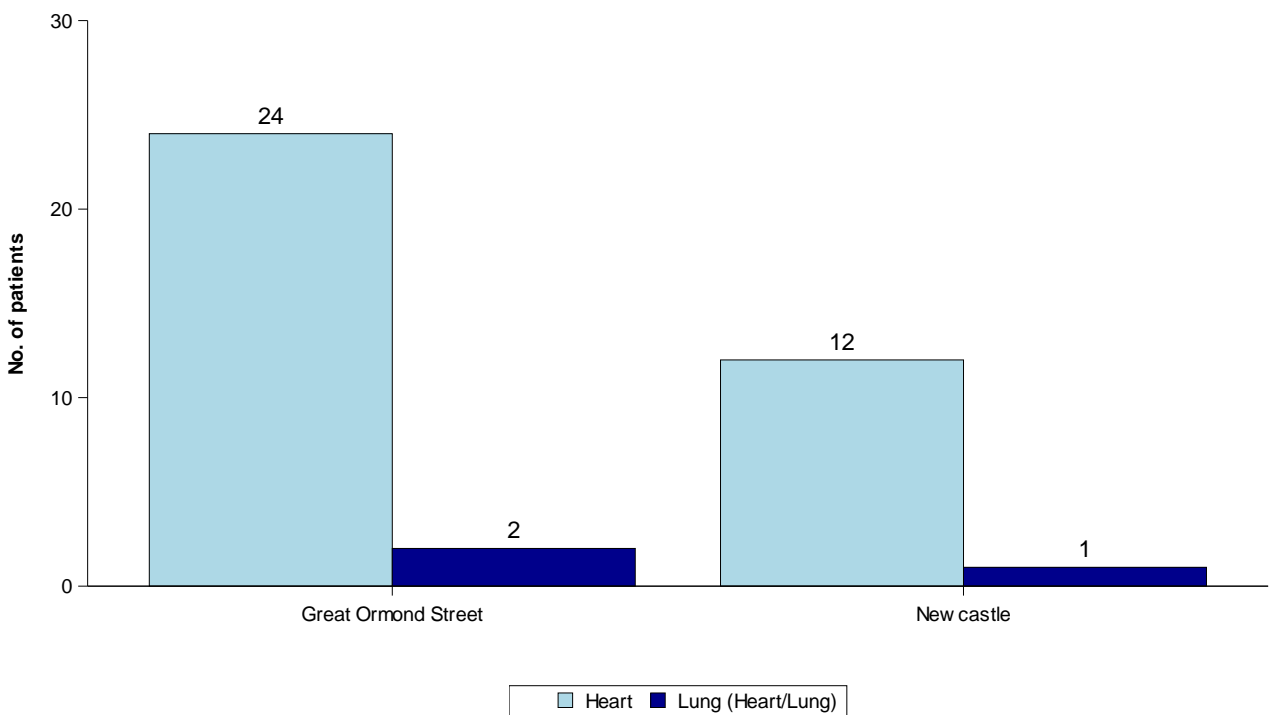


Figure 2.4 shows the total number of transplants performed in each of the last ten years. The number of heart transplants last year was 174, 5% lower than in 2018/2019. The number of lung transplants last year also fell from 2018/2019 by 3%, to 161, the lowest it has been over the last 10 years.

Figure 2.4 Number of cardiothoracic organ transplants in the UK, by financial year, 1 April 2010 to 31 March 2020

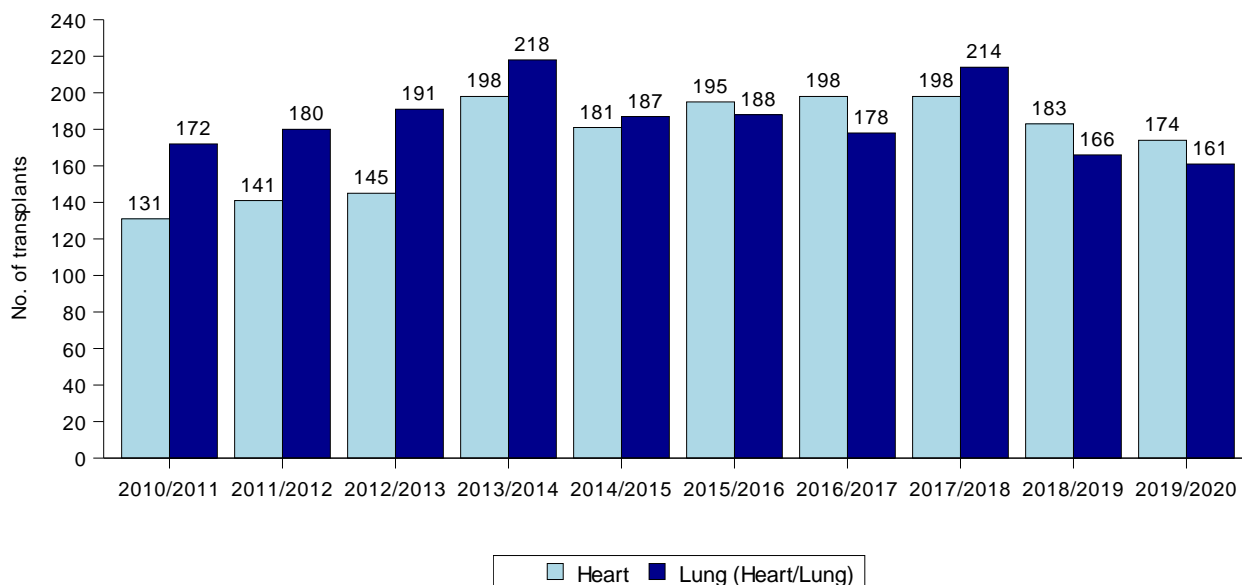


Figure 2.5 and **Figure 2.6** show the number of adult and paediatric transplants carried out in the most recent financial year at each centre. Papworth performed the highest number of lung transplants with similar numbers from Harefield. Papworth also performed the highest number of heart transplants. Newcastle performed the highest number of paediatric heart transplants and both Newcastle and Great Ormond Street Hospital performed equal number of lung transplants. Compared with the previous year (see [sections 5.1](#) and [17.1](#)), Harefield and Papworth and Great Ormond Street Hospital performed fewer heart transplants. All other centres performed more heart transplants in 2019/2020 than the previous year. For adult lung transplantation, Manchester and Newcastle performed a greater number compared with 2018/2019. Harefield and Papworth performed fewer, and Birmingham performed the same amount in 2019/2020 as the previous year. In paediatric lung transplantation, Great Ormond Street Hospital performed fewer transplants in 2019/2020 compared with the previous year whereas Newcastle’s figures were unchanged. (see [sections 11.1](#) and [22.1](#))

Figure 2.5 Number of adult cardiothoracic organ transplants in the UK, by centre, 1 April 2019 to 31 March 2020

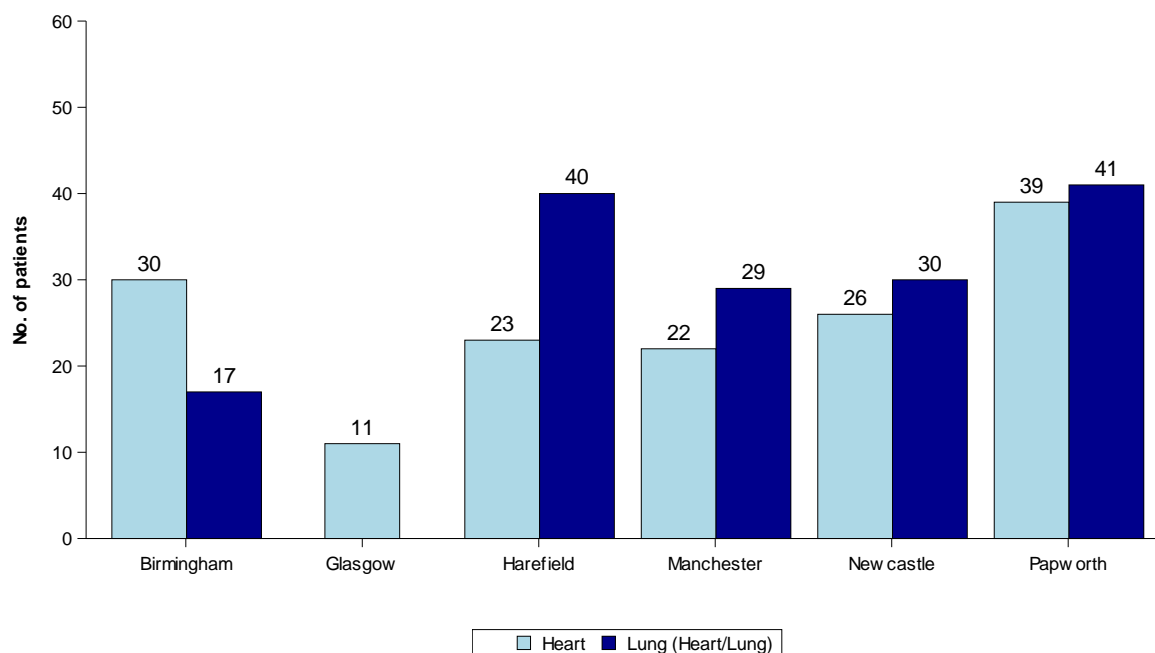


Figure 2.6 Number of paediatric cardiothoracic organ transplants in the UK, by centre, 1 April 2019 to 31 March 2020

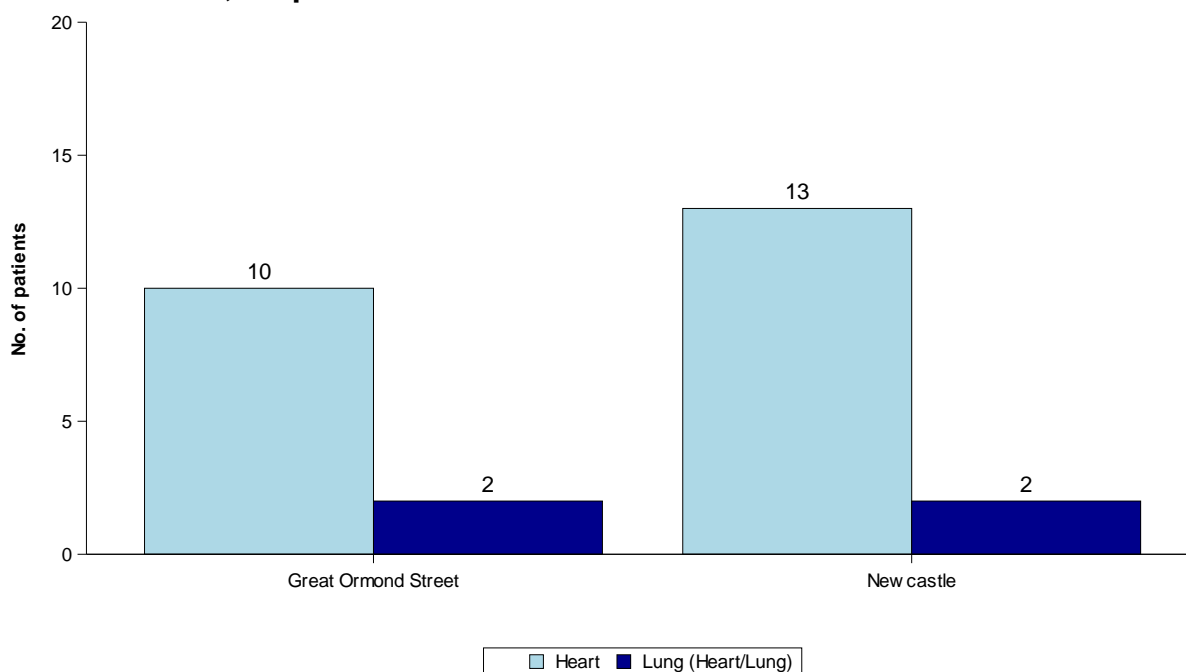
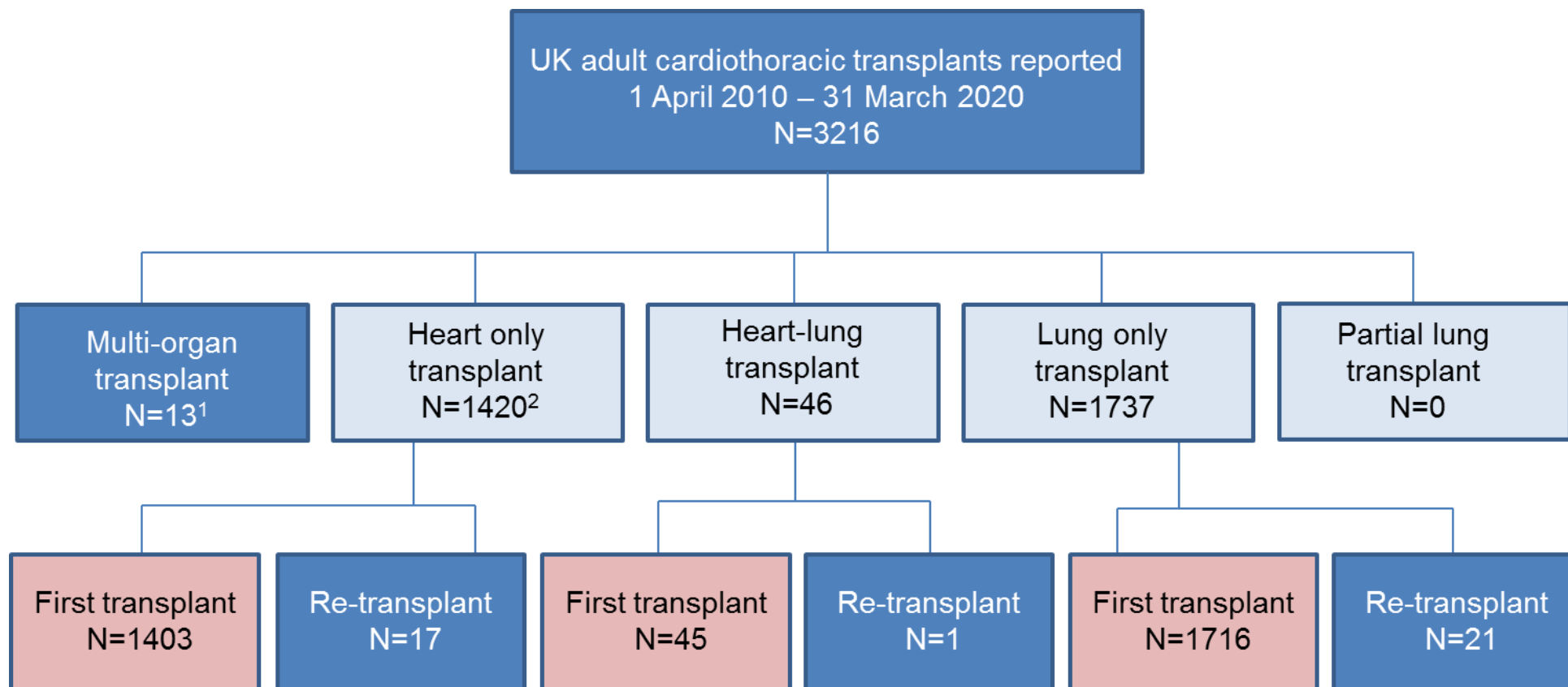


Figure 2.7 shows a breakdown of the 3,216 adult cardiothoracic organ transplants performed in the UK in the ten year period while **Figure 2.8** shows a similar breakdown for the 383 paediatric transplants performed during the same period. In the remainder of this report, [multi-organ transplants](#) are excluded, hence 3,203 adult and all paediatric transplants are analysed further (those in the light blue boxes). In the survival sections, first transplants from deceased donors only are analysed (those in the pink boxes) and the time period of transplants is restricted to allow time for follow-up data on patients to be reported to the registry.

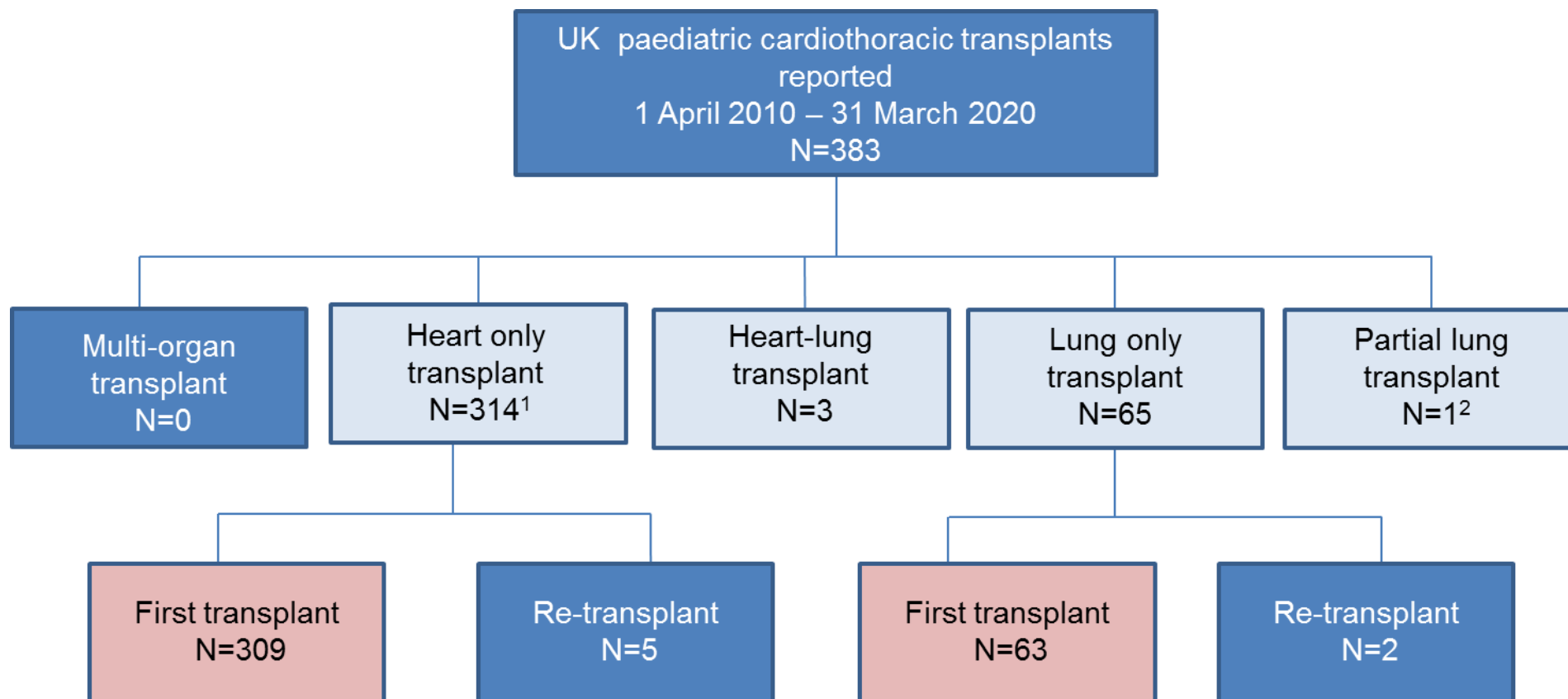
Figure 2.7 Adult cardiothoracic organ transplants performed in the UK, 1 April 2010 to 31 March 2020



¹ Includes 7 heart and kidney, 3 heart and liver, 2 lung and liver and 1 lung and kidney transplant

² Includes 109 DCD heart transplants and 3 domino donor transplants

Figure 2.8 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2010 to 31 March 2020



¹ Includes 4 DCD heart transplants

² Deceased donor transplant

2.2 Geographical variation in registration and transplant rates

Figure 2.9 shows rates of registration to the heart transplant list per million population (pmp) between 1 April 2019 and 31 March 2020 compared with heart transplant rates pmp for the same time period, by recipient country/NHS region of residence. **Table 2.1** shows the actual numbers as well as rates. 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. The UK heart registration and transplant rates are 4.8 pmp and 2.6 pmp respectively.

Since there will inevitably be some random variation in rates between areas, the systematic component of variation (SCV) was used to identify if the variation is more (or less) than a random effect for the different NHS regions in England only. Only first registrations and transplants in the 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 0.0048 (p-value = 0.229) and 0.0303 (p-value = 0.081), respectively. The p-value shows the probability that an SCV of this size (or higher) would be observed by chance if only random variation existed and therefore, there is no evidence of geographical variation beyond what would be expected at random for registrations and weak evidence for transplants. 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 2.10 and **Table 2.2** shows the same information but for registrations to the lung transplant list and lung transplants. The UK lung registration and transplant rates are 4.2 pmp and 2.4 pmp respectively. For lungs, registration and transplant rates yielded a SCV of 0 (p-value >0.999) and 0 (p-value >0.999), respectively, and therefore indicating no evidence of geographical variation beyond what would be expected at random.

Figure 2.9 Comparison of heart registration rates (pmp) with transplant rates (pmp) by recipient country/NHS region of residence

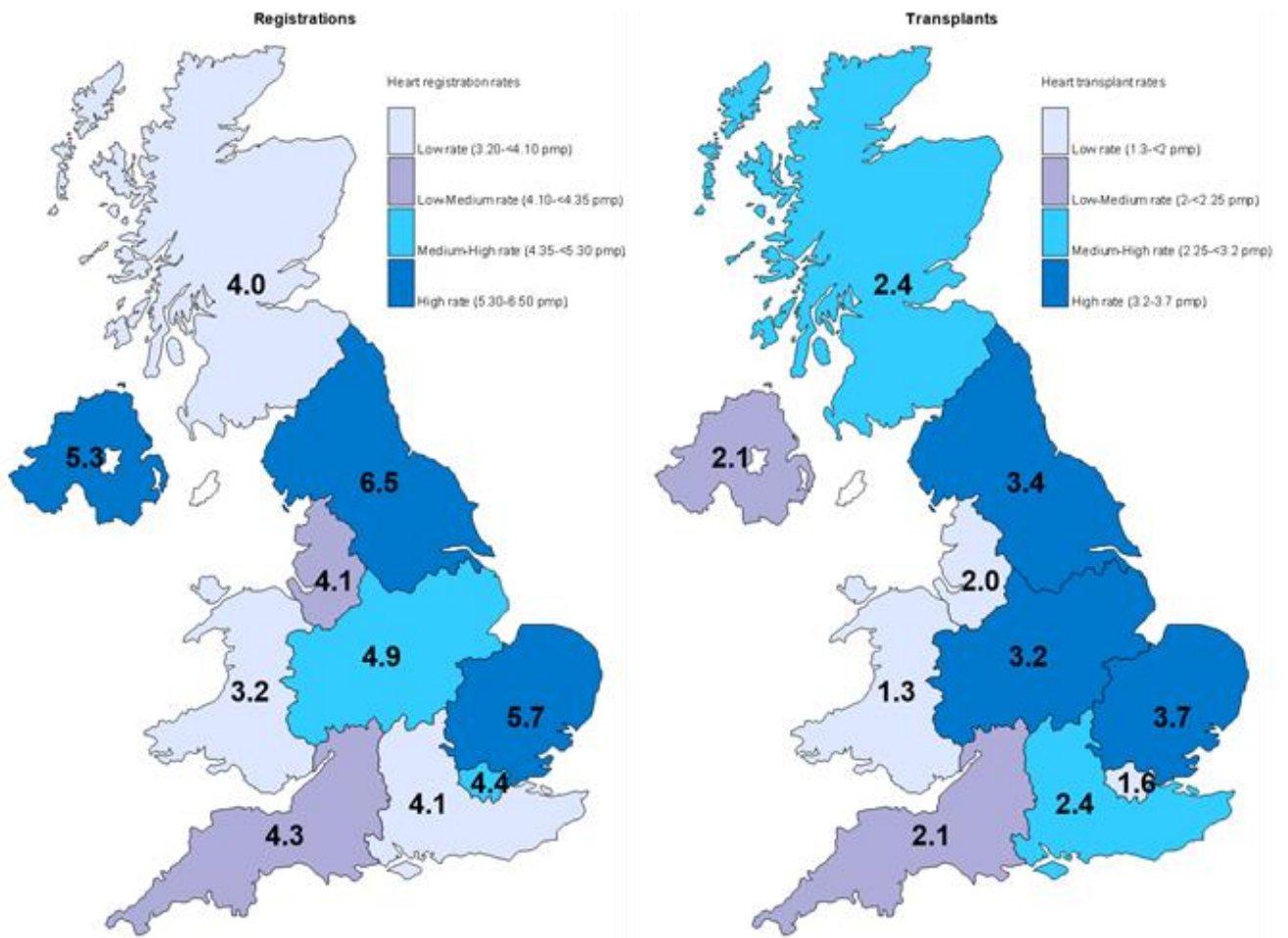


Table 2.1 Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2019 – 31 March 2020, by Country/NHS region

Country/ NHS region	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire	56	(6.5)	29	(3.4)
North West	29	(4.1)	14	(2)
Midlands	52	(4.9)	34	(3.2)
East of England	37	(5.7)	24	(3.7)
London	39	(4.4)	14	(1.6)
South East	36	(4.1)	21	(2.4)
South West	24	(4.3)	12	(2.1)
England	273	(4.9)	148	(2.6)
Isle of Man	0	(0.0)	0	(0.0)
Channel Islands	0	(0.0)	0	(0.0)
Wales	10	(3.2)	4	(1.3)
Scotland	22	(4.0)	13	(2.4)
Northern Ireland	10	(5.3)	4	(2.1)
TOTAL	319¹	(4.8)	173²	(2.6)

¹ Registrations include 4 recipients whose postcode was unknown and excludes 2 recipients who reside in the Republic of Ireland

² Transplants include 4 recipients whose postcode was unknown

Figure 2.10 Comparison of lung registration rates (pmp) with transplant rates (pmp) by recipient country/NHS region of residence

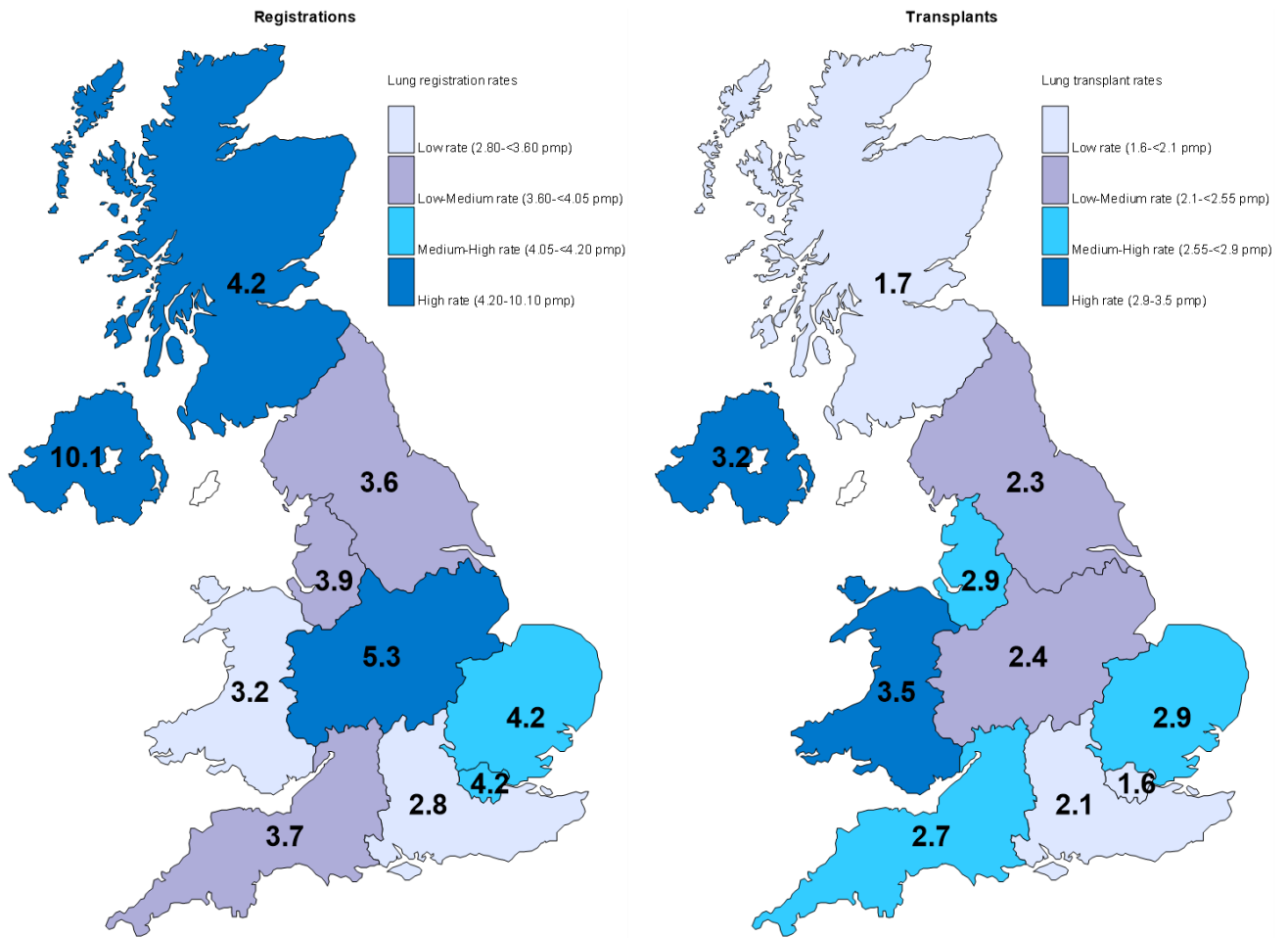


Table 2.2 Lung registration and transplant rates per million population (pmp) in the UK, 1 April 2019 – 31 March 2020, by Country/NHS region

Country/ NHS region	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire	31	(3.6)	20	(2.3)
North West	27	(3.9)	20	(2.9)
Midlands	56	(5.3)	25	(2.4)
East of England	27	(4.2)	19	(2.9)
London	37	(4.2)	14	(1.6)
South East	25	(2.8)	19	(2.1)
South West	21	(3.7)	15	(2.7)
England	224	(4.0)	132	(2.4)
Isle of Man	0	(0.0)	1	(12.5)
Channel Islands	2	(12.5)	1	(6.3)
Wales	10	(3.2)	11	(3.5)
Scotland	23	(4.2)	9	(1.7)
Northern Ireland	19	(10.1)	6	(3.2)
TOTAL	278	(4.2)	160¹	(2.4)

¹ Transplants exclude 1 recipient who resides in the Republic of Ireland

ADULT HEART TRANSPLANTATION

Transplant List



3.1 Adult heart only transplant list as at 31 March, 2011 – 2020

Figure 3.1 shows the number of adult patients on the heart transplant list at 31 March each year between 2011 and 2020 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list has generally increased each year, from 104 in 2011 to 271 in 2020. The number of patients on the urgent list has increased from 5 in 2011 to 28 in 2020. There was one super-urgent patient on the list on 31 March 2020.

Figure 3.1 Number of adult patients on the heart transplant list at 31 March each year, by urgency status

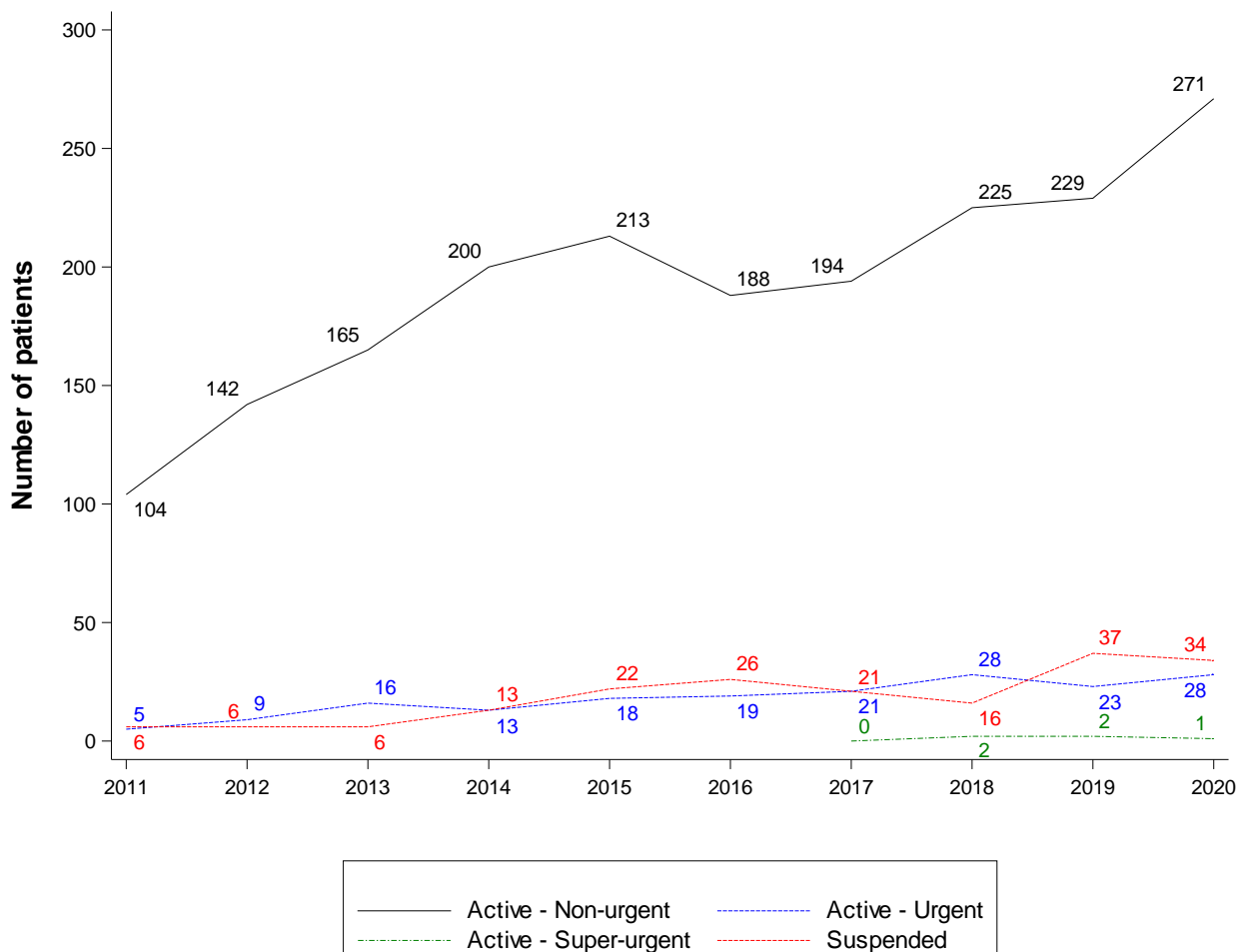


Figure 3.2 shows the number of adult patients on the [active heart transplant list](#) at 31 March 2020 by centre and urgency. **Figure 3.3** provides a similar breakdown by centre and mechanical circulatory support (MCS) status. In total, there were 300 adult patients waiting. The number of patients on the urgent transplant list at 31 March 2020 ranged from 2 at Papworth and Manchester to 10 at Harefield. Manchester had one patient on the super-urgent transplant list. A total of 128 patients were on long term MCS (including left-, right- and bi-ventricular assist devices and total artificial hearts), representing 43% of the national waiting list, but varying between 9% and 74% across centres.

Figure 3.2 Number of adult patients on the active heart transplant list at 31 March 2020, by centre and urgency

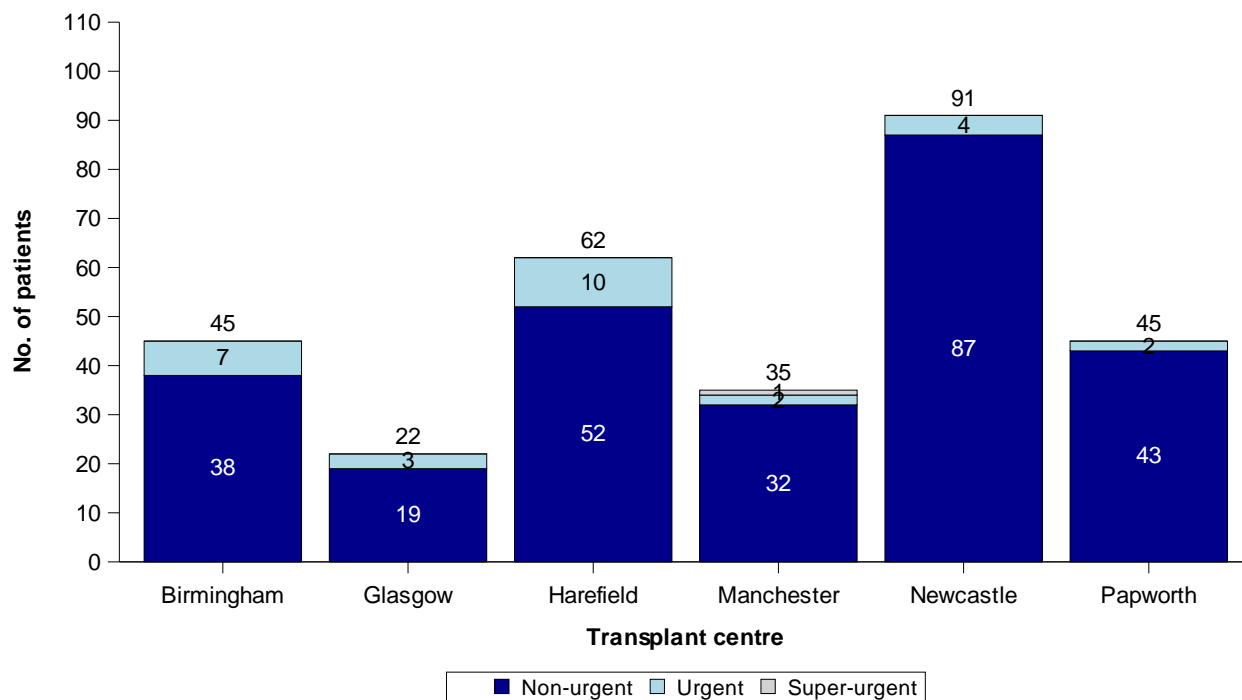


Figure 3.3 Number of adult patients on the active heart transplant list at 31 March 2020, by centre and mechanical circulatory support status

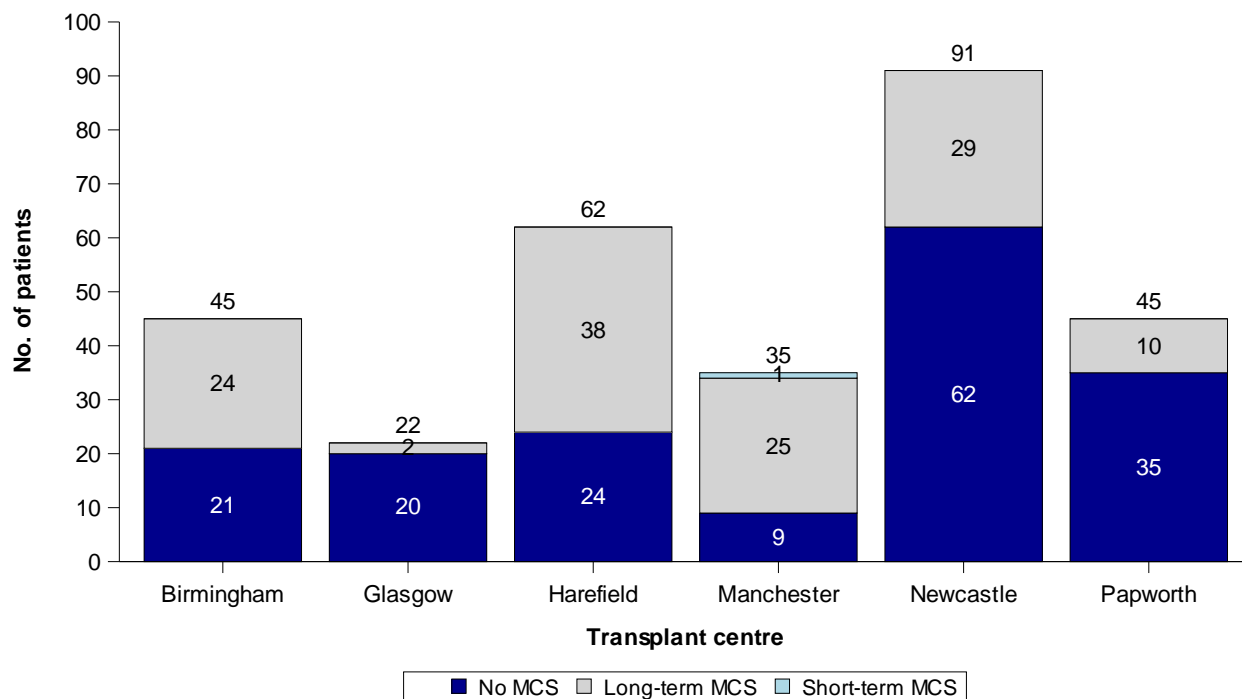
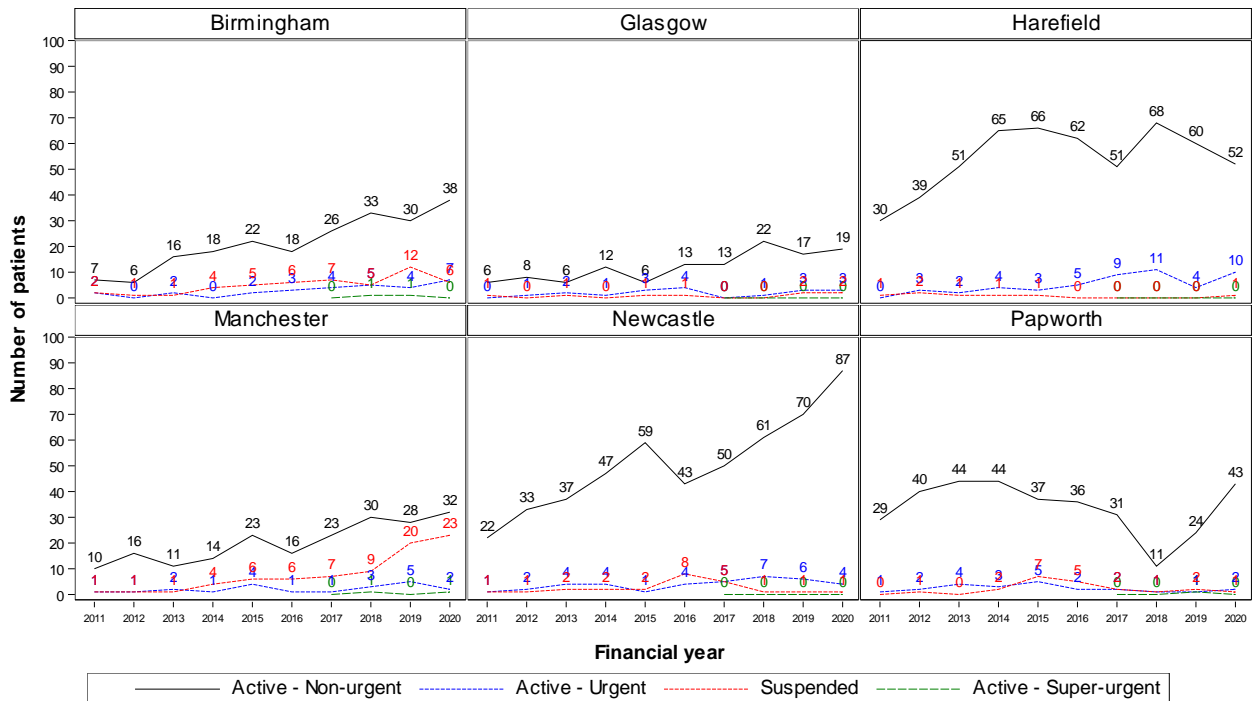


Figure 3.4 shows the trend over time in the number of adult patients on the heart transplant list at 31 March each year across centres. All centres have seen a general increase over the decade, however Papworth saw a decreasing trend between 2014 and 2018, but have had a rise in recent years.

Figure 3.4 Number of adult patients on the heart transplant list at 31 March each year for the last 10 years, by centre



3.2 Demographic characteristics, 1 April 2019 – 31 March 2020

There were 278 adult patient registrations onto the heart transplant list between 1 April 2019 and 31 March 2020. Demographic characteristics of these patients are shown by centre and overall in **Table 3.1**. Nationally, 71% of patients were male and the [median](#) age was 52 years. Note that there were 39 super-urgent heart registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

Table 3.1 Demographic characteristics of adult patients registered onto the heart transplant list between 1 April 2019 and 31 March 2020, by centre								
		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Number of registrations		49 (100)	20 (100)	56 (100)	33 (100)	59 (100)	61 (100)	278 (100)
Highest urgency during registration	Non-urgent	15 (31)	10 (50)	22 (39)	14 (42)	28 (47)	35 (57)	124 (45)
	Urgent	26 (53)	8 (40)	23 (41)	14 (42)	25 (42)	19 (31)	115 (41)
	Super-urgent	8 (16)	2 (10)	11 (20)	5 (15)	6 (10)	7 (11)	39 (14)
Recipient sex	Male	37 (76)	16 (80)	39 (70)	24 (73)	38 (64)	44 (72)	198 (71)
	Female	12 (24)	4 (20)	17 (30)	9 (27)	21 (36)	17 (28)	80 (29)
Recipient ethnicity	White	42 (86)	20 (100)	40 (71)	28 (85)	56 (95)	52 (85)	238 (86)
	Non-white	7 (14)	0 (0)	16 (29)	5 (15)	3 (5)	9 (15)	40 (14)
Recipient age (years)	Median (IQR)	53 (34, 60)	51 (42, 59)	54 (39, 58)	52 (38, 58)	49 (34, 58)	53 (45, 58)	52 (37, 58)
	Missing	0	0	0	0	0	0	0
Primary Disease	Coronary heart disease	16 (33)	2 (10)	9 (16)	4 (12)	10 (17)	6 (10)	47 (17)
	Cardiomyopathy	28 (57)	16 (80)	37 (66)	26 (79)	36 (61)	38 (62)	181 (65)
	Congenital heart disease	1 (2)	0 (0)	2 (4)	1 (3)	10 (17)	3 (5)	17 (6)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)	1 (0)
	Other	4 (8)	2 (10)	8 (14)	2 (6)	1 (2)	14 (23)	31 (11)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)	1 (0)
Previous open heart surgery	None	31 (63)	18 (90)	30 (54)	17 (52)	25 (42)	48 (79)	169 (61)
	One	14 (29)	2 (10)	21 (38)	16 (48)	26 (44)	13 (21)	92 (33)
	More than one	4 (8)	0 (0)	5 (9)	0 (0)	8 (14)	0 (0)	17 (6)
Previous thoracotomy	No	44 (90)	17 (85)	48 (86)	31 (94)	57 (97)	59 (97)	256 (92)
	Yes	5 (10)	3 (15)	8 (14)	2 (6)	2 (3)	2 (3)	22 (8)
Serum Bilirubin (umol/l)	Median (IQR)	21 (12, 28)	11 (8, 14)	13 (10, 29)	20 (13, 31)	15 (10, 25)	16 (11, 23)	16 (10, 27)
	Missing	0	0	0	0	2	0	2
Serum Creatinine (umol/l)	Median (IQR)	90 (77, 113)	90 (87, 99)	98 (78, 121)	91 (76, 126)	101 (76, 123)	99 (84, 122)	96 (79, 120)
	Missing	0	0	0	0	2	0	2

3.3 Post-registration outcomes, 1 April 2016 – 31 March 2017

The registration outcomes of adult patients listed for a heart transplant between 1 April 2016 and 31 March 2017 are summarised in **Figures 3.5 - 3.9**, nationally and by centre, for non-urgent, urgent and super-urgent registrations respectively. The possible outcomes for patients on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists (e.g. from the non-urgent to the urgent list), dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be “transplanted”. Note that the super-urgent heart allocation scheme was introduced in October 2016.

Figure 3.5 shows the non-urgent post-registration outcomes; within six months of listing 10% of non-urgent heart patients had been transplanted and 3% had died on the list, while after three years 17% had been transplanted and 11% had died on the list. Also, 19% had been moved to the urgent heart list within 6 months, reaching 33% by three years. Removals from the list were for a variety of reasons, most commonly due to improved condition.

Figure 3.5 Post-registration outcome for 151 non-urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017

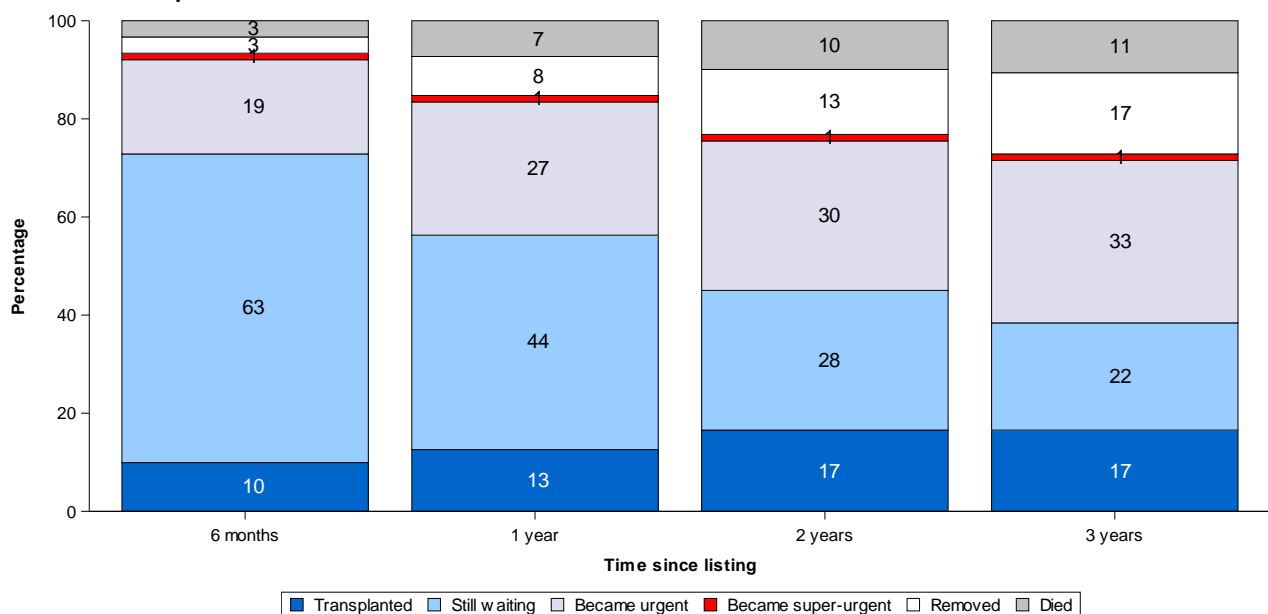


Figure 3.6 shows the three year non-urgent registration outcomes by centre. The non-urgent transplant rate at three years was highest at Papworth (33%) and lowest at Birmingham (4%). Please note that some centres had a very small number of non-urgent registrations in this time period (as shown by the numbers above the bars).

Figure 3.6 Three year registration outcomes by centre, for non-urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017

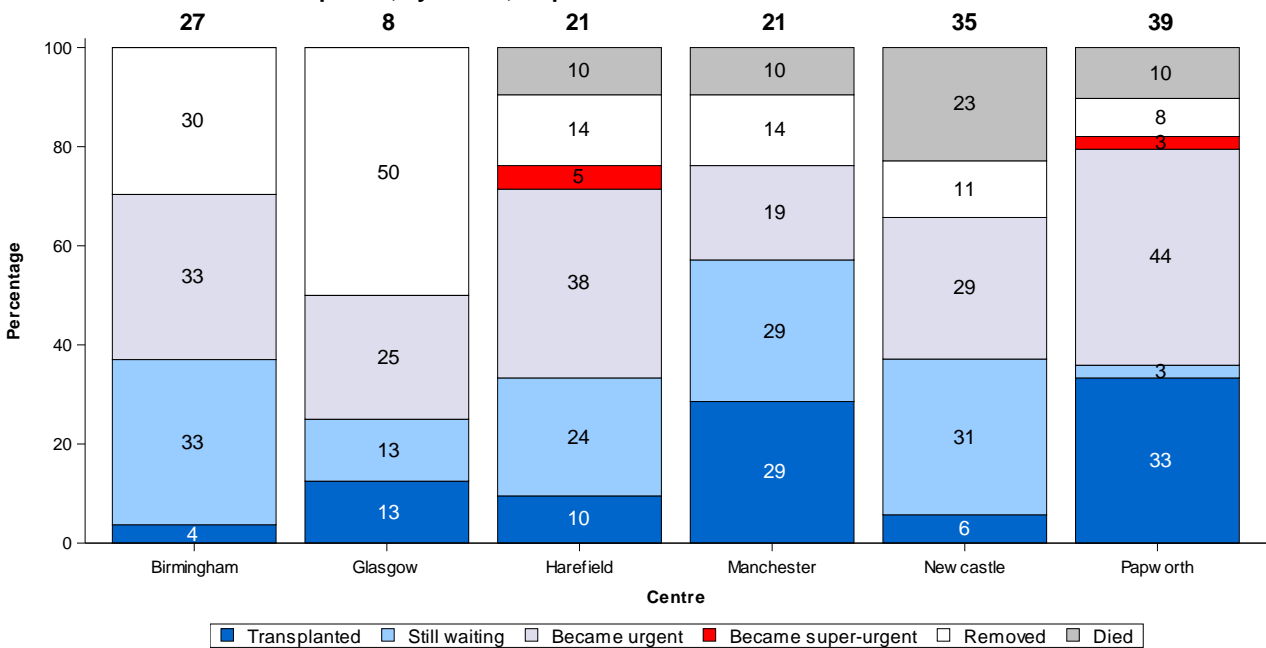


Figure 3.7 shows post-registration outcomes for urgent patients (including those previously on the non-urgent list). The chance of transplant is much higher from the urgent list compared with the non-urgent list; within 6 months, 70% had been transplanted, 3% had died on the list and 16% were removed. The most common reason for removal from the urgent heart list was due to recipients receiving a VAD. **Figure 3.8** shows the one month urgent registration outcomes by centre. The urgent transplant rate at one month was highest at Manchester (65%) and equally lowest at Glasgow and Harefield (20%).

Figure 3.7 Post-registration outcome for 158 urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017

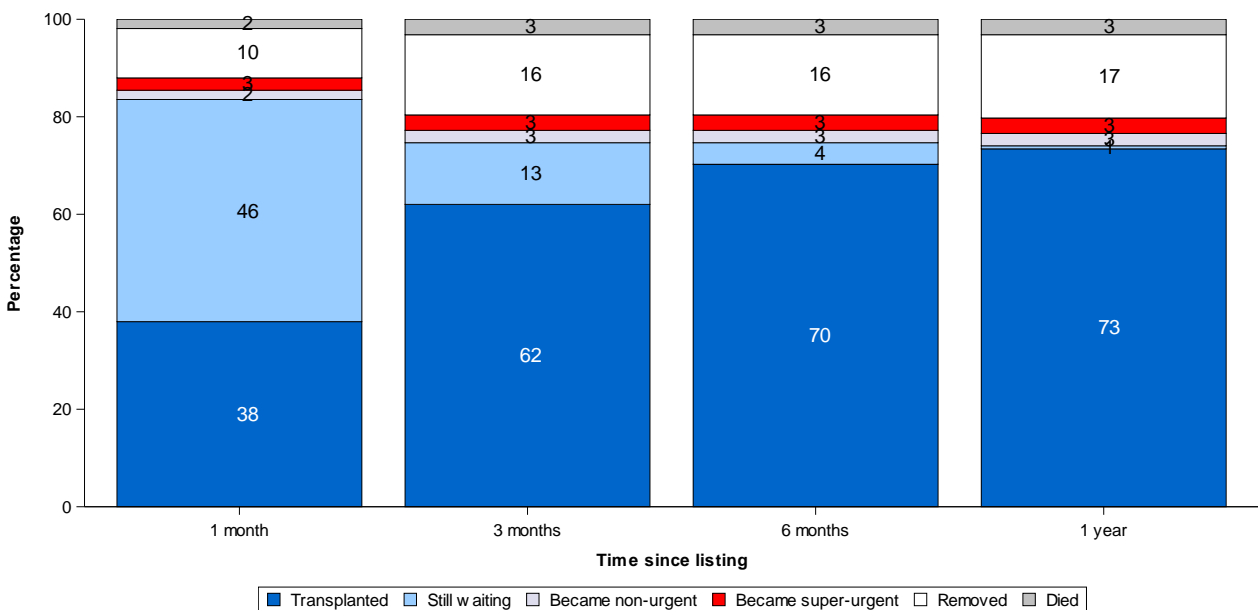


Figure 3.8 One month registration outcomes by centre, for urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017

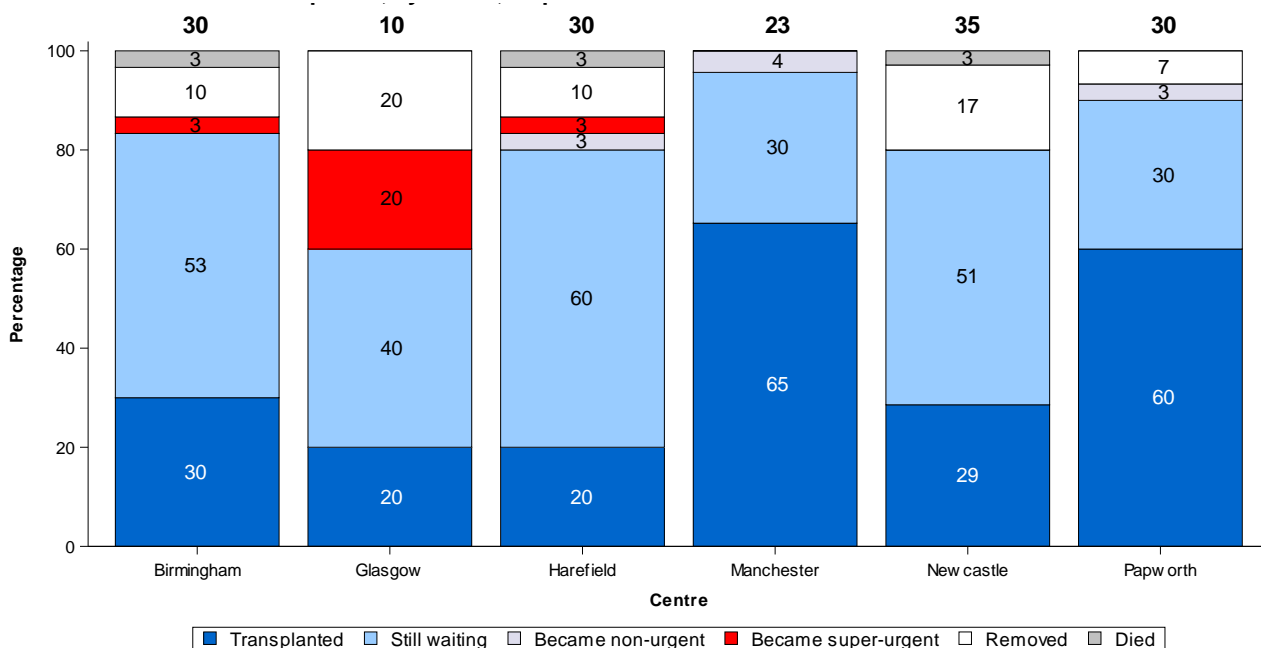
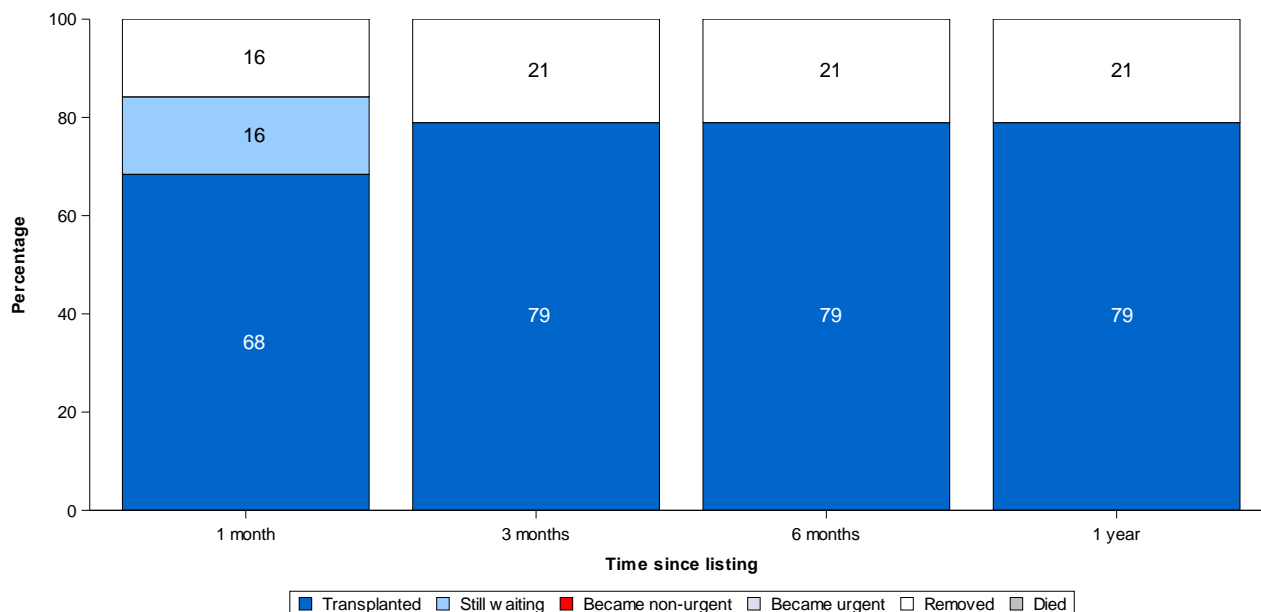


Figure 3.9 shows post-registration outcomes for super-urgent patients (including those previously on the non-urgent and urgent lists). The chance of transplant is much higher from the super-urgent list compared with the non-urgent and urgent lists; within 3 months, 79% had been transplanted, and the remaining 21% were removed. Please note that there is no figure breaking down super-urgent registration outcomes by centre due to the small numbers.

Figure 3.9 Post-registration outcome for 19 urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017



3.4 Median waiting time to transplant, 1 April 2014 - 31 March 2017

The [median](#) waiting time to heart transplant from registration for adult patients is shown in **Figure 3.10** and **Table 3.2**. This is estimated for patients registered on the heart only transplant list between 1 April 2014 and 31 March 2017 using the [Kaplan Meier](#) method (before the introduction of the super-urgent heart allocation scheme in October 2016). This is split by the urgency of the patient at registration; non-urgent or urgent. All waiting time from initial registration is considered, regardless of any change in urgency (including time on the super-urgent heart list for any patients that became super-urgent after October 2016). Any suspended time is discounted.

The overall national [median](#) waiting time to transplant from non-urgent registration was 589 days (1.6 years) and ranged from 166 days at Papworth to 1501 days at Newcastle. For urgent registrations, the national [median](#) waiting time was 36 days, and ranged from 19 days at Papworth to 58 days at Harefield. The 95% [confidence intervals](#) for some of these medians are very wide, indicating the variation in individual waiting times within groups. Please note that a 95% confidence interval could not be calculated for patients registered as non-urgent at initial registration for both Glasgow and Newcastle.

Figure 3.10 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2014 and 31 March 2017, by centre and urgency status at registration

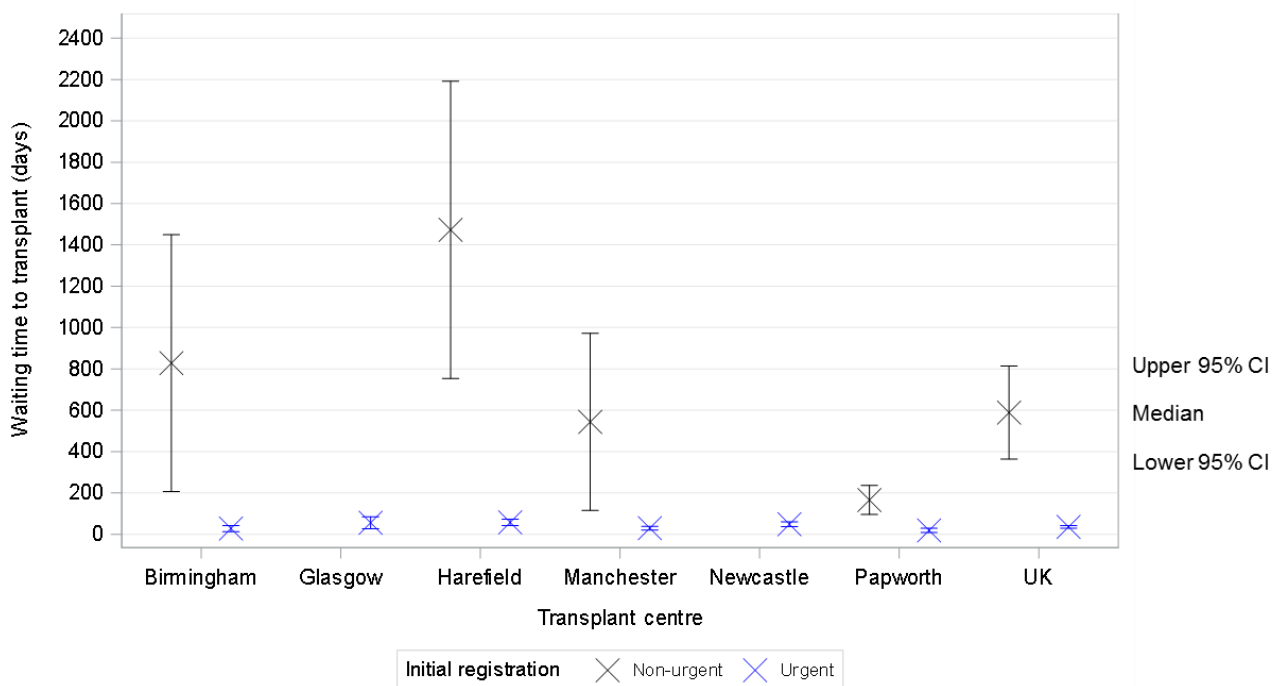


Table 3.2 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and centre, 1 April 2014 to 31 March 2017

Transplant centre	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Overall			
Birmingham	143	98	44 - 152
Glasgow	64	160	0 - 435
Harefield	109	334	161 - 507
Manchester	112	60	16 - 104
Newcastle	137	596	136 - 1056
Papworth	156	83	31 - 135
UK	721	135	92 - 178
Non-urgent at initial registration			
Birmingham	77	828	207 - 1449
Glasgow ¹	29	853	-
Harefield	62	1473	754 - 2192
Manchester	45	544	116 - 972
Newcastle ¹	78	1501	-
Papworth	114	166	96 - 236
UK	405	589	364 - 814
Urgent at initial registration			
Birmingham	66	28	13 - 43
Glasgow	35	56	27 - 85
Harefield	47	58	43 - 73
Manchester	67	30	21 - 39
Newcastle	59	49	37 - 61
Papworth	42	19	9 - 29
UK	316	36	30 - 42

¹A 95% confidence interval could not be calculated

The median waiting time to heart transplant for adult patients is also considered by blood group. This is shown in **Figure 3.11** and **Table 3.3** by both blood group and urgency status at registration. For both urgent and non-urgent registrations, blood group O patients have the longest average wait compared with the other groups. The confidence intervals for blood group AB patients are particularly wide due to small numbers of patients in these groups.

Figure 3.11 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2014 and 31 March 2017, by blood group and urgency at registration

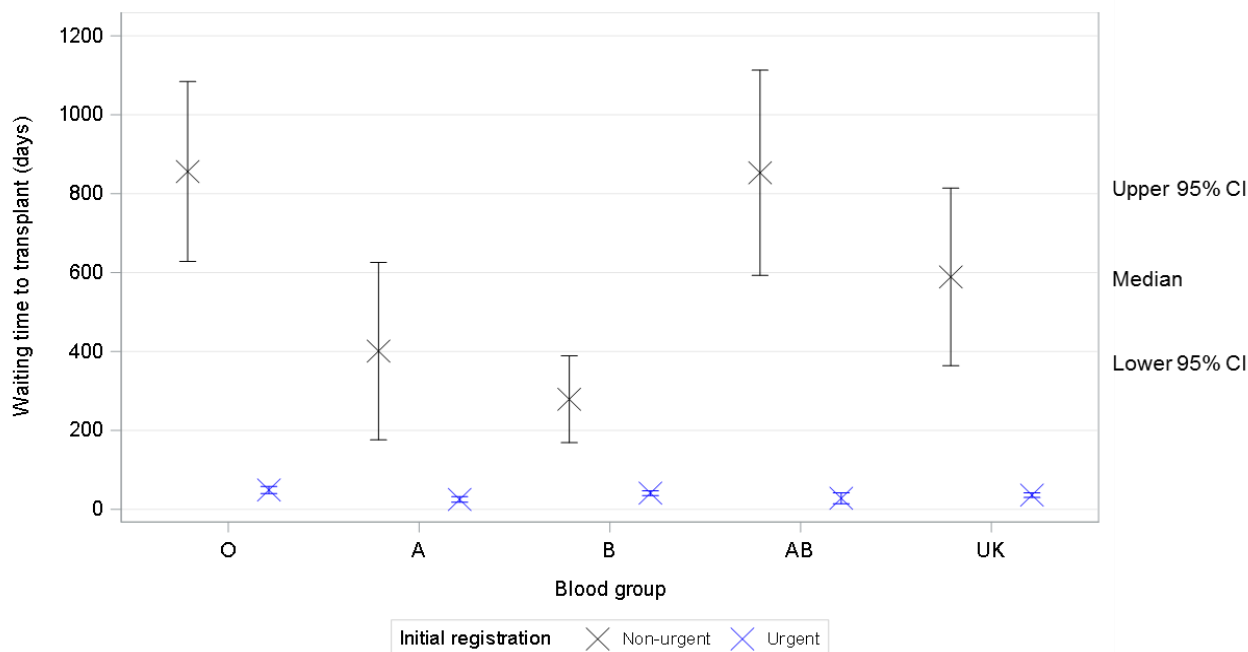
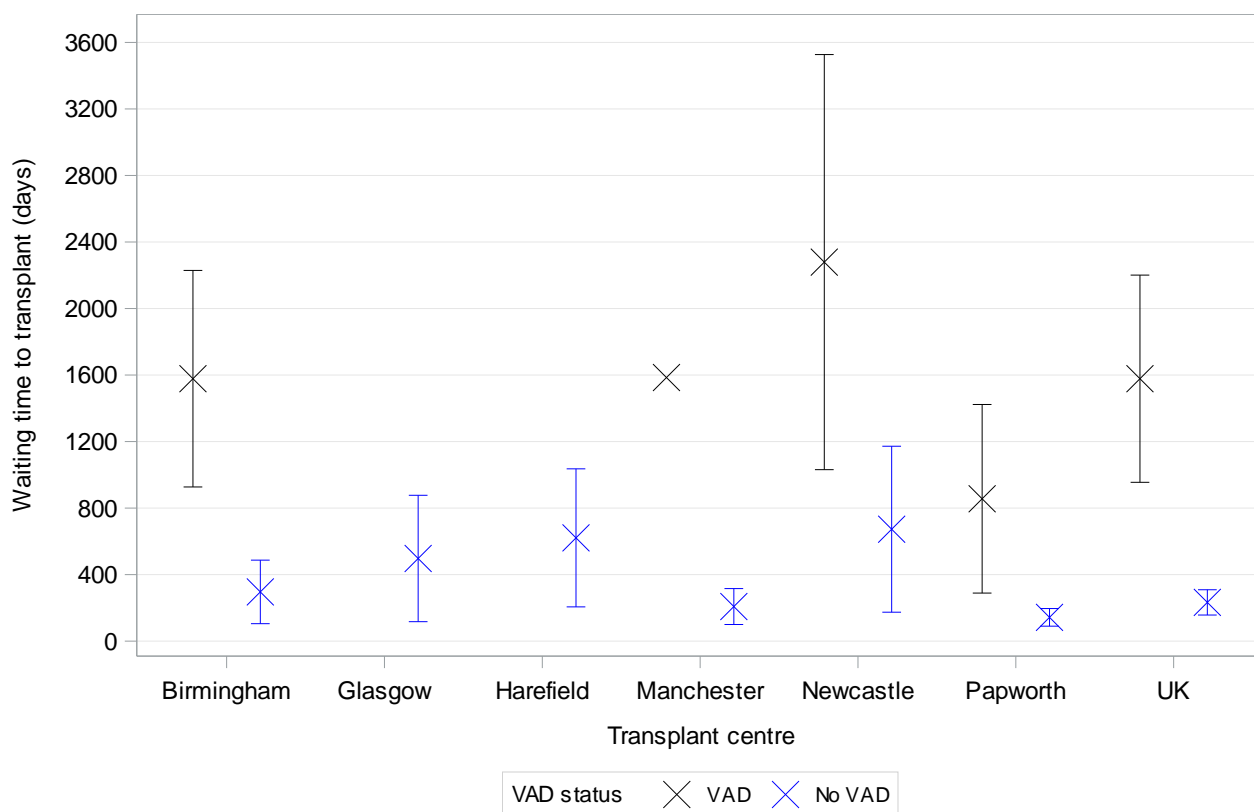


Table 3.3 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2014 to 31 March 2017

Blood group	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Overall			
O	298	260	142 - 378
A	304	86	52 - 120
B	89	160	38 - 282
AB	30	82	11 - 153
UK	721	135	92 - 178
Non-urgent at initial registration			
O	172	856	628 - 1084
A	169	401	176 - 626
B	53	279	169 - 389
AB	11	853	593 - 1113
UK	405	589	364 - 814
Urgent at initial registration			
O	126	49	40 - 58
A	135	25	18 - 32
B	36	41	35 - 47
AB	19	28	14 - 42
UK	316	36	30 - 42

The [median](#) waiting time to heart transplant for adult patients is shown by [VAD](#) status in **Figure 3.12** and **Table 3.4**. This considers whether a patient ever had an implantable left-ventricular assist device (LVAD) as a bridge to heart transplant compared with not, and is restricted to those who were initially non-urgent. Nationally, those ever on LVAD support wait on average 6.8 times longer (unadjusted) than those never on LVAD support (log-rank $p < 0.0001$). Note that median waiting time estimates could not be obtained for patients on LVAD support at Glasgow due to small numbers, while for Harefield an estimate could not be obtained as not enough patients had been transplanted at time of analysis. Please note that the time period has been extended to include data from 2013/2014 due to small numbers.

Figure 3.12 Median waiting time to heart transplant for adult patients registered onto the non-urgent list between 1 April 2013 and 31 March 2017, by centre and whether the patient had an implantable left-ventricular assist device (LVAD)



Median waiting times could not be estimated for patients on LVAD support at Glasgow and Harefield.

Table 3.4 Median active waiting time to heart transplant for adult patients registered on the non-urgent transplant list 1 April 2013 to 31 March 2017, by centre and whether the patient had an implantable left-ventricular assist device (LVAD)

Transplant centre	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Ever on LVAD support			
Birmingham	30	1578	927 - 2229
Glasgow ¹	6	-	-
Harefield ²	54	-	-
Manchester ³	23	1585	-
Newcastle	63	2279	1031 - 3527
Papworth	30	856	289 - 1423
UK	206	1578	955 - 2201
Never on LVAD support			
Birmingham	70	296	105 - 487
Glasgow	38	497	117 - 877
Harefield	46	621	206 - 1036
Manchester	47	208	100 - 316
Newcastle	54	673	174 - 1172
Papworth	121	143	90 - 196
UK	376	233	157 - 309

¹ Median waiting time for groups with less than 10 patients are not presented due to small numbers

² Median waiting time cannot be estimated as not enough patients had been transplanted by the time of analysis

³ Confidence interval cannot be estimated as not enough patients had been transplanted by the time of analysis

ADULT HEART TRANSPLANTATION

Response to Offers



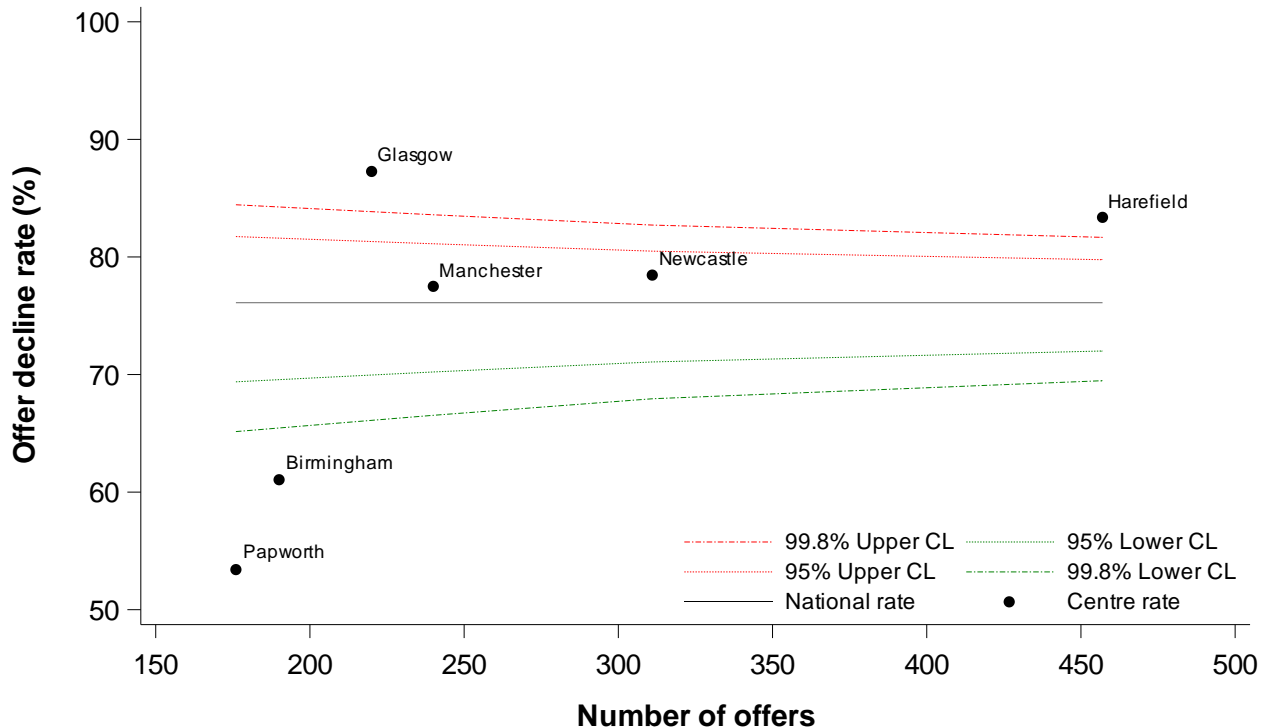
4. Response to Offers

This section presents an analysis of adult DBD donor heart offer decline rates. This only considers offers of hearts between 1 April 2017 and 31 March 2020 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. No response to a group offer is considered an assumed decline. To account for this in the analysis of non-urgent offers post-22 June 2017, any centre who is ranked above the accepting centre in the allocation sequence for that donor is assumed to have declined the heart.

Figure 4.1 compares individual centre decline rates with the national rate using a [funnel plot](#). The offer decline rate for Glasgow and Harefield is above the upper 99.8% [confidence limit](#), indicating that they have a significantly higher decline rate than the national rate. The offer decline rates for both Birmingham and Papworth are below the lower 99.8% [confidence limit](#), indicating that they have a significantly lower decline rate than the national rate.

Figure 4.1 UK adult DBD donor heart offer decline rates by centre, 1 April 2017 to 31 March 2020



ADULT HEART TRANSPLANTATION

Transplants



5.1 Adult heart transplants, 1 April 2010 – 31 March 2020

Figure 5.1 shows the number of adult heart transplants performed per year over the last ten years, by donor type. Last year there were 149 adult heart transplants nationally; nine lower than the previous year and 18 less than the most active year over the last decade, which was 2013/2014. Comparing 2019/20 with the previous year we see that the number of DBD transplants is comparable, however the slight drop in overall numbers is caused by fewer DCD heart transplants. Compared with 2010/2011, overall activity has increased by 64%.

Figure 5.1 Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2010 to 31 March 2020

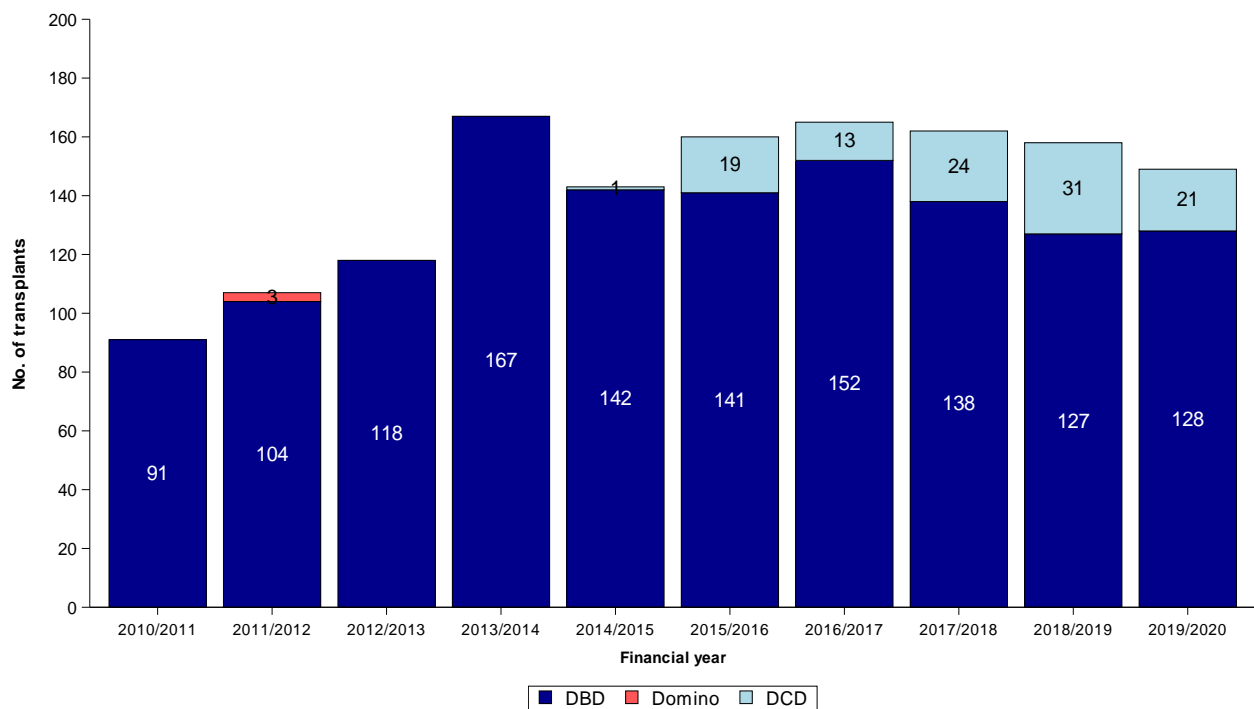
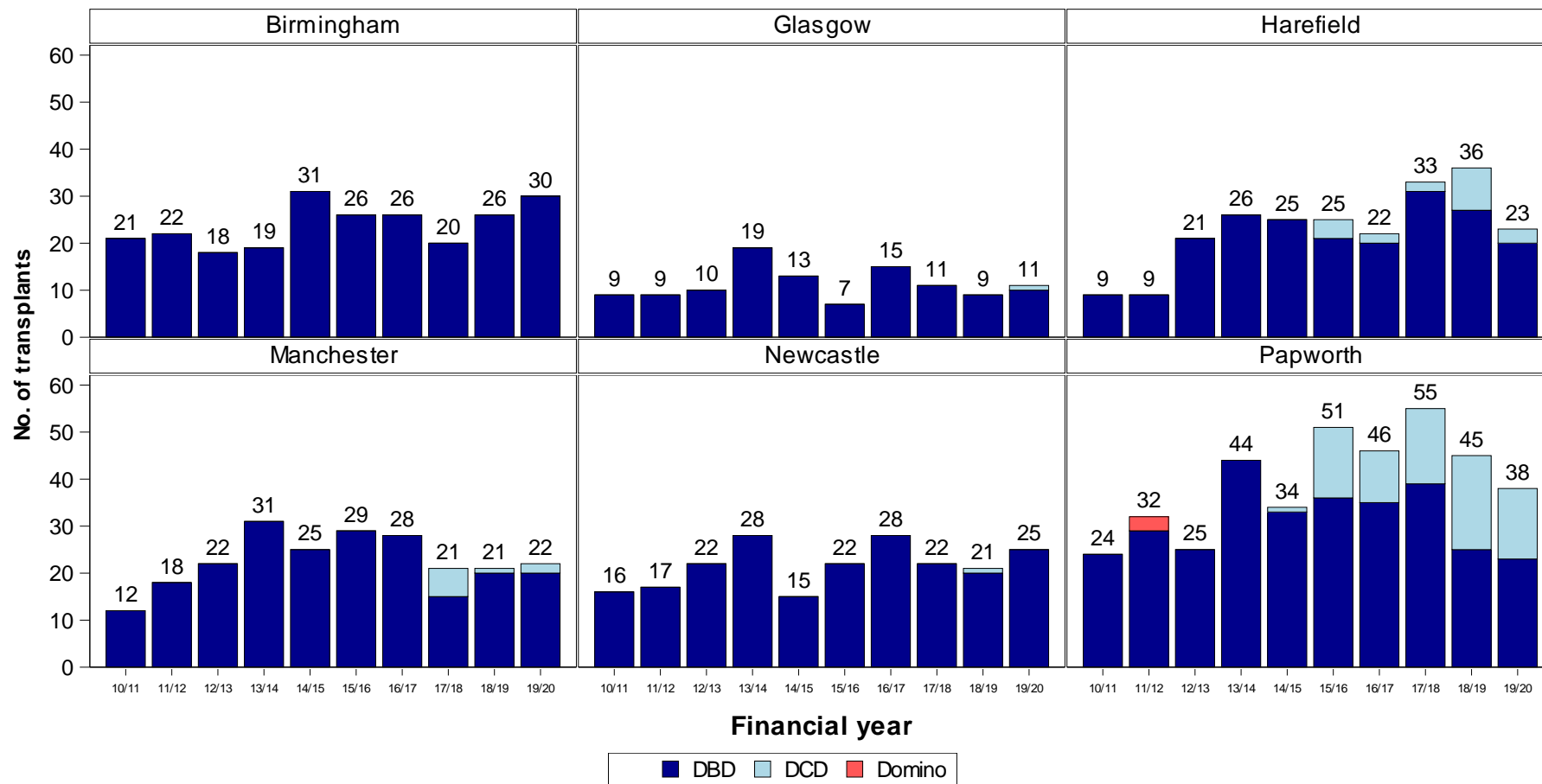


Figure 5.2 shows the number of adult heart transplants performed per centre, per year, over the last ten years, by donor type.

Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2010 to 31 March 2020



Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants, performed by four centres in this time period, represented 14% of last year's adult heart transplant activity. The highest number of transplants were performed by Papworth.

Figure 5.3 Number of adult heart transplants in the UK, by centre and donor type, 1 April 2019 to 31 March 2020

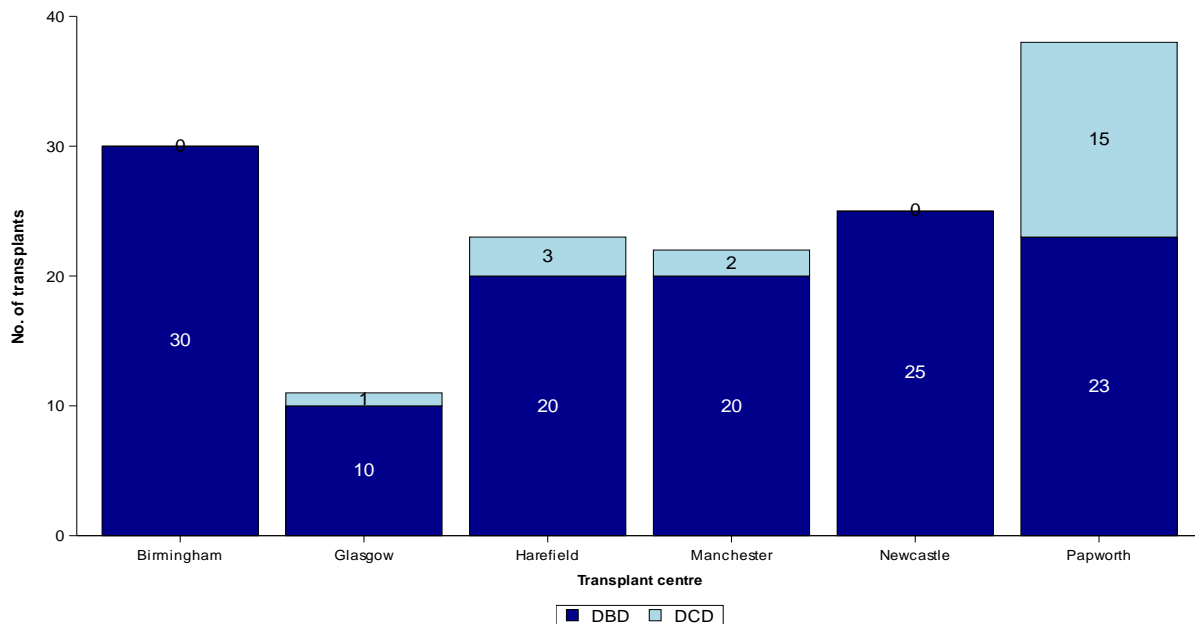


Figure 5.4 and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time, the proportion of urgent transplants has increased; from 56% in 2010/2011 to 85% in 2019/2020, including 29 super-urgent transplants. Papworth performed the highest number of non-urgent transplants over the time period.

Figure 5.4 Number of adult heart transplants in the UK, by financial year and urgency status, 1 April 2010 to 31 March 2020

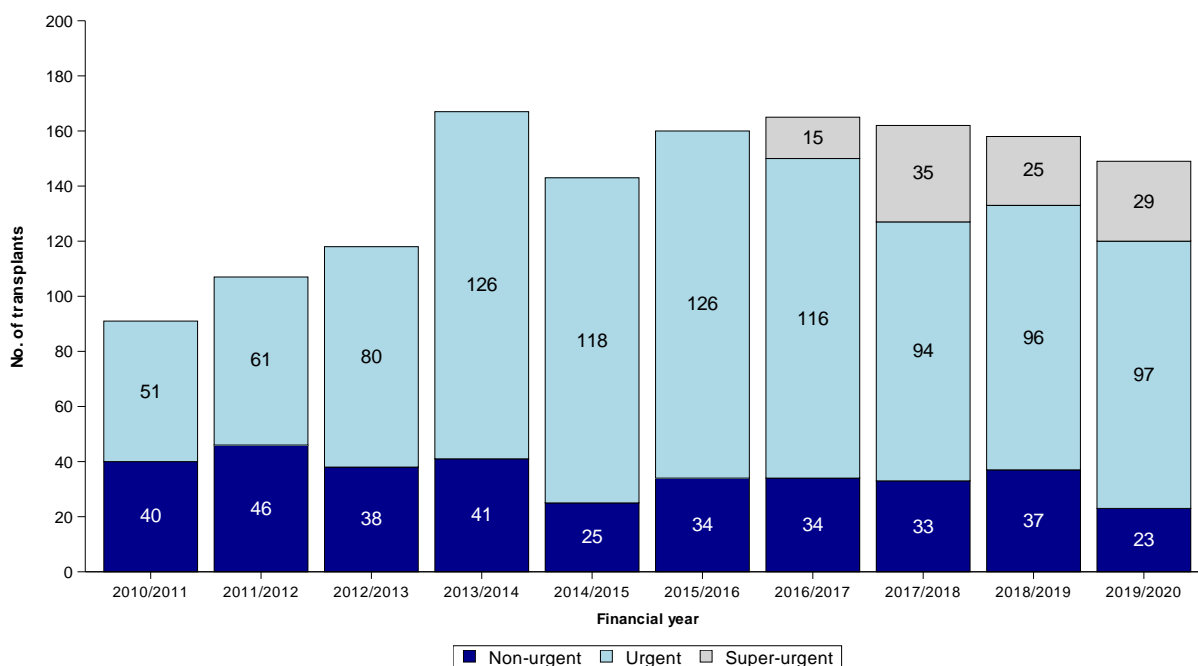
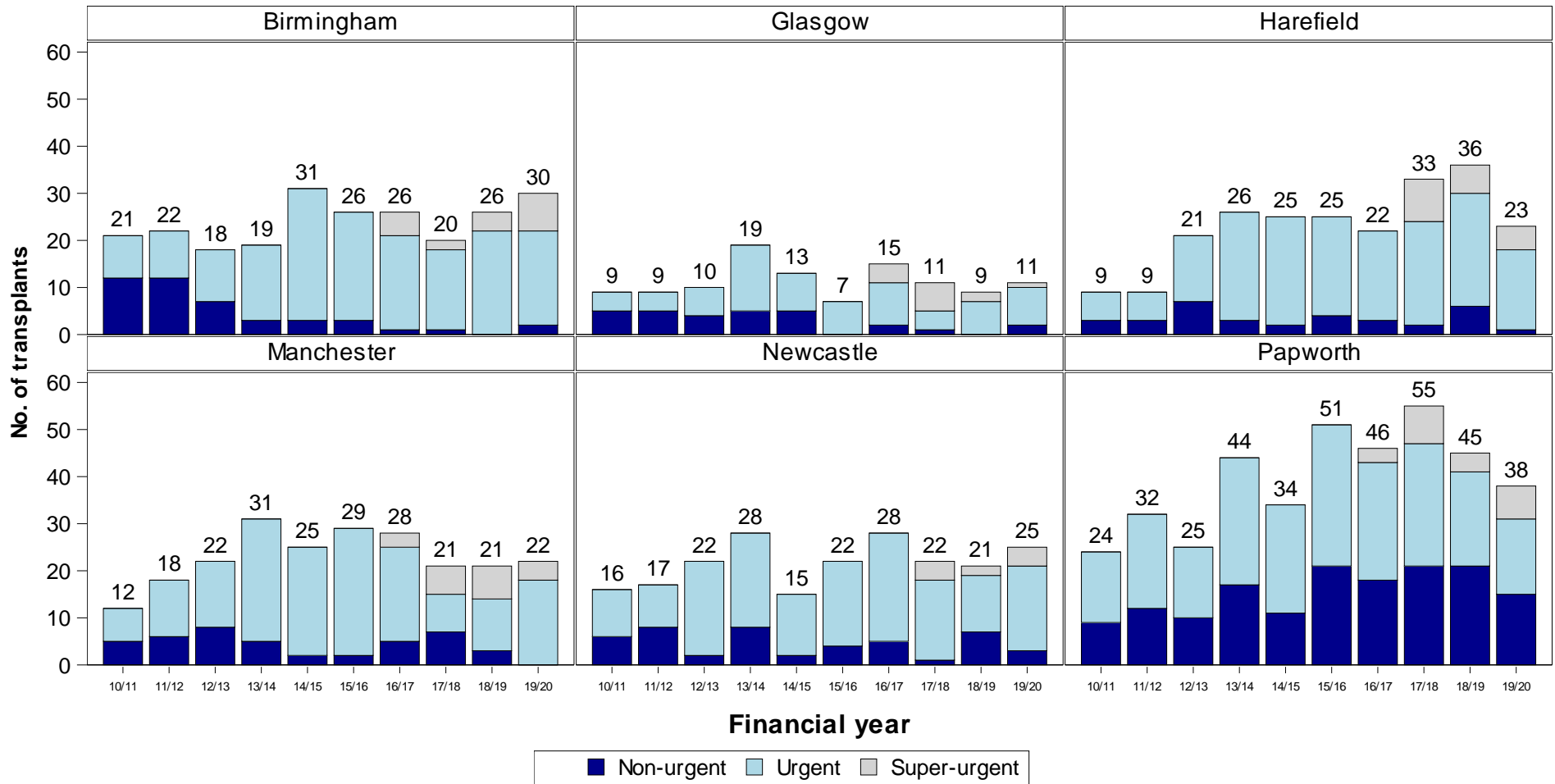
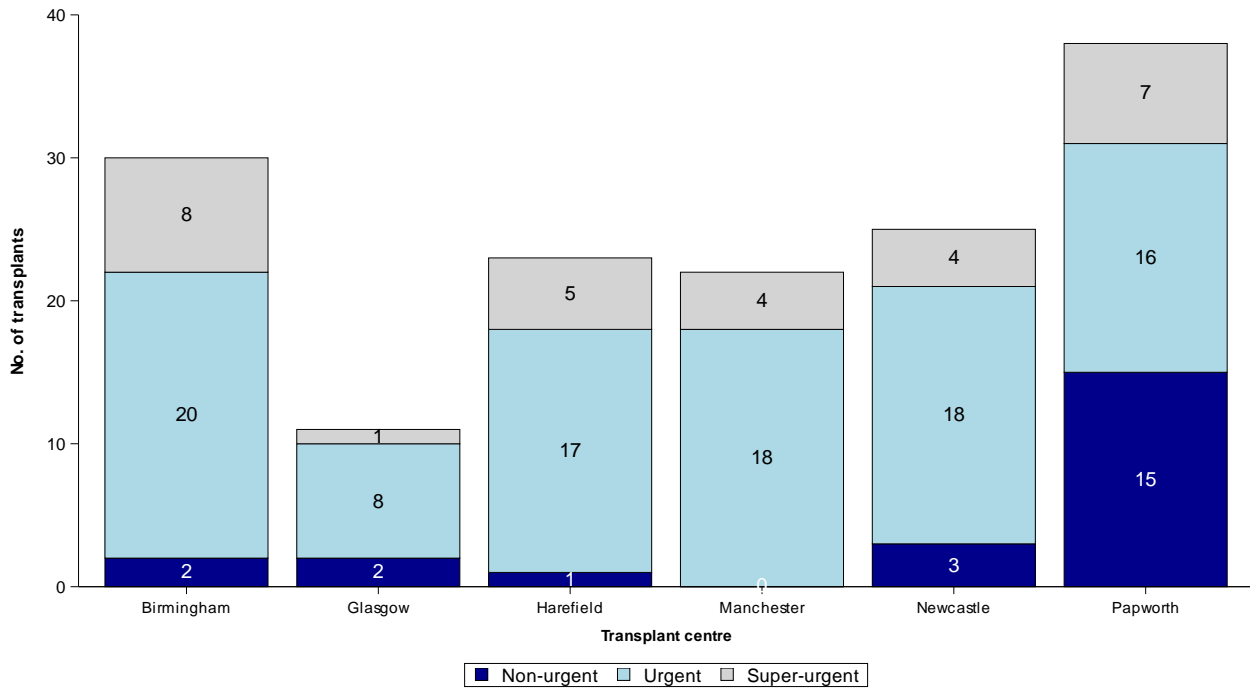


Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2010 to 31 March 2020



Last year's activity is shown by centre and urgency status in **Figure 5.6**. Papworth performed the highest number of non-urgent heart transplants, representing 65% of all non-urgent transplants performed in 2019/2020. Of the 23 non-urgent transplants, 9 (39%) used DCD donor hearts.

Figure 5.6 Number of adult heart transplants in the UK, by centre and urgency status, 1 April 2019 to 31 March 2020



5.2 Demographic characteristics of transplants, 1 April 2019 – 31 March 2020

The demographic characteristics of the 149 adult heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 69% of heart recipients were male and the [median](#) age was 51 years while the median age for donors was 35 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 5.1		Demographic characteristics of adult heart transplants, 1 April 2019 to 31 March 2020, by centre						
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		30 (100)	11 (100)	23 (100)	22 (100)	25 (100)	38 (100)	149 (100)
Urgency status at transplant	Non-urgent	2 (7)	2 (18)	1 (4)	0 (0)	3 (12)	15 (39)	23 (15)
	Urgent	20 (67)	8 (73)	17 (74)	18 (82)	18 (72)	16 (42)	97 (65)
	Super-urgent	8 (27)	1 (9)	5 (22)	4 (18)	4 (16)	7 (18)	29 (20)
Recipient sex	Male	21 (70)	7 (64)	15 (65)	14 (64)	17 (68)	28 (74)	102 (69)
	Female	9 (30)	4 (36)	8 (35)	8 (36)	8 (32)	10 (26)	47 (32)
Recipient ethnicity	White	27 (90)	10 (91)	17 (74)	19 (86)	22 (88)	33 (87)	128 (86)
	Non-white	3 (10)	1 (9)	6 (26)	3 (14)	3 (12)	5 (13)	21 (14)
Recipient age (years)	Median (IQR)	53 (34, 59)	50 (39, 57)	54 (37, 59)	52 (43, 59)	43 (29, 56)	54 (48, 60)	51 (37, 58)
	Missing	0	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	77 (67, 87)	78 (68, 85)	72 (65, 81)	74 (67, 81)	70 (61, 76)	72 (61, 92)	72 (64, 84)
	Missing	0	0	0	0	0	0	0
Recipient primary disease	Coronary heart disease	7 (23)	1 (9)	1 (4)	4 (18)	4 (16)	7 (18)	24 (16)
	Cardiomyopathy	21 (70)	10 (91)	19 (83)	14 (64)	16 (64)	28 (74)	108 (73)
	Congenital heart disease	0 (0)	0 (0)	0 (0)	1 (5)	3 (12)	1 (3)	5 (3)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
	Other	2 (7)	0 (0)	3 (13)	3 (14)	1 (4)	2 (5)	11 (7)
NYHA class	I	1 (3)	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	2 (1)
	II	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	2 (1)
	III	15 (50)	4 (36)	10 (43)	6 (27)	8 (32)	21 (55)	64 (43)
	IV	12 (40)	7 (64)	12 (52)	16 (73)	17 (68)	16 (42)	80 (54)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient in hospital pre-transplant	No	4 (13)	2 (18)	5 (22)	0 (0)	6 (24)	14 (37)	31 (21)
	Yes	25 (83)	9 (82)	18 (78)	22 (100)	19 (76)	24 (63)	117 (79)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)

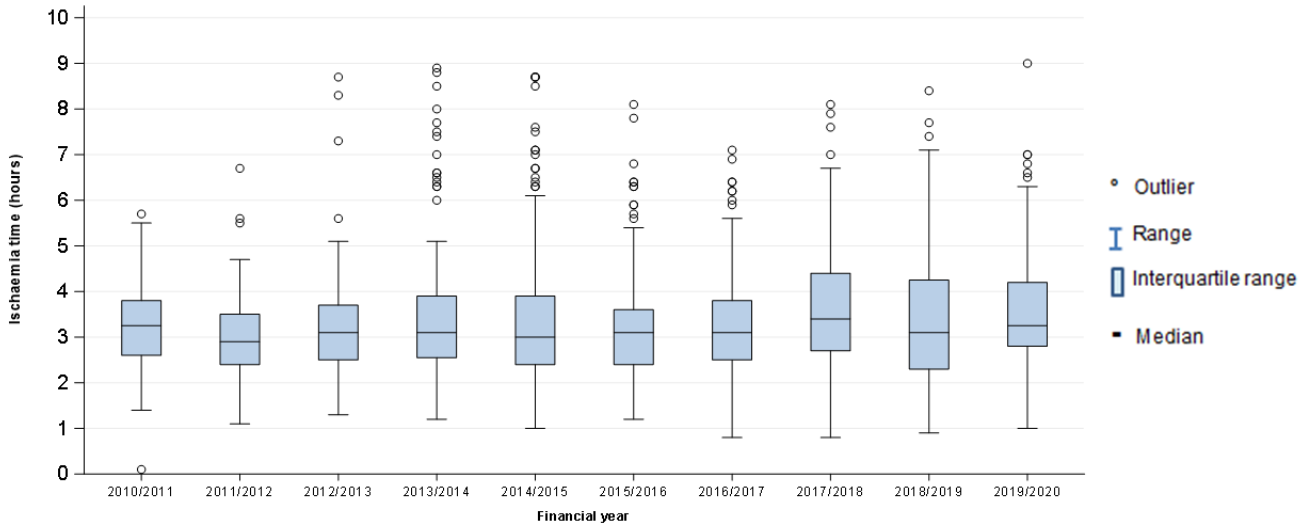
Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2019 to 31 March 2020, by centre		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
If in hospital, recipient on ventilator	No	24 (96)	9 (100)	17 (94)	22 (100)	16 (84)	24 (100)	112 (96)
	Yes	1 (4)	0 (0)	1 (6)	0 (0)	2 (11)	0 (0)	4 (3)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	1 (1)
If in hospital, recipient on VAD	None	16 (64)	8 (89)	13 (72)	16 (73)	13 (68)	16 (67)	82 (70)
	Left	2 (8)	0 (0)	3 (17)	3 (14)	4 (21)	0 (0)	12 (10)
	Right	0 (0)	0 (0)	1 (6)	0 (0)	0 (0)	1 (4)	2 (2)
	Both	6 (24)	1 (11)	1 (6)	3 (14)	1 (5)	7 (29)	19 (16)
	Missing	1 (4)	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	2 (2)
If in hospital, recipient on TAH	No	25 (100)	9 (100)	18 (100)	22 (100)	19 (100)	24 (100)	117 (99)
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
If in hospital, recipient on ECMO	No	23 (92)	9 (100)	15 (83)	22 (100)	15 (79)	24 (100)	108 (92)
	Yes	1 (4)	0 (0)	3 (17)	0 (0)	4 (21)	0 (0)	8 (7)
	Missing	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
If in hospital, recipient on inotropes	No	5 (20)	3 (33)	1 (6)	5 (23)	4 (21)	7 (29)	25 (21)
	Yes	20 (80)	6 (67)	17 (94)	17 (77)	14 (74)	17 (71)	91 (78)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	1 (1)
If in hospital, recipient on IABP	No	25 (100)	3 (33)	18 (100)	22 (100)	19 (100)	24 (100)	111 (95)
	Yes	0 (0)	6 (67)	0 (0)	0 (0)	0 (0)	0 (0)	6 (5)
Recipient CMV status	No	18 (60)	6 (55)	11 (48)	15 (68)	15 (60)	22 (58)	87 (58)
	Yes	12 (40)	5 (45)	12 (52)	7 (32)	9 (36)	15 (39)	60 (40)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	1 (3)	2 (1)
Recipient HCV status	No	29 (97)	11 (100)	23 (100)	22 (100)	24 (96)	38 (100)	147 (99)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	2 (1)
Recipient HBV status	No	30 (100)	11 (100)	23 (100)	22 (100)	24 (96)	38 (100)	148 (99)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
Recipient HIV status	No	30 (100)	11 (100)	23 (100)	22 (100)	25 (96)	38 (100)	148 (99)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
Recipient serum creatinine (umol/l)	Median (IQR)	88 (69, 119)	81 (76, 101)	84 (74, 119)	89 (74, 114)	98 (76, 130)	99 (80, 117)	92 (75, 117)
	Missing	1	0	0	0	0	0	1

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2019 to 31 March 2020, by centre		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Donor sex	Male	18 (60)	9 (82)	17 (74)	14 (64)	18 (72)	28 (74)	104 (70)
	Female	12 (40)	2 (18)	6 (26)	8 (36)	7 (28)	10 (26)	45 (30)
Donor ethnicity	White	28 (93)	10 (91)	20 (87)	18 (82)	23 (92)	36 (95)	135 (91)
	Non-white	2 (7)	0 (0)	3 (13)	4 (18)	2 (8)	2 (5)	13 (9)
	Missing	0 (0)	1 (9)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Donor age (years)	Median (IQR)	40 (25, 47)	32 (25, 45)	34 (23, 47)	36 (26, 49)	37 (27, 44)	33 (27, 39)	35 (26, 44)
	Missing	0	0	0	0	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	24 (23, 29)	24 (21, 27)	25 (22, 27)	24 (22, 26)	24 (21, 29)	26 (23, 29)	25 (22, 28)
	Missing	0	0	0	0	0	0	0
Donor cause of death	CVA	23 (77)	9 (82)	20 (87)	21 (95)	20 (80)	28 (74)	121 (81)
	Trauma	2 (7)	0 (0)	3 (13)	1 (5)	1 (4)	4 (11)	11 (7)
	Others	5 (17)	2 (18)	0 (0)	0 (0)	4 (16)	6 (16)	17 (11)
Donor hypotension	No	25 (83)	8 (73)	19 (83)	14 (64)	14 (56)	30 (79)	110 (74)
	Yes	3 (10)	2 (18)	4 (17)	8 (36)	7 (28)	7 (18)	31 (21)
	Missing	2 (7)	1 (9)	0 (0)	0 (0)	4 (16)	1 (3)	8 (5)
Donor past diabetes	No	30 (100)	11 (100)	23 (100)	22 (100)	25 (100)	38 (100)	149 (100)
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Donor past cardiothoracic disease	No	29 (97)	11 (100)	23 (100)	22 (100)	23 (92)	38 (100)	146 (98)
	yes	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	2 (1)
Donor past hypertension	No	28 (93)	10 (91)	22 (96)	21 (95)	22 (88)	37 (97)	140 (94)
	Yes	1 (3)	1 (9)	1 (4)	1 (5)	3 (12)	1 (3)	8 (5)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Donor past tumour	No	29 (97)	11 (100)	23 (100)	22 (100)	24 (96)	36 (95)	145 (97)
	Yes	1 (3)	0 (0)	0 (0)	0 (0)	1 (4)	2 (5)	4 (3)
Donor past smoker	No	11 (37)	2 (18)	10 (43)	11 (50)	12 (48)	10 (26)	56 (38)
	Yes	19 (63)	9 (82)	13 (57)	11 (50)	13 (52)	28 (74)	93 (62)
Total ischaemia time (hours)	Median (IQR)	3.4 (3.1, 4.8)	2.2 (1.4, 2.7)	5.2 (4.3, 5.8)	3.2 (2.6, 3.8)	3.1 (3.0, 3.6)	3.2 (2.7, 4.6)	3.4 (2.8, 4.5)
	Missing	1	1	0	0	0	0	2

5.3 Total ischaemia time, 1 April 2010 – 31 March 2020

Figure 5.7 shows [boxplots](#) of the total ischaemia time for [DBD](#) donor hearts transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. In cases where organ maintenance systems were used (15%) not all of this time duration is ischaemic, and no adjustment has been made for this. The national [median](#) total ischaemia time has remained relatively consistent over the last decade.

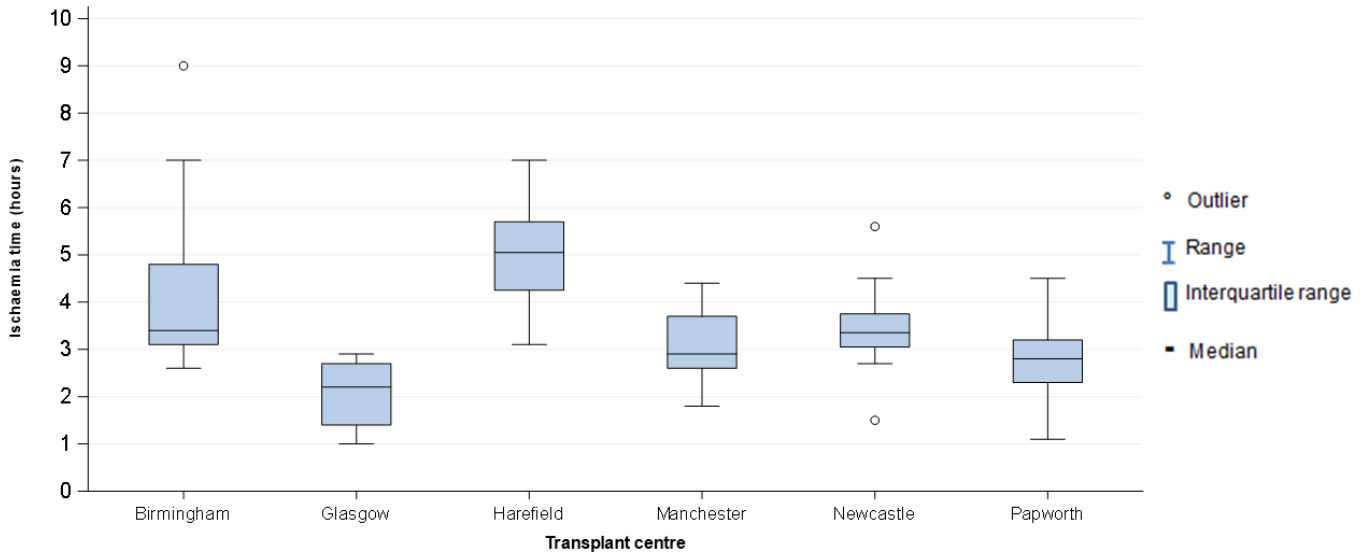
Figure 5.7 Boxplots of total ischaemia time for DBD donor hearts transplanted into adult recipients, by financial year, 1 April 2010 to 31 March 2020



Does not take into account use of donor organ maintenance systems which have been in use since 2013/2014

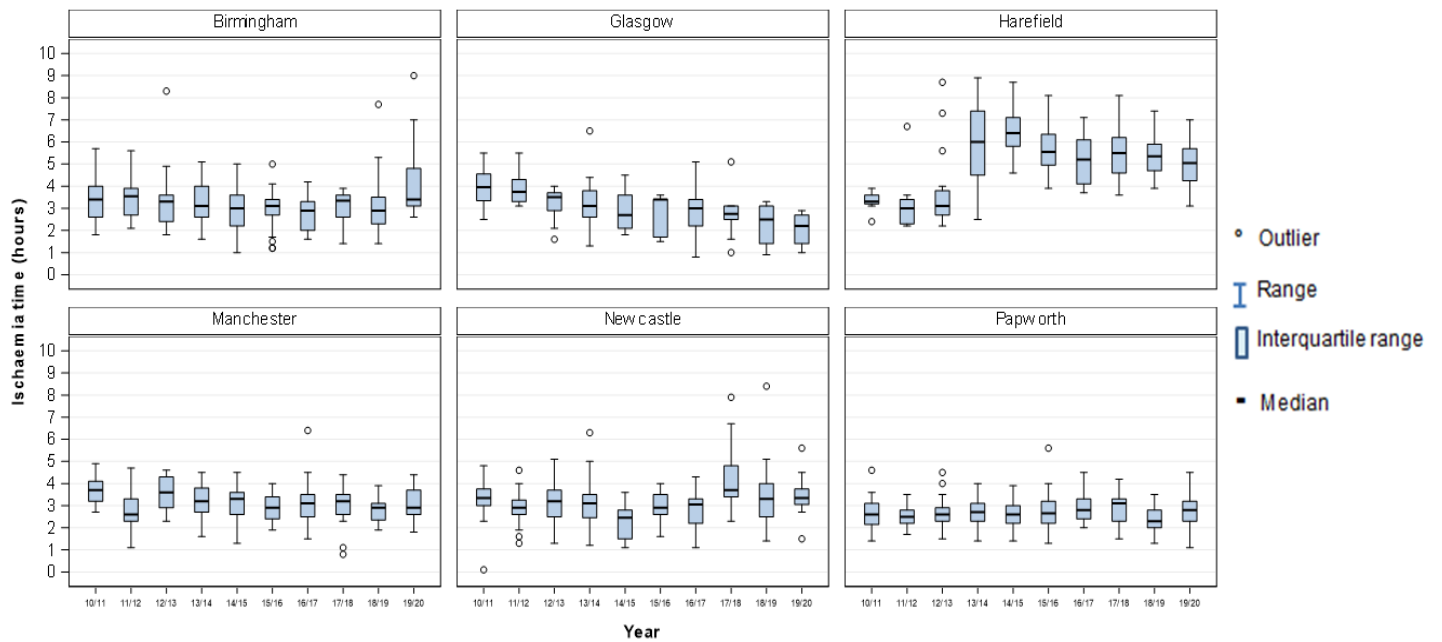
Figure 5.8 and Figure 5.9 show [boxplots](#) of total ischaemia time by centre in the latest financial year (2019/2020) and over the last 10 years, respectively. The increase in observed [median](#) total ischaemia time at Harefield from 2013/2014 onwards is explained by their increasing use of the Organ Care System (OCS); in 2019/2020, 100% of DBD hearts transplanted by Harefield used OCS compared with 0%-20% for other centres, who have a median of between 2.2 and 3.4 hours.

Figure 5.8 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre, 1 April 2019 to 31 March 2020



Includes time on the Organ Care System (OCS), where centres used the OCS in a variable proportion of transplants: Birmingham 20%, Glasgow 0%, Harefield 100%, Manchester 0%, Newcastle 0% and Papworth 0%

Figure 5.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre and financial year, 1 April 2010 to 31 March 2020



Includes time on the Organ Care System (OCS), where most centres used the OCS in a small proportion of transplants, except Harefield who used the OCS in the majority of transplants from 2013/2014 onwards

ADULT HEART TRANSPLANTATION

Post-Transplant Survival



6. Post-Transplant Survival

This section presents survival post adult heart transplantation. [Funnel plots](#) are used to compare the [risk-adjusted](#) survival rate at each centre with the national rate. The [unadjusted survival rates](#) are presented in the tables for reference, but these do not account for differences in the [case mix](#) at each centre. The [risk-adjusted](#) rates do account for these differences as much as possible and so provide a fairer comparison across centres. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A3.1](#).

The survival analyses exclude [multi-organ transplants](#) and include first time transplants only. Thirty-day, 90-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2015 to 31 March 2019 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2011 to 31 March 2015. [Survival rates](#) are presented by transplant centre in **Tables 6.1-6.4** and **Figures 6.1-6.4** as well as disease group in **Tables 6.5-6.6**. DCD heart transplants are excluded but separate tables (**Table 6.7** and **6.8**) at the end of this section provide [unadjusted survival rates](#) for the small number of DCD heart transplant recipients between 1 April 2015 and 31 March 2019.

6.1 Survival by centre

Table 6.1 and **Figure 6.1** show the 30-day post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 550 first adult [DBD](#) heart only transplants in the period 1 April 2015 to 31 March 2019. All of the centres' rates were statistically consistent with the national rate of survival which was 91.5%.

Table 6.1 30 day patient survival rates after first adult DBD heart transplant, by centre, 1 April 2015 to 31 March 2019					
Centre	Number of transplants	% 30 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	97	88.7	(80.5 - 93.6)	87.8	(78.0 - 93.3)
Glasgow	42	92.9	(79.5 - 97.6)	88.4	(64.1 - 96.3)
Harefield	97	84.5	(75.7 - 90.4)	89.6	(82.8 - 93.8)
Manchester	91	95.6	(88.7 - 98.3)	93.7	(83.3 - 97.6)
Newcastle	90	92.2	(84.4 - 96.2)	94.4	(88.2 - 97.3)
Papworth	133	94.7	(89.3 - 97.5)	93.1	(85.5 - 96.7)
UK	550	91.5	(88.8 - 93.5)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 6.1 Risk-adjusted 30 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2015 to 31 March 2019

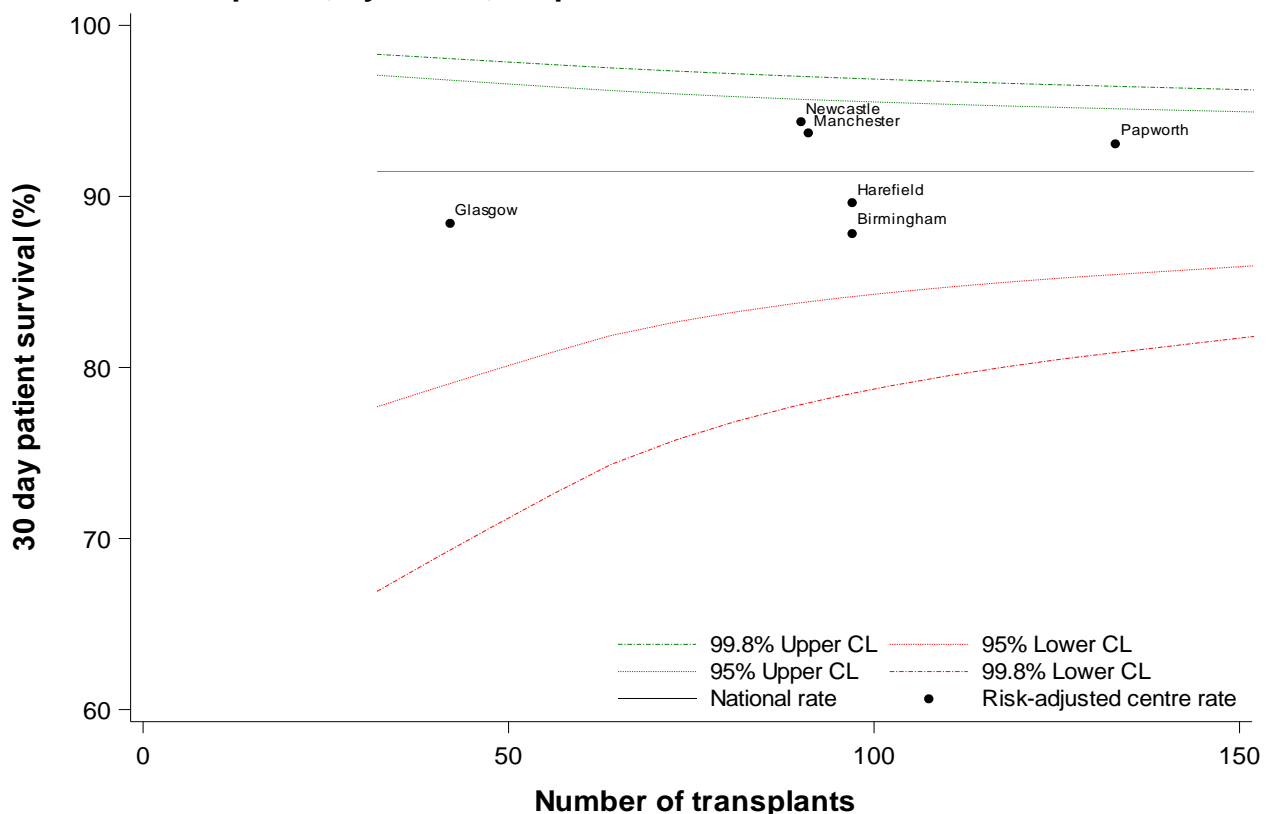


Table 6.2 and **Figure 6.2** show the 90-day post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 550 first adult DBD heart only transplants in the period 1 April 2015 to 31 March 2019. All of the centres' rates were statistically consistent with the national rate of survival which was 87.3%.

Table 6.2 90 day patient survival after first adult DBD heart transplant, by centre, 1 April 2015 and 31 March 2019					
Centre	Number of transplants	% 90 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	97	83.5	(74.5 - 89.5)	80.8	(68.7 - 88.2)
Glasgow	42	90.5	(76.6 - 96.3)	86.5	(64.0 - 94.9)
Harefield	97	76.3	(66.5 - 83.6)	85.0	(77.4 - 90.0)
Manchester	91	92.3	(84.5 - 96.3)	89.2	(77.3 - 94.9)
Newcastle	90	88.9	(80.3 - 93.9)	91.4	(83.9 - 95.3)
Papworth	133	92.5	(86.5 - 95.9)	90.3	(82.0 - 94.8)
UK	550	87.3	(84.2 - 89.8)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 6.2 Risk-adjusted 90 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2015 to 31 March 2019

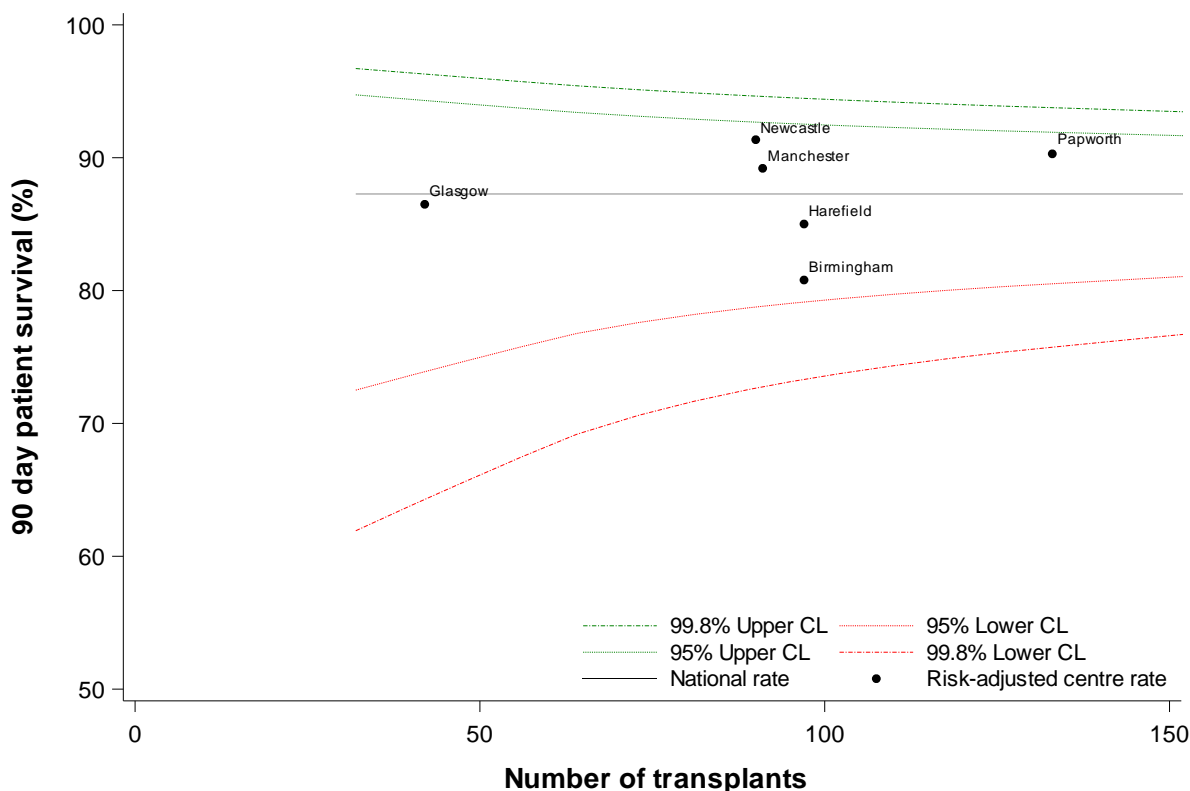


Table 6.3 and **Figure 6.3** show the 1-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 550 first adult DBD heart only transplants in the period 1 April 2015 to 31 March 2019. The national rate of survival was 83.2%. None of the centres' rates were statistically significantly different to the national rate, as their rates lie within the funnel.

Table 6.3 1 year patient survival rates after first adult DBD heart transplant, by centre, 1 April 2015 to 31 March 2019					
Centre	Number of transplants	% 1 year survival (95% CI)			
		<u>Unadjusted</u>		<u>Risk-adjusted</u>	
Birmingham	97	80.2	(70.8 - 86.9)	77.1	(64.1 - 85.4)
Glasgow	42	90.5	(76.6 - 96.3)	86.5	(63.9 - 94.9)
Harefield	97	70	(59.7 - 78.1)	81.1	(72.7 - 86.8)
Manchester	91	86.7	(77.8 - 92.2)	83.0	(70.0 - 90.3)
Newcastle	90	84.4	(75.2 - 90.5)	86.7	(77.6 - 92.1)
Papworth	133	89.5	(82.9 - 93.6)	86.7	(77.6 - 92.1)
UK	550	83.2	(79.8 - 86.1)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 6.3 Risk-adjusted one-year patient survival rates for adult DBD heart transplants, by centre, 1 April 2015 to 31 March 2019

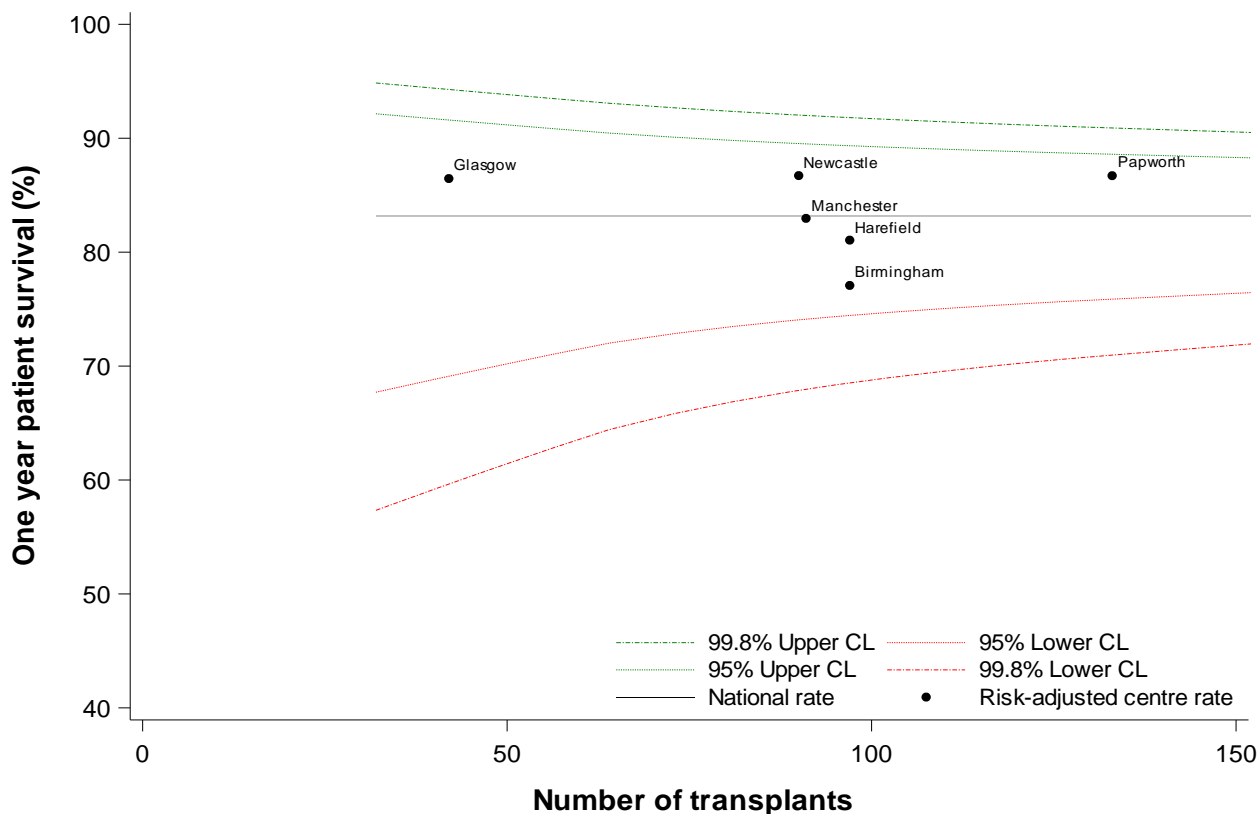
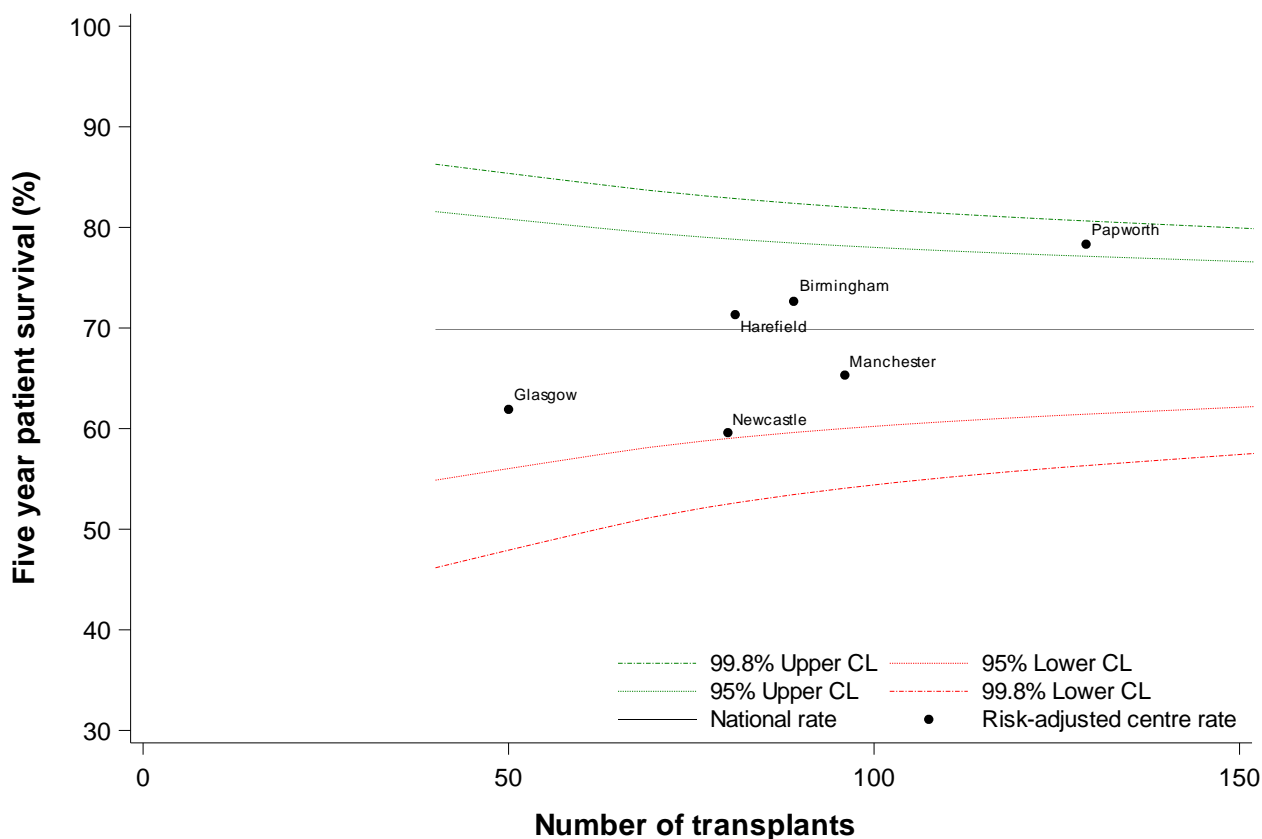


Table 6.4 and **Figure 6.4** show the 5-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 525 first adult DBD heart only transplants in the period 1 April 2011 to 31 March 2015. The national rate of survival was 69.9%. The rate for Papworth lies between the upper 95% and 99.8% confidence limits, indicating that it may be significantly higher than the national rate.

Table 6.4 5 year patient survival rates after first adult DBD heart transplant, by centre 1 April 2011 to 31 March 2015					
Centre	Number of transplants	% 5 year survival (95% CI)			
		<u>Unadjusted</u>		<u>Risk-adjusted</u>	
Birmingham	89	71.1	(60.3 - 79.5)	72.7	(59.5 - 81.5)
Glasgow	50	61.8	(46.8 - 73.7)	61.9	(40.3 - 75.7)
Harefield	81	72.7	(61.5 - 81.1)	71.3	(56.5 - 81.1)
Manchester	96	65.6	(55.2 - 74.2)	65.3	(51.2 - 75.3)
Newcastle	80	64.9	(53.3 - 74.3)	59.6	(41.5 - 72.1)
Papworth	129	76.7	(68.4 - 83.1)	78.3	(69.0 - 84.8)
UK	525	69.9	(65.7 - 73.6)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 6.4 Risk-adjusted five year patient survival rates for adult DBD heart transplants, by centre, 1 April 2011 to 31 March 2015



6.2 Survival by disease group

Tables 6.5 and 6.6 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 1 year and 5 years post-transplant, respectively. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A3.1](#), except centre was used in place of disease group. There were no statistically significant differences in [survival rates](#) across disease groups.

Table 6.5 1 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2015 and 31 March 2019

Disease group	Number of transplants	% 1 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Congenital heart disease	39	74.4	(57.6 - 85.3)	69.1	(42.6 - 83.4)
Coronary heart disease	68	85.2	(74.3 - 91.8)	81.6	(65.9 - 90.1)
Dilated cardiomyopathy	314	84.9	(80.4 - 88.4)	86.5	(82.0 - 89.8)
Other	129	80.6	(72.6 - 86.4)	77.9	(67.2 - 85.0)
UK	550	83.2	(79.8 - 86.1)		

Table 6.6 5 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2011 and 31 March 2015

Disease group	Number of transplants	% 5 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Congenital heart disease	39	68.7	(51.4 - 80.9)	69.5	(46.3 - 82.7)
Coronary heart disease	84	65.3	(54.1 - 74.5)	70.1	(57.0 - 79.2)
Dilated cardiomyopathy	305	71.6	(66.2 - 76.3)	70.9	(64.0 - 76.4)
Other	97	69	(58.7 - 77.2)	66.5	(52.1 - 76.6)
UK	525	69.9	(65.7 - 73.6)		

6.3 Survival by VAD status

Tables 6.7 presents [unadjusted survival rates](#) by mechanical circulatory support (MCS) status at time of transplant, at 30 days, 90 days and 1 year post-transplant, respectively. Short-term MCS includes CentriMag, percutaneous [VADs](#) and extracorporeal membrane oxygenation and long-term MCS includes left-, right- and bi- VADs and total artificial hearts. In this [unadjusted](#) analysis there was a significant difference between survival rates across MCS status (log-rank $p < 0.0001$), with patients not on support at time of transplant having superior survival.

Table 6.7 Unadjusted patient survival rates after first adult DBD heart transplant, by mechanical support status, 1 April 2015 and 31 March 2019

Mechanical support status	Number of transplants	% 30 day survival (95% CI)		% 90 day survival (95% CI)		% 1 year survival (95% CI)	
		Unadjusted		Unadjusted		Unadjusted	
Short-term support	74	89.2	(79.5 - 94.4)	83.8	(73.2 - 90.4)	77.0	(65.7 - 85)
Long-term support	90	80.0	(70.2 - 86.9)	73.3	(62.9 - 81.3)	69.9	(59.3 - 78.3)
No support	386	94.6	(91.8 - 96.4)	91.2	(87.9 - 93.6)	87.5	(83.7 - 90.4)
UK	550	91.5	(88.8 - 93.5)	87.3	(84.2 - 89.8)	83.2	(79.8 - 86.1)

6.4 Survival post DCD heart transplant

Tables 6.8 - 6.10 present short-term patient [survival rates](#) following DCD heart only transplant, by centre and nationally. During the time period 1 April 2015 to 31 March 2019 transplants were performed by four of the six adult centres, and there were 13 deaths within 1 year.

Table 6.8 30 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2015 and 31 March 2019

Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Harefield	16	1	93.8	(63.2 - 99.1)
Manchester ¹	7	0	-	-
Newcastle ¹	1	0	-	-
Papworth	63	1	98.4	(89.3 – 99.8)
UK	87	2	97.7	(91.1 – 99.4)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

This table excludes 1 patient at Harefield who received a DCD heart transplant as a re-graft and who died within 30 days of DCD heart transplant

Table 6.9 90 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2015 and 31 March 2019

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Harefield ¹	16	3	81.3	(52.5 - 93.5)
Manchester ¹	7	1	-	-
Newcastle ¹	1	0	-	-
Papworth	63	4	93.7	(84.0 - 97.6)
UK	87	8	90.8	(82.5 - 95.3)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

This table excludes 1 patient at Harefield who received a DCD heart transplant as a re-graft and who died within 30 days of DCD heart transplant

Table 6.10 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2015 and 31 March 2019

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Harefield ¹	16	5	68.8	(40.5 - 85.6)
Manchester ¹	7	2	-	-
Newcastle ¹	1	0	-	-
Papworth	63	6	90.5	(80.0 – 95.6)
UK	87	13	85.1	(75.7 - 91.0)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

This table excludes 1 patient at Harefield who received a DCD heart transplant as a re-graft and who died within 30 days of DCD heart transplant

ADULT HEART TRANSPLANTATION

Survival from Listing



7. Survival from Listing

Survival from listing was analysed for patients 18 years or older registered for the first time for a heart transplant between 1 January 2008 and 31 December 2019. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A2.1](#).

One and five year [risk-adjusted survival rates](#) from the point of heart transplant listing are shown as [funnel plots](#) in **Figures 7.1** and **7.2** respectively. These rates are also shown in **Table 7.1**. Note that all rates (at 1 and 5 years) were calculated from the same cohort of patients, and the number of patients remaining at risk of death after each time horizon (i.e. not already censored or deceased) is included in **Table 7.1** for reference.

Manchester's and Papworth's survival rates fell above the upper 99.8% [confidence limits](#) at one and five years respectively, indicating significantly high survival from listing at these time points. Newcastle's five year survival rate fell below the lower 99.8% [confidence limits](#), indicating significantly low survival from listing at this time point. There was also some evidence of lower survival at one year at Newcastle and Birmingham, and a higher survival at five years at Papworth and Manchester, compared with the national rates.

Table 7.1 Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2008 to 31 December 2019							
Centre	Number at risk ¹ at day 0	One year			Five year		
		Survival rate (%)	(95% CI)	Number at risk ¹	Survival rate (%)	(95% CI)	Number at risk ¹
Birmingham	372	79.1	(73.7 - 83.4)	227	61.7	(54.0 - 68.2)	89
Glasgow	193	84.6	(78.6 - 88.9)	126	67.8	(58.6 - 74.9)	42
Harefield	411	84.7	(80.6 - 87.9)	282	65.1	(58.5 - 70.7)	93
Manchester	338	90.6	(86.6 - 93.4)	261	72.2	(65.8 - 77.5)	101
Newcastle	429	79.7	(74.8 - 83.6)	305	55.1	(47.2 - 61.8)	106
Papworth	533	87.4	(84.1 - 90.0)	392	73.7	(68.5 - 78.0)	166
UK	2276	84.5	(82.8 - 85.9)	1593	66.2	(63.7 - 68.5)	597

Centre has reached the lower 99.8% confidence limit

Centre has reached the lower 95% confidence limit

Centre has reached the upper 95% confidence limit

Centre has reached the upper 99.8% confidence limit

¹ Number of patients with reported follow-up beyond this time point

Figure 7.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2008 – 31 December 2019

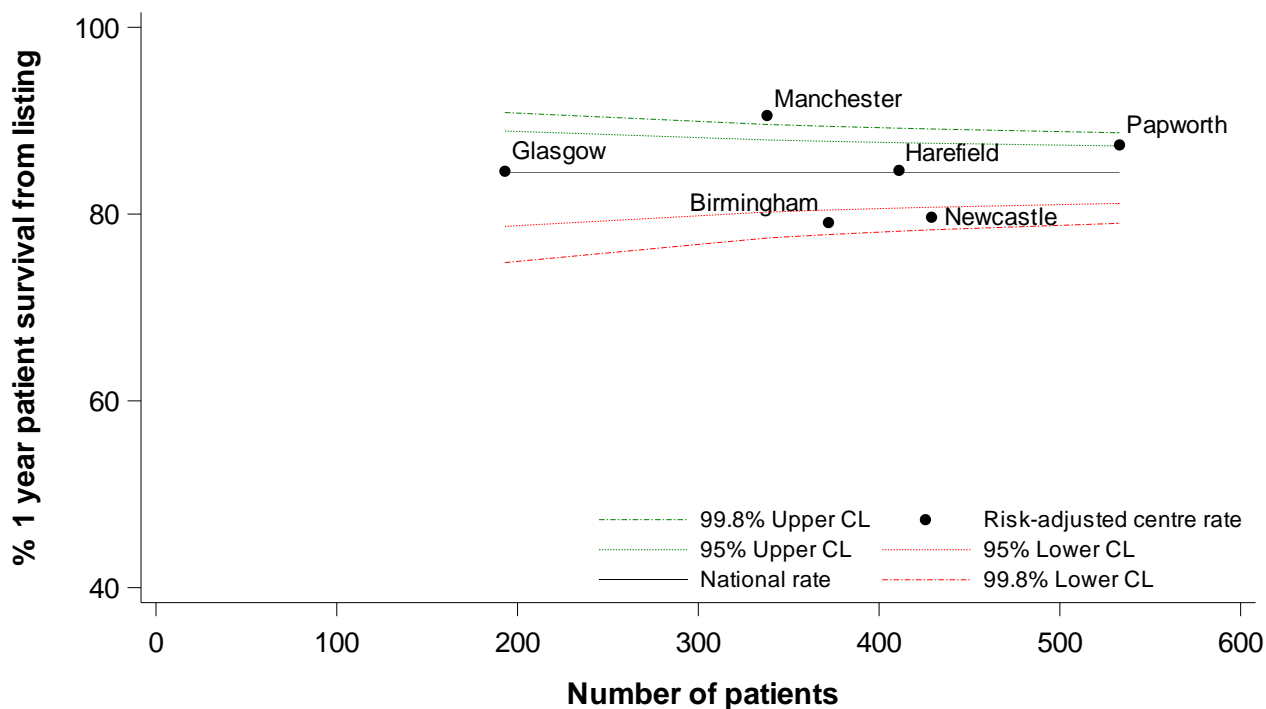
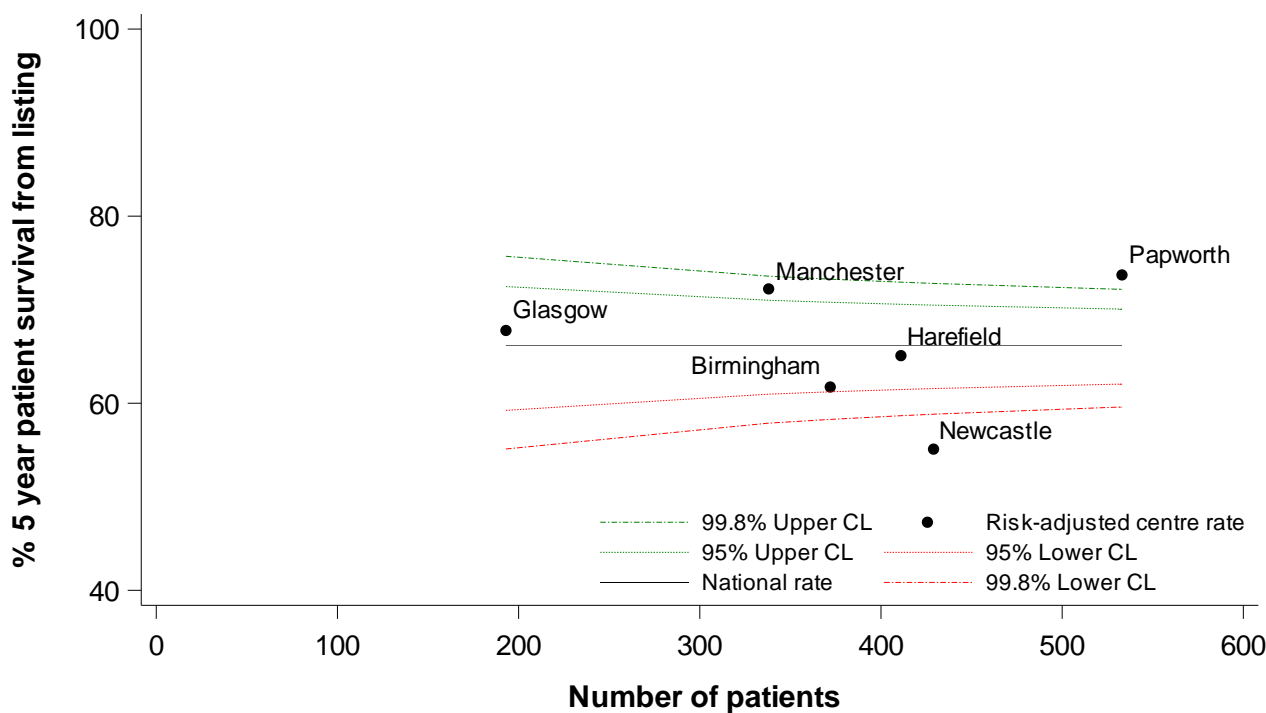


Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2008 – 31 December 2019



ADULT HEART TRANSPLANTATION

Form Return Rates



8. Adult heart form return rates, 1 January – 31 December 2019

Form return rates are reported in **Table 8.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult heart transplants between 1 January and 31 December 2019 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. All active centres have a 98% or greater return rate for this period.

Table 8.1 Form return rates for adult heart transplants, 1 January 2019 to 31 December 2019

Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up	
	No. required	% returned	No. required	% returned	No. required	% returned	No. required	% returned
Birmingham Queen Elizabeth Hospital	31	100	26	100	18	100	235	98
Royal Bournemouth General Hospital	-	-	-	-	-	-	1	100
Glasgow Golden Jubilee Hospital	9	100	13	100	7	100	147	99
Harefield Hospital	22	100	25	100	27	100	518	99
Manchester Wythenshawe Hospital	22	100	17	100	19	100	252	99
Newcastle Freeman Hospital	27	100	21	100	19	100	306	100
Oxford, John Radcliffe Hospital	-	-	-	-	-	-	1	0
Royal Papworth Hospital	50	100	46	100	42	100	599	99
Plymouth, Derriford Hospital	-	-	-	-	-	-	1	0
Sheffield Northern General Hospital	-	-	-	-	-	-	45	93
Truro, Royal Cornwall Hospital	-	-	-	-	-	-	1	100
Overall	161	100	148	100	132	100	2106	99

ADULT LUNG TRANSPLANTATION

Transplant List



9.1 Adult lung and heart-lung transplant list as at 31 March, 2011 – 2020

Figure 9.1 shows the number of adult patients on the lung and heart-lung transplant lists at 31 March each year between 2011 and 2020 split by urgency status of the patient. The number of patients on the active non-urgent lung transplant list has increased since 2011, reaching 346 on 31 March 2020. The number of patients on the heart-lung list has remained fairly stable throughout the period. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2020, there were no adult patients on either the urgent or super-urgent lists.

Figure 9.1 Number of adult patients on the lung and heart-lung transplant lists at 31 March each year

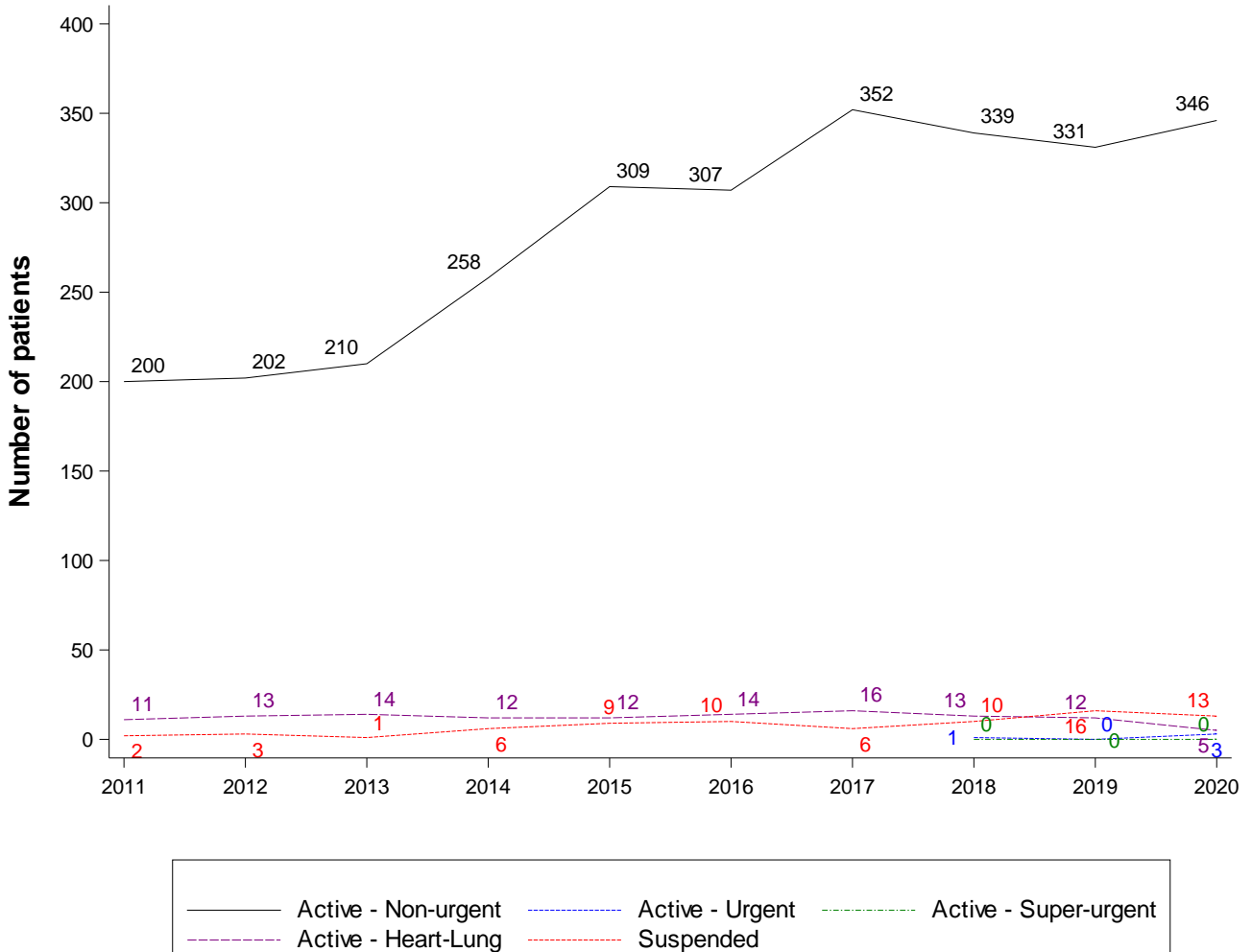


Figure 9.2 shows the number of adult patients on the [active lung and heart-lung transplant lists](#) on 31 March 2020 by centre. In total, there were 354 adult patients waiting, including 5 patients waiting for a heart-lung transplant. Newcastle had the highest number of patients on the transplant list while Papworth had the lowest.

Figure 9.2 Number of adult patients on the active lung and heart-lung transplant lists at 31 March 2020, by centre

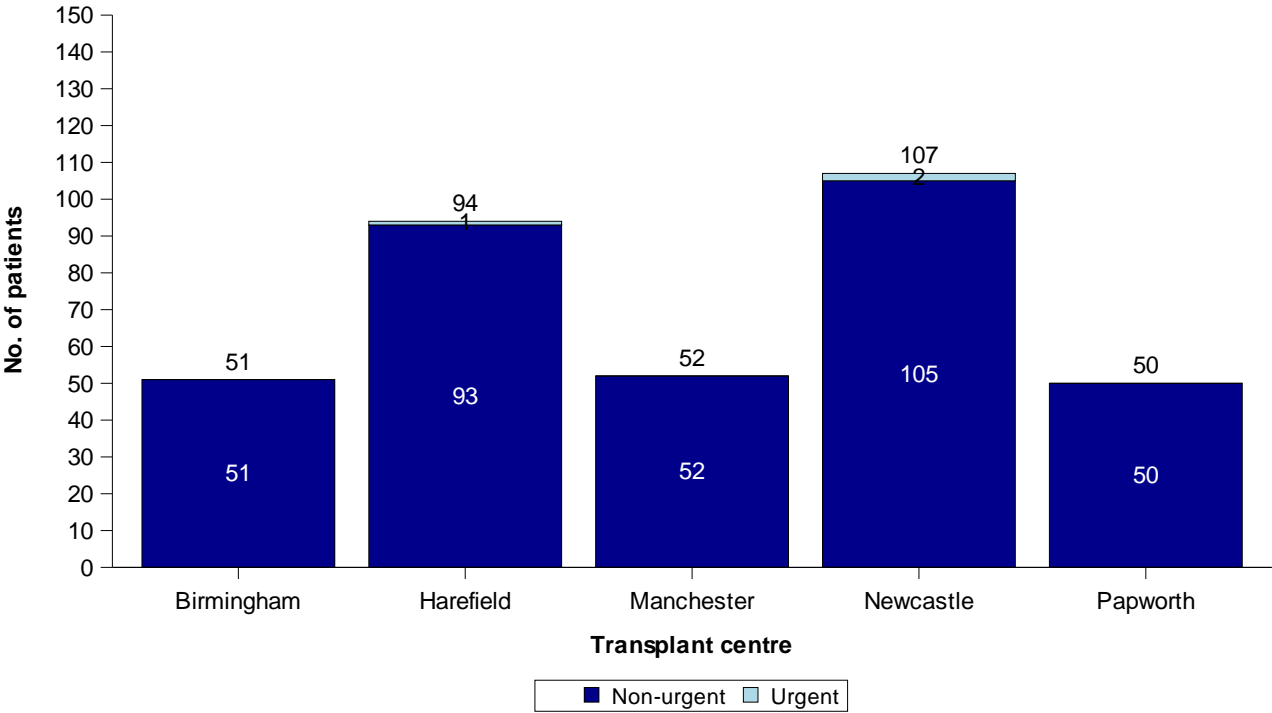
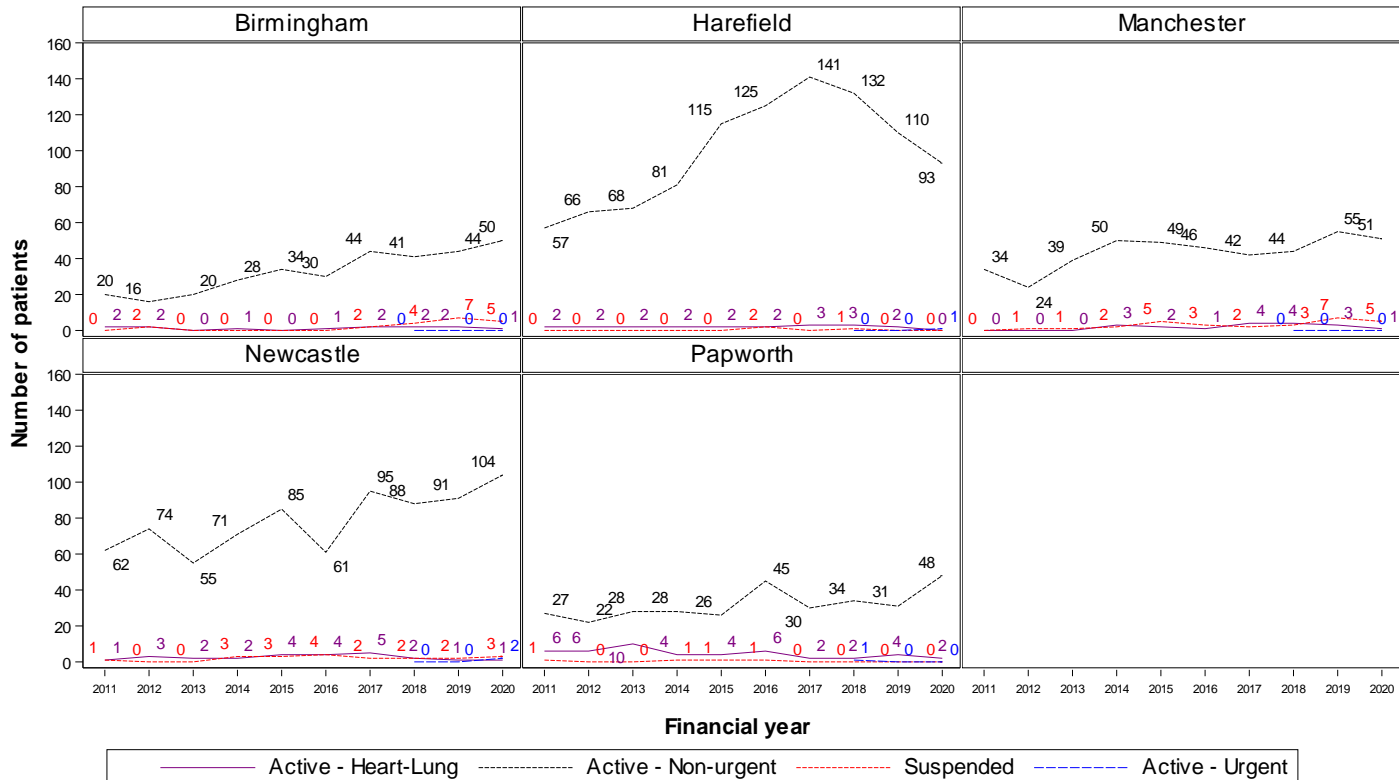


Figure 9.3 shows the trend over time in the number of adult patients on the lung transplant list at 31 March each year across centre. Harefield have experienced a marked increase in their lung list since 2011 compared with other centres, however in the last three years it has decreased.

Figure 9.3 Number of adult patients on the lung transplant list at 31 March each year for the last 10 years, by centre



9.2 Demographic characteristics, 1 April 2019 – 31 March 2020

There were 270 adult patient registrations onto the lung or heart-lung transplant lists between 1 April 2019 and 31 March 2020. Demographic characteristics of these patients are shown by centre and overall in **Table 9.1**. Nationally, 58% of patients were male and the [median](#) age was 54 years. Note that there were 25 urgent lung registrations and 2 super-urgent lung registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

Table 9.1 Demographic characteristics of adult patients registered onto the lung transplant list between 1 April 2019 and 31 March 2020, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		40 (100)	64 (100)	32 (100)	73 (100)	61 (100)	270 (100)
Highest urgency on the lung list during registration	Non-urgent	37 (93)	60 (94)	30 (94)	62 (85)	54 (89)	243 (90)
	Urgent	3 (8)	3 (5)	2 (6)	10 (14)	7 (11)	25 (9)
	Super-urgent	0 (0)	1 (2)	0 (0)	1 (1)	0 (0)	2 (1)
Recipient sex	Male	23 (58)	37 (58)	20 (63)	42 (58)	34 (56)	156 (58)
	Female	16 (40)	27 (42)	12 (38)	31 (42)	27 (44)	113 (42)
	Missing	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0)
Recipient ethnicity	White	33 (83)	48 (75)	30 (94)	73 (100)	56 (92)	240 (89)
	Non-white	7 (18)	16 (25)	2 (6)	0 (0)	5 (8)	30 (11)
Recipient age (years)	Median (IQR)	55 (45, 60)	44 (29, 55)	54 (45, 59)	58 (47, 62)	54 (47, 59)	54 (42, 59)
	Missing	0	0	0	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	6 (15)	23 (36)	8 (25)	13 (18)	3 (5)	53 (20)
	Fibrosing lung disease	20 (50)	13 (20)	7 (22)	34 (47)	19 (31)	93 (34)
	COPD and emphysema	6 (15)	19 (30)	14 (44)	14 (19)	14 (23)	67 (25)
	Primary pulmonary hypertension	3 (8)	2 (3)	0 (0)	4 (5)	0 (0)	9 (3)
	Other	4 (10)	6 (9)	3 (9)	8 (11)	25 (41)	46 (17)
	Missing	1 (3)	1 (2)	0 (0)	0 (0)	0 (0)	2 (1)
Smoker	No	40 (100)	63 (98)	32 (100)	73 (100)	60 (98)	268 (99)
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (0)
	Missing	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	1 (0)
Lung function - FEV1 (litres)	Median (IQR)	1.34 (0.89, 1.74)	0.96 (0.55, 1.42)	0.71 (0.56, 1.45)	1.21 (0.73, 1.65)	0.99 (0.78, 1.49)	1.06 (0.67, 1.63)
	Missing	2	3	1	3	2	11
Lung function – FVC (litres)	Median (IQR)	1.93 (1.49, 2.43)	2.00 (1.55, 2.65)	2.25 (1.79, 2.82)	1.79 (1.42, 2.61)	1.86 (1.34, 2.70)	1.96 (1.44, 2.63)
	Missing	2	3	1	5	1	12

9.3 Post-registration outcomes, 1 April 2016 – 31 March 2017

The registration outcomes of adult patients listed for a lung transplant between 1 April 2016 and 31 March 2017 are summarised nationally in **Figure 9.4** and by centre in **Figure 9.5**. The possible outcomes for patients on the list include receiving a transplant, removal from the list, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be “transplanted”.

Nationally, within six months of registration, 26% of lung patients had been transplanted and 11% had died. Three years after listing, 47% have been transplanted and 21% had died. Note that the urgent and super-urgent lung allocation schemes were introduced in May 2017 and a small number of patients in this cohort were moved to these new lists after this date. By centre, within 1 year of registration, the proportion transplanted ranged from 23% at Newcastle to 53% at both Manchester and Papworth. Removals from the list were predominantly due to deteriorating condition.

Figure 9.4 Post-registration outcome for 330 lung only registrations made in the UK, 1 April 2016 to 31 March 2017

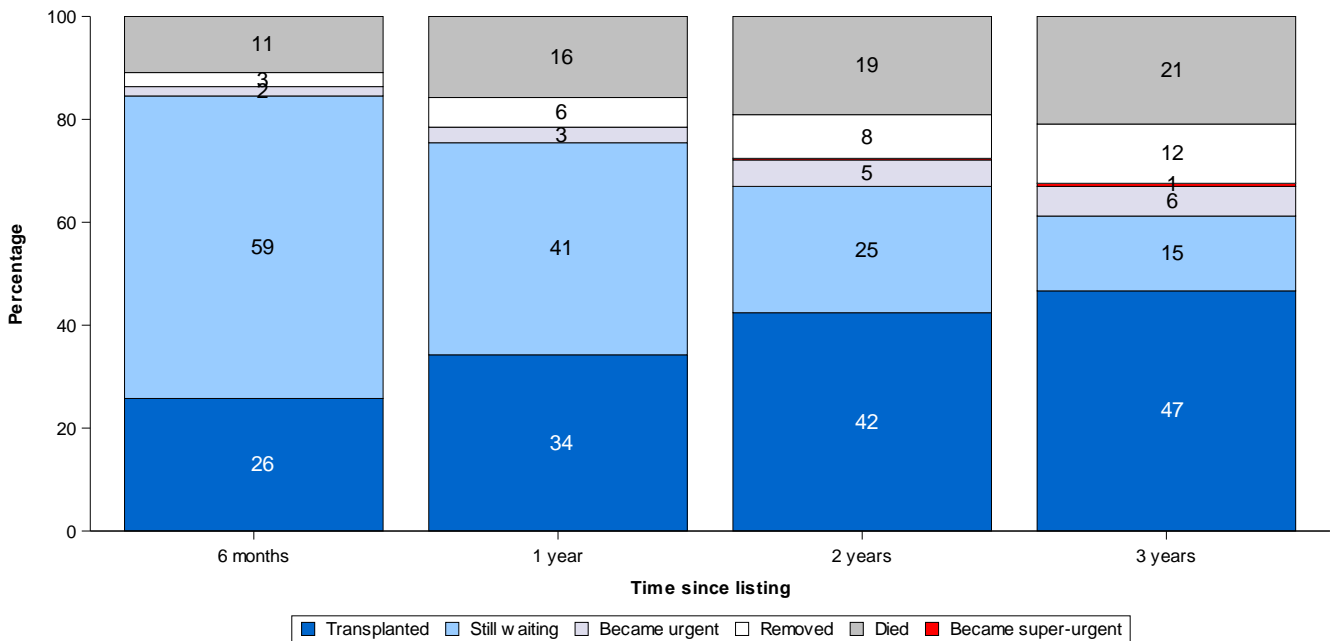
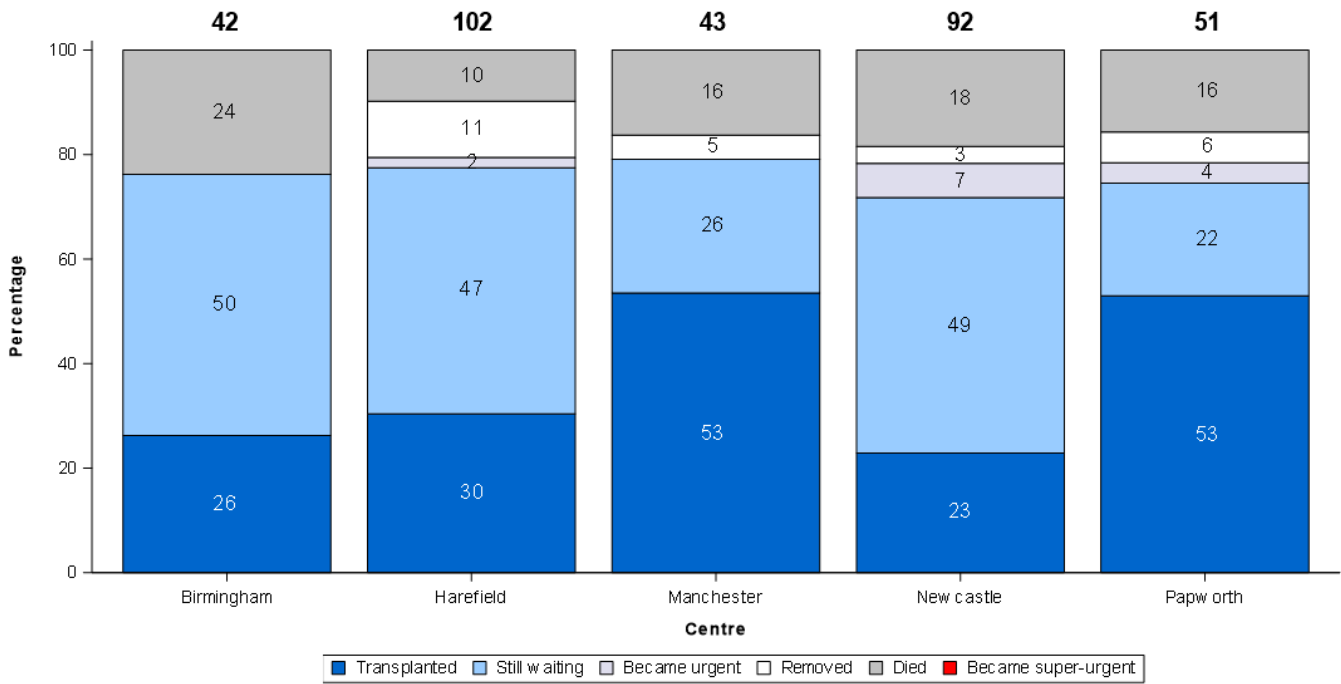


Figure 9.5 1 year registration outcomes by centre, for lung only registrations made in the UK, 1 April 2016 to 31 March 2017



9.4 Median waiting time to transplant, 1 April 2014 - 31 March 2017

The [median](#) waiting time to lung transplant from registration for adult patients is shown in **Figure 9.6** and **Table 9.2**. This is estimated for patients registered on the lung only transplant list between 1 April 2014 and 31 March 2017 using the [Kaplan Meier](#) method (before the introduction of the super-urgent and urgent lung allocation schemes in May 2017 but for patients that were moved to these lists after May 2017 this waiting time is included). The national [median](#) waiting time was 422 days and ranged from 212 days at Papworth to 617 days at Newcastle (log-rank $p < 0.0001$).

Figure 9.6 Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2014 and 31 March 2017, by centre

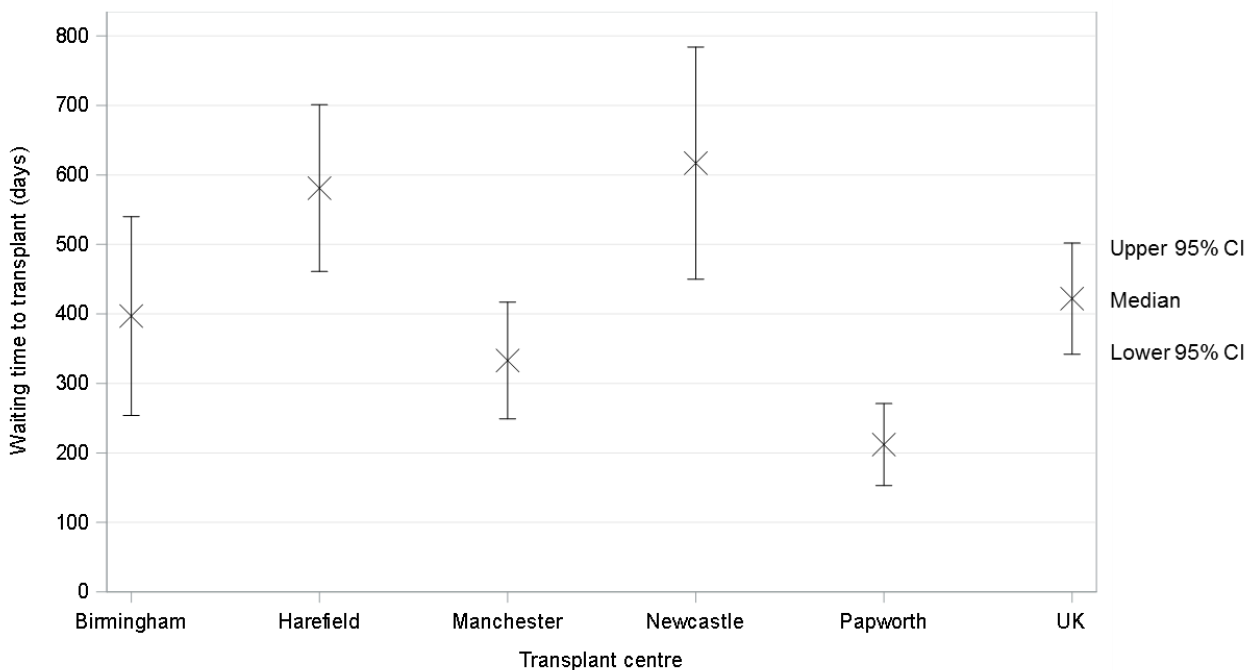


Table 9.2 Median active waiting time to lung transplant for adult patients registered on the transplant list, by centre, 1 April 2014 to 31 March 2017

Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Birmingham	118	397	254 - 540
Harefield	284	581	461 - 701
Manchester	113	333	249 - 417
Newcastle	194	617	450 - 784
Papworth	169	212	153 - 271
UK	878	422	342 - 502

The [median](#) waiting time to lung transplant for adult patients is also considered by blood group. This is shown in **Figure 9.7** and **Table 9.3**. Blood group O patients have the longest average wait (614 days) compared with the other blood groups (log-rank $p < 0.0001$).

Figure 9.7 Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2014 and 31 March 2017, by blood group

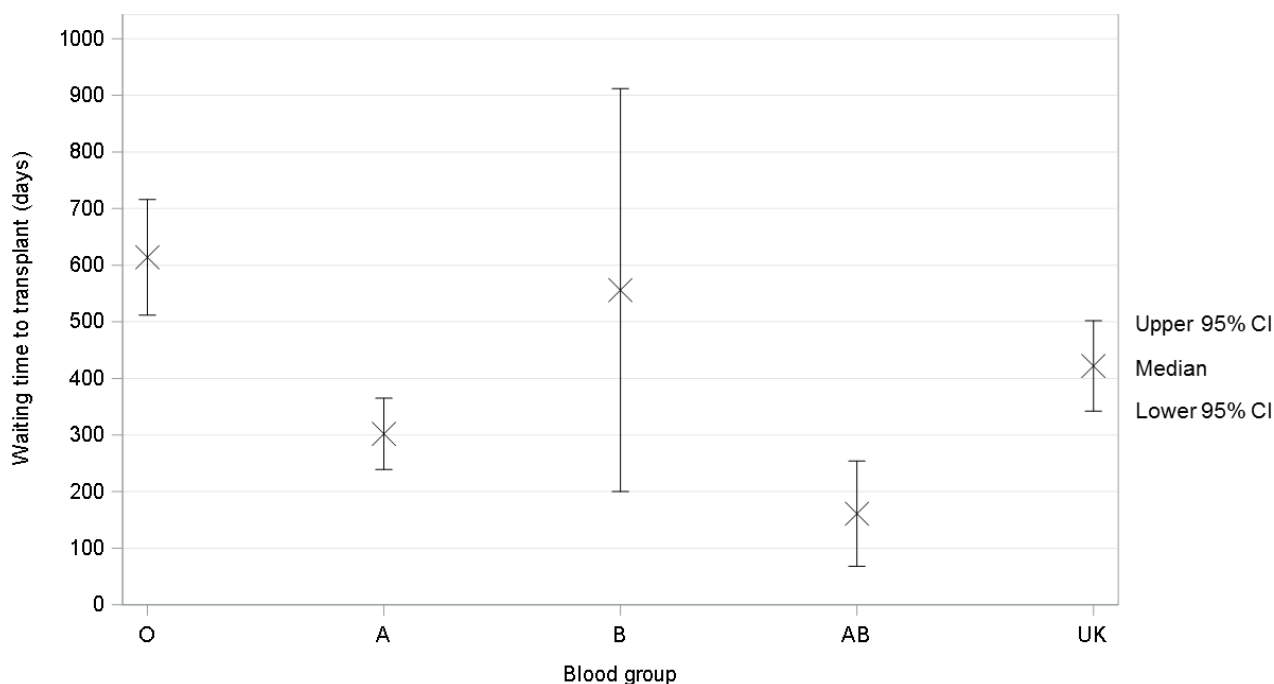


Table 9.3 Median active waiting time to lung transplant for adult patients registered on the transplant list, by blood group, 1 April 2014 to 31 March 2017			
Blood group	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
A	374	302	239 - 365
AB	32	161	68 - 254
B	81	556	200 - 912
O	391	614	512 - 716
UK	878	422	342 - 502

ADULT LUNG TRANSPLANTATION

Response to Offers



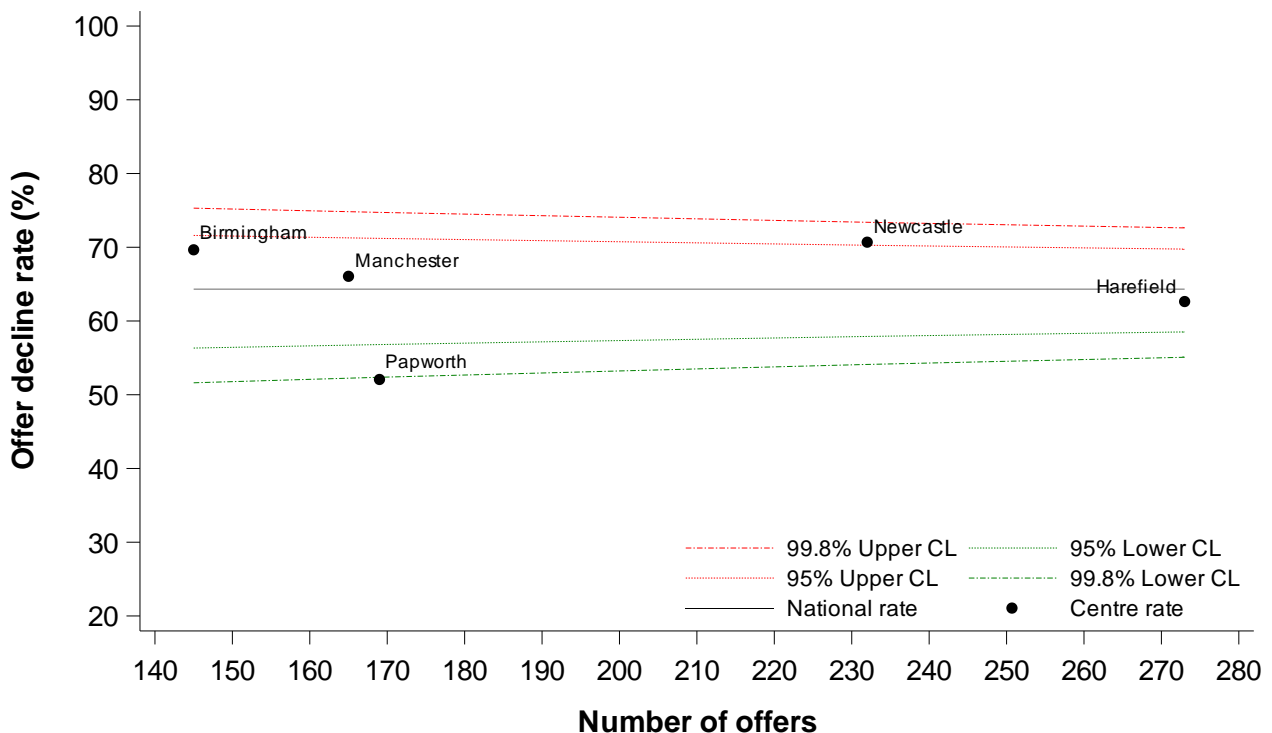
10. Response to Offers

This section presents an analysis of adult DBD donor lung offer decline rates. This only considers offers of bilateral lungs between 1 April 2017 and 31 March 2020 that were eventually transplanted and excludes all fast track offers. A bilateral lung offer is counted as accepted if either both the lungs were accepted or just a single lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lung(s) is/are declined as well as cases where both the heart and lung(s) are declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. No response to a group offer is considered an assumed decline. To account for this in the analysis of non-urgent offers post-22 June 2017, any centre who is ranked above the accepting centre in the allocation sequence for that donor is assumed to have declined the lungs.

Figure 10.1 compares individual centre decline rates with the national rate using [funnel plots](#). The offer decline rate for Newcastle is above the higher 95% [confidence limit](#), giving some evidence to suggest a higher decline rate compared with the national rate. The decline rate for Papworth lies below the lower 99.8% confidence interval indicating a significantly lower rate than the national rate. All offer decline rates for other centres lie between the upper and lower 95% [confidence limit](#), indicating no evidence of a significantly different decline rate compared with the national rate.

Figure 10.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2017 to 31 March 2020



ADULT LUNG TRANSPLANTATION

Transplants



11.1 Adult lung and heart-lung transplants, 1 April 2010 – 31 March 2020

Figure 11.1 and **11.2** show the number of adult lung transplants performed per year over the last ten years, by donor type, nationally and by centre, respectively. The number of transplants increased over the first half of the period, reaching a peak of 210 in 2013/2014. The number has since fallen (except in 2017/2018 which was another peak year), with only 156 transplants last year. **Figure 11.2** shows that only Newcastle and Manchester performed more transplants in 2019/2020 compared with the previous year. Last year DCD lung transplantation represented approximately 21% of the total activity. Last year's activity is shown by centre and donor type in **Figure 11.3**. The highest number of transplants were performed by Papworth.

Figure 11.1 Number of adult lung transplants in the UK, by financial year and donor type, 1 April 2010 to 31 March 2020

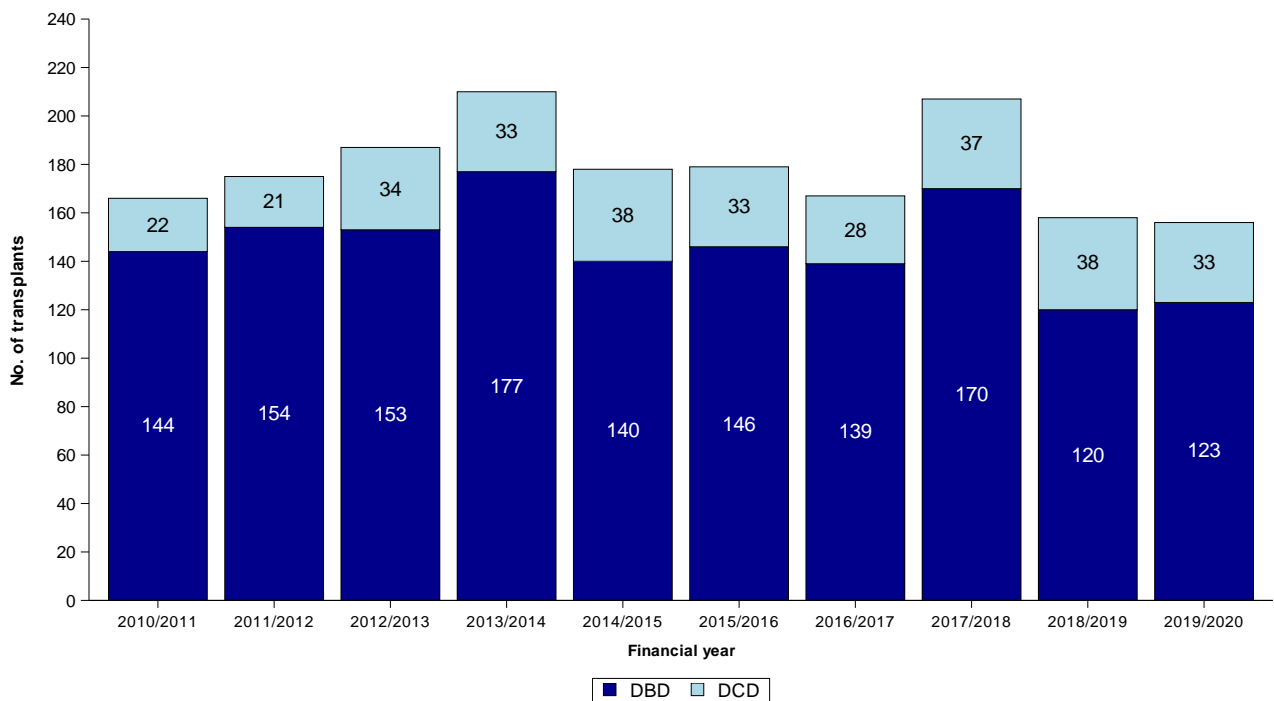


Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2010 to 31 March 2020

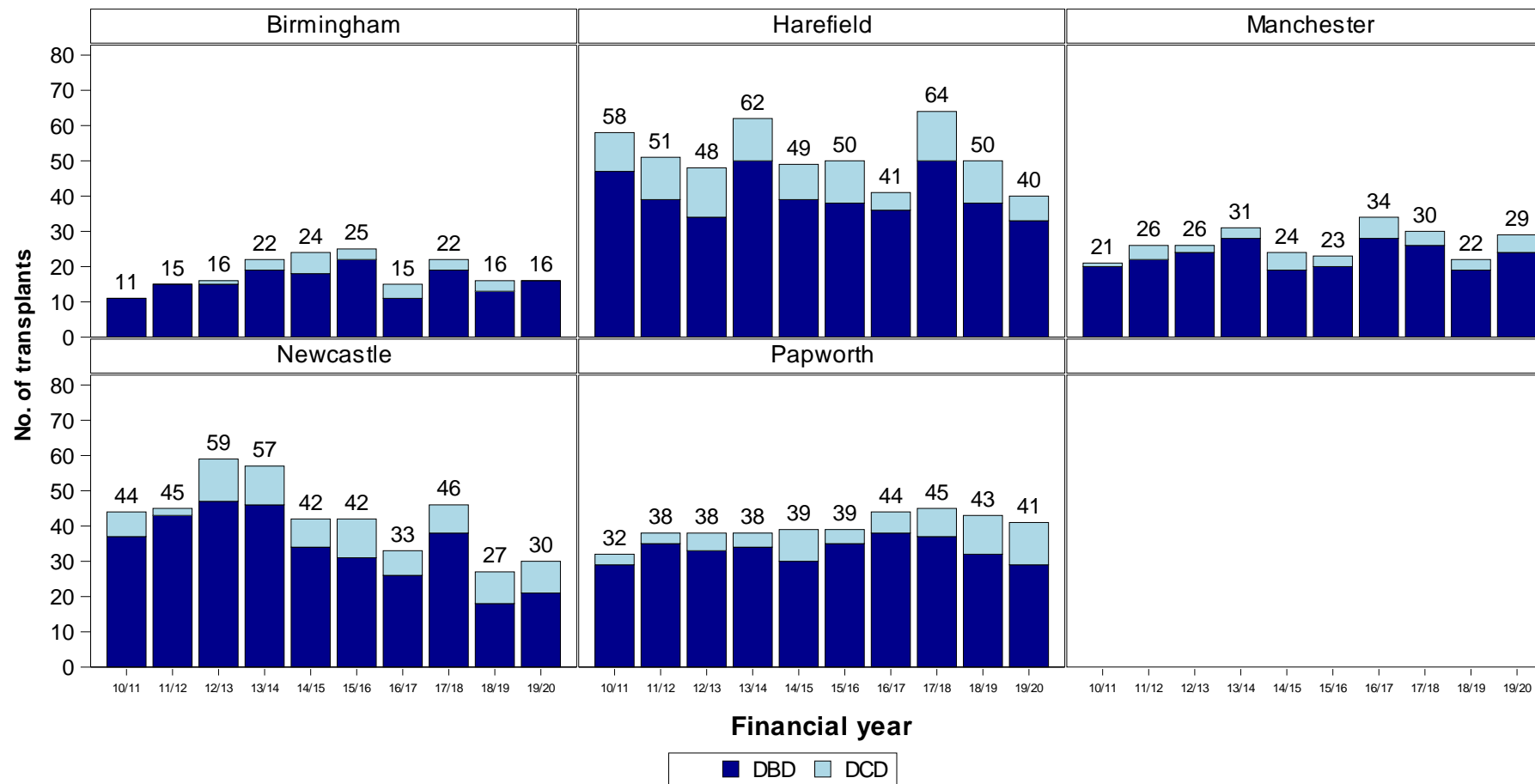


Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2019 to 31 March 2020

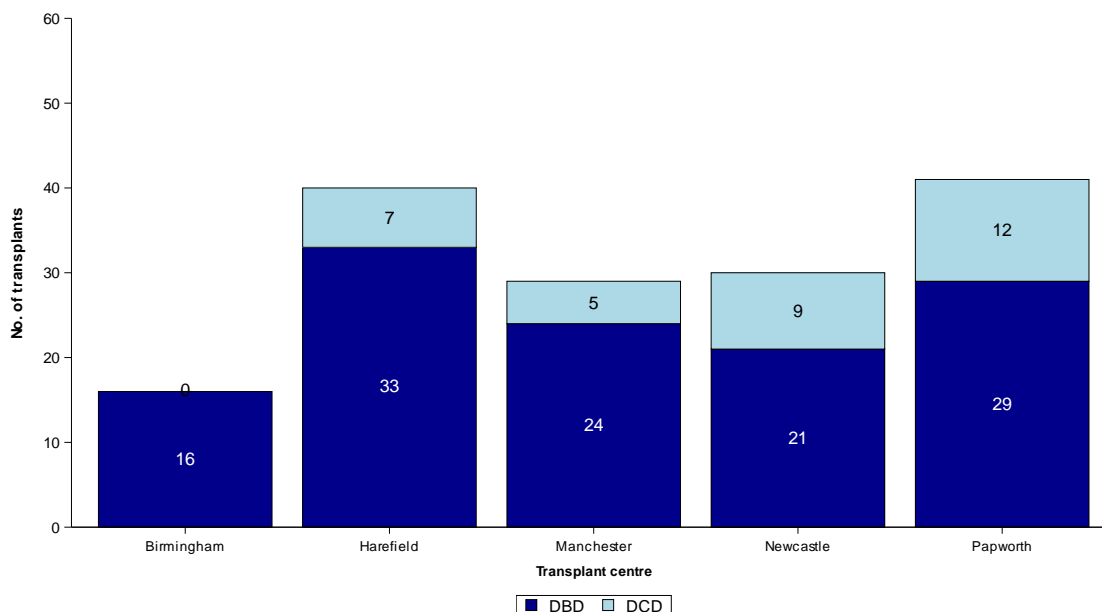


Figure 11.4 and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. The number of transplants by transplant type in the latest financial year (2019/2020) is shown by centre in **Figure 11.6**. There was a total of 46 heart-lung block transplants, and no partial lung transplants, over the decade. The overall proportion of single lung transplants has decreased from 14% in 2010/2011 to 9% in 2019/2020. When broken down by centre, it can be seen that Newcastle and Birmingham have reduced their use of single lungs. In the last financial year Papworth was the highest user of single lungs and Manchester, Birmingham and Papworth were the only centres to have performed heart-lung block transplants (**Figure 11.6**).

Figure 11.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2010 to 31 March 2020

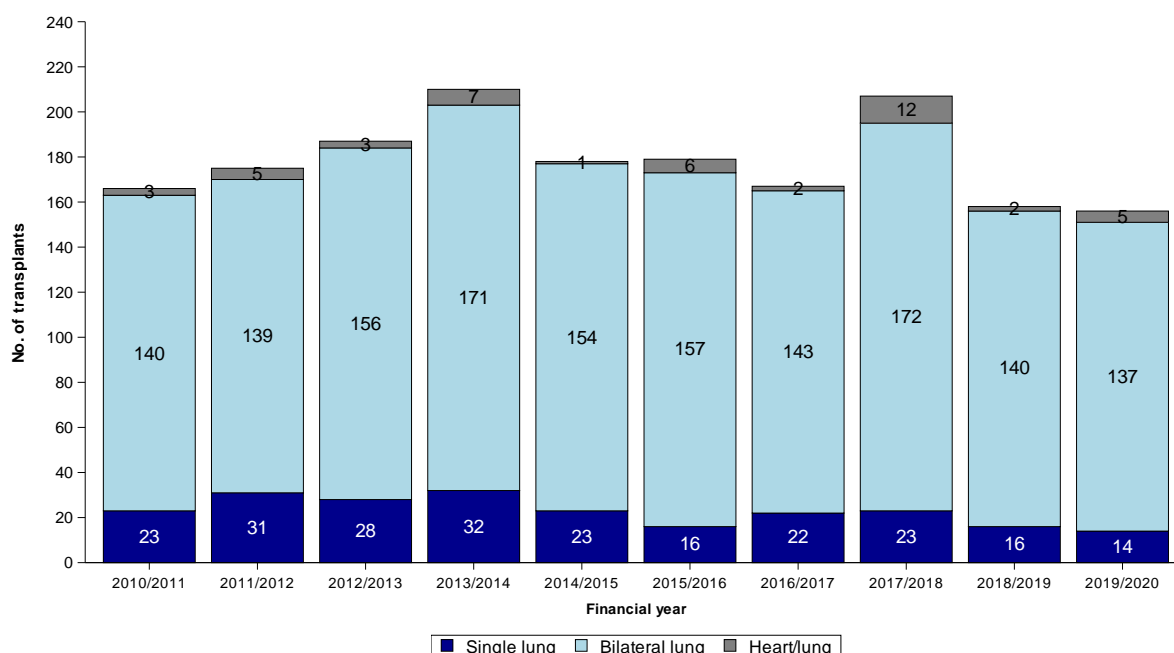


Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2010 to 31 March 2020

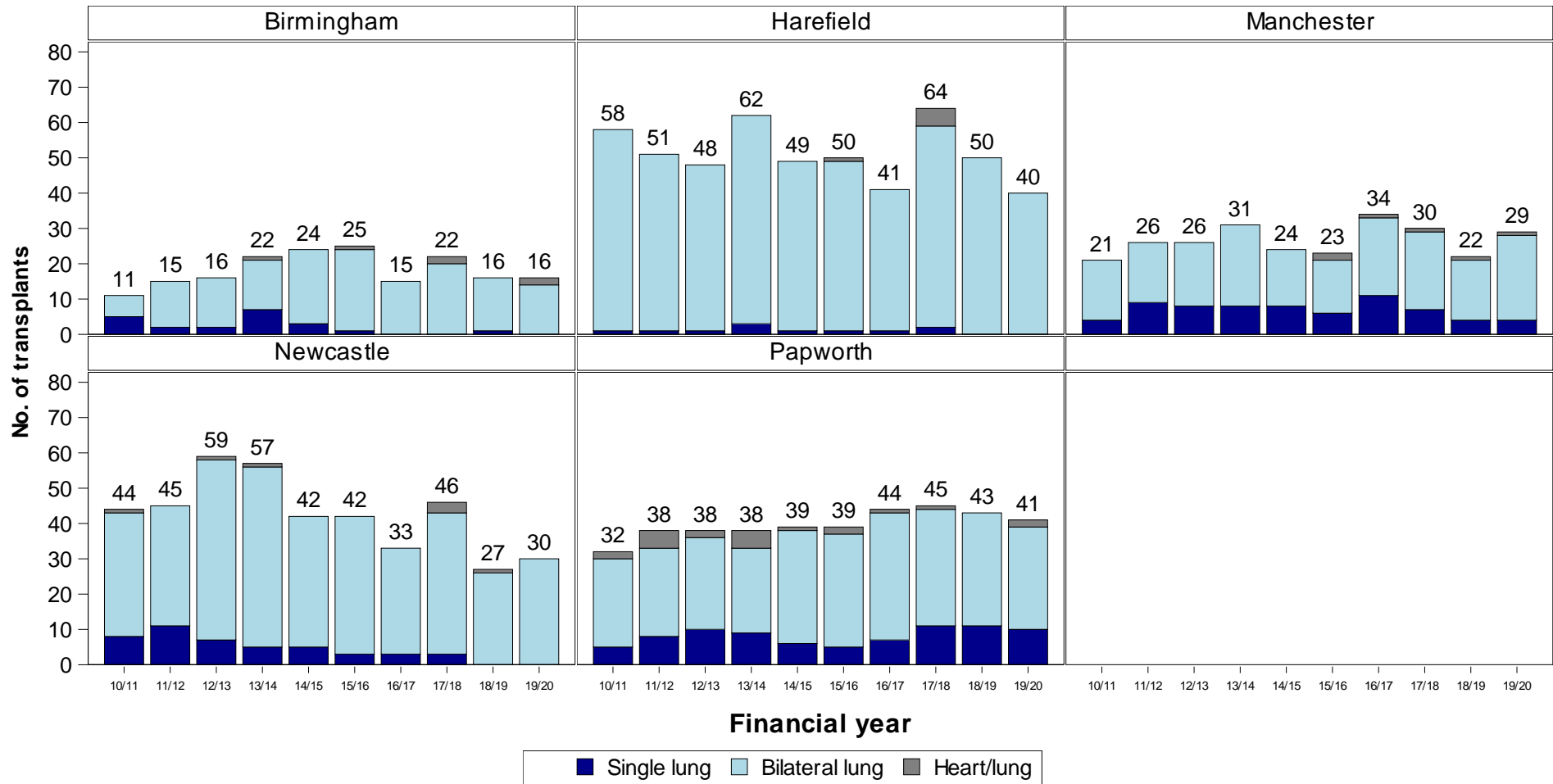
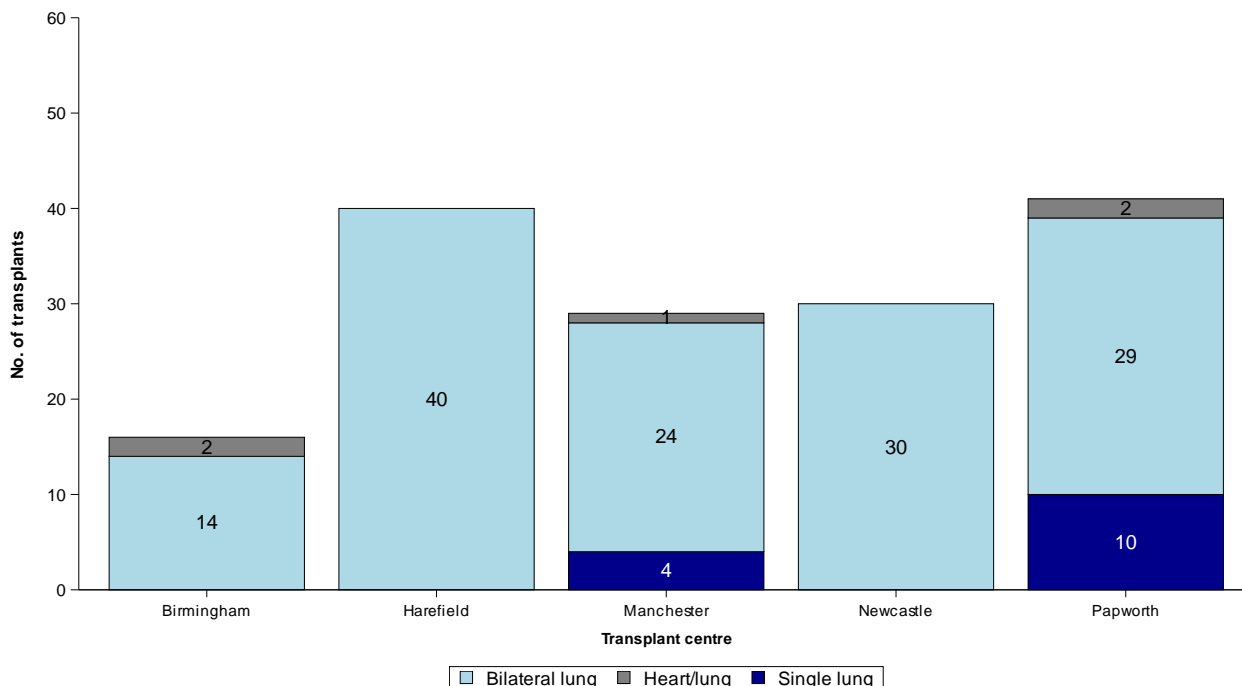


Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2019 to 31 March 2020



On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. The number of lung only transplants per year by urgency status is shown in **Figure 11.7**; the proportion of urgent or super-urgent lung transplants decreased slightly over the last two years compared with 2017/2018. **Figure 11.8** shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 23 urgent lung only transplants (ranging from 1 at Birmingham to 10 at Newcastle) and 6 super-urgent lung only transplants (5 performed by Harefield and 1 by Newcastle). Heart-lung patients have access to urgent transplantation through the heart allocation scheme. Of the 5 adult heart-lung transplants in 2019/2020, 2 were urgent (Figure not shown).

Figure 11.7 Number of adult lung only transplants in the UK, by financial year and urgency status, 1 April 2010 to 31 March 2020

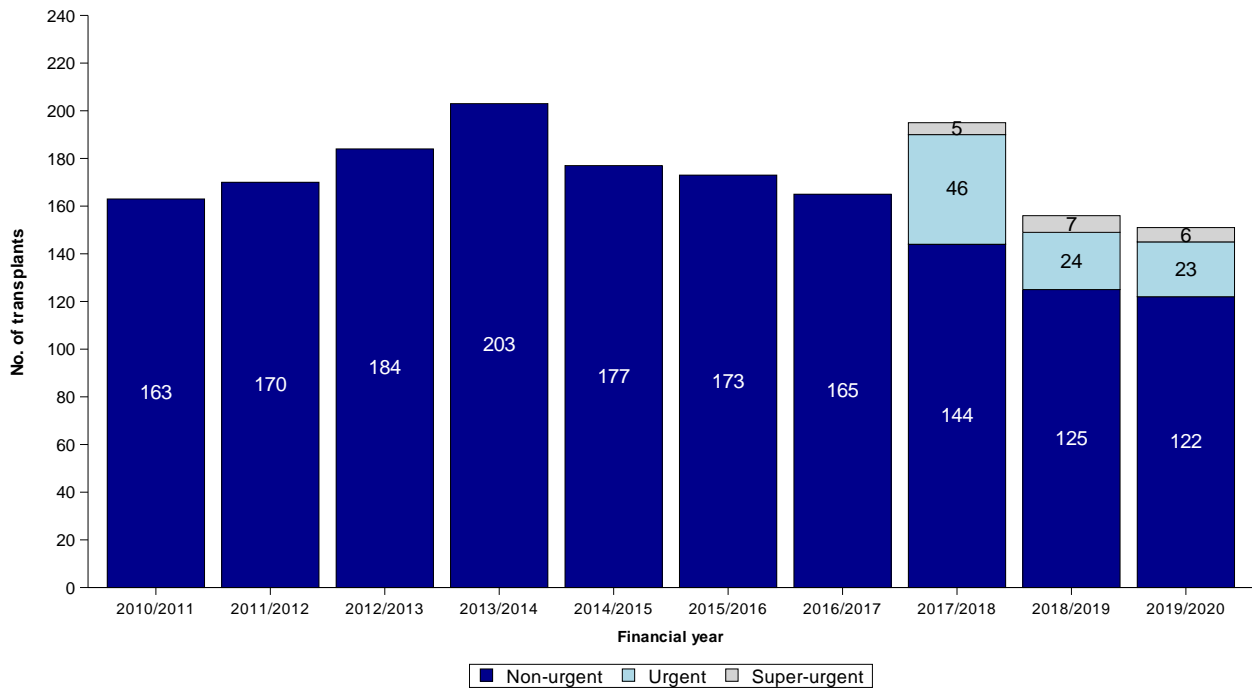
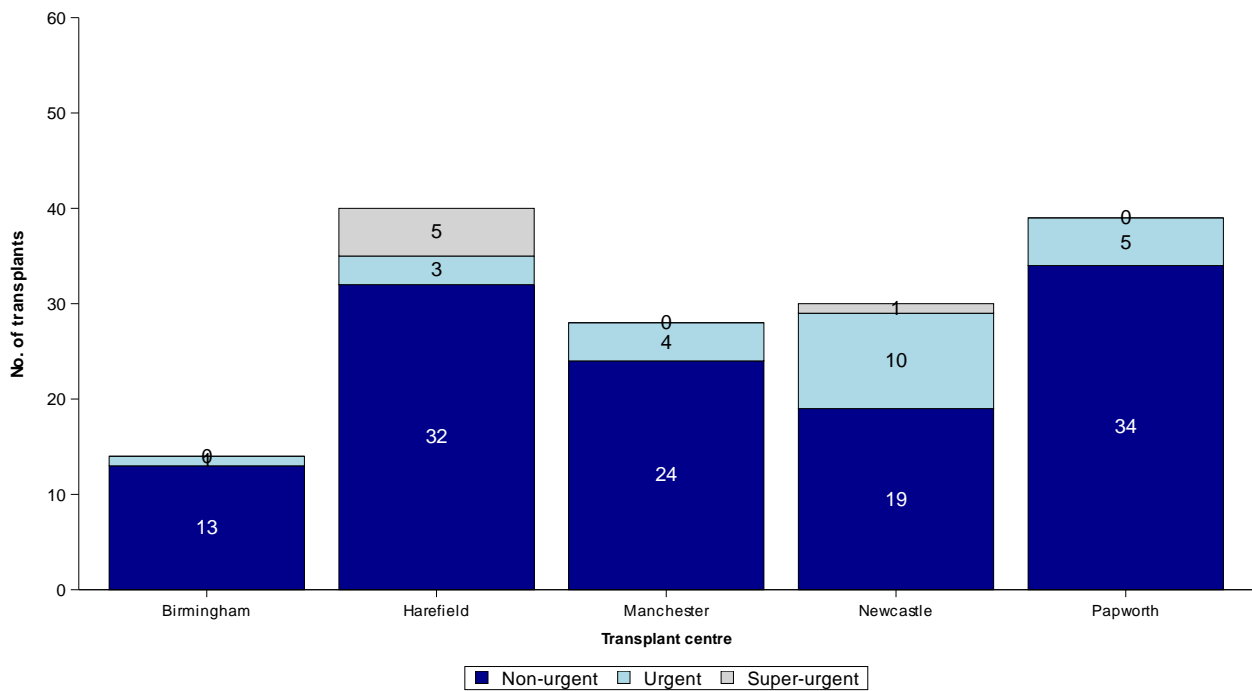


Figure 11.8 Number of adult lung only transplants in the UK, by centre and urgency status, 1 April 2019 to 31 March 2020



11.2 Demographic characteristics of transplants, 1 April 2019 – 31 March 2020

The demographic characteristics of the 156 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 57% of lung recipients were male and the [median](#) age was 53 years while the median age of donors was 47 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2019 to 31 March 2020, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		16 (100)	40 (100)	29 (100)	30 (100)	41 (100)	156 (100)
Urgency status at transplant	Non-urgent	15 (94)	32 (80)	24 (83)	19 (63)	35 (85)	125 (80)
	Urgent	1 (6)	3 (8)	5 (17)	10 (33)	6 (15)	25 (16)
	Super-urgent	0 (0)	5 (13)	0 (0)	1 (3)	0 (0)	6 (4)
Transplant type	Single lung	0 (0)	0 (0)	4 (14)	0 (0)	10 (24)	14 (9)
	Bilateral lung	14 (88)	40 (100)	24 (83)	30 (100)	29 (71)	137 (88)
	Heart-lung	2 (13)	0 (0)	1 (3)	0 (0)	2 (5)	5 (3)
Recipient sex	Male	7 (44)	21 (53)	15 (52)	20 (67)	26 (63)	89 (57)
	Female	9 (56)	19 (48)	14 (48)	9 (30)	15 (37)	66 (42)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Recipient ethnicity	White	15 (94)	37 (93)	27 (93)	30 (100)	36 (88)	145 (93)
	Non-white	1 (6)	3 (8)	2 (7)	0 (0)	5 (12)	11 (7)
Recipient age (years)	Median (IQR)	55 (41, 60)	45 (35, 60)	54 (46, 59)	55 (42, 61)	54 (46, 60)	53 (42, 60)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	64 (60, 68)	60 (52, 70)	72 (65, 80)	73 (62, 83)	72 (60, 79)	68 (58, 77)
	Missing	0	0	0	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	1 (6)	20 (50)	5 (17)	7 (23)	5 (12)	38 (24)
	Fibrosing lung disease	1 (6)	5 (13)	6 (21)	14 (47)	14 (34)	40 (26)
	COPD and emphysema	10 (63)	14 (35)	13 (45)	7 (23)	12 (29)	56 (36)
	Primary pulmonary hypertension	1 (6)	0 (0)	2 (7)	2 (7)	1 (2)	6 (4)
	Other	3 (19)	1 (3)	3 (10)	0 (0)	9 (22)	16 (10)
NYHA class	I	6 (38)	0 (0)	0 (0)	0 (0)	0 (0)	6 (4)
	II	0 (0)	4 (10)	0 (0)	0 (0)	1 (2)	5 (3)
	III	1 (6)	21 (53)	27 (93)	25 (83)	12 (29)	86 (55)
	IV	1 (6)	7 (18)	2 (7)	5 (17)	28 (68)	43 (28)
	Missing	8 (50)	8 (20)	0 (0)	0 (0)	0 (0)	16 (10)

DRAFT FOR STAKEHOLDER REVIEW

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2019 to 31 March 2020, by centre		Birmingham	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Recipient in hospital pre-transplant	No	15 (94)	32 (80)	25 (86)	20 (67)	34 (83)	126 (81)
	Yes	1 (6)	8 (20)	4 (14)	10 (33)	7 (17)	30 (19)
If in hospital, recipient on ventilator	No	0 (0)	7 (88)	2 (50)	10 (100)	7 (100)	26 (87)
	Yes	1 (100)	1 (13)	2 (50)	0 (0)	0 (0)	4 (13)
If in hospital, recipient on inotropes	No	1 (100)	6 (75)	4 (100)	9 (90)	7 (100)	27 (90)
	Yes	0 (0)	2 (25)	0 (0)	1 (10)	0 (0)	3 (10)
If in hospital, recipient on ECMO	No	1 (100)	3 (38)	4 (100)	9 (90)	7 (100)	24 (80)
	Yes	0 (0)	5 (63)	0 (0)	1 (10)	0 (0)	6 (20)
Recipient CMV status	No	8 (50)	17 (43)	16 (55)	13 (43)	26 (63)	80 (51)
	Yes	8 (50)	20 (50)	13 (45)	16 (53)	15 (37)	72 (46)
	Missing	0 (0)	3 (8)	0 (0)	1 (3)	0 (0)	4 (3)
Recipient HCV status	No	16 (100)	40 (100)	29 (100)	29 (97)	41 (100)	155 (99)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Recipient HBV status	No	16 (100)	40 (100)	29 (100)	29 (97)	41 (100)	155 (99)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Recipient HIV status	No	16 (100)	40 (100)	29 (100)	29 (97)	41 (100)	155 (99)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Recipient serum creatinine (umol/l)	Median (IQR)	74 (60, 87)	55 (46, 71)	69 (50, 83)	68 (48, 84)	60 (53, 68)	64 (51, 78)
	Missing	0	0	0	0	0	0
Donor sex	Male	5 (31)	21 (53)	12 (41)	11 (37)	12 (29)	61 (39)
	Female	11 (69)	19 (48)	17 (59)	19 (63)	29 (71)	95 (61)
Donor ethnicity	White	15 (94)	34 (85)	27 (93)	26 (87)	37 (90)	139 (89)
	Non-white	1 (6)	6 (15)	2 (7)	3 (10)	3 (7)	15 (10)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	1 (2)	2 (1)
Donor age (years)	Median (IQR)	42 (28, 57)	49 (36, 61)	44 (29, 58)	49 (31, 60)	42 (33, 56)	47 (31, 58)
	Missing	0	0	0	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	27 (23, 31)	25 (22, 28)	25 (23, 29)	23 (22, 25)	26 (22, 29)	25 (22, 28)
	Missing	0	0	0	0	0	0

DRAFT FOR STAKEHOLDER REVIEW

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2019 to 31 March 2020, by centre		Birmingham	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Donor cause of death	CVA	15 (94)	37 (93)	25 (86)	25 (83)	38 (93)	140 (90)
	Trauma	0 (0)	1 (3)	1 (3)	1 (3)	0 (0)	3 (2)
	Others	1 (6)	2 (5)	3 (10)	4 (13)	3 (7)	13 (8)
Donor hypotension	No	10 (63)	31 (78)	20 (69)	6 (20)	38 (93)	105 (67)
	Yes	5 (31)	7 (18)	8 (28)	17 (57)	2 (5)	39 (25)
	Missing	1 (6)	2 (5)	1 (3)	7 (23)	1 (2)	12 (8)
Donor past cardiothoracic disease	No	14 (88)	35 (88)	28 (97)	29 (97)	36 (88)	142 (91)
	Yes	2 (13)	5 (13)	1 (3)	0 (0)	4 (10)	12 (8)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	1 (2)	2 (1)
Donor past hypertension	No	11 (69)	28 (70)	24 (83)	20 (67)	33 (80)	116 (74)
	Yes	5 (31)	12 (30)	5 (17)	9 (30)	7 (17)	38 (24)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	1 (2)	2 (1)
Donor past tumour	No	14 (88)	40 (100)	29 (100)	29 (97)	39 (95)	151 (97)
	Yes	2 (13)	0 (0)	0 (0)	1 (3)	2 (5)	5 (3)
Donor past smoker	No	7 (44)	22 (55)	19 (66)	22 (73)	25 (61)	95 (61)
	Yes	9 (56)	18 (45)	10 (34)	8 (27)	16 (39)	61 (39)
Total ischaemia time (hours)	Median (IQR)	5.5 (4.1, 6.8)	9.1 (7.8, 11.0)	5.8 (4.9, 6.2)	6.2 (5.8, 7.0)	6.8 (5.9, 8.4)	6.5 (5.6, 8.4)
	Missing	1	0	0	1	0	2

11.3 Total ischaemia time, 1 April 2010 – 31 March 2020

Figure 11.9 shows [boxplots](#) of the total ischaemia time for [DBD](#) donor lungs transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion (of second lung if applicable) and can be considered the out of body time. In cases where organ maintenance systems were used (3%), not all of this time duration is ischaemic, and no adjustment has been made for this. The national [median](#) total ischaemia time has increased from 5.6 hours to 6.1 hours over the last decade.

Figure 11.9 Boxplots of total ischaemia time in adult DBD donor lung transplants, by financial year, 1 April 2010 to 31 March 2020

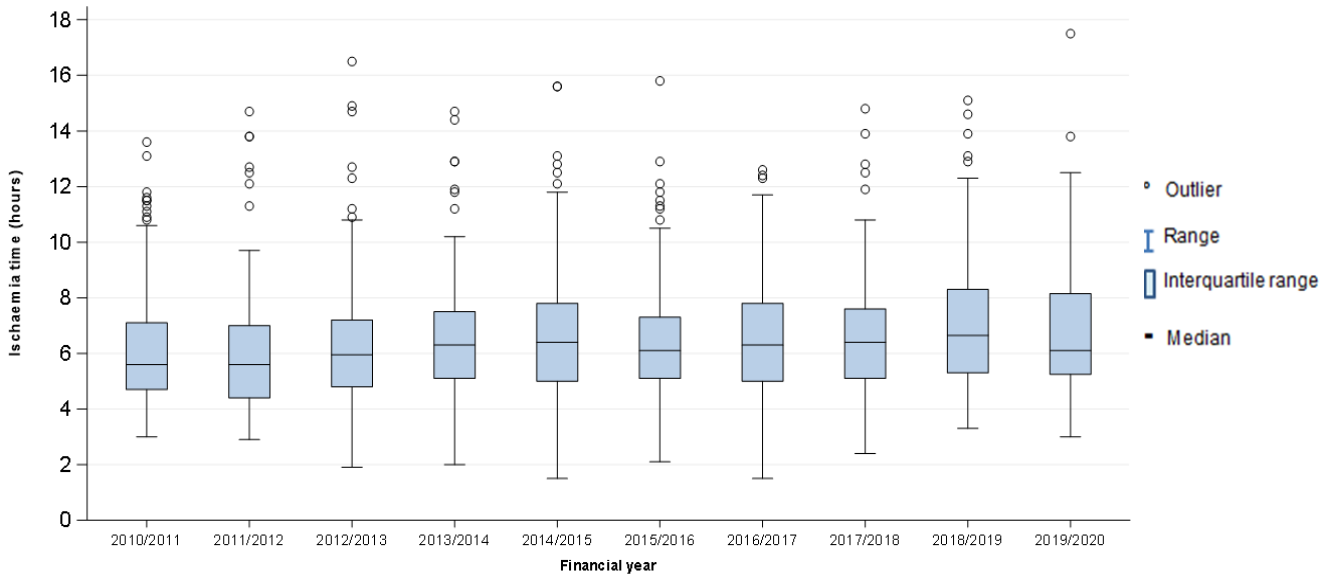


Figure 11.10 and **Figure 11.11** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2019/2020) and over the last 10 years, respectively. Ischaemia times were longest in 2019/2020 for lungs transplanted by Harefield and shortest for Manchester. Harefield have seen the most noticeable increase in ischaemia times over the decade with other centres also seeing a general increase, except Manchester who have seen a decrease over the decade.

Figure 11.10 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2019 to 31 March 2020

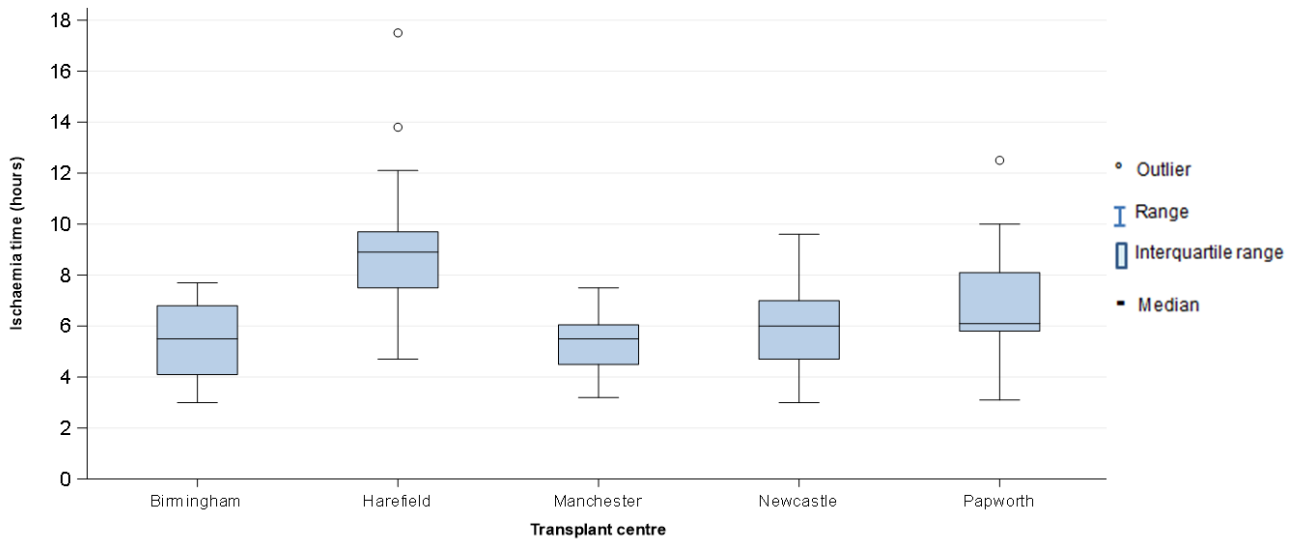
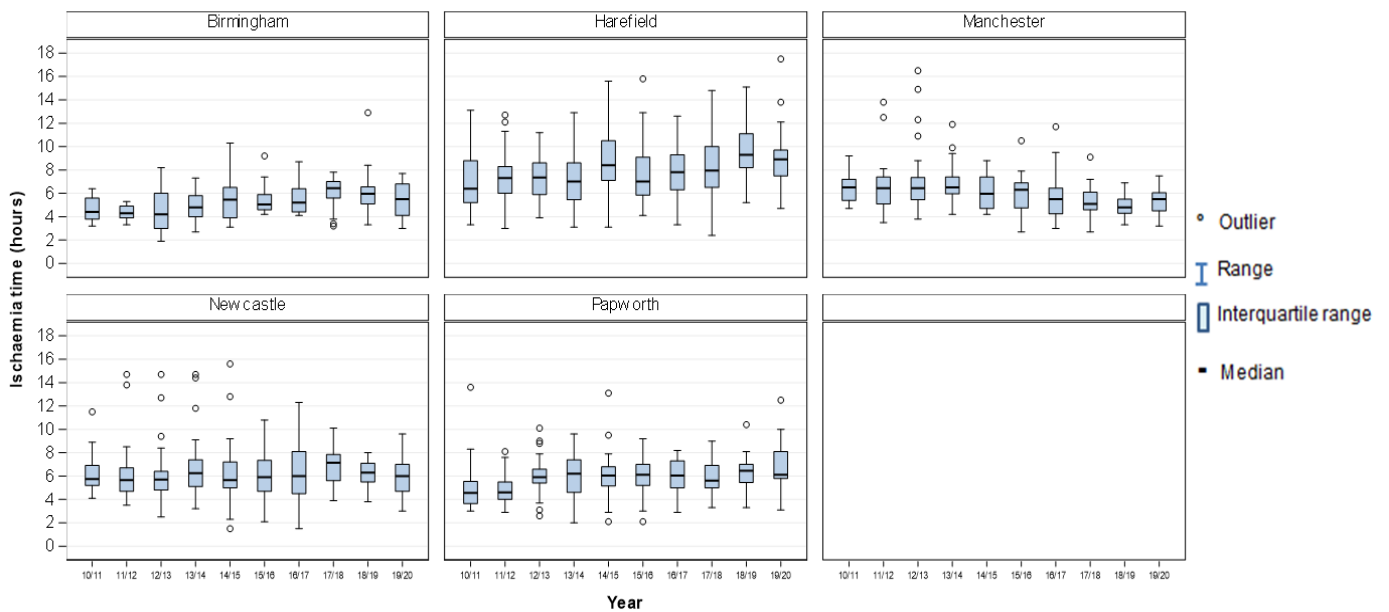


Figure 11.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2010 to 31 March 2020



ADULT LUNG TRANSPLANTATION

Post-Transplant Survival



12. Post-Transplant Survival

This section presents survival post adult lung transplantation. [Funnel plots](#) are used to compare the [risk-adjusted](#) survival rate at each centre with the national rate. The [unadjusted survival rates](#) are presented in the tables for reference, but these do not account for differences in the [case mix](#) at each centre. The [risk-adjusted](#) rates do account for these differences as much as possible and so provide a fairer comparison across centres. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A3.2](#).

The survival analyses exclude [multi-organ transplants](#) and include first time transplants only. Ninety-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2015 to 31 March 2019 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2011 to 31 March 2015. Both DBD and DCD lung transplants are included. [Survival rates](#) are presented by transplant centre in **Tables 12.1-12.3** and **Figures 12.1-12.3** as well as disease group in **Tables 12.4-12.5**. Heart-lung transplants are excluded but separate tables (**Table 12.6** and **12.7**) at the end of this section provide [unadjusted survival rates](#) for the small number of heart-lung transplant recipients between 1 April 2011 and 31 March 2019.

12.1 Survival by centre

Table 12.1 and **Figure 12.1** show the 90-day post-transplant [unadjusted](#) and [risk-adjusted](#) patient survival rate for each centre and nationally for the 679 first adult lung only transplants in the period 1 April 2015 to 31 March 2019. Manchester's survival rate at 90 days falls above the 95% upper confidence limit, suggesting there is some evidence that the survival rate is higher than the national average at this time period. All other centres were statistically consistent with the national rate of survival which was 90.9%.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre, 1 April 2015 to 31 March 2019					
Centre	Number of transplants	% 90 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	75	86.7	(76.6 - 92.6)	87.2	(76.2 - 93.1)
Harefield	193	91.2	(86.2 - 94.4)	90.0	(84.0 - 93.8)
Manchester	104	96.2	(90.1 - 98.5)	96.4	(90.5 - 98.7)
Newcastle	144	87.5	(80.9 - 91.9)	89.0	(82.6 - 93.1)
Papworth	163	92	(86.7 - 95.3)	91.6	(85.5 - 95.1)
UK	679	90.9	(88.4 - 92.8)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 12.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2015 to 31 March 2019

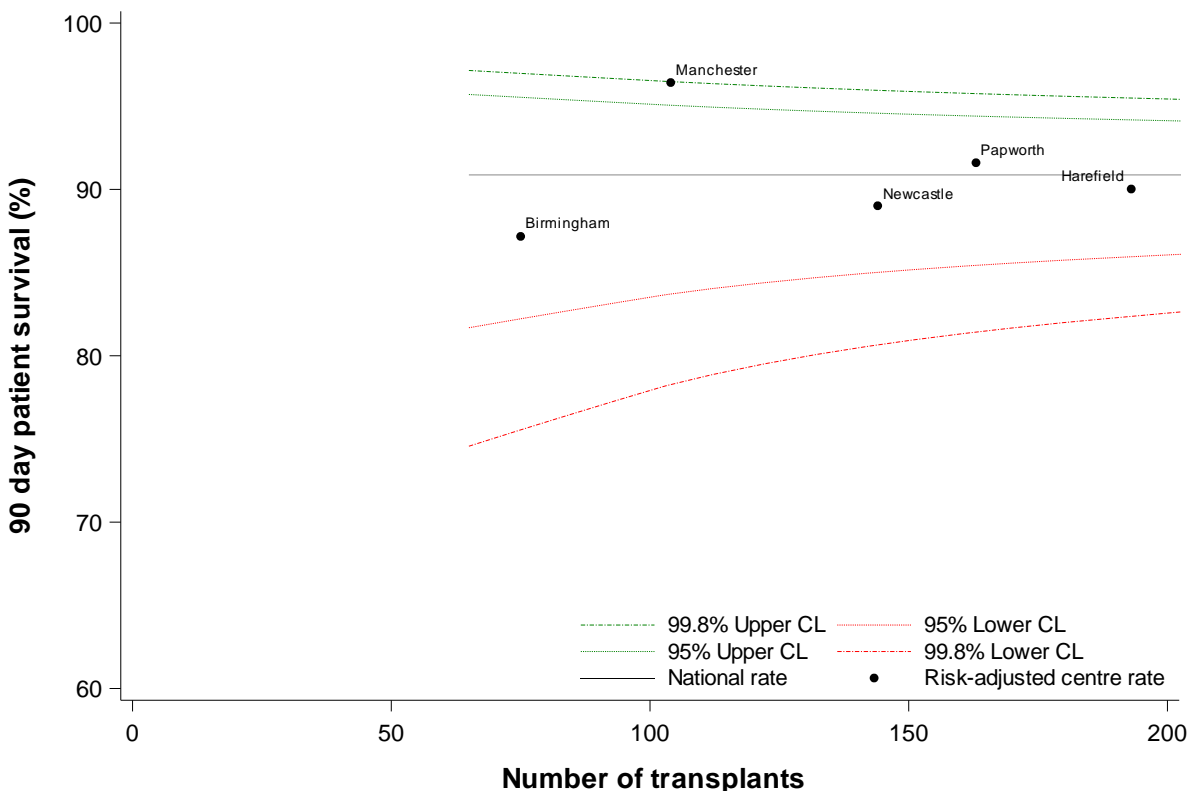


Table 12.2 and **Figure 12.2** show the 1-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 679 first adult lung only transplants in the period 1 April 2015 to 31 March 2019. The national rate of survival was 82.6%. The rates for all centres were statistically consistent with the national rate.

Table 12.2 1 year patient survival rates after first adult lung transplant, by centre, 1 April 2015 to 31 March 2019					
Centre	Number of transplants	% 1 year survival (95% CI)			
		<u>Unadjusted</u>		<u>Risk-adjusted</u>	
Birmingham	75	75.5	(63.9 - 83.8)	74.3	(59.3 - 83.8)
Harefield	193	84.3	(78.3 - 88.8)	84.2	(77.3 - 88.9)
Manchester	104	86.5	(78.2 - 91.8)	87.4	(78.8 - 92.6)
Newcastle	144	82.5	(75.3 - 87.8)	83.2	(75.1 - 88.6)
Papworth	163	81.5	(74.6 - 86.7)	80.4	(71.9 - 86.3)
UK	679	82.6	(79.5 - 85.3)		

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2015 to 31 March 2019

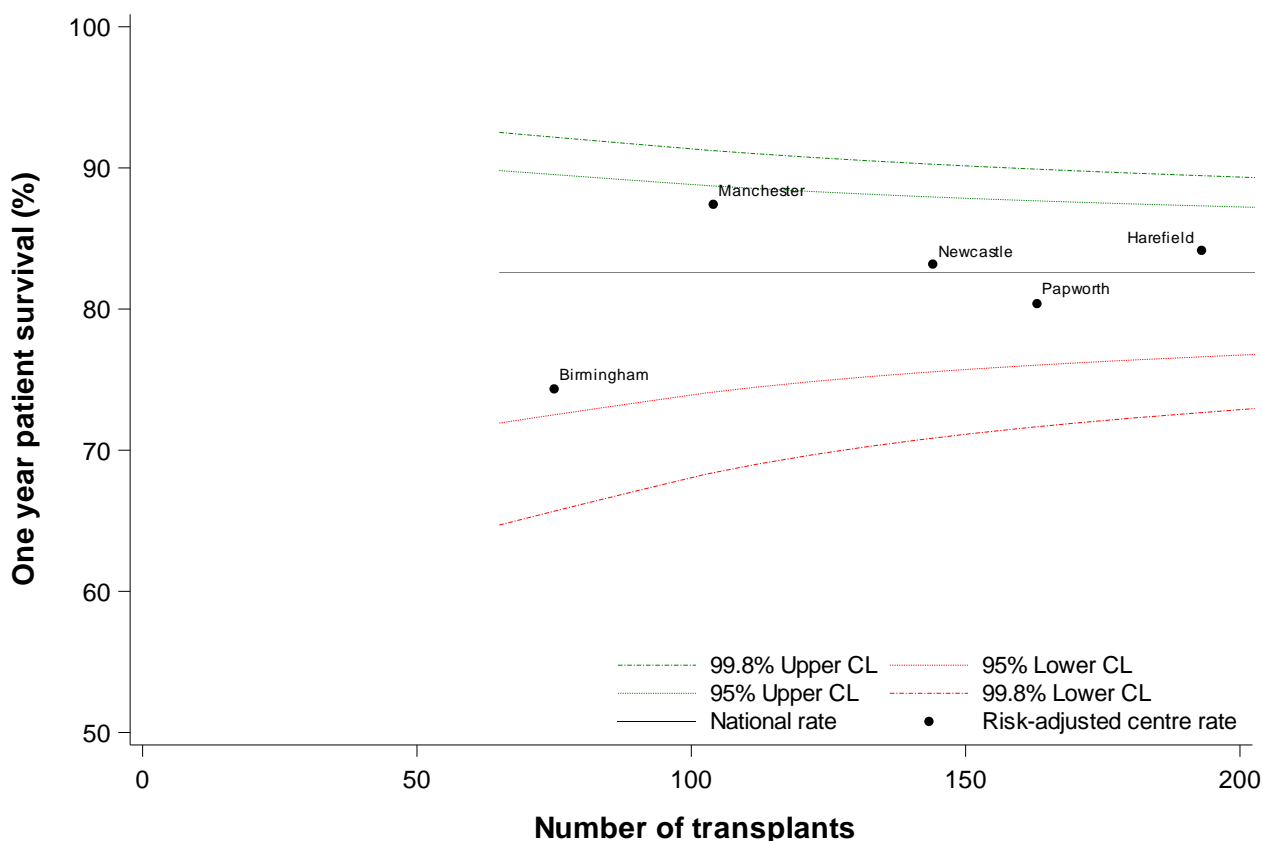
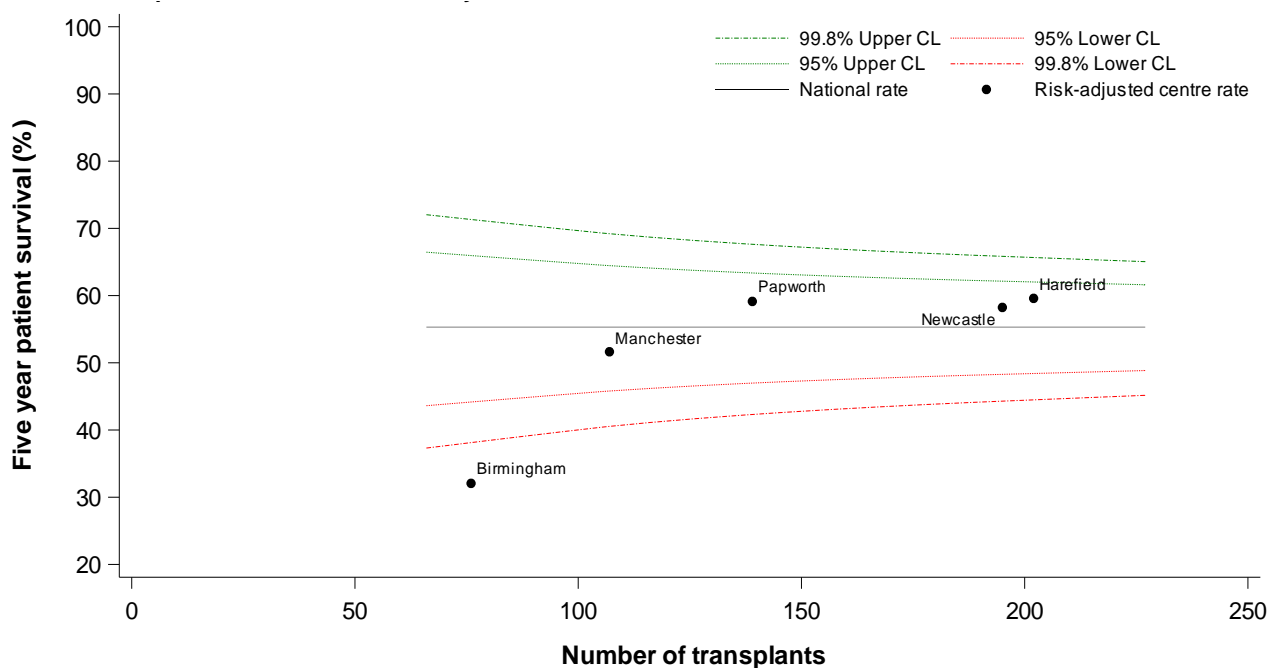


Table 12.3 and **Figure 12.3** show the 5-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 707 first adult lung only transplants in the period 1 April 2011 to 31 March 2015. Birmingham's survival rate at 5 years falls below the 99.8% lower confidence limit, indicating lower than average survival at this time period. All other centres were statistically consistent with the national rate of survival of 55.3%.

Table 12.3 5 year patient survival rates after first adult lung transplant, by centre, 1 April 2011 to 31 March 2015				
Centre	Number of transplants	% 5 year survival (95% CI)		
		<u>Unadjusted</u>		<u>Risk-adjusted</u>
Birmingham	76	41.7	(30.5 - 52.6)	32.1 (8.7 - 49.4)
Harefield	202	62.2	(55.1 - 68.5)	59.6 (49.4 - 67.7)
Manchester	107	46.7	(37.1 - 55.8)	51.6 (37.3 - 62.7)
Newcastle	195	57.8	(50.4 - 64.4)	58.2 (48.1 - 66.4)
Papworth	139	55.9	(47.3 - 63.7)	59.1 (47.5 - 68.2)
UK	719	55.3	(51.6 - 58.9)	

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

Figure 12.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2011 to 31 March 2015



12.2 Survival by disease group

Tables 12.4 and 12.5 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 1 year and 5 years post-transplant, respectively. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A3.2](#), except centre was used in place of disease group. There were no statistically significant differences in [survival rates](#) across disease groups at 1 year, however diseases grouped into the “other” category show some evidence of lower than average survival at 5 years.

Table 12.4 1 year patient survival rates after first adult lung transplant, by disease group, 1 April 2015 to 31 March 2019

Disease group	Number of transplants	% 1 year survival (95% CI)			
			Unadjusted		Risk-adjusted
Cystic fibrosis and bronchiectasis	212	84.7	(79.1 - 88.9)	81.1	(73.3 - 86.6)
COPD and emphysema	171	81.6	(74.9 - 86.7)	83.9	(77.1 - 88.7)
Fibrosing lung disease	152	82.1	(75.0 - 87.3)	81.7	(73.3 - 87.4)
Other	144	81.2	(73.8 - 86.7)	83.5	(75.9 - 88.7)
UK	679	82.6	(79.5 - 85.3)		

Table 12.5 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2011 to 31 March 2015

Disease group	Number of transplants	% 5 year survival (95% CI)			
			Unadjusted		Risk-adjusted
Cystic fibrosis and bronchiectasis	211	62.7	(55.8 - 68.9)	59.7	(49.7 - 67.7)
COPD and emphysema	236	58.3	(51.8 - 64.3)	54.4	(44.5 - 62.6)
Fibrosing lung disease	152	46.2	(38.1 - 54.0)	57.1	(46.6 - 65.5)
Other	120	48.0	(38.8 - 56.7)	46.8	(31.8 - 58.6)
UK	719	55.3	(51.6 - 58.9)		

12.3 Survival by transplant type

Table 12.6 presents [unadjusted survival rates](#) by transplant type (single lung against bilateral lung), at 90 days, 1 year and 5 years post-transplant, respectively. Survival rates at 90 days and 1 year are based on transplants performed between 1 April 2015 and 31 March 2019 whereas the 5 year survival rates are for transplants performed between 1 April 2011 and 31 March 2015. Survival rates across transplant types were comparable at 90 days and 1 year, however a significant difference was found at 5 years post transplant (log-rank $p < 0.001$).

Table 12.6 Unadjusted patient survival rates after first adult DBD heart transplant, by transplant type, 1 April 2015 to 31 March 2019 (90 day and 1 year), and 1 April 2011 to 31 March 2015 (5 year)

Transplant type	N	90 day		N	1 year		N	5 year	
		% survival (95% CI) Unadjusted			% survival (95% CI) Unadjusted			% survival (95% CI) Unadjusted	
Single lung	75	92.0	(83.1 - 96.3)	75	82.6	(71.8 - 89.5)	113	39.4	(30.3 - 48.3)
Bilateral lung	604	90.7	(88.1 - 92.8)	604	82.6	(79.3 - 85.4)	606	58.3	(54.2 - 62.1)
UK	679	90.9	(88.4 - 92.8)	679	82.6	(79.5 - 85.3)	719	55.3	(51.6 - 58.9)

12.4 Survival post heart-lung transplant

Table 12.6 and **Table 12.7** present short-term patient [survival rates](#) following combined heart-lung transplant, by centre and nationally. During the time period 1 April 2011 to 31 March 2019, a small number of transplants were performed, with most being performed at Papworth, hence centre-specific rates are only reported for Papworth. The national rates of survival were 83.8% at 90 days and 72.5% at one year.

Table 12.6 90 day patient survival after first adult heart-lung transplant, by centre, 1 April 2011 and 31 March 2019				
Centre	Number of transplants	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Birmingham ¹	4	0	-	-
Harefield ¹	6	3	-	-
Manchester ¹	5	0	-	-
Newcastle ¹	6	1	-	-
Papworth	16	2	87.5	(58.6 – 96.7)
UK	37	6	83.8	(67.4 – 92.4)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

Table 12.7 1 year patient survival after first adult heart-lung transplant, by centre, 1 April 2011 and 31 March 2019				
Centre	Number of transplants	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Birmingham ¹	4	0	-	-
Harefield ¹	6	5	-	-
Manchester ¹	5	1	-	-
Newcastle ¹	6	2	-	-
Papworth	16	2	87.5	(58.6 - 96.7)
UK	37	10	72.5	(54.9 - 84.2)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

ADULT LUNG TRANSPLANTATION

Survival from Listing



13. Survival from Listing

Survival from listing was analysed for patients 18 years or older registered for the first time for a lung transplant between 1 January 2008 and 31 December 2019. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in [Appendix A2.1](#).

One and five year [risk-adjusted survival rates](#) from the point of lung transplant listing are shown as [funnel plots](#) in **Figures 13.1** and **13.2** respectively. These rates are also shown in **Table 13.1**. Note that all rates (at 1 and 5 years) were calculated from the same cohort of patients, and the number of patients remaining at risk of death after each time horizon (i.e. not already censored or deceased) is included in **Table 13.1** for reference.

The one year rate for Newcastle fell outside the lower 95% [confidence limit](#) but within the 99.8% [confidence limit](#), providing some evidence of a lower than average [survival rate](#). The one and five year [survival rates](#) from listing for Birmingham were both below the 99.8% [confidence limit](#) indicating lower than average survival. The one and five year [survival rates](#) from listing for Manchester and Harefield respectively fell above the 99.8% [confidence limits](#) indicating higher than average survival.

Table 13.1 Risk-adjusted 1 and 5 year patient survival from listing for first lung only transplants in patients registered between 1 January 2008 to 31 December 2019							
Centre	Number at risk ¹ at day 0	One year			Five year		
		Survival rate (%)	(95% CI)	Number at risk ¹	Survival rate (%)	(95% CI)	Number at risk ¹
Birmingham	354	68.9	(62.2 - 74.4)	219	29.6	(18.5 - 39.2)	42
Harefield	837	81.3	(77.9 - 84.1)	633	54.5	(49.1 - 59.3)	210
Manchester	435	84.4	(80.2 - 87.7)	330	52.8	(45.3 - 59.3)	90
Newcastle	741	74.6	(70.7 - 78.0)	504	48.7	(42.8 - 54.0)	183
Papworth	554	79.4	(75.3 - 82.8)	378	49.3	(42.4 - 55.4)	125
UK	2921	78.2	(76.7 - 79.7)	2064	49.1	(46.9 - 51.2)	650

	Centre has reached the lower 99.8% confidence limit
	Centre has reached the lower 95% confidence limit
	Centre has reached the upper 95% confidence limit
	Centre has reached the upper 99.8% confidence limit

¹ Number of patients with reported follow-up beyond this time point

Figure 13.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2008 – 31 December 2019

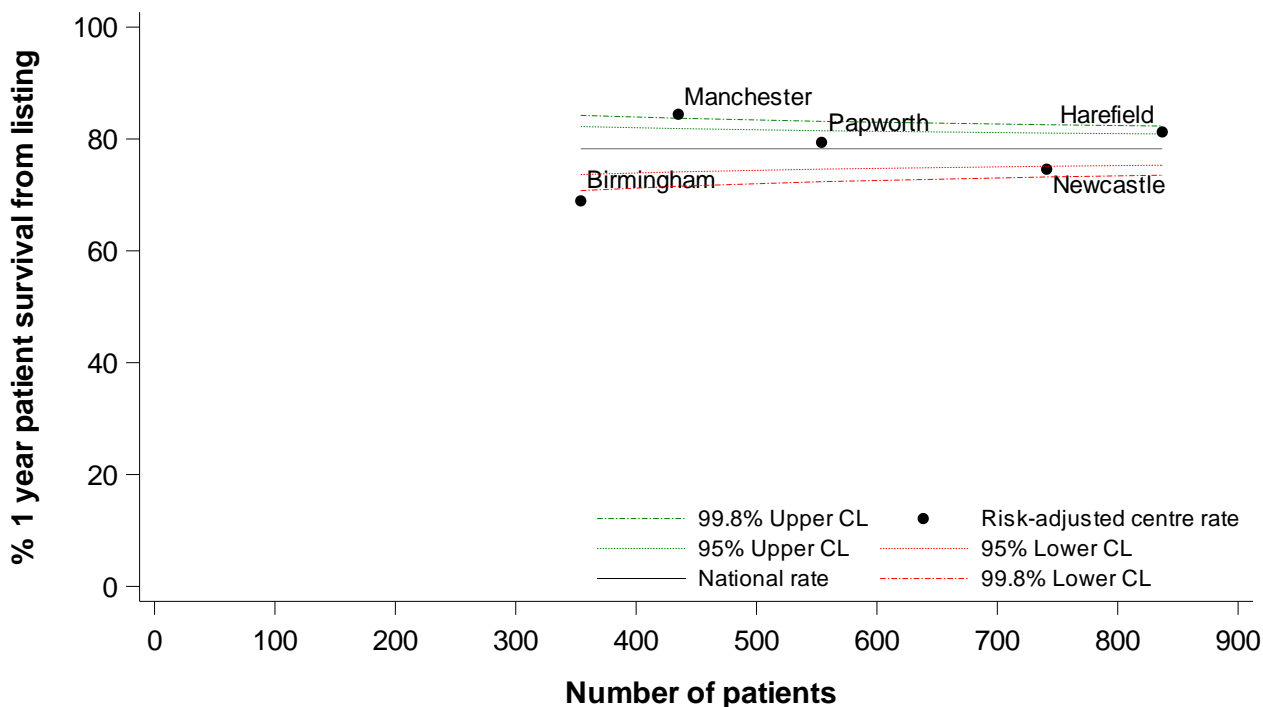
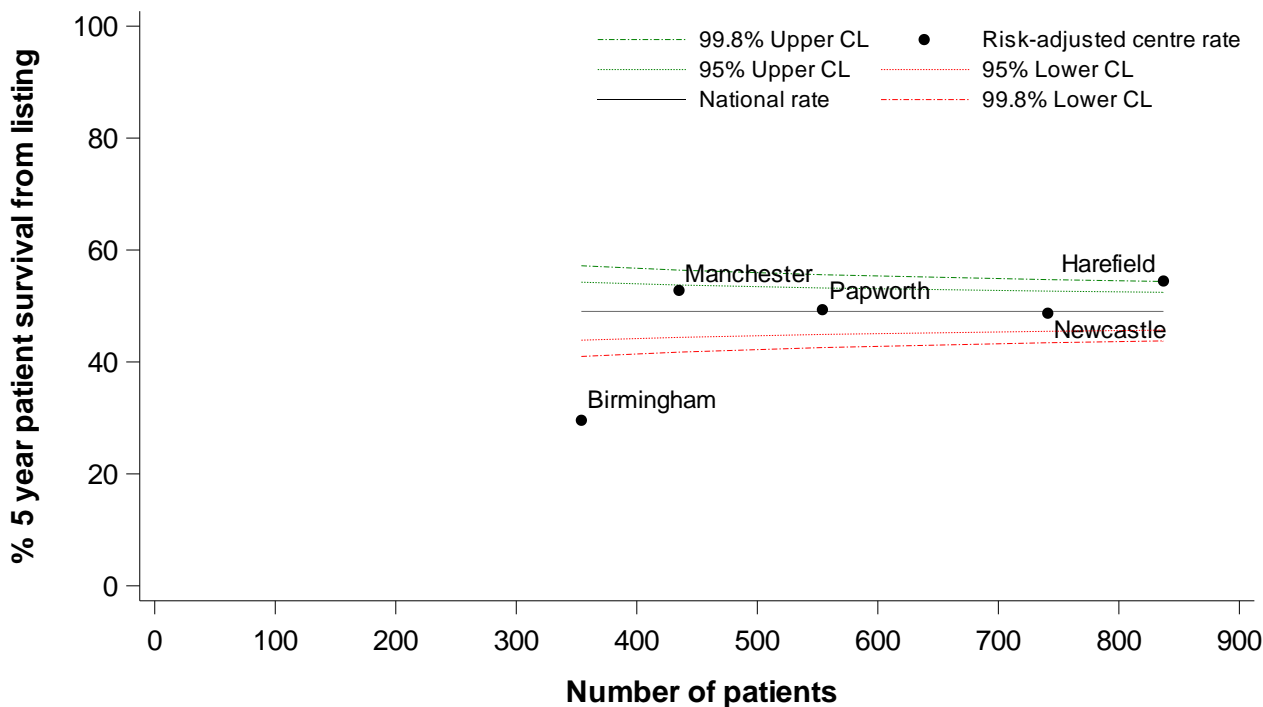


Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2008 – 31 December 2019



ADULT LUNG TRANSPLANTATION

Form Return Rates



14. Adult lung form return rates, 1 January – 31 December 2019

Form return rates are reported in **Table 14.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult lung and heart-lung transplants between 1 January and 31 December 2019 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. All active centres have a form return rate of 99% or greater for this period.

Table 14.1 Form return rates for adult lung transplants, 1 January 2019 to 31 December 2019

Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up	
	No. required	% returned	No. required	% returned	No. required	% returned	No. required	% returned
Birmingham Queen Elizabeth Hospital	17	100	20	100	17	100	99	99
Harefield Hospital	40	100	45	100	49	100	419	100
Leeds St James's Hospital	-	-	-	-	-	-	1	100
London King's College Hospital	-	-	-	-	-	-	1	100
Manchester Wythenshawe Hospital	25	100	24	100	23	100	175	99
Newcastle Freeman Hospital	32	100	36	100	26	100	341	100
Royal Papworth Hospital	44	100	47	100	47	100	293	99
Sheffield Northern General Hospital	-	-	-	-	-	-	3	100
Truro Royal Cornwall Hospital	-	-	-	-	-	-	1	0
Overall	158	100	172	100	162	100	1333	99

PAEDIATRIC HEART TRANSPLANTATION

Transplant List



15.1 Paediatric heart only transplant list as at 31 March, 2011 – 2020

Figure 15.1 shows the number of paediatric patients on the heart transplant list at 31 March each year between 2011 and 2020 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased significantly during the first half of the decade, then fell to 16 in 2018 but has since risen to 20 in 2020. The number of patients on the urgent transplant list has also increased in recent years with 16 paediatric patients waiting on 31 March 2020.

Figure 15.1 Number of paediatric patients on the heart transplant list at 31 March each year, by urgency status

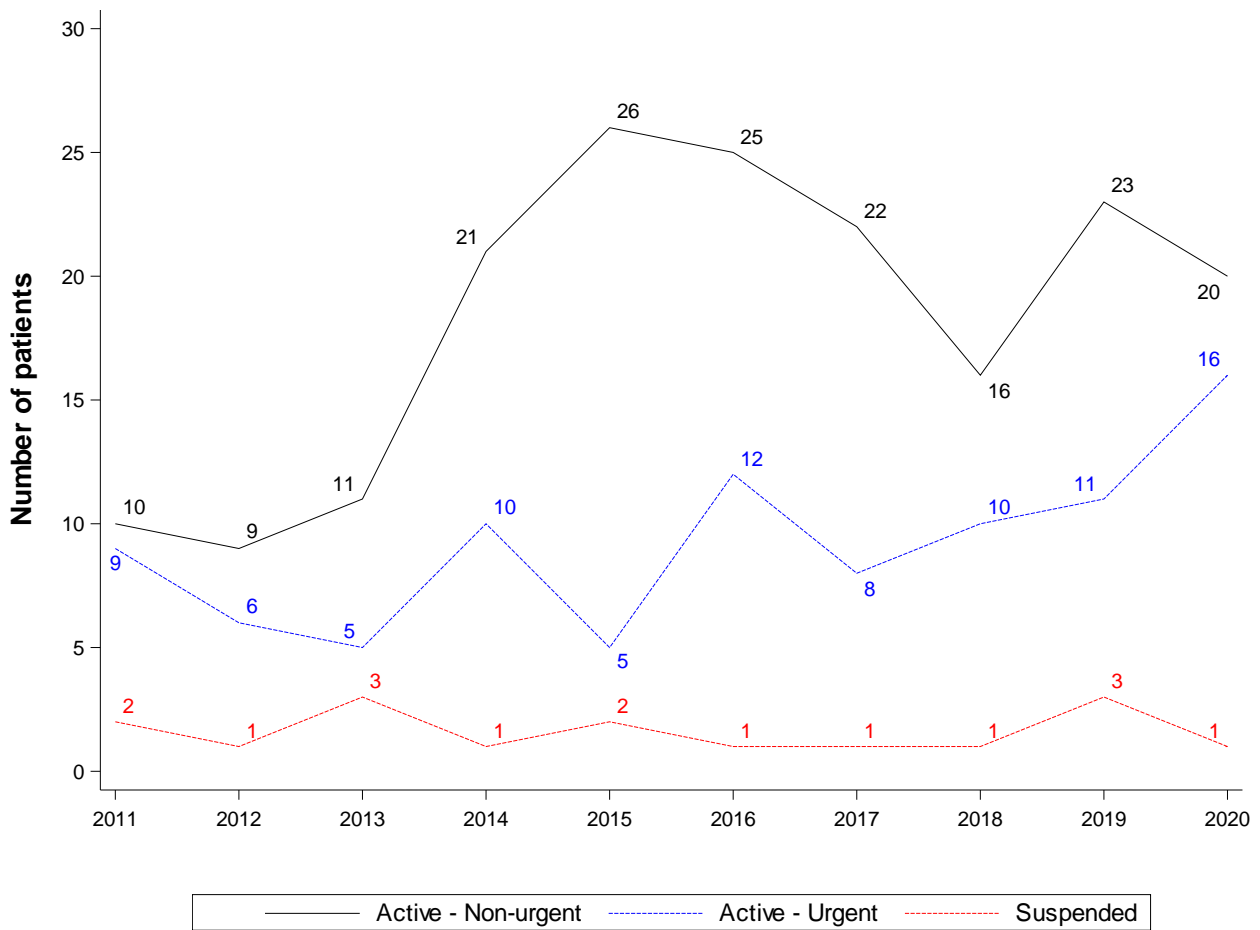


Figure 15.2 shows the number of paediatric patients on the [active heart transplant list](#) at 31 March 2020 by centre and urgency. In total, there were 36 paediatric patients waiting. Great Ormond Street Hospital had the largest overall number of paediatric patients on the transplant list, with equal number of patients on the non-urgent and urgent lists. **Figure 15.3** shows the number of patients split by centre and mechanical circulatory support (MCS) status where MCS includes ventricular assist devices and extracorporeal membrane oxygenation. A total of 4 (11%) of the paediatric heart list were on MCS at 31 March 2020.

Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2020, by centre and urgency

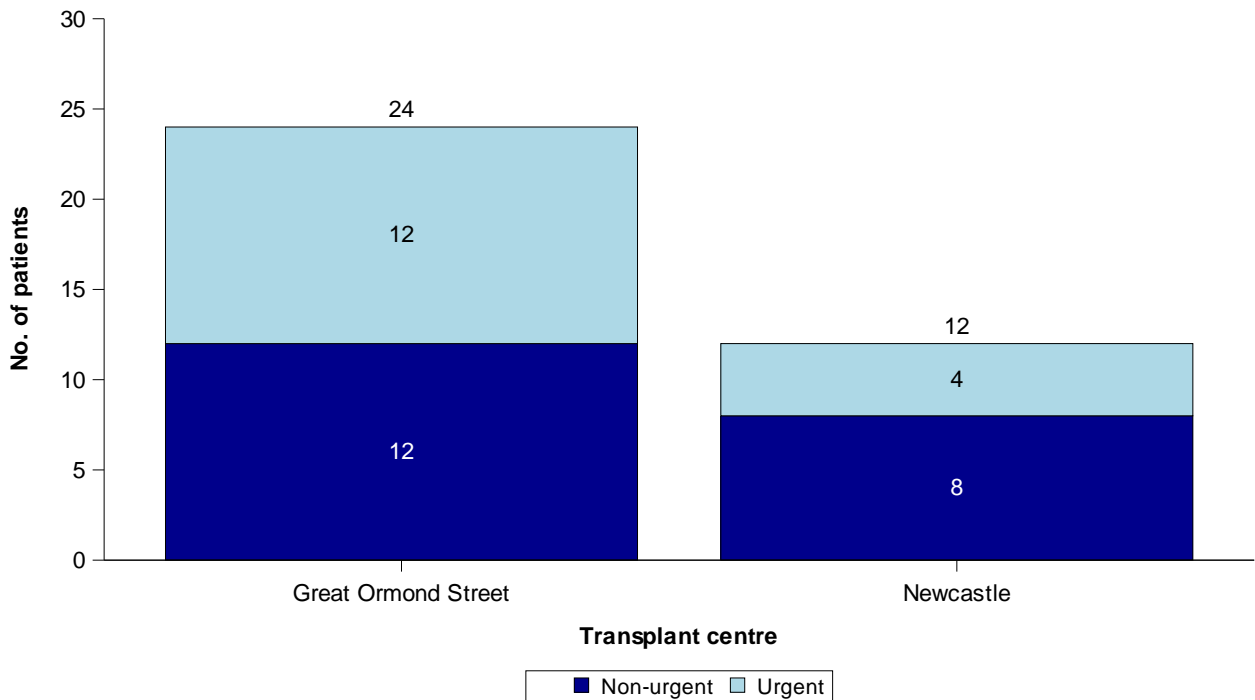


Figure 15.3 Number of paediatric patients on the active heart transplant list at 31 March 2020, by centre and mechanical circulatory support status

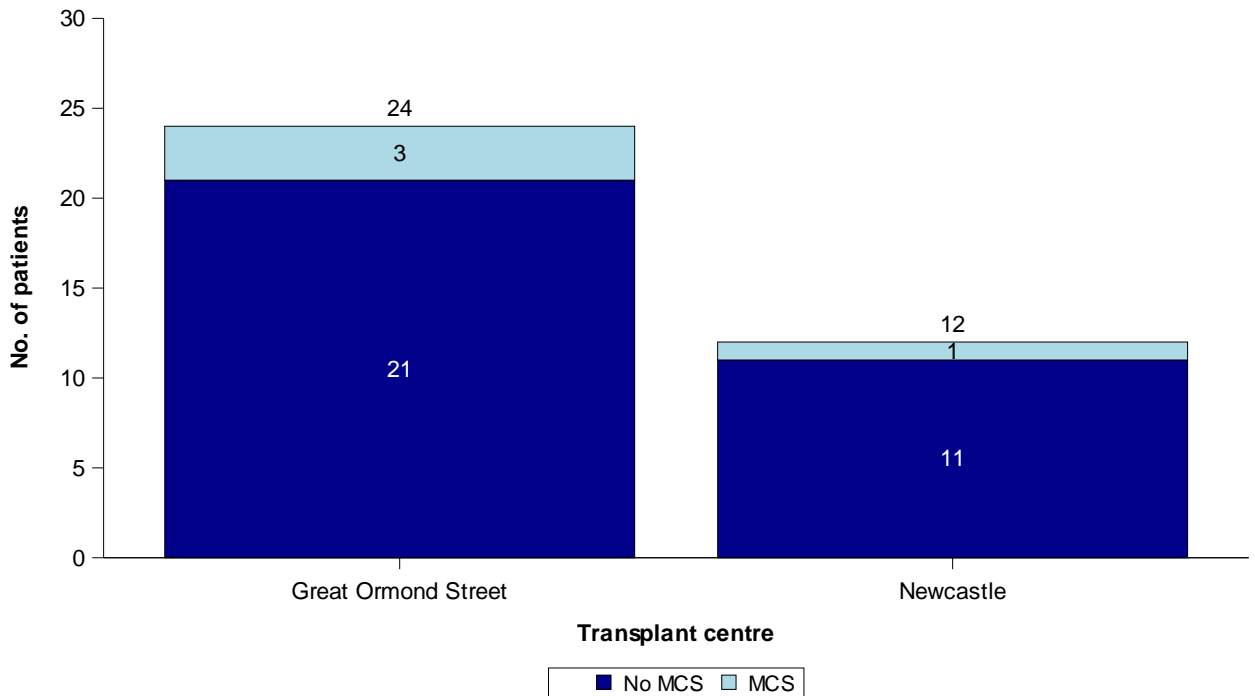
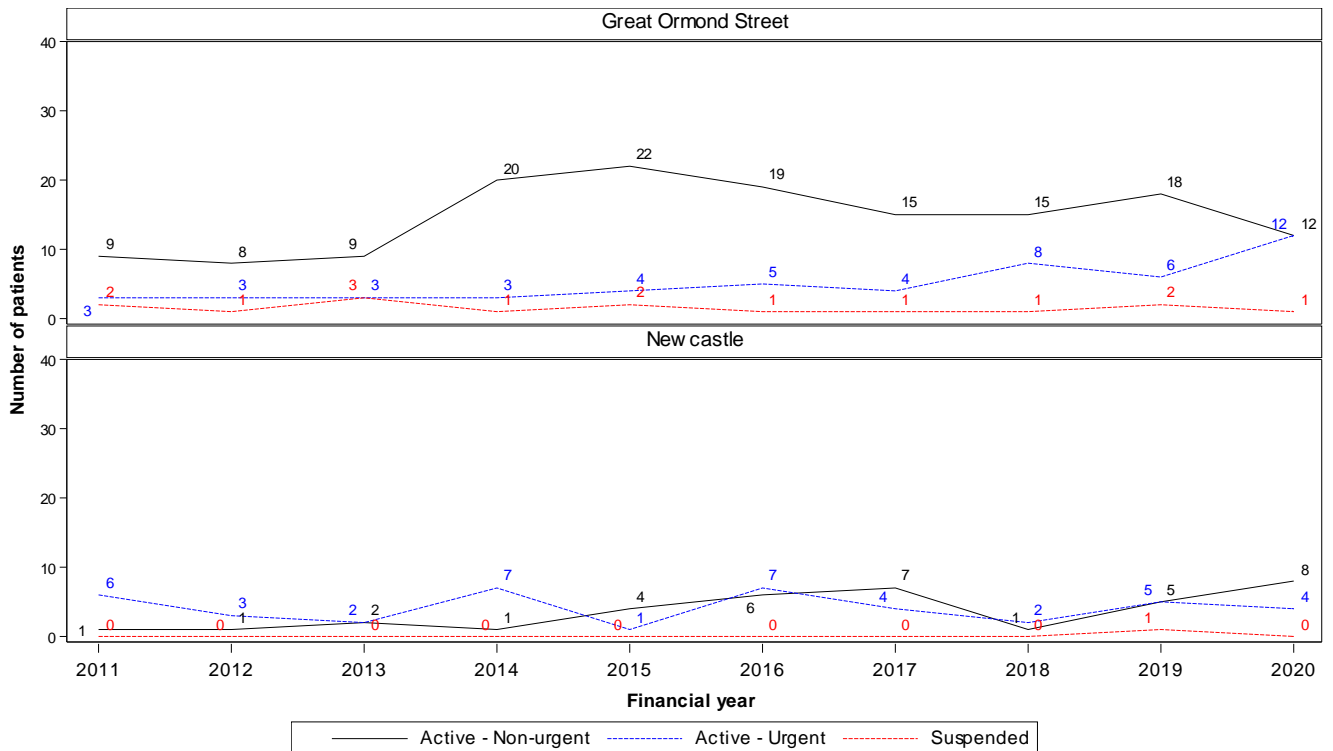


Figure 15.4 shows the trend over time in the number of paediatric patients on the heart transplant list at 31 March each year across each centre. Great Ormond Street Hospital experienced a substantial increase in their non-urgent list in 2014 and since then it has reduced slightly with 12 patients on the list at 31 March 2020. Their urgent list has seen an increase in recent years. Newcastle’s non-urgent list decreased in 2017/18 to 1 but has since risen again this year to 8. There has been no clear upward or downward trend in their urgent list.

Figure 15.4 Number of paediatric patients on the heart transplant list at 31 March each year for the last 10 years, by centre



15.2 Demographic characteristics, 1 April 2019 – 31 March 2020

There were 39 paediatric patient registrations onto the heart transplant list between 1 April 2019 and 31 March 2020. Demographic characteristics of these patients are shown by centre and overall in **Table 15.1**. Nationally, 51% of the patients were male and the [median](#) age was 4 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 15.1 Demographic characteristics of paediatric patients registered onto the heart transplant list between 1 April 2019 and 31 March 2020, by centre				
		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		16 (100)	23 (100)	39 (100)
Highest urgency during registration	Non-urgent	2 (13)	3 (13)	5 (13)
	Urgent	14 (88)	20 (87)	34 (87)
Recipient sex	Male	8 (50)	12 (52)	20 (51)
	Female	8 (50)	11 (48)	19 (49)
Recipient ethnicity	White	10 (63)	19 (83)	29 (74)
	Non-white	5 (31)	4 (17)	9 (23)
	Missing	1 (6)	0 (0)	1 (3)
Recipient age (years)	Median (IQR)	4 (1, 10)	4 (1, 11)	4 (1, 11)
	Missing	0	0	0
Recipient height (cm)	Median (IQR)	97 (74, 143)	93 (75, 140)	93 (75, 140)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	14 (8, 31)	15 (9, 35)	15 (9, 32)
	Missing	0	0	0
Primary Disease	Coronary heart disease	0 (0)	1 (4)	1 (3)
	Cardiomyopathy	12 (75)	9 (39)	21 (54)
	Congenital heart disease	4 (25)	11 (48)	15 (39)
	Graft failure/rejection	0 (0)	1 (4)	1 (3)
	Others	0 (0)	1 (4)	1 (3)
Previous open heart surgery	None	9 (56)	6 (26)	15 (39)
	One	3 (19)	8 (35)	11 (28)
	More than one	4 (25)	9 (39)	13 (33)
Previous thoracotomy	No	15 (94)	21 (91)	36 (92)
	Yes	1 (6)	2 (9)	3 (8)
Serum Bilirubin (umol/l)	Median (IQR)	7 (6, 11)	11 (6, 15)	9 (6, 15)
	Missing	0	2	2
Serum Creatinine (umol/l)	Median (IQR)	27 (20, 35)	40 (26, 63)	30 (23, 47)
	Missing	0	1	1

15.3 Post-registration outcomes, 1 April 2016 – 31 March 2017

The registration outcomes of paediatric patients listed for a non-urgent heart transplant between 1 April 2016 and 31 March 2017 are summarised in **Figure 15.5**. The same information is presented in **Figure 15.6** for those listed for an urgent heart transplant between 1 April 2016 and 31 March 2017 (including those previously on the non-urgent list). The possible outcomes for patients on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists (e.g. from the non-urgent list to the urgent list), dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be “transplanted”.

Within the first 6 months of listing, it is shown that 11% had been transplanted and 6% had died, and 39% were added to the urgent list. At 3 years, still only 11% had been transplanted, however, now 61% of non-urgent recipients were added to the urgent list. As can be seen in **Figure 15.6**, recipients have a greater chance of transplant on the urgent heart list comparative to the non-urgent list. Removals from the urgent list were for a mixture of improved and deteriorating condition.

Figure 15.5 Post-registration outcome for 18 new non-urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017

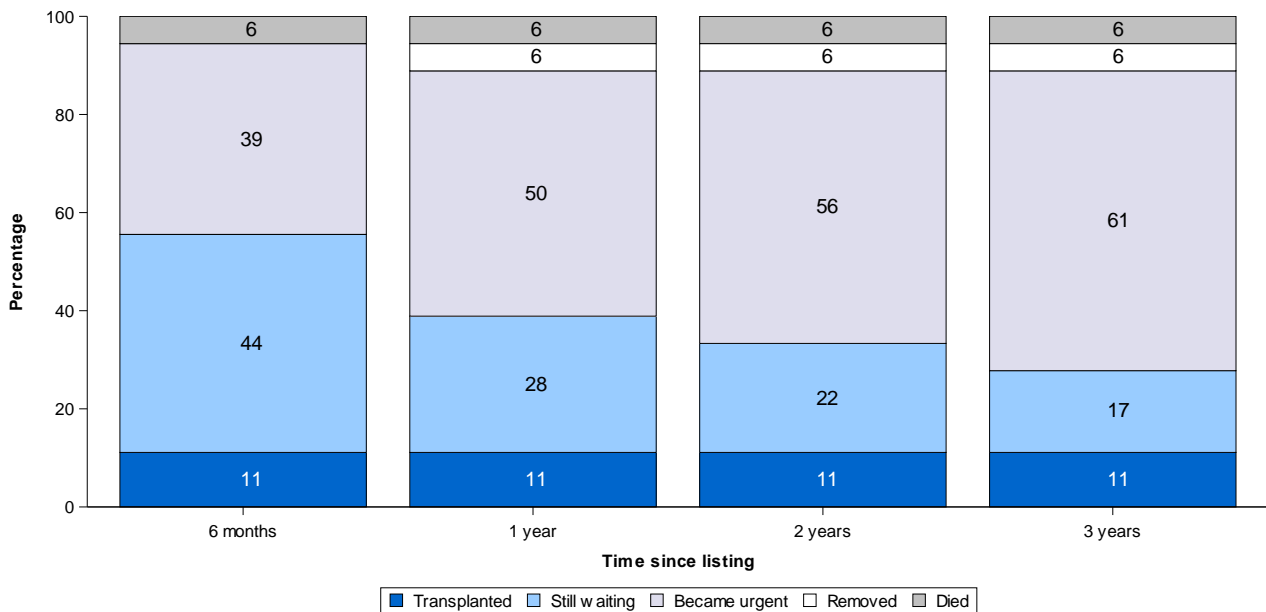
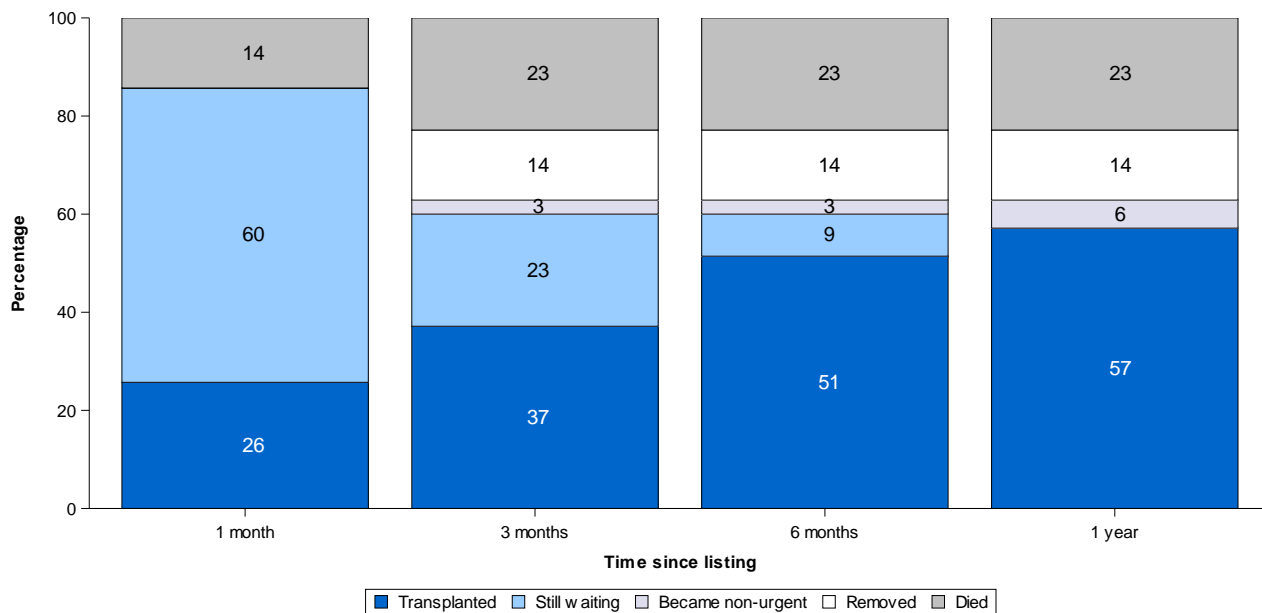


Figure 15.6 Post-registration outcome for 35 new urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2017



15.4 Median waiting time to transplant, 1 April 2014 - 31 March 2017

Table 15.2 shows the [median](#) waiting time to heart transplant from listing for paediatric patients registered between 1 April 2014 and 31 March 2017. This is estimated using the [Kaplan Meier](#) method and is split by the urgency of the patient at initial registration; non-urgent or urgent. All waiting time from initial registration is considered for patients, regardless of any change in urgency. Any suspended time is discounted.

The national [median](#) waiting time to paediatric heart transplant was 427 days from non-urgent registration and 102 days from urgent registration. Waiting times were not seen to be significantly different across centres and urgency status. The [median](#) waiting time to heart transplant for paediatric patients is also considered by blood group in **Table 15.3**.

Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and centre, 1 April 2014 to 31 March 2017			
Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Overall			
Great Ormond Street Hospital	70	199	153 - 245
Newcastle	82	106	59 - 153
UK	152	154	114 - 194
Non-urgent at initial registration			
Great Ormond Street Hospital	32	662	202 - 1122
Newcastle	21	176	65 - 287
UK	53	427	112 - 742
Urgent at initial registration			
Great Ormond Street Hospital	38	105	67 - 143
Newcastle	61	77	6 - 148
UK	99	102	58 - 146

Table 15.3 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and blood group, 1 April 2014 to 31 March 2017

Blood group	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Overall			
O	79	180	133 - 227
A	42	72	11 - 133
B	27	217	130 - 304
AB ¹	4	-	-
UK	152	154	114 - 194
Non-urgent at initial registration			
O	28	491	0 - 990
A	14	98	20 - 176
B	11	662	203 - 1121
AB	0	-	-
UK	53	427	112 - 742
Urgent at initial registration			
O	51	106	67 - 145
A	28	42	11 - 73
B	16	154	85 - 223
AB ¹	4	-	-
UK	99	102	58 - 146

¹ Median waiting time for groups with less than 10 registrations are not presented due to small numbers

PAEDIATRIC HEART TRANSPLANTATION

Response to Offers



16. Response to Offers

Table 16.1 compares individual centre paediatric heart offer decline rates over the three years between 1 April 2017 and 31 March 2020. This only considers offers of UK DBD donor hearts that were eventually transplanted and excludes fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. No response to a group offer is considered an assumed decline. To account for this in the analysis of non-urgent offers post-22 June 2017, any centre who is ranked above the accepting centre in the allocation sequence for that donor is assumed to have declined the heart.

The number of overall offers received per year has remained relatively constant with Newcastle generally having a lower offer decline rate than Great Ormond Street Hospital (GOSH), however this is based on small numbers.

Table 16.1 UK paediatric DBD donor heart offer decline rates by transplant centre and year, 1 April 2017 to 31 March 20120								
Centre	2017/18		2018/19		2019/20		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
GOSH	15	(73.3)	16	(50.0)	14	(78.6)	45	(66.7)
Newcastle	11	(27.3)	8	(25.0)	15	(46.7)	34	(35.3)
UK	26	(53.8)	24	(41.7)	29	(62.1)	79	(53.2)

PAEDIATRIC HEART TRANSPLANTATION

Transplants



17.1 Paediatric heart transplants, 1 April 2010 – 31 March 2020

Figure 17.1 and **17.2** show the number of paediatric heart transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants was highest in 2010/2011 and lowest in the most recent year 2019/20. Last year's activity is shown by centre in **Figure 17.3**. The 23 transplants carried out in 2019/2020 comprised 13 at Newcastle and 10 at Great Ormond Street Hospital.

Figure 17.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2010 to 31 March 2020

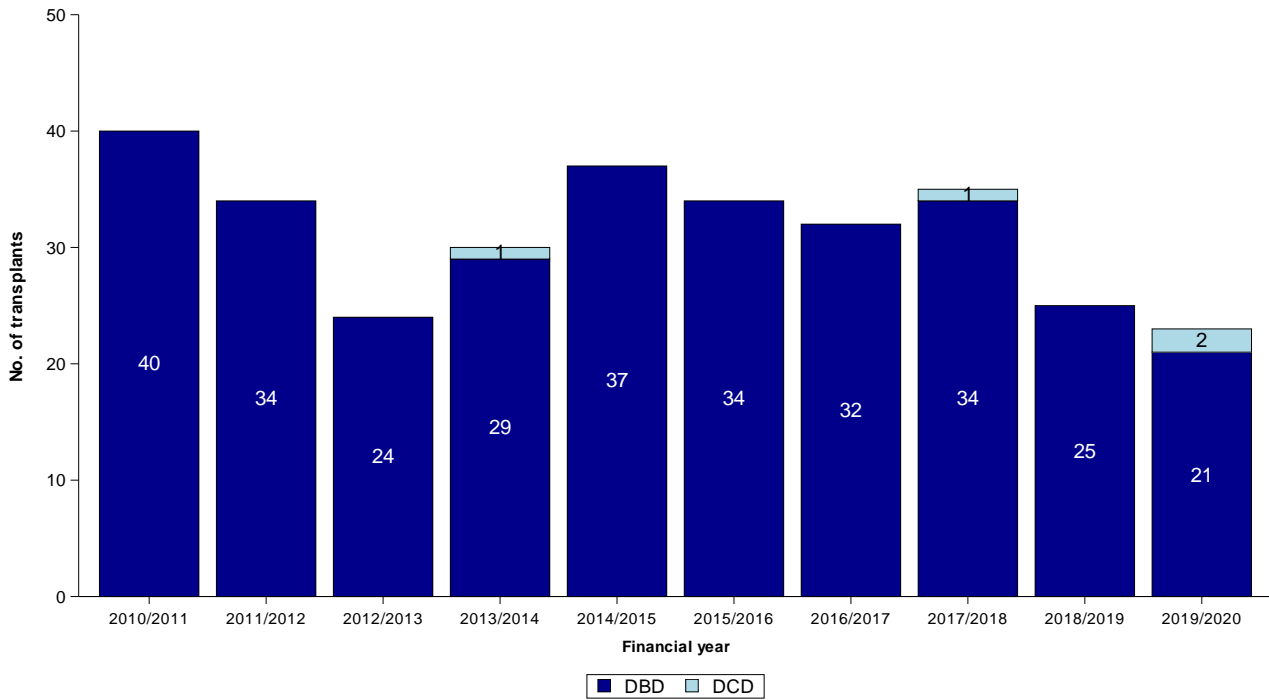


Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2010 to 31 March 2020

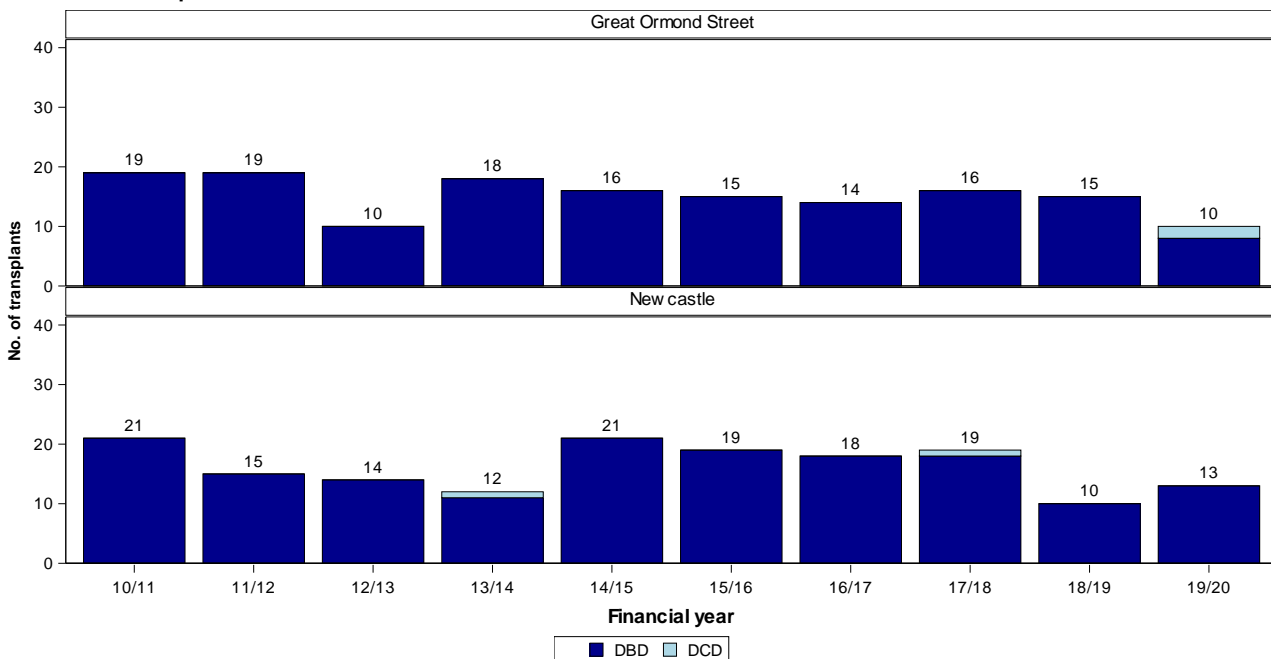


Figure 17.3 Number of paediatric heart transplants in the UK, by centre and donor type, 1 April 2019 to 31 March 2020

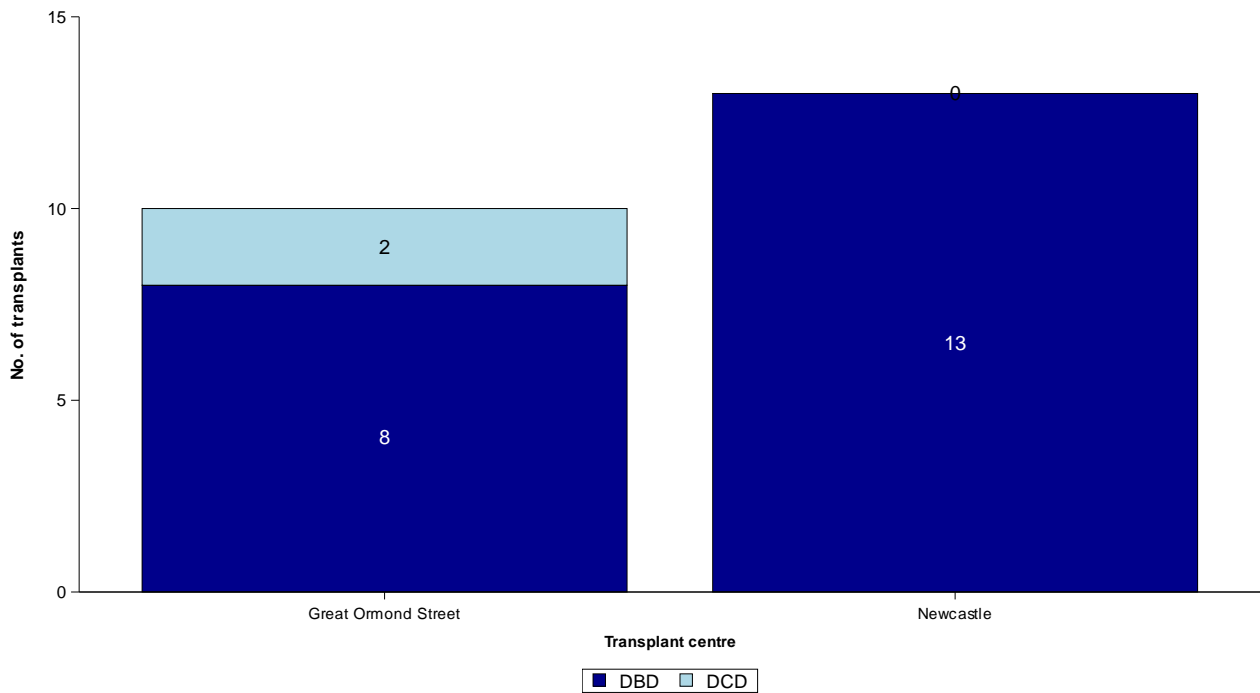


Figure 17.4 and **17.5** show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. In the last year the proportion of non-urgent transplants performed has been low compared with the preceding five years, but overall the proportion of non-urgent transplants was 17%. Last year's activity is shown by centre and urgency status in **Figure 17.6**.

Figure 17.4 Number of paediatric heart transplants in the UK, by financial year and urgency status, 1 April 2010 to 31 March 2020

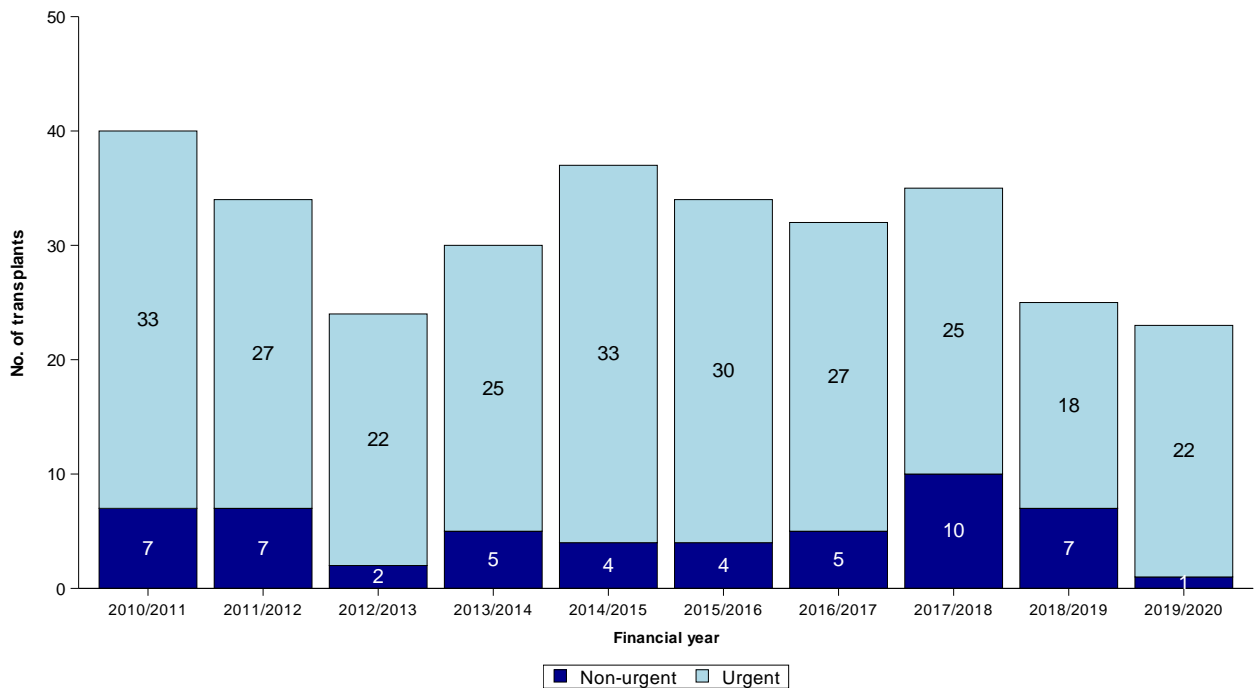


Figure 17.5 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2010 to 31 March 2020

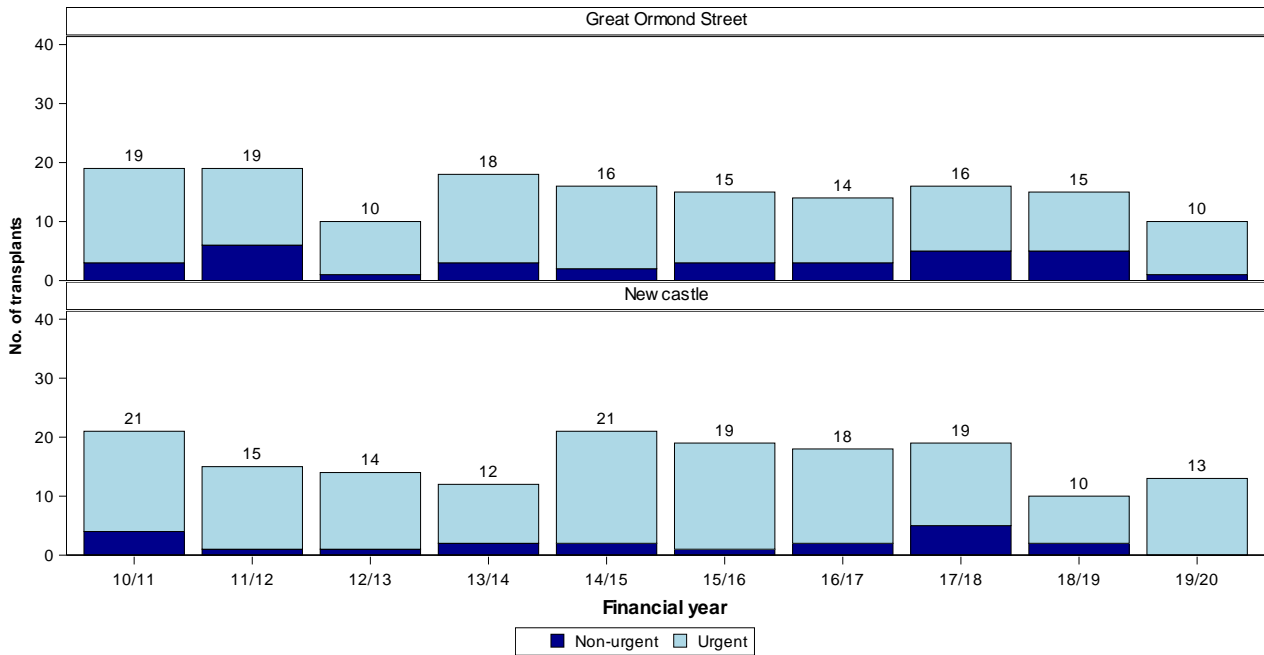
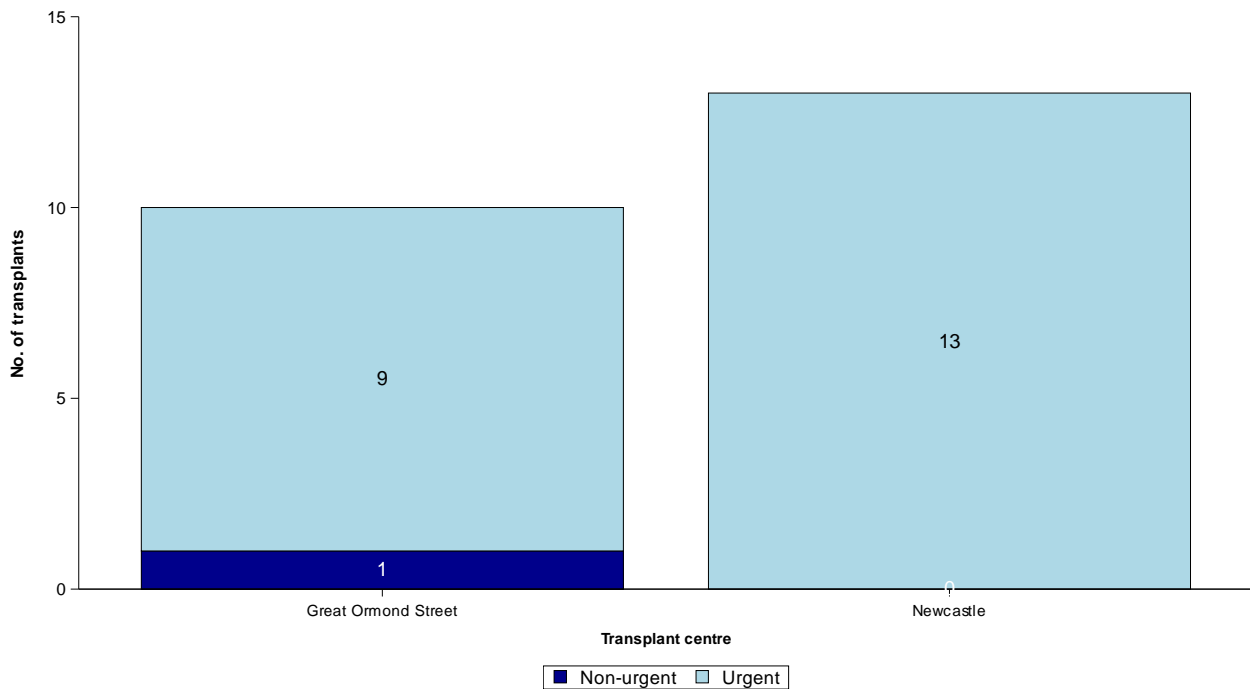


Figure 17.6 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2019 to 31 March 2020



17.2 Demographic characteristics of transplants, 1 April 2019 – 31 March 2020

The demographic characteristics of the 23 paediatric heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 17.1**. Nationally, 52% of heart recipients were female and the [median](#) age was 7 years, while the median age of donors was 15 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2019 to 31 March 2020, by centre				
		Great Ormond Street Hospital	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		10 (100)	13 (100)	23 (100)
Urgency status at transplant	Non-urgent	1 (10)	0 (0)	1 (4)
	Urgent	9 (90)	13 (100)	22 (96)
Recipient sex	Male	5 (50)	6 (46)	11 (48)
	Female	5 (50)	7 (54)	12 (52)
Recipient ethnicity	White	6 (60)	11 (85)	17 (74)
	Non-white	4 (40)	2 (15)	6 (26)
Recipient age (years)	Median (IQR)	8 (5, 12)	6 (1, 12)	7 (4, 12)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	28 (15, 36)	19 (10, 39)	24 (12, 39)
	Missing	0	0	0
Recipient primary disease	Coronary heart disease	0 (0)	0 (0)	0 (0)
	Cardiomyopathy	8 (80)	8 (62)	16 (70)
	Congenital heart disease	2 (20)	4 (31)	6 (26)
	Graft failure/rejection	0 (0)	1 (8)	1 (4)
NYHA class	I	0 (0)	0 (0)	0 (0)
	II	2 (20)	0 (0)	2 (9)
	III	3 (30)	1 (8)	4 (17)
	IV	5 (50)	12 (92)	17 (74)
Recipient in hospital pre-transplant	No	3 (30)	1 (8)	4 (17)
	Yes	7 (70)	12 (92)	19 (83)
If in hospital, recipient on ventilator	No	5 (71)	8 (67)	13 (68)
	Yes	2 (29)	3 (25)	5 (26)
	Missing	0 (0)	1 (8)	1 (5)
If in hospital, recipient on VAD	None	2 (29)	5 (42)	7 (37)
	Left	3 (43)	2 (17)	5 (26)
	Right	0 (0)	0 (0)	0 (0)
	Both	2 (29)	4 (33)	6 (32)
	Missing	0 (0)	1 (8)	1 (5)
If in hospital, recipient on TAH	No	7 (100)	12 (100)	19 (100)
If in hospital, recipient on ECMO	No	6 (86)	11 (92)	17 (90)
	Yes	1 (14)	0 (0)	1 (5)
	Missing	0 (0)	1 (8)	1 (5)
If in hospital, recipient on inotropes	No	5 (71)	1 (8)	6 (32)
	Yes	2 (29)	10 (83)	12 (63)
	Missing	0 (0)	1 (8)	1 (5)
If in hospital, recipient on IABP	No	7 (100)	11 (92)	18 (95)
	Missing	0 (0)	1 (8)	1 (5)

Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2019 to 31 March 2020, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Recipient CMV status	No	6 (60)	9 (69)	15 (65)
	Yes	3 (30)	3 (23)	6 (26)
	Missing	1 (10)	1 (8)	2 (9)
Recipient HCV status	No	9 (90)	12 (92)	21 (91)
	Missing	1 (10)	1 (8)	2 (9)
Recipient HBV status	No	9 (90)	12 (92)	21 (91)
	Missing	1 (10)	1 (8)	2 (9)
Recipient HIV status	No	9 (90)	12 (92)	21 (91)
	Missing	1 (10)	1 (8)	2 (9)
Recipient serum creatinine (umol/l)	Median (IQR)	36 (25, 47)	35 (25, 44)	35 (25, 47)
	Missing	0	0	0
Donor sex	Male	4 (40)	7 (54)	11 (48)
	Female	6 (60)	6 (46)	12 (52)
Donor ethnicity	White	8 (80)	9 (69)	17 (74)
	Non-white	1 (10)	3 (23)	4 (17)
	Missing	1 (10)	1 (8)	2 (9)
Donor age (years)	Median (IQR)	21 (10, 30)	14 (3, 19)	15 (6, 24)
	Missing	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	19 (18, 22)	20 (17, 22)	19 (17, 22)
	Missing	0	0	0
Donor cause of death	CVA	8 (80)	11 (85)	19 (83)
	Others	2 (20)	2 (15)	4 (17)
Donor hypotension	No	7 (70)	3 (23)	10 (44)
	Yes	2 (20)	7 (54)	9 (39)
	Missing	1 (10)	3 (23)	4 (17)
Donor past diabetes	No	10 (100)	12 (92)	22 (96)
	Missing	0 (0)	1 (8)	1 (4)
Donor past cardiothoracic disease	No	9 (90)	12 (92)	21 (91)
	Missing	1 (10)	1 (8)	2 (9)
Donor past hypertension	No	10 (100)	12 (92)	22 (96)
	Missing	0 (0)	1 (8)	1 (4)
Donor past tumour	No	9 (90)	12 (92)	21 (91)
	Yes	1 (10)	0 (0)	1 (4)
	Missing	0 (0)	1 (8)	1 (4)
Donor past smoker	No	6 (60)	11 (85)	17 (74)
	Yes	4 (40)	1 (8)	5 (22)
	Missing	0 (0)	1 (8)	1 (4)
Total ischaemia time (hours)	Median (IQR)	3.9 (2.6, 4.8)	3.5 (2.9, 4.1)	3.7 (2.9, 4.4)
	Missing	1	0	1

17.3 Total ischaemia time, 1 April 2010 – 31 March 2020

Figure 17.7 shows [boxplots](#) of total ischaemia time for [DBD](#) donor hearts transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The national [median](#) total ischaemia time varied between 3.4 and 3.9 hours over the decade with no upward or downward trend.

Figure 17.7 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by financial year, 1 April 2010 to 31 March 2020

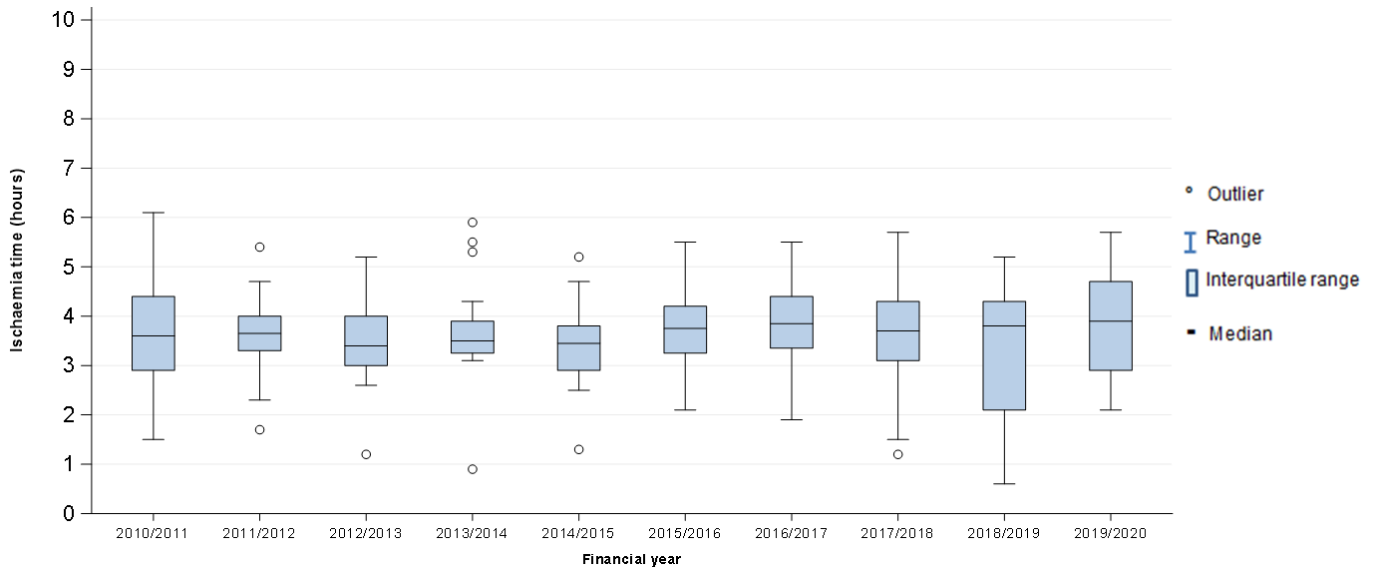


Figure 17.8 and **Figure 17.9** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2019/2020) and over the last 10 years, respectively. Generally, the median ischaemia times for Newcastle were marginally shorter than the median ischaemia times for Great Ormond Street Hospital.

Figure 17.8 Boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients, by transplant centre, 1 April 2019 to 31 March 2020

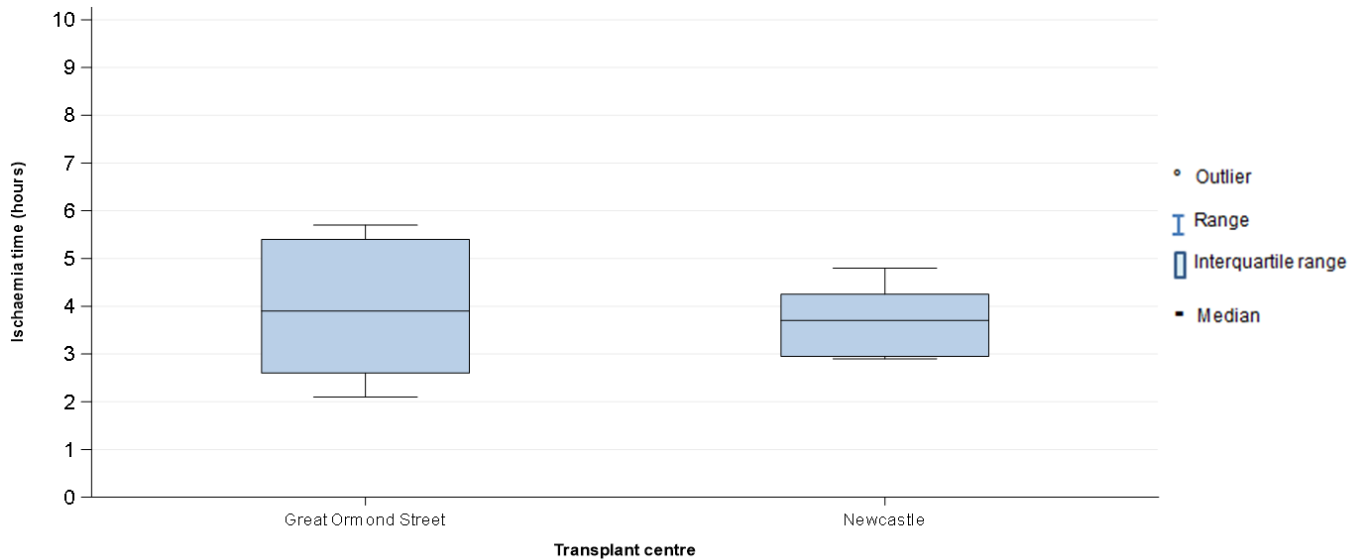
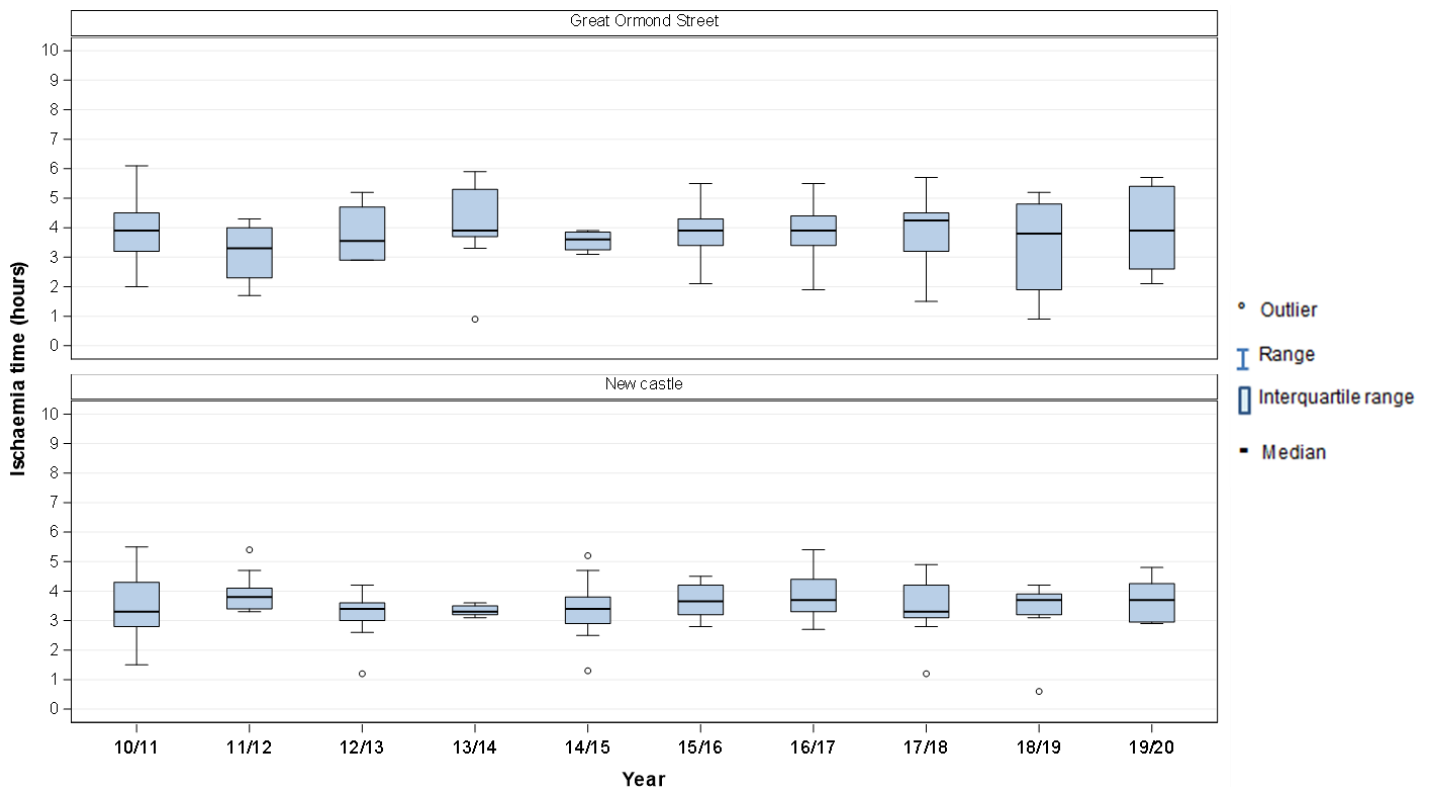


Figure 17.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2010 to 31 March 2020



PAEDIATRIC HEART TRANSPLANTATION

Post-Transplant Survival



18. Post-Transplant Survival

The survival analyses presented in this section exclude [multi-organ transplants](#) and include first time transplants only. Thirty-day, ninety-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2015 to 31 March 2019 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2011 to 31 March 2015.

The 30-day post-transplant [unadjusted](#) patient survival rate for each centre and nationally are shown in **Table 18.1** for the 122 first paediatric heart only transplants in the period 1 April 2015 to 31 March 2019. As the 95% [confidence limits](#) for the survival estimates for Great Ormond Street Hospital and Newcastle overlap this indicates that there is no statistically significant difference between the rates at the two centres.

Table 18.1 30 day patient survival rates after first paediatric heart only transplant, by centre, 1 April 2015 to 31 March 2019				
Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	59	1	98.3	(88.6 - 99.8)
Newcastle	63	4	93.7	(84.0 - 97.6)
UK	122	5	95.9	(90.4 - 98.3)

The 90 day post-transplant [unadjusted survival rates](#) are shown in **Table 18.2**. There was no statistically significant difference between the two centres' rates.

Table 18.2 90 day patient survival rates after first paediatric heart only transplant, by centre, 1 April 2015 to 31 March 2019				
Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	59	1	98.3	(88.6 - 99.8)
Newcastle	63	4	93.7	(84.0 - 97.6)
UK	122	5	95.9	(90.4 - 98.3)

The one year post-transplant [unadjusted survival rates](#) are shown in **Table 18.3**. Again, there was no statistically significant difference between the two centres' rates.

Table 18.3 1 year day patient survival after first paediatric heart only transplant, by centre, 1 April 2015 to 31 March 2019				
Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	59	1	98.3	(88.6 - 99.8)
Newcastle	63	7	88.9	(78.1 - 94.5)
UK	122	8	93.4	(87.3 - 96.7)

Five year [survival rates](#) were estimated from the 123 first paediatric heart only transplants performed in the period 1 April 2011 to 31 March 2015. The [unadjusted patient survival rates](#) are shown in **Table 18.4**. There was no statistically significant difference between the two centres' rates.

Table 18.4 5 year patient survival after first paediatric heart only transplant, by centre, 1 April 2011 to 31 March 2015				
Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	63	11	82	(69.8 - 89.6)
Newcastle	60	12	79.3	(66.4 - 87.7)
UK	123	23	80.7	(72.3 - 86.7)

PAEDIATRIC HEART TRANSPLANTATION

Form Return Rates



19. Paediatric heart form return rates, 1 January – 31 December 2019

Form return rates are reported in **Table 19.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric heart transplants between 1 January and 31 December 2018 for the transplant record, and all follow up forms issued in this time period. There are no forms from either centre outstanding for this period.

Table 19.1 Form return rates for paediatric heart transplants, 1 January 2019 to 31 December 2019									
Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up		
	No. requested	% returned	No. requested	% returned	No. requested	% returned	No. requested	% returned	
Great Ormond Street Hospital	9	100	11	100	13	100	113	100	
Newcastle, Freeman Hospital	11	100	9	100	15	100	197	100	
Overall	20	100	20	100	28	100	310	100	

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List



20.1 Paediatric lung and heart/lung transplant list as at 31 March, 2011 – 2020

Figure 20.1 shows the number of paediatric patients on the lung transplant list at 31 March each year between 2011 and 2020 split by urgency status. The number of patients on the active lung transplant list was highest in 2013. It has since decreased to 2 as at 31 March 2020. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2020, there were no patients on the super-urgent list and one patient on the urgent list. There are usually 3 or fewer paediatric patients active for a heart-lung transplant, but none at the end of the last three financial years.

Figure 20.1 Number of paediatric patients on the lung transplant list at 31 March, by year

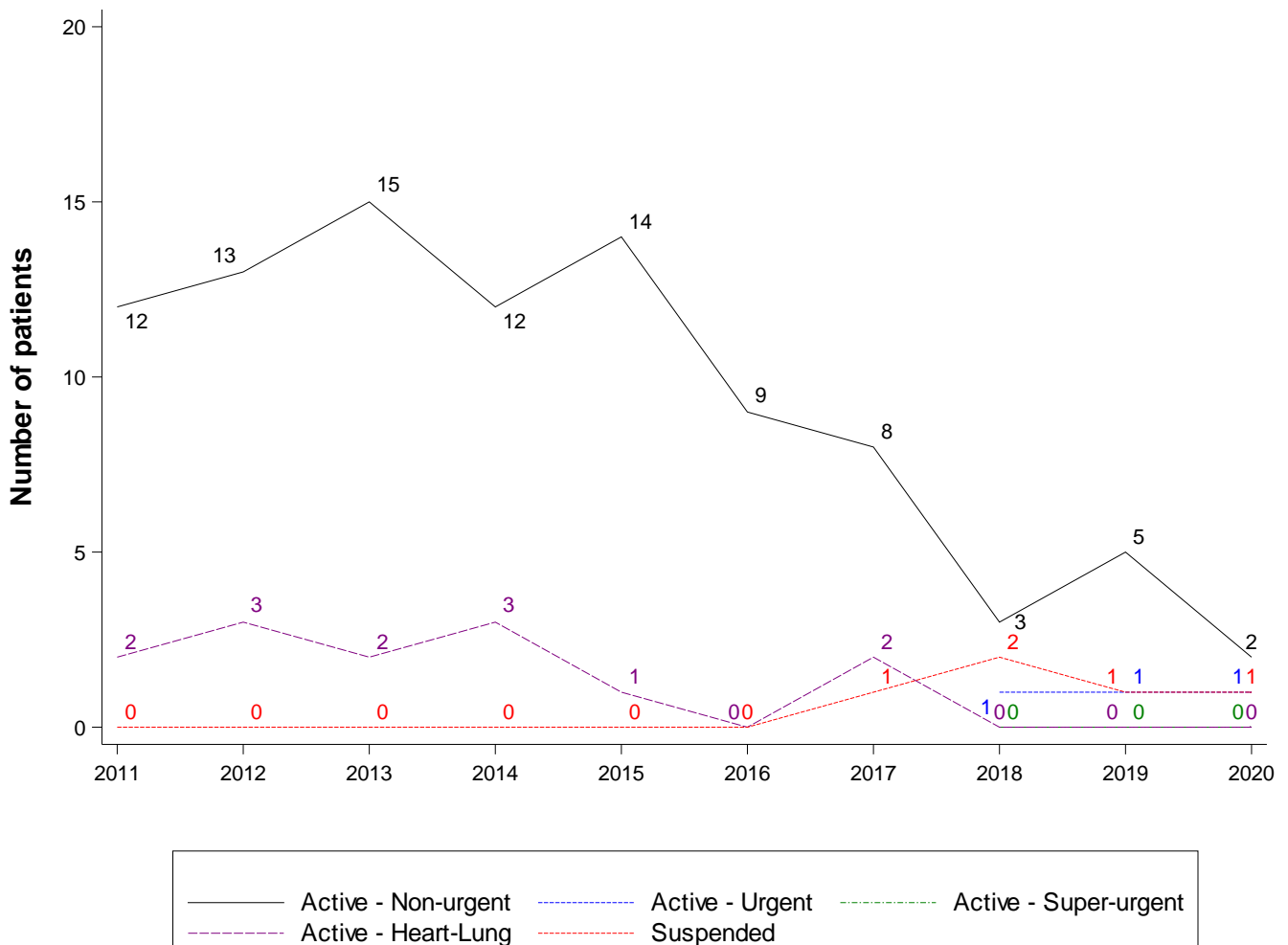


Figure 20.2 shows the number of paediatric patients on the [active lung transplant list](#) at 31 March 2020 by centre. In total, there were 3 paediatric patients waiting; 2 at Great Ormond Street Hospital and 1 at Newcastle. One patient at Great Ormond Street Hospital was on the urgent list and no patients were on the super-urgent list at either centre.

Figure 20.2 Number of paediatric patients on the active lung transplant list at 31 March 2020, by centre and urgency

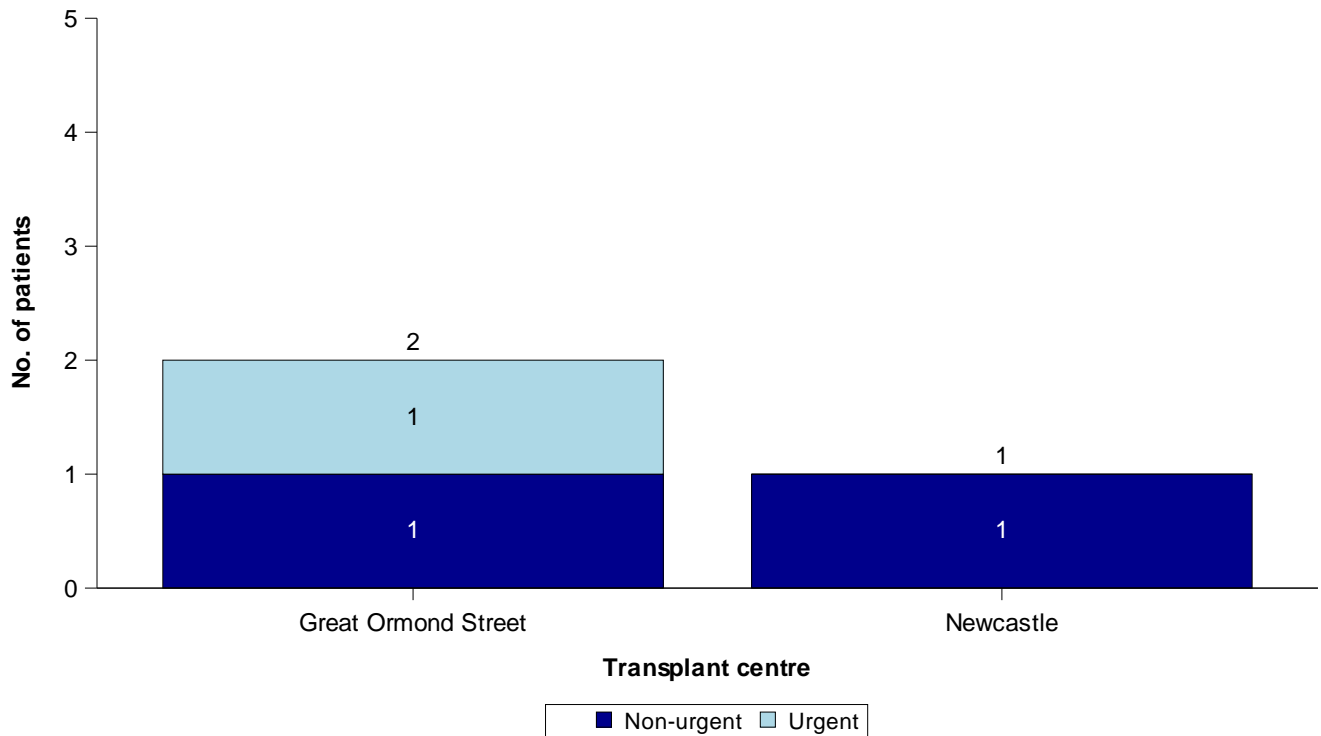
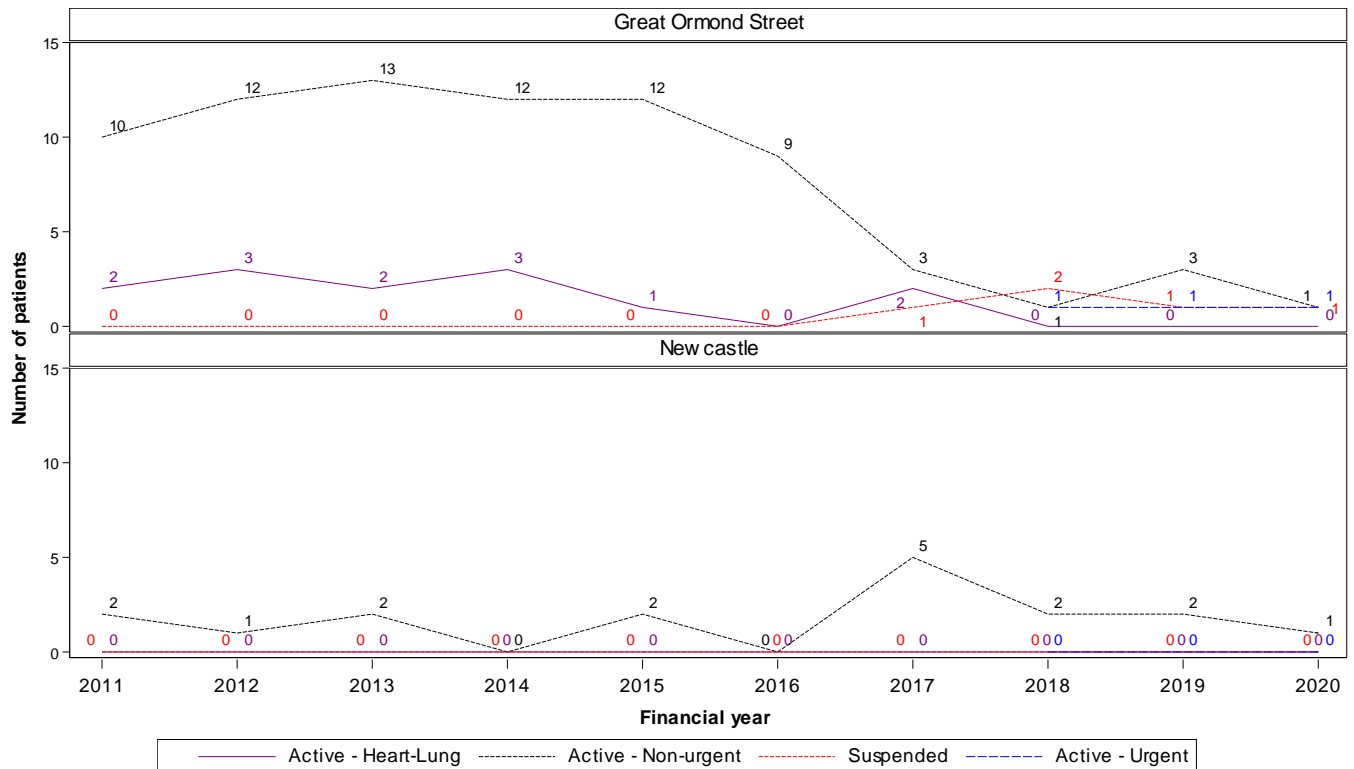


Figure 20.3 shows the trend over time in the number of paediatric patients on the lung transplant list at each centre at 31 March each year between 2011 and 2020. Great Ormond Street Hospital experienced an increase in their list between 2011 and 2013 but after remaining high for several years it has now decreased to just one patient on the non-urgent list on 31 March 2020. Newcastle had a peak of five patients on their list in 2017, but this has now decreased to one.

Figure 20.3 Number of paediatric patients on the lung transplant list at 31 March each year for the last 10 years, by centre



20.2 Demographic characteristics, 1 April 2018 – 31 March 2020

There were 13 paediatric registrations onto the lung transplant list between 1 April 2018 and 31 March 2020 (two years analysed due to small numbers). Demographic characteristics of these patients are shown by centre and overall in **Table 20.1**. Nationally, 71% of the patients were female and the [median](#) age was 13 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 20.1 Demographic characteristics of paediatric patients registered onto the lung transplant list between 1 April 2018 and 31 March 2020, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		12 (100)	2 (100)	14(100)
Year of registration	2018/2019	9 (75)	1 (50)	10 (71)
	2019/2020	3 (25)	1 (50)	4 (29)
Highest urgency during registration	Non-urgent	10 (83)	1 (50)	11 (79)
	Urgent	2 (17)	0 (0)	2 (14)
	Super-Urgent	0 (0)	1 (50)	1 (7)
Recipient sex	Male	3 (25)	1 (50)	4 (29)
	Female	9 (75)	1 (50)	10 (71)
Recipient ethnicity	White	11 (92)	2 (100)	13 (93)
	Non-white	1 (8)	0 (0)	1 (7)
Recipient age (years)	Median (IQR) ¹	14 (12, 14)	-	13 (11, 14)
	Missing	0	0	0
Height (cm)	Median (IQR) ¹	151 (145, 166)	-	147 (122, 162)
	Missing	0	0	0
Weight (kg)	Median (IQR) ¹	42 (38, 67)	-	42 (22, 63)
	Missing	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	3 (25)	0 (0)	3 (21)
	Fibrosing lung disease	1 (8)	1 (50)	2 (14)
	Primary pulmonary hypertension	4 (33)	0 (0)	4 (29)
	Other heart/lung disease	4 (33)	1 (50)	5 (36)
Lung function - FEV1 (litres)	Median (IQR) ¹	1.68 (0.58, 2.80)	-	1.68 (0.58, 2.80)
	Missing	1	2	3
Lung function – FVC (litres)	Median (IQR) ¹	2.08 (0.85, 3.87)	-	2.08 (0.85, 3.87)
	Missing	1	2	3

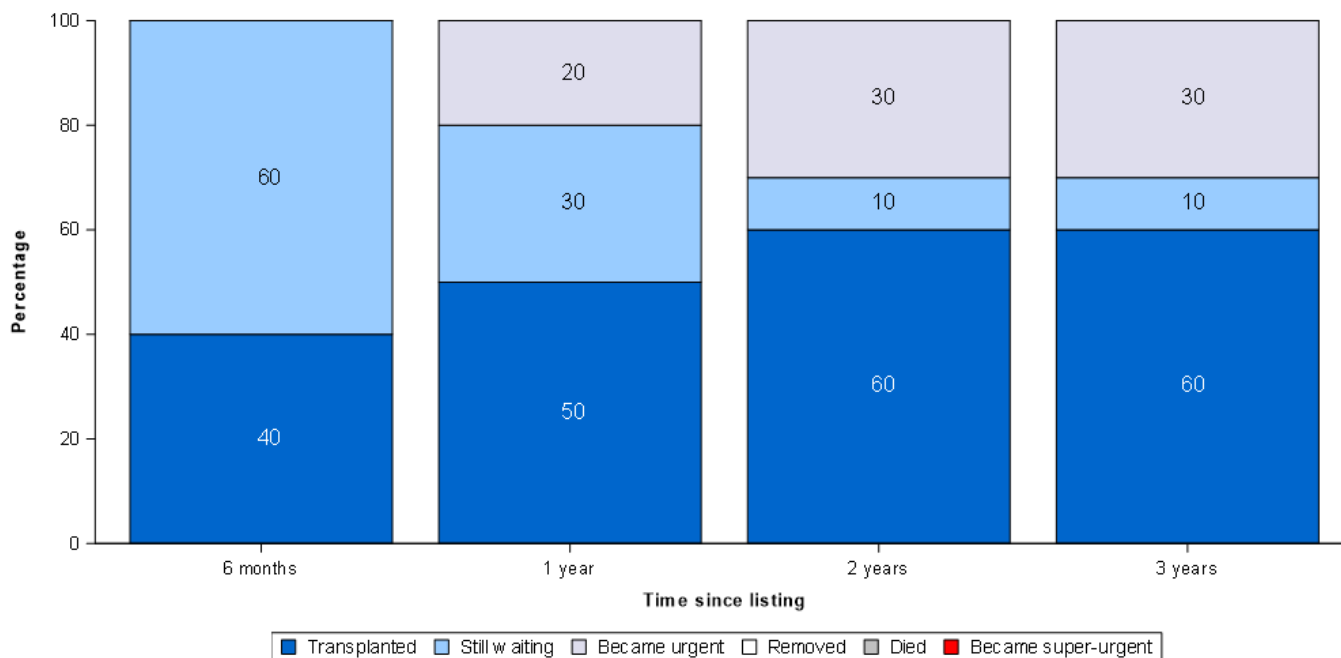
¹ Medians for groups with less than 5 registrations are not presented due to small numbers

20.3 Post-registration outcomes, 1 April 2016 – 31 March 2017

The registration outcomes of paediatric patients listed for a lung transplant between 1 April 2016 and 31 March 2017 are summarised in **Figure 20.4**. The possible outcomes for patients on the list include receiving a transplant, removal from the list, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be “transplanted”.

Within six months of listing, 40% of patients were transplanted and the remaining 60% were still waiting whilst after three years, the transplant rate had increased to 60%, and 30% had been moved to the urgent list. Please note this is only based on 10 patients. Note also that the urgent and super-urgent lung allocation schemes were introduced in May 2017.

Figure 20.4 Post-registration outcome for 10 new lung only registrations made in the UK, 1 April 2016 to 31 March 2017



20.4 Median waiting time to transplant, 1 April 2014 - 31 March 2017

The [median](#) waiting time to lung transplant from registration for paediatric patients registered between 1 April 2014 and 31 March 2017 is shown in **Table 20.2**. This is estimated using the [Kaplan Meier](#) method. Any suspended time is discounted, but any time on the urgent list which was introduced in May 2017 is included. The national median waiting time to paediatric lung transplant was 233 days.

Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the transplant list, by centre, 1 April 2014 to 31 March 2017

Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Great Ormond Street Hospital	19	162	85 - 239
Newcastle ¹	11	445	124 - 766
UK	30	233	194 - 272

PAEDIATRIC LUNG TRANSPLANTATION

Response to Offers



21. Response to Offers

Table 21.1 compares individual centre paediatric bilateral lung offer decline rates between 1 April 2017 and 31 March 2020. This only considers offers of UK DBD donor lungs that were eventually transplanted and excludes fast track offers. A bilateral lung offer is counted as accepted if both lungs or just one lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lung(s) is/are declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

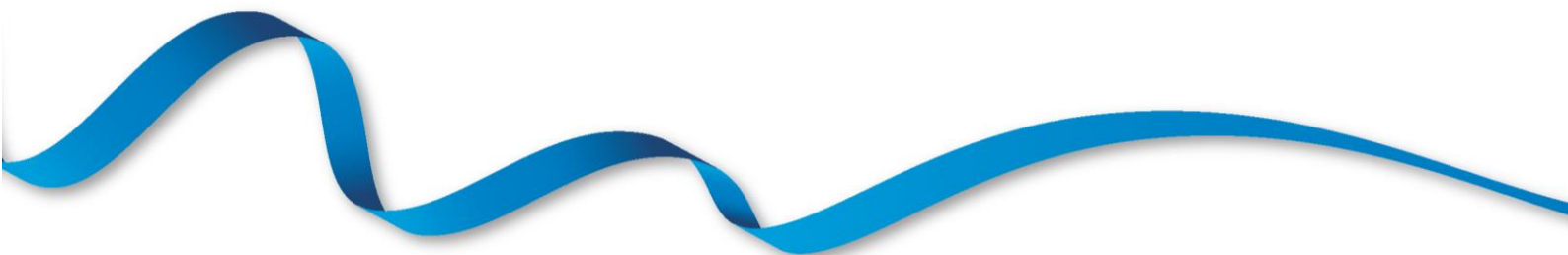
On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. No response to a group offer is considered an assumed decline. To account for this in the analysis of non-urgent offers post-22 June 2017, any centre who is ranked above the accepting centre in the allocation sequence for that donor is assumed to have declined the lungs.

The national decline rate was 87.0% and was relatively similar between centres given the small numbers of offers.

Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2017 to 31 March 2020		
Centre	Number of offers	Decline rate (%)
Great Ormond Street Hospital	11	(90.9)
Newcastle	12	(83.3)
UK	23	(87.0)

PAEDIATRIC LUNG TRANSPLANTATION

Transplants



22.1 Paediatric lung and heart-lung transplants, 1 April 2010 – 31 March 2020

Figure 22.1 and 22.2 show the number of paediatric lung and heart-lung transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants increased between 2013/2014 and 2016/2017 but has since decreased to four in 2019/2020. The majority of paediatric lung transplants over the decade were performed by Great Ormond Street Hospital. The number of transplants in the latest financial year (2019/2020) is shown by centre and donor type in Figure 22.3. All transplants used DBD donor lungs.

Figure 22.1 Number of paediatric lung transplants in the UK, by financial year and donor type, 1 April 2010 to 31 March 2020

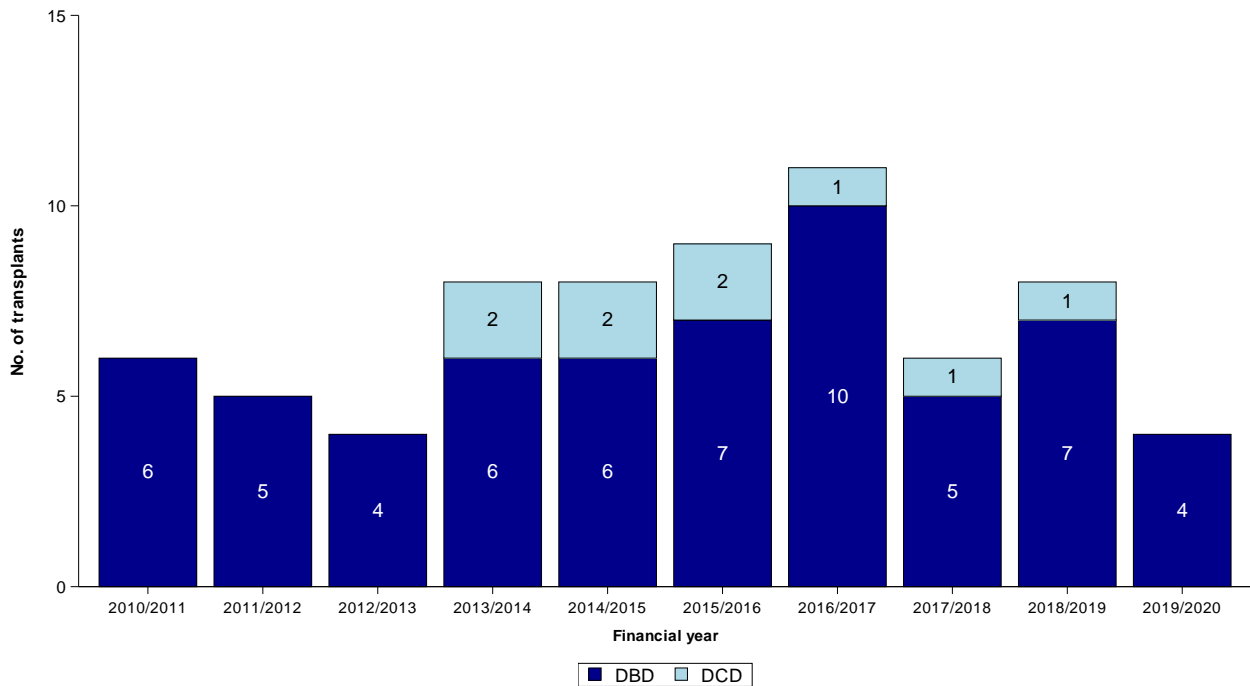


Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2010 to 31 March 2020

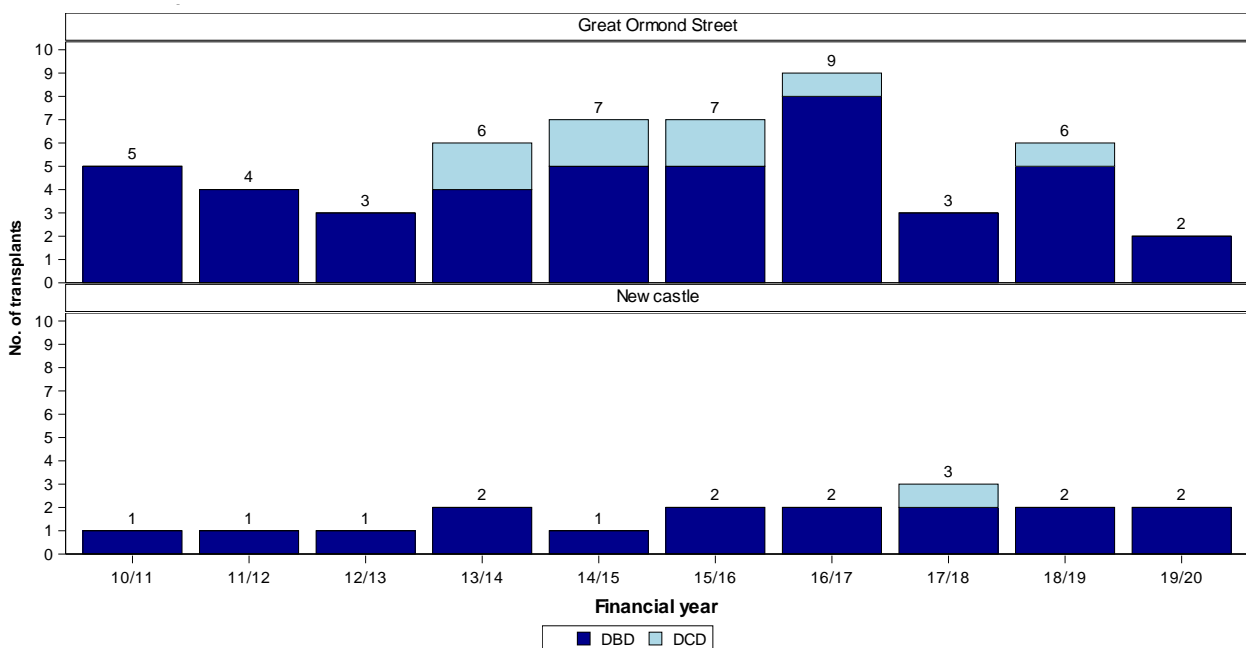


Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2019 to 31 March 2020

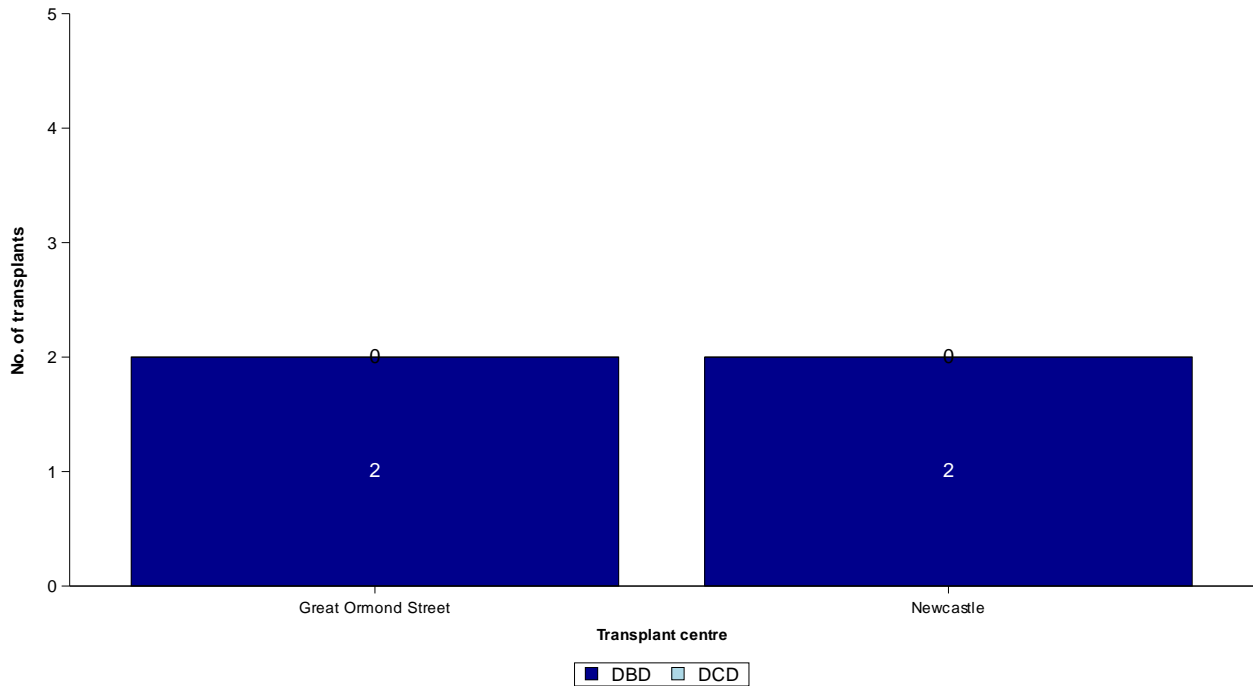


Figure 22.4 and 22.5 show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period there have been three paediatric heart-lung block transplants. Newcastle performed one partial lung transplant in 2012/2013. The number of transplants in the latest financial year (2019/2020) is shown by centre and transplant type in **Figure 22.6**.

Figure 22.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2010 to 31 March 2020

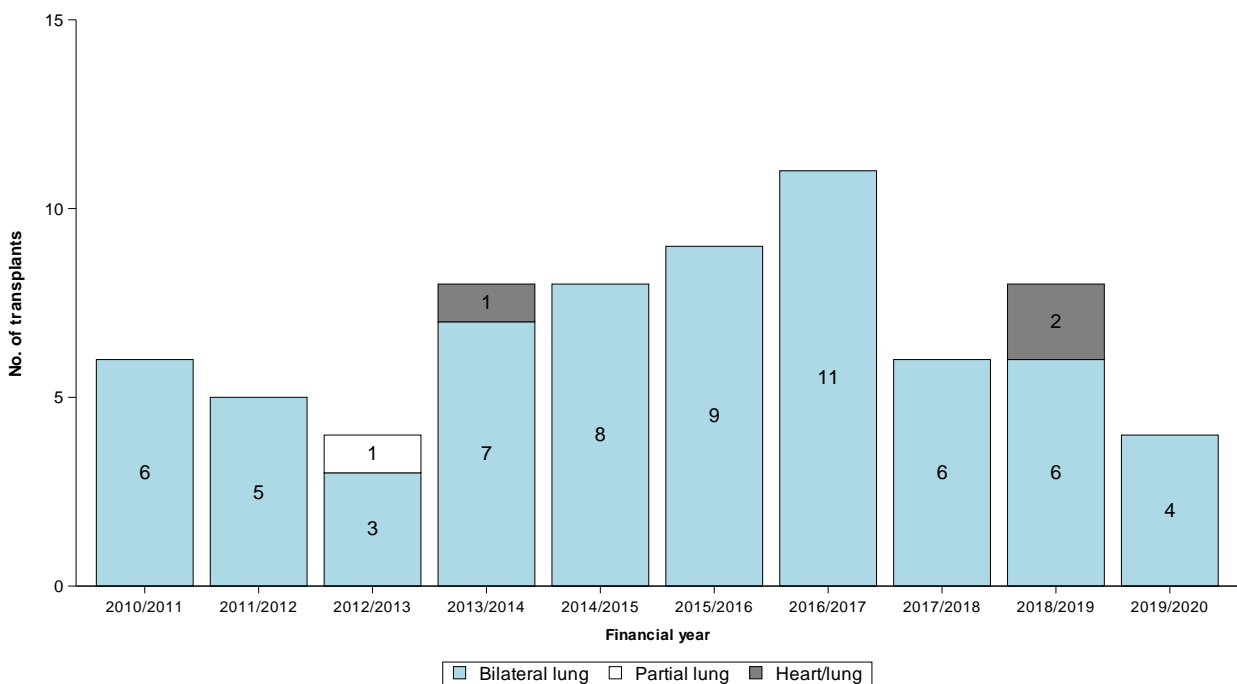


Figure 22.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2010 to 31 March 2020

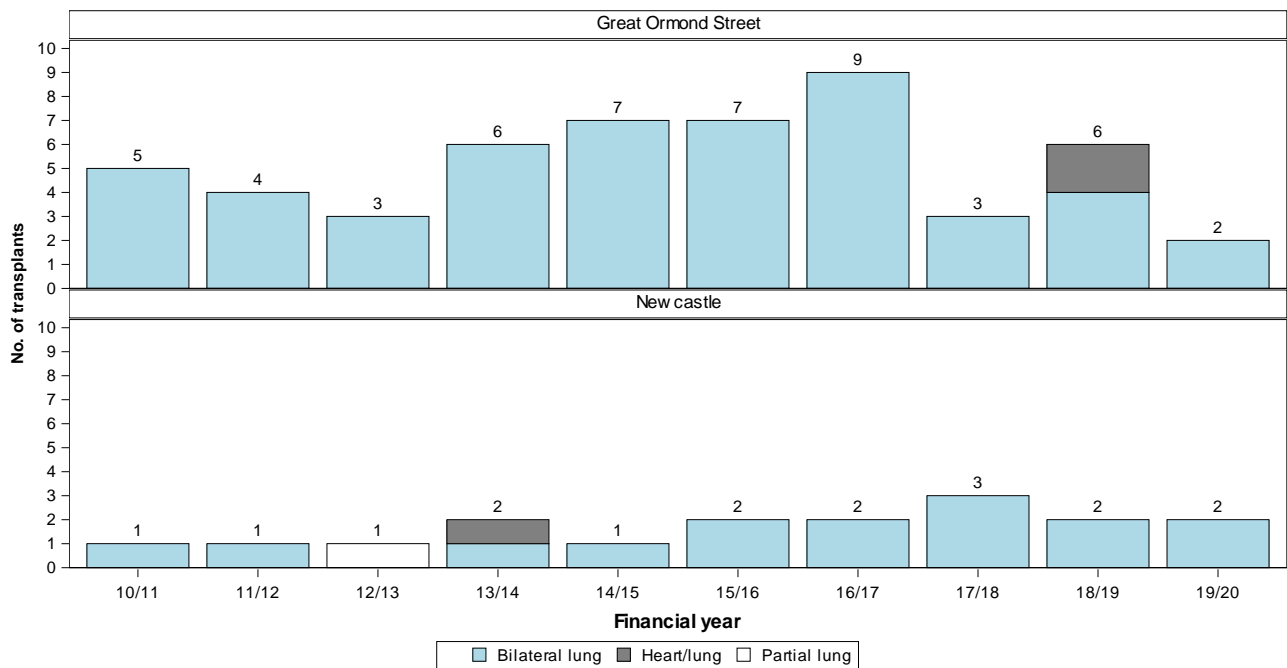
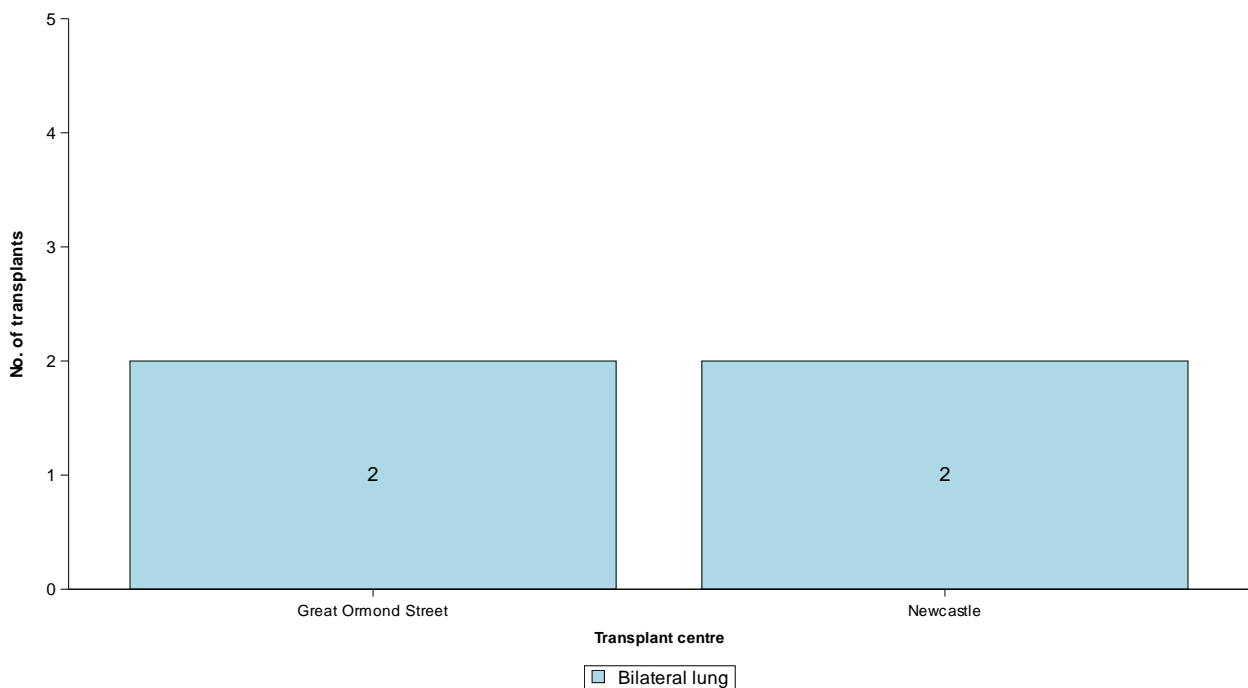


Figure 22.6 Number of paediatric lung transplants in the UK, by centre and transplant type, 1 April 2019 to 31 March 2020



On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. **Figure 22.7** displays the number of paediatric lung only transplants performed in the last 10 financial years by urgency. The number of lung only transplants by urgency status in the latest financial year (2019/2020) is shown by centre in **Figure 22.7**. There were no urgent lung only transplants last year and one super-urgent transplant.

Figure 22.7 Number of paediatric lung only transplants in the UK, by financial year and urgency, 1 April 2010 to 31 March 2020

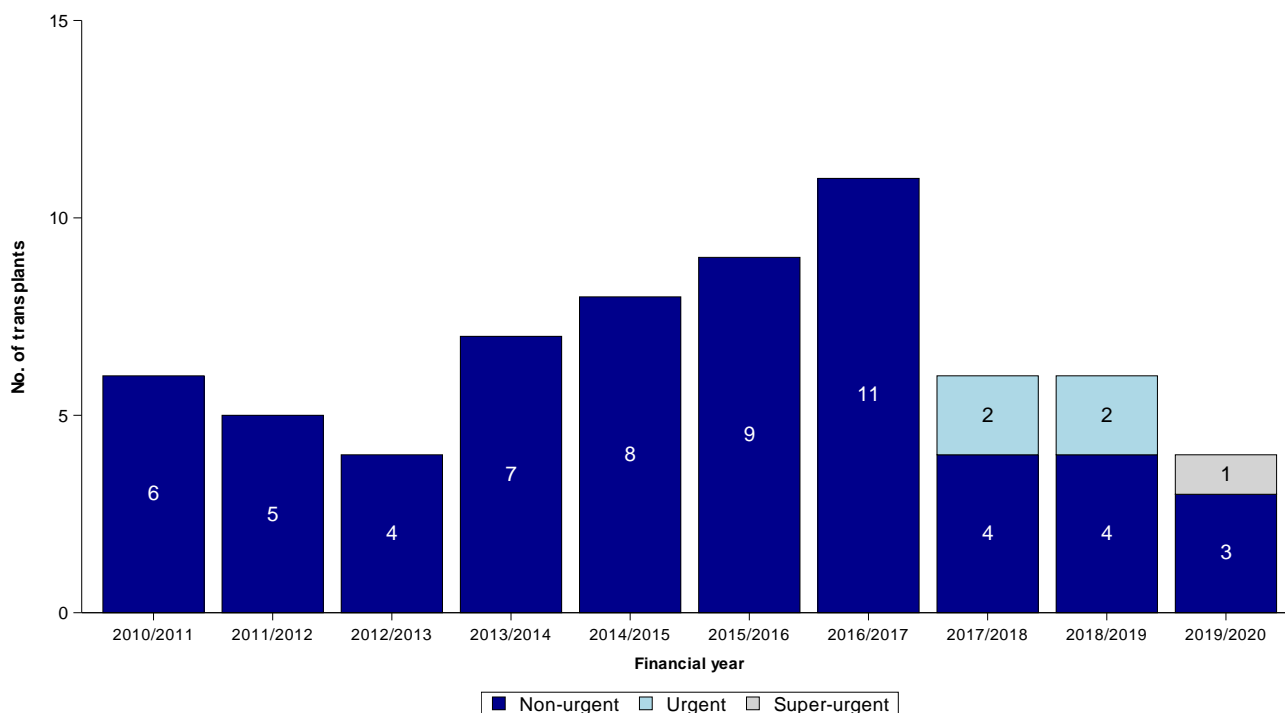
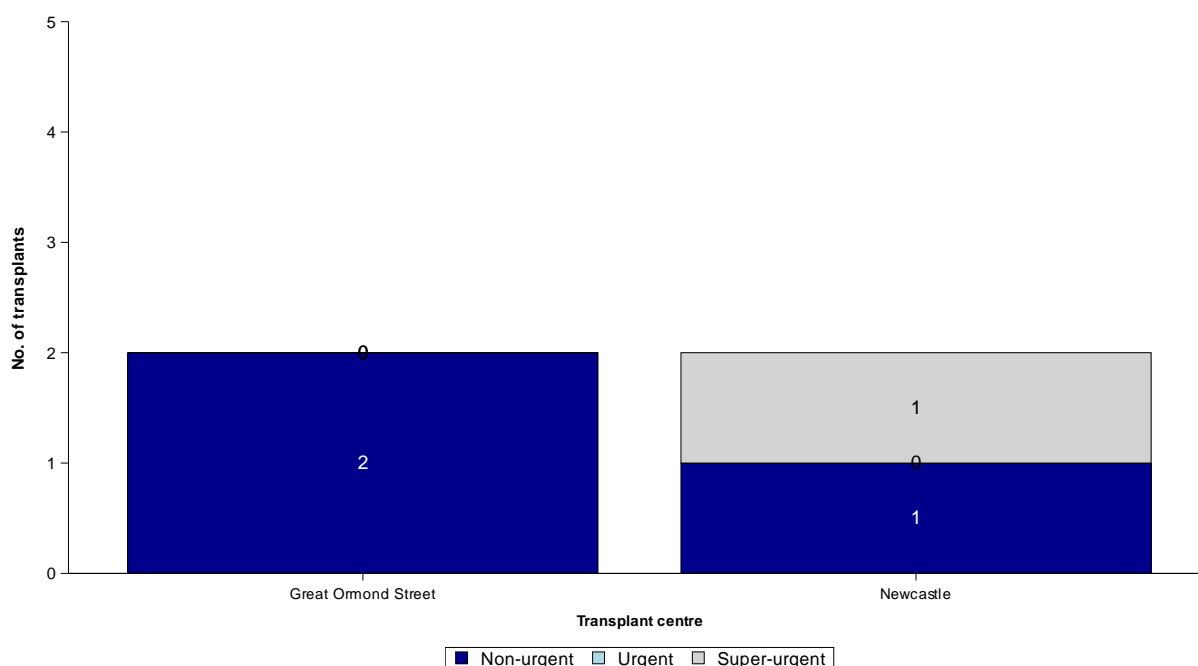


Figure 22.8 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2019 to 31 March 2020



22.2 Demographic characteristics of transplants, 1 April 2018 – 31 March 2020

The demographic characteristics of the 12 paediatric lung transplant recipients and donors in the last two years are shown by centre and overall in **Table 22.1**. Nationally, 67% of lung recipients were female and the [median](#) age was 14 years, while the median age of donors was 19 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2018 to 31 March 2020, by centre				
		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of transplants		8 (100)	4 (100)	12 (100)
Year of transplant	2018/2019	6 (75)	2 (50)	8 (67)
	2019/2020	2 (25)	2 (50)	4 (33)
Urgency status at transplant	Non-urgent	7 (88)	1 (25)	8 (67)
	Urgent	1 (13)	2 (50)	3 (25)
	Super-urgent	0 (0)	1 (25)	1 (8)
Recipient sex	Male	2 (25)	2 (50)	4 (33)
	Female	6 (75)	2 (50)	8 (67)
Recipient ethnicity	White	7 (88)	4 (100)	11 (92)
	Non-white	1 (13)	0 (0)	1 (8)
Recipient age (years)	Median (IQR) ¹	14 (13, 15)	-	14 (11, 15)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR) ¹	58 (42, 72)	-	42 (28, 67)
	Missing	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	2 (25)	2 (50)	4 (33)
	Fibrosing lung disease	0 (0)	1 (25)	1 (8)
	Primary pulmonary hypertension	3 (38)	0 (0)	3 (25)
	Other heart/lung disease	3 (38)	1 (25)	4 (33)
NYHA class	I	0 (0)	0 (0)	0 (0)
	II	0 (0)	0 (0)	0 (0)
	III	1 (13)	2 (50)	3 (25)
	IV	5 (63)	2 (50)	7 (58)
	Missing	2 (25)	0 (0)	2 (17)
Recipient in hospital pre-transplant	No	8 (100)	2 (50)	10 (83)
	Yes	0 (0)	2 (50)	2 (17)
If in hospital, recipient on ventilator	No	-	1 (50)	1 (50)
	Yes	-	1 (50)	1 (50)
If in hospital, recipient on inotropes	No	-	1 (50)	1 (50)
	Yes	-	1 (50)	1 (50)
Recipient CMV status	No	3 (38)	3 (75)	6 (50)
	Yes	5 (63)	0 (0)	5 (42)
	Missing	0 (0)	1 (25)	1 (8)

Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2018 to 31 March 2020, by centre

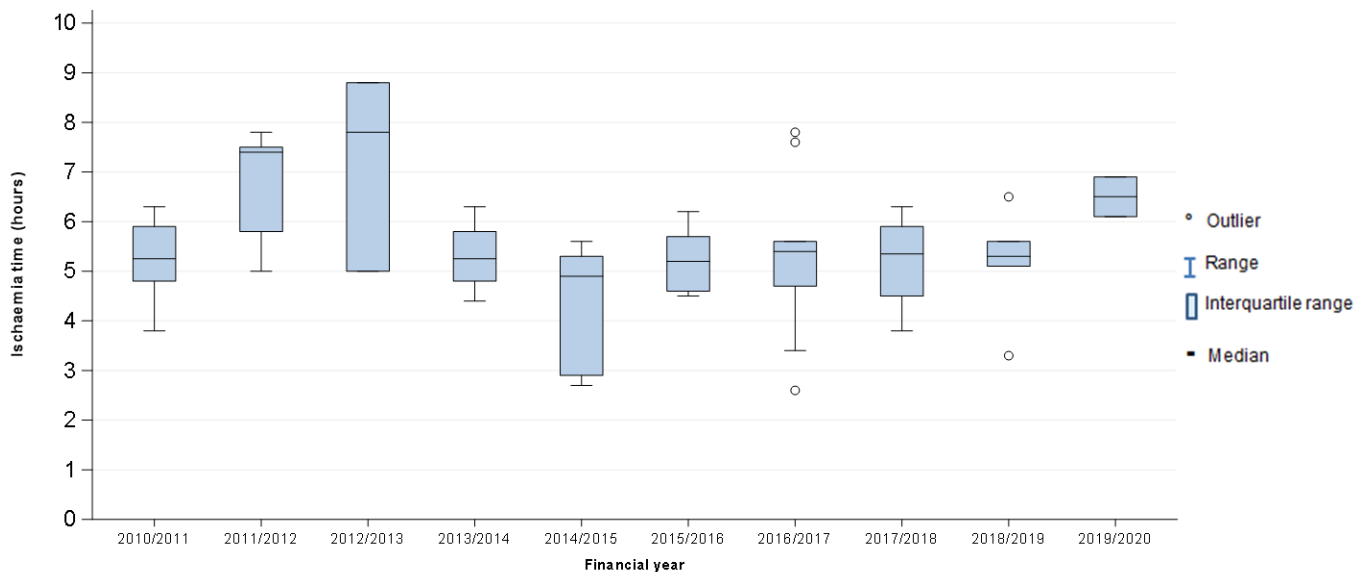
		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Recipient HCV status	No	8 (100)	3 (75)	11 (92)
	Missing	0 (0)	1 (25)	1 (8)
Recipient HBV status	No	8 (100)	3 (75)	11 (92)
	Missing	0 (0)	1 (25)	1 (8)
Recipient HIV status	No	8 (100)	3 (75)	11 (92)
	Missing	0 (0)	1 (25)	1 (8)
Recipient serum creatinine (umol/l)	Median (IQR) ¹	56 (45, 75)	-	45 (27, 66)
	Missing	1	0	1
Donor sex	Male	4 (50)	2 (50)	6 (50)
	Female	4 (50)	2 (50)	6 (50)
Donor ethnicity	White	7 (88)	3 (75)	10 (83)
	Non-white	1 (13)	0 (0)	1 (8)
	Missing	0 (0)	1 (25)	1 (8)
Donor age (years)	Median (IQR) ¹	29 (19, 48)	-	19 (12, 38)
	Missing	0	0	0
Donor BMI (kg/m ²)	Median (IQR) ¹	22 (20, 26)	-	20 (17, 22)
	Missing	0	0	0
Donor cause of death	CVA	5 (63)	2 (50)	7 (58)
	Others	3 (38)	2 (50)	5 (42)
Donor hypotension	No	6 (75)	0 (0)	6 (50)
	Yes	2 (25)	2 (50)	4 (33)
	Missing	0 (0)	2 (50)	2 (17)
Donor past cardiothoracic disease	No	7 (88)	3 (75)	10 (83)
	Yes	1 (13)	0 (0)	1 (8)
	Missing	0 (0)	1 (25)	1 (8)
Donor past hypertension	No	8 (100)	3 (75)	11 (92)
	Missing	0 (0)	1 (25)	1 (8)
Donor past tumour	No	8 (100)	3 (75)	11 (92)
	Missing	0 (0)	1 (25)	1 (8)
Donor past smoker	No	7 (88)	4 (100)	11 (92)
	Yes	1 (13)	0 (0)	1 (8)
Total ischaemia time (hours)	Median (IQR) ¹	6.3 (5.1, 6.9)	-	5.9 (5.1, 6.8)
	Missing	2	0	2

¹ Medians for groups with less than 5 observations are not presented due to small numbers

22.3 Total ischaemia time, 1 April 2010 – 31 March 2020

Figure 22.9 shows [boxplots](#) of total ischaemia time for [DBD](#) donor lungs transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The [median](#) total ischaemia time varied quite substantially over the decade, however these are based on a very small number of transplants per year (≤ 10). No further breakdown by centre is shown due to small numbers.

Figure 22.9 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2010 to 31 March 2020



PAEDIATRIC LUNG TRANSPLANTATION

Post-Transplant Survival



23. Post-Transplant Survival

The survival analyses presented in this section exclude heart-lung transplants and other [multi-organ transplants](#) and include first time transplants only. Partial lung transplants are also excluded. Both DBD and DCD lung transplants are included. Ninety-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2015 to 31 March 2019 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2011 to 31 March 2015.

The 90-day post-transplant [unadjusted](#) patient [survival rates](#) are shown in **Table 23.1** for the 31 first paediatric lung only transplants in the period 1 April 2015 to 31 March 2019. Only 8 of these transplants were performed by Newcastle so it was not possible to generate a robust survival rate, however there were no reported deaths within 90 days for these patients. Nationally, the 90 day survival rate following first paediatric lung transplant was 90.3%.

Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre, 1 April 2015 to 31 March 2019

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	23	3	87	(64.8 - 95.6)
Newcastle ¹	8	0	-	-
UK	31	3	90.3	(72.9 - 96.8)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

There were two additional deaths between 90 days and 1 year for the 31 paediatric lung only transplants performed in the period 1 April 2015 to 31 March 2019; one from each centre.

Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2015 to 31 March 2019

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	23	4	82.6	(60.1 - 93.1)
Newcastle ¹	8	1	-	-
UK	31	5	83.5	(64.8 - 92.8)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

Five year [survival rates](#) were estimated from the 22 first lung only transplants performed in the period 1 April 2011 to 31 March 2015. The unadjusted patient [survival rates](#) are shown in **Table 23.3**, however, again it was not possible to generate an estimate for Newcastle.

Table 23.3 5 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2011 to 31 March 2015

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	19	4	78.3	(51.9 - 91.3)
Newcastle ¹	3	1	-	-
UK	22	5	75.6	(50.8 - 89.1)

¹ Survival rates for groups with less than 10 patients are not presented due to small numbers

PAEDIATRIC LUNG TRANSPLANTATION

Form Return Rates



24. Paediatric lung form return rates, 1 January – 31 December 2019

Form return rates are reported in **Table 24.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric lung and heart-lung transplants between 1 January and 31 December 2019 for the transplant record, and all follow up forms issued in this time period. There are no outstanding forms for this period for either centre.

Table 24.1 Form return rates for paediatric lung transplants, 1 January 2019 to 31 December 2019									
Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up		
	No. requested	% returned	No. requested	% returned	No. requested	% returned	No. requested	% returned	
Great Ormond Street Hospital	5	100	6	100	3	100	18	100	
Newcastle, Freeman Hospital	4	100	2	100			16	100	
Overall	9	100	8	100	3	100	34	100	

APPENDIX



A1: Number of patients analysed

The cohort of patients in this report varies by section/analysis. Tables **A1.1** and **A1.2** below summarise the number of adult and paediatric (respectively) transplants in each cohort and the section this applies to. For the survival from listing analysis, see the Methods section in **A2** below.

Table A1.1 Adult transplants analysed				
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2010 – 31 March 2020	• Introduction	None	1430	1786
1 April 2010 – 31 March 2020	• Transplants	• Multi-organ transplants	1420	1783
1 April 2015 – 31 March 2019	Post-transplant survival – <ul style="list-style-type: none"> • 30/90-day • 1-year survival 	<ul style="list-style-type: none"> • Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants 	550	679
1 April 2011 – 31 March 2015	Post-transplant survival – <ul style="list-style-type: none"> • 5-year survival 	<ul style="list-style-type: none"> • Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants 	525	719

Table A1.2 Paediatric transplants analysed				
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2010 – 31 March 2020	• Introduction	None	314	69
1 April 2010 – 31 March 2020	• Transplants	• Multi-organ transplants	314	69
1 April 2015 – 31 March 2019	Post-transplant survival – <ul style="list-style-type: none"> • 30/90-day • 1-year survival 	<ul style="list-style-type: none"> • Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants 	122	31
1 April 2011 – 31 March 2015	Post-transplant survival – <ul style="list-style-type: none"> • 5-year survival 	<ul style="list-style-type: none"> • Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants 	123	22

Geographical variation analysis

Registration rates

All NHS group 1 patients who were registered onto the heart or lung transplant list with an active status between 1 April 2019 and 31 March 2020 were extracted from the UK Transplant Registry on 3 July 2020 (numerator). Patients registered for a heart-lung block were excluded. Patients were assigned to NHS regions in England using their postcode of residence, as reported at registration. The number of registrations per million population (pmp) by NHS region was obtained using mid-2018 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No NHS region age- or sex-specific standardisation of rates was performed.

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

Transplant rates

Transplant rates pmp were obtained as the number of heart transplants on NHS group 1 recipients between 1 April 2019 and 31 March 2020 (numerator), divided by the mid-2018 population estimates from the ONS (denominator). Patients who received a heart-lung block transplant were excluded. 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 2019 and 31 March 2020 were included. If a patient was re-registered during the time period, only the first registration was considered. If a patient underwent more than one heart transplant in the time period, only the first transplant was considered.

A2: Methods

Offer decline rates

The offer decline rate analysis was limited to heart or lung offers from [DBD](#) donors who died at a UK hospital and the heart or lung was eventually accepted and transplanted. Any offers from DCD donors were excluded.

[Funnel plots](#) were used to compare centre specific offer decline rates and indicate how consistent the rates of the individual transplant centres are with the national rate. The overall national offer decline rate is shown by the solid line while the 95% and 99.8% confidence lines are indicated via a thin and thick dotted line, respectively. Each dot in the plot represents an individual transplant centre. Centres that are positioned above the upper limits indicate an offer decline rate that is higher than the national rate, while centres positioned below the lower limits indicate an offer decline

Unadjusted post-transplant survival rates

[Kaplan-Meier](#) methods were used to estimate the [unadjusted](#) patient [survival rates](#). 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.

Risk-adjusted post-transplant survival rates

A risk-adjusted [survival rate](#) is an estimate of what the survival rate at a centre would have been if they had had the same mix of patients as that seen nationally. The risk-adjusted rate therefore presents estimates in which differences in patient mix across centres have been removed as much as possible. For that reason, it is valid to only compare centres using risk-adjusted rather than unadjusted rates, as differences among the latter can be attributed to differences in patient mix.

Risk-adjusted survival estimates were obtained through indirect standardisation. A [Cox Proportional Hazards model](#) was used to determine the probability of survival for each patient based on their individual risk factor values. The sum of these probabilities for all patients at a centre gives the number, E, of patients or grafts expected to survive at least one year or five years after transplant at that centre. The number of patients who actually survive the given time period is given by O. The risk-adjusted estimate is then calculated by multiplying the ratio O/E by the overall unadjusted survival rate across all centres. The risk-adjustment models used were based on results from previous studies that looked at factors affecting the [survival rates](#) of interest. The factors included in the models are shown in [A3](#).

Missing values were imputed using multiple imputation where missing values for heart transplants ranged from <1% for several variables to 9.2% for respiratory arrest, and for lung transplants ranged from <1% for several variables to 9.5% for recipient cholesterol at registration (the proportion missing for some centres was higher). Multiple imputation was implemented in SAS Enterprise Guide, using chained equations. The form of the imputation model used to estimate missing values consisted of a list of transplant related variables as well as the outcome variables (survival time and censoring indicator). Twenty imputations were run with 50 burn-in iterations before each imputation. Post-transplant survival models were fitted to the resulting 20 datasets and estimates were obtained for each parameter in the model by analysing the results of these 20 models collectively.

Funnel plots

The funnel plot is a graphical method to show how consistent the [survival rates](#) of the different transplant centres are compared to the national rate. The graph shows for each centre, a survival rate plotted against the number of transplants undertaken, with the national rate and [confidence limits](#) around this national rate superimposed. In this report, 95% and 99.8% [confidence limits](#) were used. Units that lie within the [confidence limits](#) have survival rates that are statistically consistent with the national rate. When a unit is close to or outside the limits, this is an indication that the centre may have a rate that is considerably different from the national rate.

Systematic component of variation

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.

Survival from listing

Data were obtained for all patients ≥ 18 years registered for the first time for a heart or lung transplant between 1 January 2008 and 31 December 2019. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. donor type. Survival time was censored at either the date of removal from the list, or at the last known follow up date post-transplant when no death date was recorded, or at 17 July 2020 if the patient was on the transplant list at time of analysis.

Exclusions from the analysis:

- patients with ethnic group not reported
- patients with unknown gender
- patient registered for a heart-lung block or other [multi-organ transplant](#)
- patients who were not listed prior to transplant
- patients first registered on another transplant list (e.g. kidney list)
- patients registered outside the UK or not entitled to NHS treatment
- adult patients registered at paediatric centres
- patients with missing BMI

Patients registered for a heart transplant who were non-urgent and then urgently listed on the same day (or vice-versa) were recorded as urgent at registration. Patients who received a VAD and were registered on the transplant list on the same day were assumed to have received the VAD prior to registration.

In [risk-adjusted](#) survival analysis, factors recorded at time of transplant listing were adjusted for. These are detailed in **Table A2.1** and were included in the modelling whether or not statistically significant.

Table A2.1 Factors used in risk-adjusted models for patient survival from listing	
Heart	Age, gender, ethnicity, blood group, BMI, urgency status, primary disease, previous heart surgery, in hospital at registration, on VAD/ECMO support at registration, era
Lung	Age, gender, ethnicity, blood group, BMI, primary disease, previous thoracotomy, in hospital at registration, era

[Survival rates](#) at one and five years post registration were calculated from the risk adjusted survival rate (RASR), obtained as $1 - \{ \text{observed number of deaths in follow up period} / \text{expected number} \} \times \text{national mortality rate}$. The expected survival rates were estimated from fitting a [Cox model](#) to the national data, excluding transplant centre, evaluated at each patient's observed survival time. Interval estimates for one and five year rates, and the significance of differences between them across centres, were found using Poisson regression models for the logarithm of the observed number of deaths, with centre as a random effect.

A3: Risk models

Table A3.1 Risk factors and categories used in the adult heart risk adjusted 30-day, 1-year and 5-year survival models	
Donor cause of death	Vascular Trauma Hypoxic Other
Donor BMI	(modelled as continuous variable)
Donor age	(modelled as continuous variable)
Respiratory arrest	Yes No
Recipient BMI	(modelled as continuous variable)
Recipient creatinine at transplant	Non-linear spline with knots at 56, 86, 114, 175
VAD at transplant	Short-term (including ECMO) Long-term (including total artificial hearts) None
Hospital status at transplant	In hospital Not in hospital
Primary disease	Dilated cardiomyopathy Coronary heart disease Congenital heart disease Other
Sex Mismatch	RM:DM RM:DF RF:DM RF:DF
Ischaemia time (hours)	(modelled as continuous variable)
OCS used on heart	Yes No
Interaction between ischaemia time and OCS	

Table A3.2 [Risk factors](#) and categories used in the adult lung risk adjusted 90-day, 1- year and 5-year survival model

Donor CMV	Negative Positive
Donor history of smoking	No Yes
Recipient daily dose of prednisolone at registration	0 1-14 ≥ 15
Donor:recipient calculated TLC mismatch (recipient – donor)	(modelled as continuous variable)
Recipient FVC at registration	(modelled as continuous variable)
Recipient bilirubin at registration	(modelled as continuous variable)
Recipient cholesterol at registration	(modelled as continuous variable)
Recipient age at transplant	Non-linear spline with knots at 22, 45, 56, and 64.
Transplant type	Single lung Bilateral lung
Primary disease group	COPD and emphysema Cystic fibrosis and bronchiectasis Fibrosing lung disease Other

A4: Glossary of terms

Active transplant list

When a patient is registered for a transplant, they are 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 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 (any points that are a distance of more than $1.5 \times \text{IQR}$ from the box).

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%. We then say that there is a 95% chance that the [confidence interval](#) includes the true value of the quantity we wish to estimate.

Confidence limit

The upper and lower bounds of a [confidence interval](#).

Cox Proportional Hazards model

A statistical model that relates the instantaneous risk (hazard) of an event occurring at a given time point to the [risk factors](#) that influence the length of time it takes for the event to occur. This model can be used to compare the hazard of an event of interest, such as patient death, across different groups of patients.

Donor after brain death (DBD)

Donation after brainstem death means donation which takes place following the diagnosis of death using neurological criteria.

Donor after circulatory death (DCD)

Donation after circulatory death means donation which takes place following the diagnosis of death using circulatory criteria.

Funnel plot

A graphical method that shows how consistent the rates, such as [survival rates](#) or decline rates, of the different transplant units are compared to the national rate. For survival rates, the graph shows for each unit, a survival rate plotted against the number of transplants undertaken, with the national rate and [confidence limits](#) around this national rate superimposed. In this report, 95% and 99.8% [confidence limits](#) were used. Units that lie within the [confidence limits](#) have survival rates that are statistically consistent with the national rate. When a unit is close to or outside the limits, this is an indication that the centre may have a rate that is considerably different from the national rate.

Inter-quartile range

The values between which the middle 50% of the data fall. The lower boundary is the lower quartile, the upper boundary the upper quartile.

Kaplan-Meier method

A method that allows patients with incomplete follow-up information to be included in estimating [survival rates](#). For example, when estimating one year [patient survival rates](#), a patient may be followed up for only nine months before they relocate. 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. The Kaplan-Meier method can be used for any time to event analysis, including time to transplant. If not enough events have occurred or if there are not enough patients in the cohort, an estimate of the [median](#) may not be possible.

Long-term device

Long-term devices are implantable and intended to support the patient for years. Patients can be discharged from hospital with a long-term device.

Median

The midpoint in a series of numbers, so that half the data values are larger than the median, and half are smaller.

Multi-organ transplant

A transplant in which the patient receives more than one organ. For example, a patient may undergo a transplant of a heart and kidney.

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 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.

Risk-adjusted survival rate

Some transplants have a higher chance than others of failing at any given time. The differences in expected survival times arise due to differences in certain factors, the [risk factors](#), among patients. A risk-adjusted [survival rate](#) for a centre is the expected survival rate for that centre given the [case mix](#) of their patients. Adjusting for [case mix](#) in estimating centre-specific survival rates allows valid comparison of these rates across centres and to the national rate.

Risk factors

These are the characteristics of a patient, transplant or donor that influence the length of time that a graft is likely to function or a patient is likely to survive following a transplant. For example, when all else is equal, a transplant from a younger donor is expected to survive longer than that from an older donor and so donor age is a risk factor.

Unadjusted survival rate

Unadjusted [survival rates](#) do not take account of [risk factors](#) and are based only on the number of transplants at a given centre and the number and timing of those that fail within the post-transplant period of interest. In this case, unlike for risk-adjusted rates, all transplants are assumed to be equally likely to fail 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.

VAD

Ventricular Assist Device. A mechanical pump used to increase the amount of blood that flows through the body, relieving the symptoms of advanced heart failure.

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