



Blood and Transplant

**ANNUAL REPORT ON CARDIOTHORACIC
ORGAN TRANSPLANTATION**

**REPORT FOR 2017/2018
(1 APRIL 2008 – 31 MARCH 2018)**

PUBLISHED SEPTEMBER 2018

PRODUCED IN COLLABORATION WITH NHS ENGLAND



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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 2008 to 31 March 2018. 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, 2017/2018, 198 heart transplants were performed across the UK. This was exactly equal to the number performed in the previous year, 2016/2017. The number of lung transplants performed was 214, which was a 20% increase from 2016/2017 and the second highest number ever. These numbers, which are for adult and paediatric patients combined, represent 2.9 heart transplants per million population and 3.2 lung transplants per million population.
- On 31 March 2018, the national heart transplant list was particularly high, with 284 patients waiting for a heart transplant (14% higher than on 31 March 2017 and 205% higher than a decade earlier). Of these, 28 patients were on the urgent heart list; the highest number ever at year end.
- On 18 May 2017, urgent and super-urgent lung allocation schemes were introduced in the UK. Of the 290 patient registrations onto the lung transplant list in 2017/2018, 33 (11%) were urgent and 7 (2%) were super-urgent. On 31 March 2018, the national lung transplant list was 6% lower than on 31 March 2017, with a total of 357 patients waiting for a lung transplant (56% higher than a decade earlier).
- The national 30 day rate of **survival following adult heart transplantation** was 90.8%, which ranged from 83.6% to 95.3% across centres ([risk-adjusted](#)), with some evidence of a significantly higher rate at Papworth. The national 1 year survival rate was 83.2%, ranging from 76.3% to 90.0% across centres ([risk-adjusted](#)), again with some evidence of a significantly higher rate at Papworth. The national 5 year survival rate was 69.2%, ranging from 48.5% to 76.8% across centres ([risk-adjusted](#)), with some evidence of significantly lower rate at Glasgow.
- The national 90 day rate of **survival following adult lung transplantation** was 89.4%, which ranged from 81.6% to 92.9% across centres ([risk-adjusted](#)), with no significant outliers. The national 1 year survival rate was 80.0%, ranging from 68.6% to 85.1% across centres ([risk-adjusted](#)), with some evidence of a significantly lower rate at Birmingham. The national 5 year survival rate was 56.9%, ranging from 47.4% to 60.0% across centres ([risk-adjusted](#)), with no significant outliers.
- The national rate of **survival following paediatric heart transplantation** was 94.5% at 30 days, 91.1% at 1 year and 82.5% at 5 years. These rates were very similar between the two paediatric centres.
- The national rate of **survival following paediatric lung transplantation** was 94.1% at 90 days and 1 year, and 76.2% 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 2017/2018, 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 2008 and 31 March 2018, 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 the last year, 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 2009 and 2018. 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 357 in 2018, a decrease of 6% on the previous year. The number of patients waiting for a heart transplant increased substantially over the decade, from 93 in 2009 to a peak of 284 in 2018, representing a 205% 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, 2009 to 2018

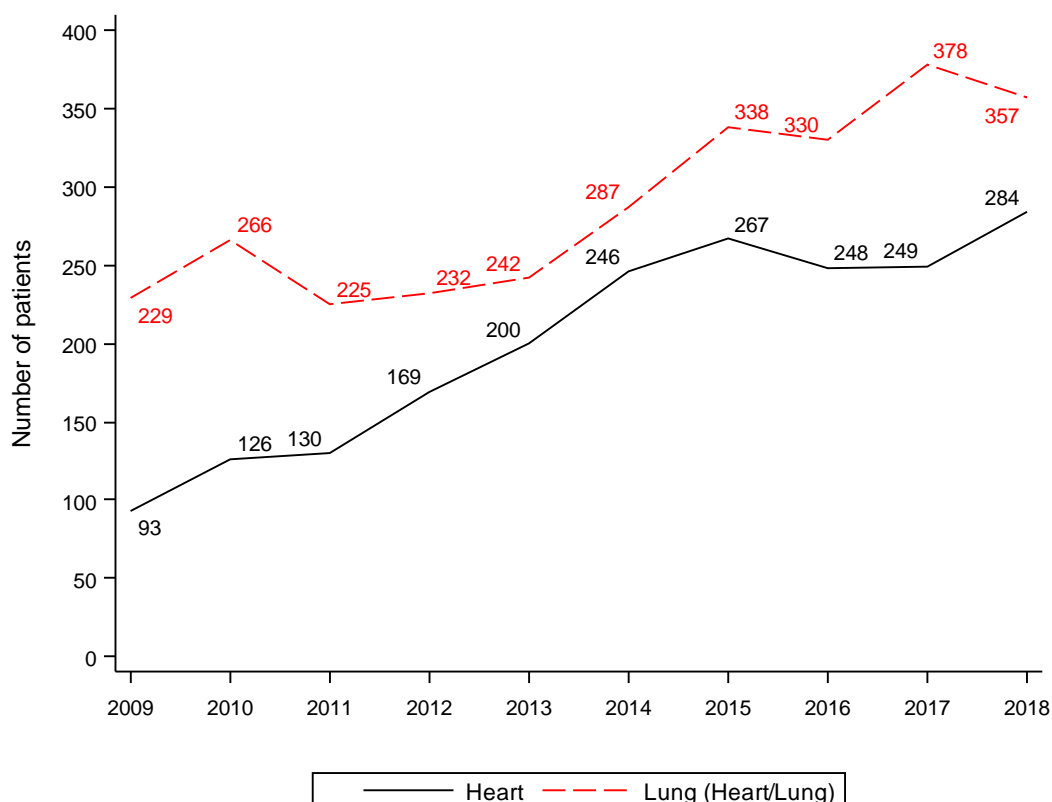


Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the [active transplant lists](#) at 31 March 2018 at each centre. In total, there were 611 adult and 30 paediatric patients waiting for a heart or lung transplant. Harefield had the highest number of adult patients on both 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 the heart transplant list, but both paediatric centres had the same number on the lung transplant list. These numbers include 3 patients waiting for a multi-organ transplant (3 heart and kidney). Compared with the previous year (numbers not shown), all centres have had an increase in their heart waiting list, except Papworth for adults and Newcastle for paediatrics. With respect to the lung waiting list, all centres have had a decrease, except Manchester and Newcastle.

Figure 2.2 Number of adult patients on the active heart and lung transplant lists at 31 March 2018, by centre

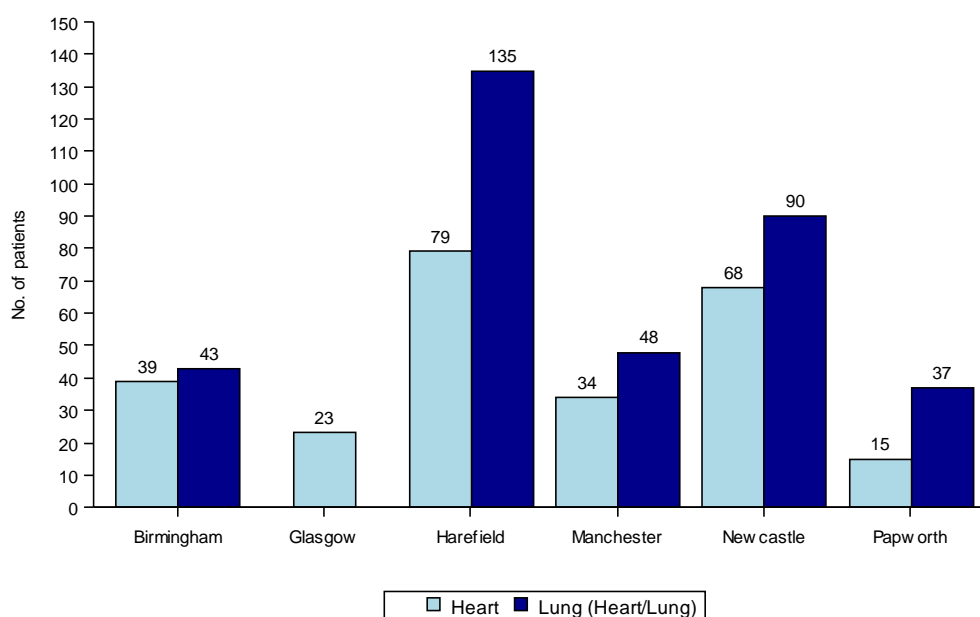


Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists at 31 March 2018, by centre

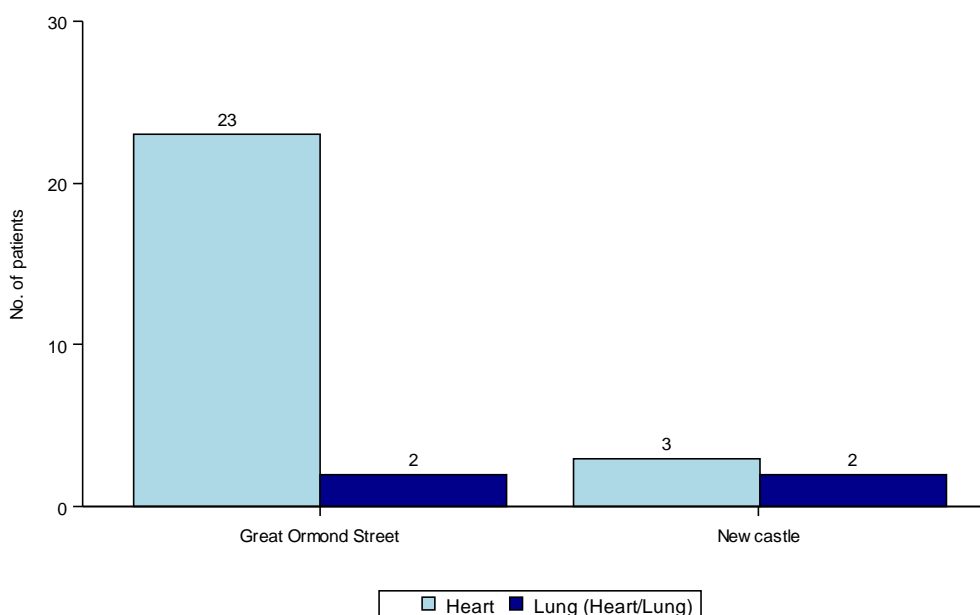


Figure 2.4 shows the total number of transplants performed in each of the last ten years. The number of heart transplants last year was 198, matching the number in 2016/2017. The number of lung transplants per year fell between 2013/2014 and 2016/2017 by 18%, but in the last year has increased to 214, a 17% increase from 2016/2017, and the second highest year ever.

Figure 2.4 Number of cardiothoracic organ transplants in the UK, by financial year, 1 April 2008 to 31 March 2018

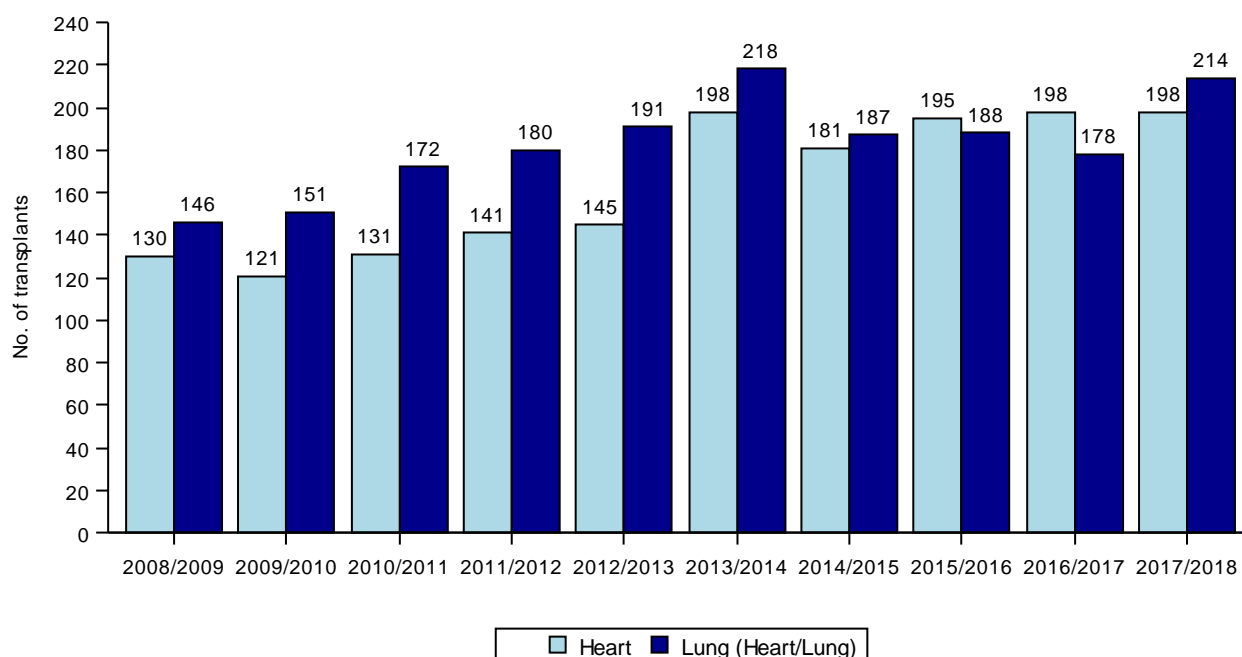


Figure 2.5 and **Figure 2.6** show the number of adult and paediatric transplants carried out in the most recent financial year at each centre. Harefield performed the highest number of lung transplants and Papworth the highest number of heart transplants. Newcastle performed the highest number of paediatric heart transplants, but both paediatric centres performed the same number of lung transplants. These numbers include 2 patients who received a multi-organ transplant (1 heart and liver, 1 lung and liver). Compared with the previous year (numbers not shown), Harefield, Papworth and Great Ormond Street Hospital performed a higher number of heart transplants, while other centres performed fewer. For lung transplantation, all centres performed a higher number compared with 2016/2017, except Manchester and Great Ormond Street Hospital.

Figure 2.5 Number of adult cardiothoracic organ transplants in the UK, by centre, 1 April 2017 to 31 March 2018

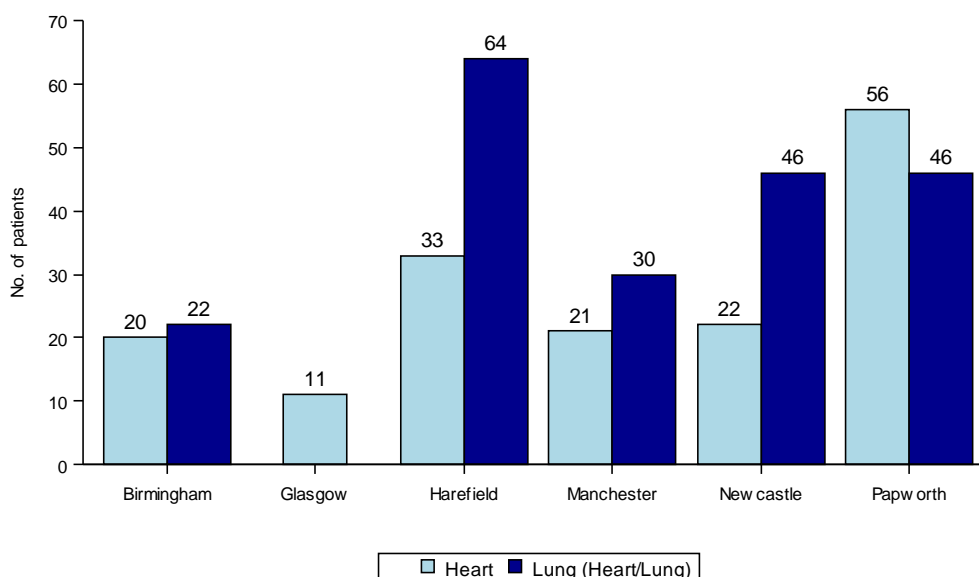


Figure 2.6 Number of paediatric cardiothoracic organ transplants in the UK, by centre, 1 April 2017 to 31 March 2018

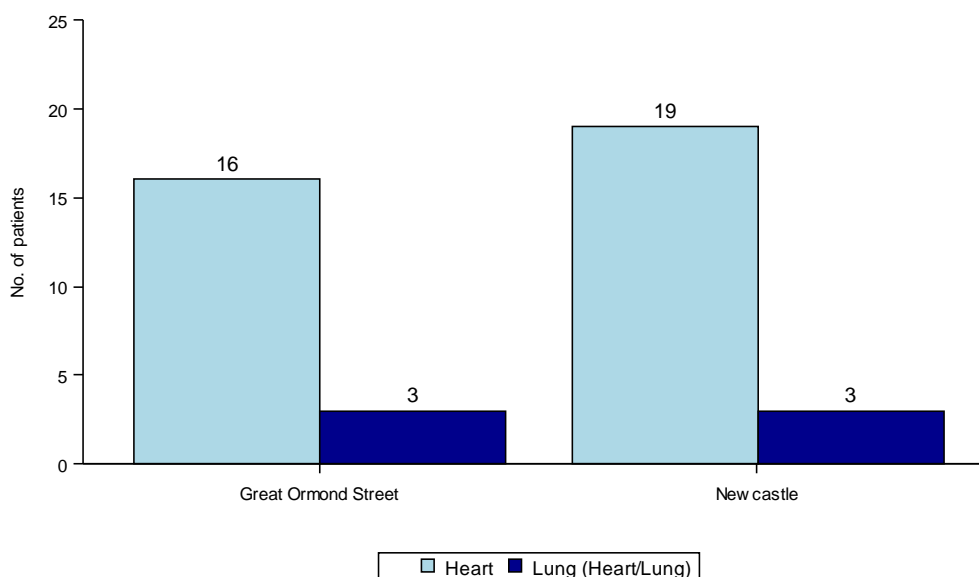
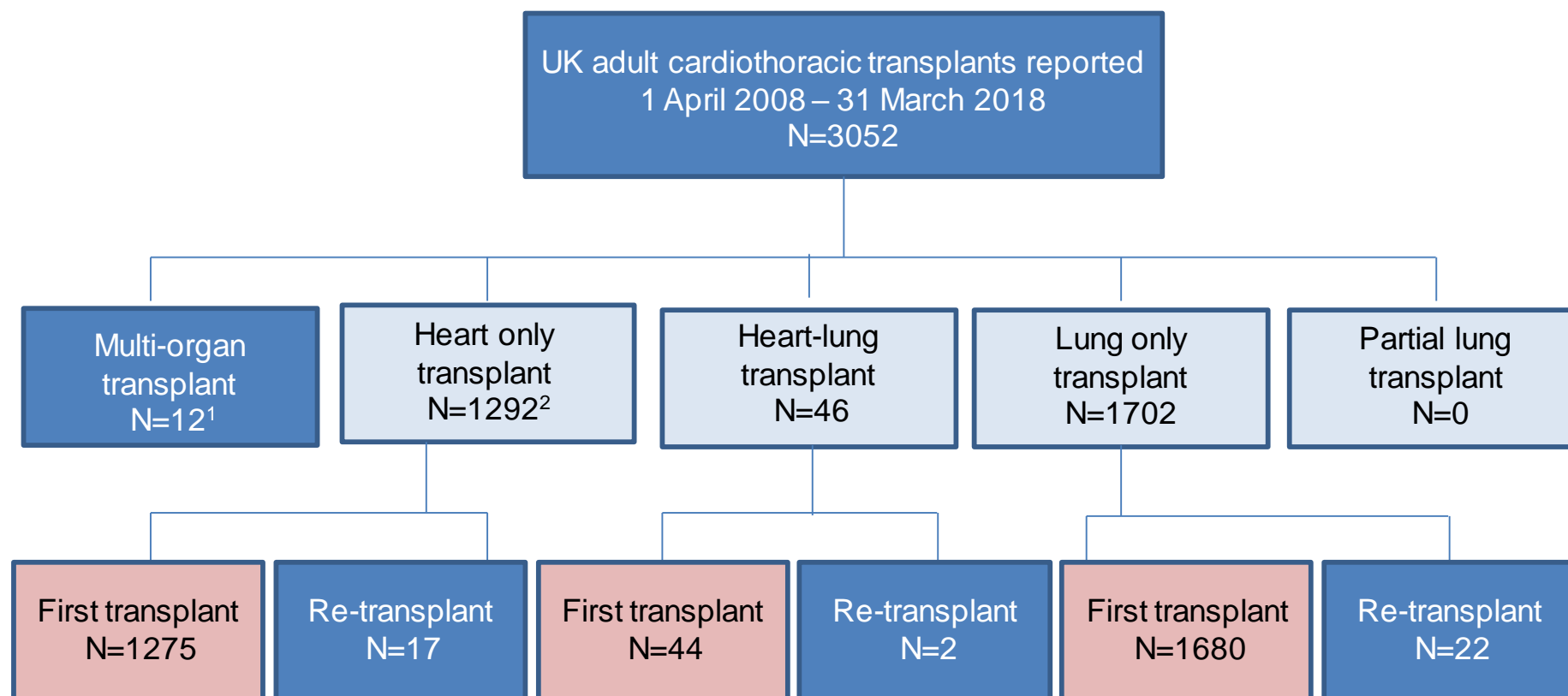


Figure 2.7 shows a breakdown of the 3,052 adult cardiothoracic organ transplants performed in the UK in the ten year period while **Figure 2.8** shows a similar breakdown for the 411 paediatric transplants performed during the same period. In the remainder of this report, [multi-organ transplants](#) are excluded, hence 3,040 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.

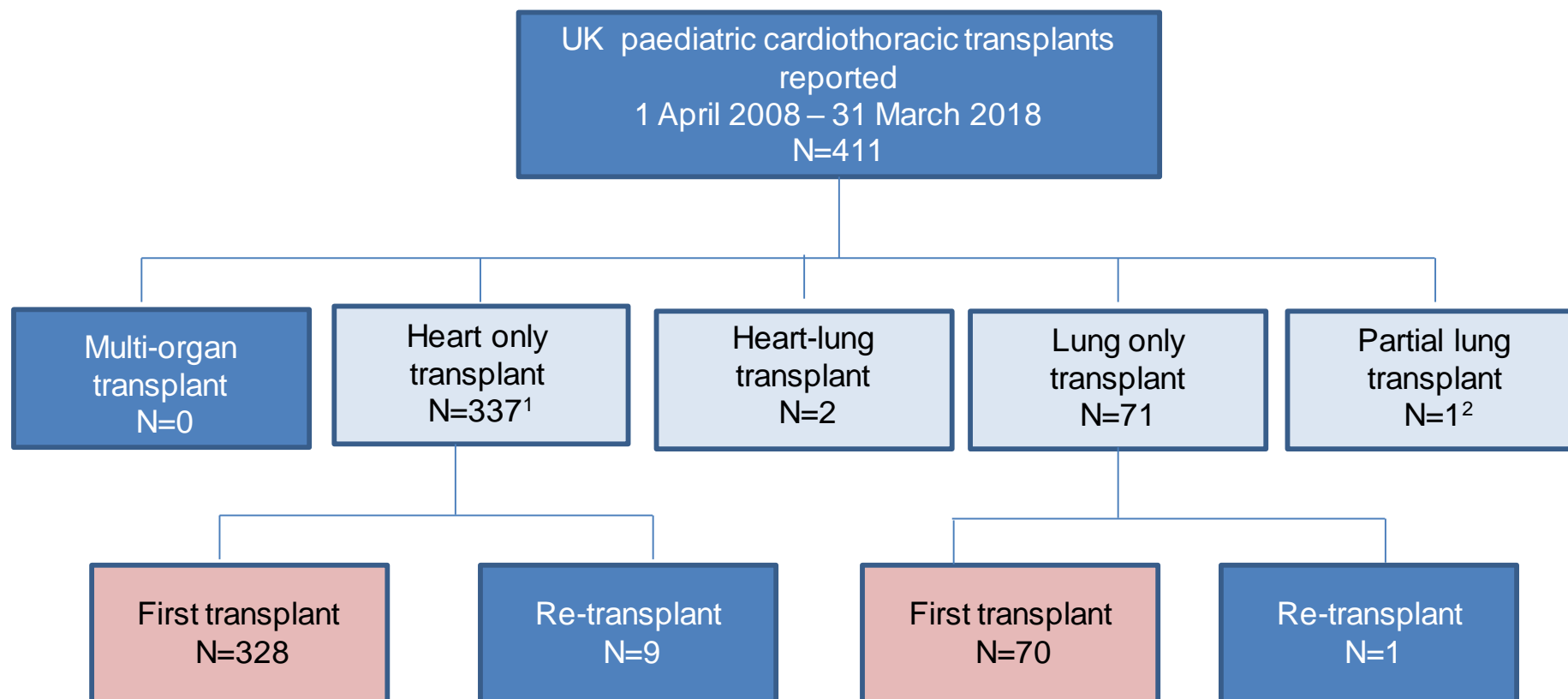
Figure 2.7 Adult cardiothoracic organ transplants performed in the UK, 1 April 2008 to 31 March 2018



¹ Includes 7 heart and kidney transplants, 2 heart and liver, 2 lung and liver and 1 lung and kidney

² Includes 57 DCD heart transplants and 3 domino donor transplants

Figure 2.8 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2008 to 31 March 2018



¹ Includes 2 DCD heart transplants and 1 domino donor transplant

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 2017 and 31 March 2018 compared with heart transplant rates pmp for the same time period, by recipient country/Strategic Health Authority (SHA) 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 5.1 pmp and 2.9 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 SHAs 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. In this analysis of heart data, both registration and transplant rates yielded a low SCV at 0 and 0, respectively, and therefore, no evidence of geographical variation beyond what would be expected at random. Note that no adjustments have been made for potential demographic differences in populations.

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 4.5 pmp and 3.2 pmp respectively. For lungs, both registration and transplant rates yielded a SCV of 0 and 0, respectively, and therefore no evidence of geographical variation beyond what would be expected at random.

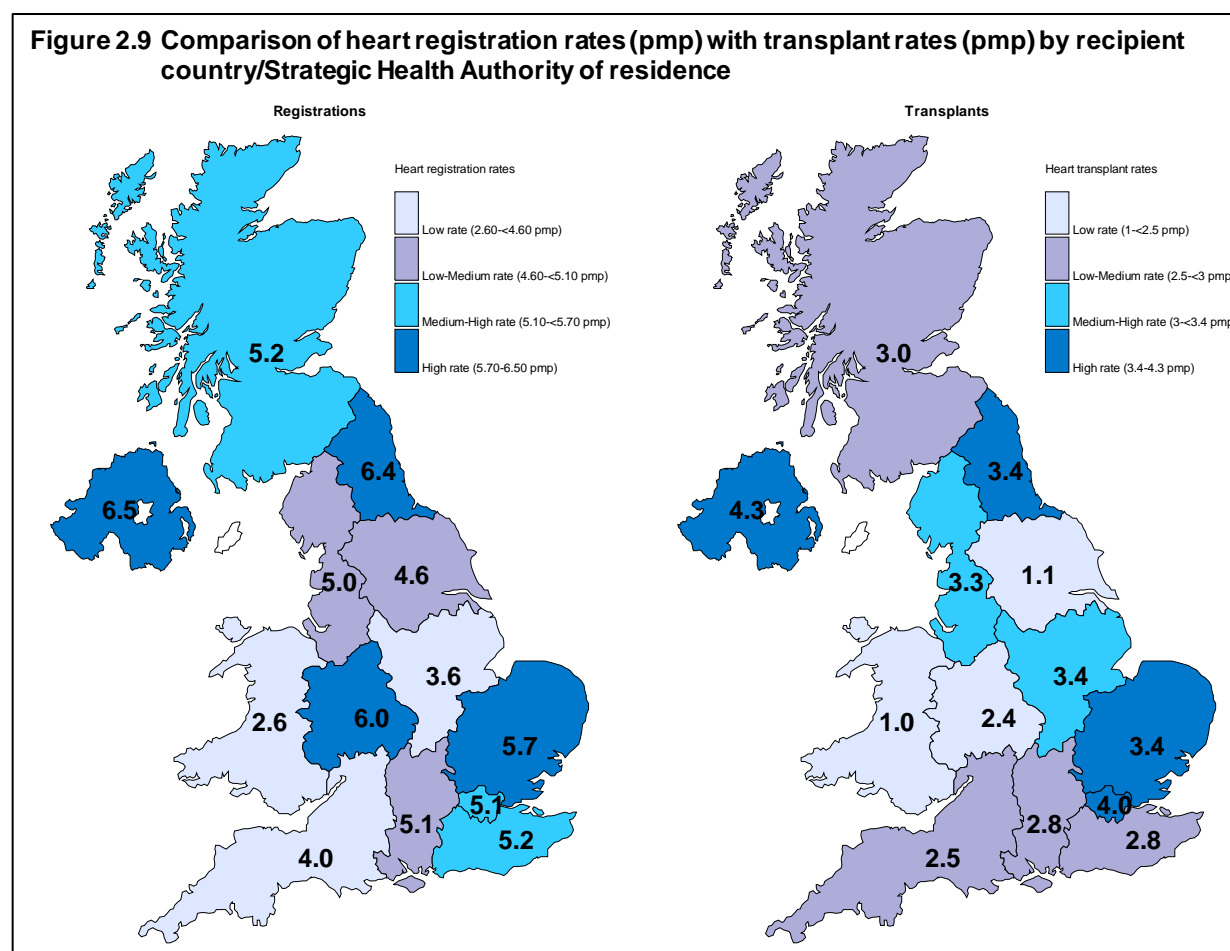


Table 2.1 Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2017 – 31 March 2018, by Country/Strategic Health Authority

Country/ Strategic Health Authority	Registrations (pmp)		Transplants (pmp)	
North East	17	(6.4)	9	(3.4)
North West	36	(5.0)	24	(3.3)
Yorkshire and The Humber	25	(4.6)	6	(1.1)
North of England	78	(5.1)	39	(2.6)
East Midlands	17	(3.6)	16	(3.4)
West Midlands	35	(6.0)	14	(2.4)
East of England	35	(5.7)	21	(3.4)
Midlands and East	87	(5.2)	51	(3.1)
London	45	(5.1)	35	(4.0)
South East Coast	24	(5.2)	13	(2.8)
South Central	22	(5.1)	12	(2.8)
South West	22	(4.0)	14	(2.5)
South of England	68	(4.7)	39	(2.7)
England	278	(5.0)	164	(3.0)
Isle of Man	2	(25)	1	(12.5)
Channel Islands	0	(0.0)	0	(0.0)
Wales	8	(2.6)	3	(1.0)
Scotland	28	(5.2)	16	(3.0)
Northern Ireland	12	(6.5)	8	(4.3)
TOTAL	333¹	(5.1)	194²	(2.9)

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

² Transplants include 2 recipients whose postcode was unknown and excludes 3 recipients who reside in the Republic of Ireland

Figure 2.10 Comparison of lung registration rates (pmp) with transplant rates (pmp) by recipient country/Strategic Health Authority of residence

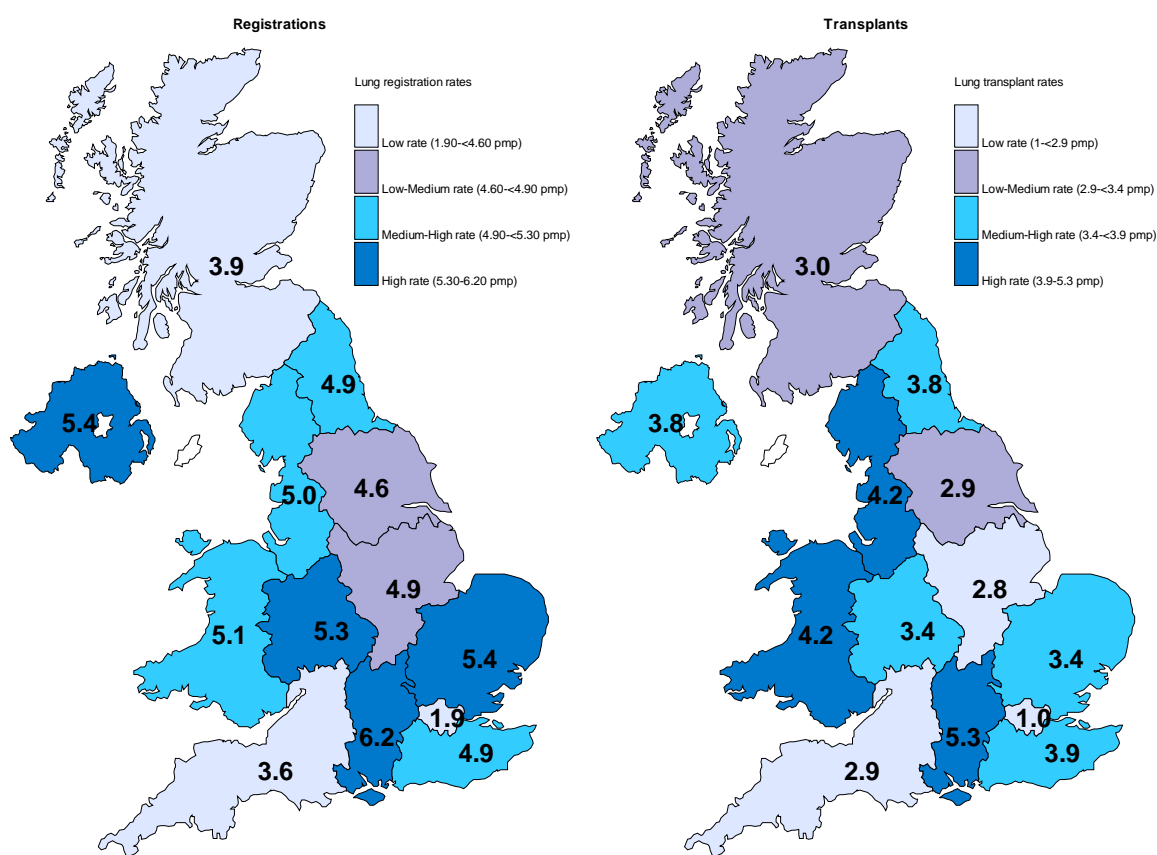


Table 2.2 Lung registration and transplant rates per million population (pmp) in the UK, 1 April 2017 – 31 March 2018, by Country/Strategic Health Authority				
Country/ Strategic Health Authority	Registrations (pmp)		Transplants (pmp)	
North East	13	(4.9)	10	(3.8)
North West	36	(5.0)	30	(4.2)
Yorkshire and The Humber	25	(4.6)	16	(2.9)
North of England	74	(4.8)	56	(3.7)
East Midlands	23	(4.9)	13	(2.8)
West Midlands	31	(5.3)	20	(3.4)
East of England	33	(5.4)	21	(3.4)
Midlands and East	87	(5.2)	54	(3.2)
London	17	(1.9)	9	(1.0)
South East Coast	23	(4.9)	18	(3.9)
South Central	27	(6.2)	23	(5.3)
South West	20	(3.6)	16	(2.9)
South of England	70	(4.8)	57	(3.9)
England	248	(4.5)	176	(3.2)
Isle of Man	0	(0.0)	0	(0.0)
Channel Islands	0	(0.0)	0	(0.0)
Wales	16	(5.1)	13	(4.2)
Scotland	21	(3.9)	16	(3.0)
Northern Ireland	10	(5.4)	7	(3.8)
TOTAL	295	(4.5)	212¹	(3.2)

¹ Transplants excludes 2 recipients who reside in the Republic of Ireland

ADULT HEART TRANSPLANTATION

Transplant List



3.1 Adult heart only transplant list as at 31 March, 2009 – 2018

Figure 3.1 shows the number of adult patients on the heart transplant list at 31 March each year between 2009 and 2018 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 76 in 2009 to 225 in 2018. The number of patients on the urgent list has increased from 2 in 2009 to 28 in 2018. There were two super-urgent patients on the list on 31 March 2018.

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

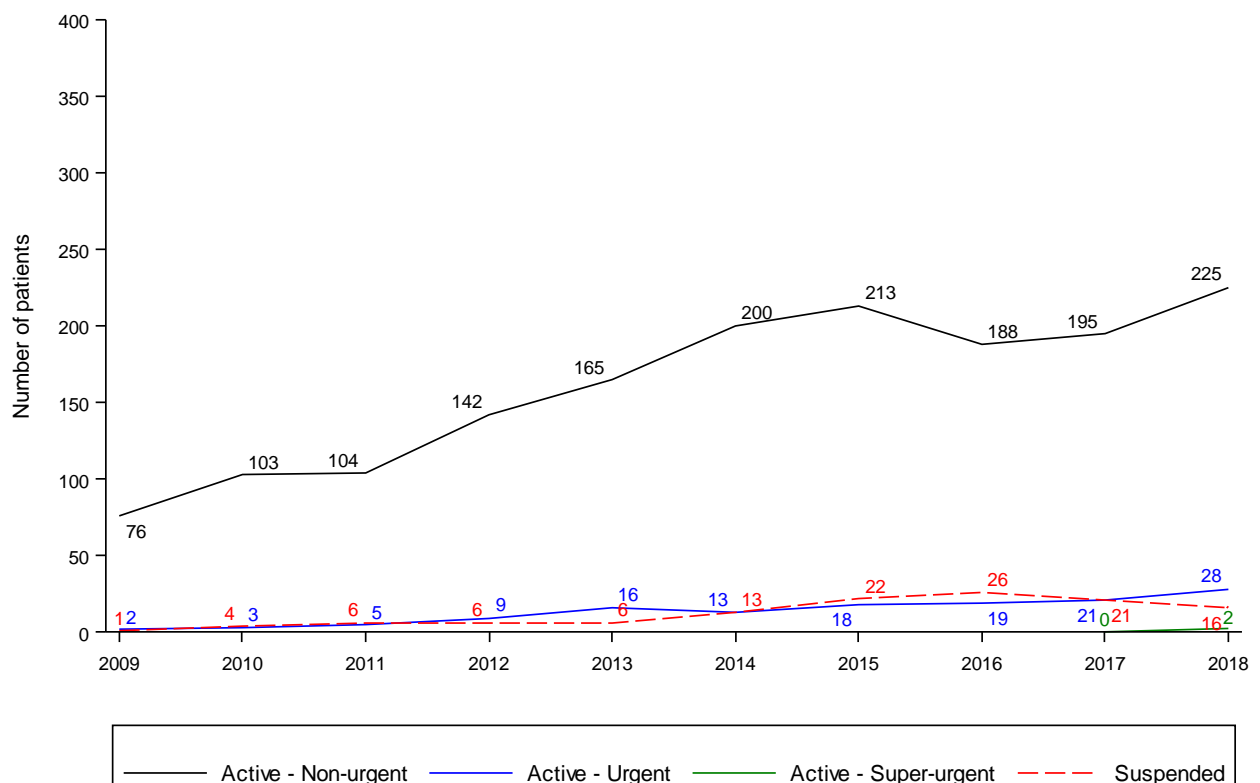


Figure 3.2 shows the number of adult patients on the [active heart transplant list](#) at 31 March 2018 by centre. In total, there were 255 adult patients waiting. Harefield had the largest number on the transplant list whilst Papworth had the smallest. The number of patients on the urgent transplant list at 31 March 2018 ranged from 1 at Glasgow and Papworth to 11 at Harefield. Birmingham and Manchester had one patient each on the super-urgent transplant list.

Figure 3.2 Number of adult patients on the active heart transplant list at 31 March 2018, by centre

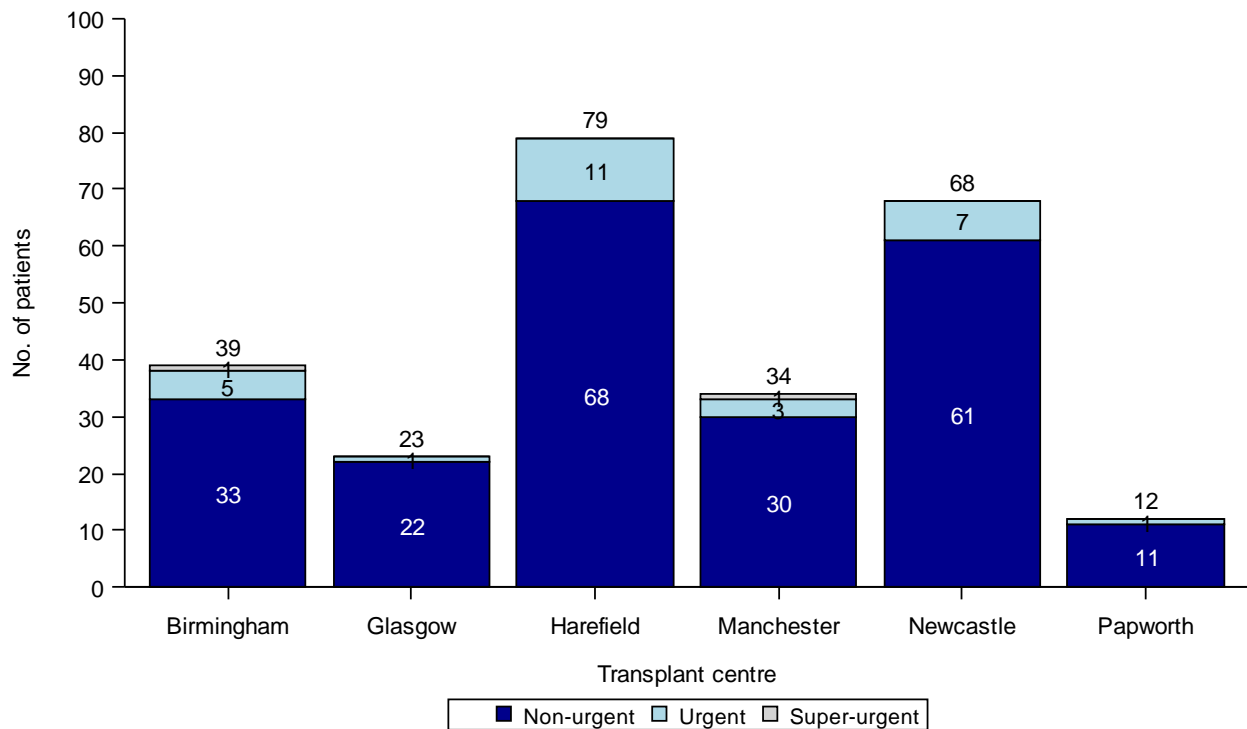
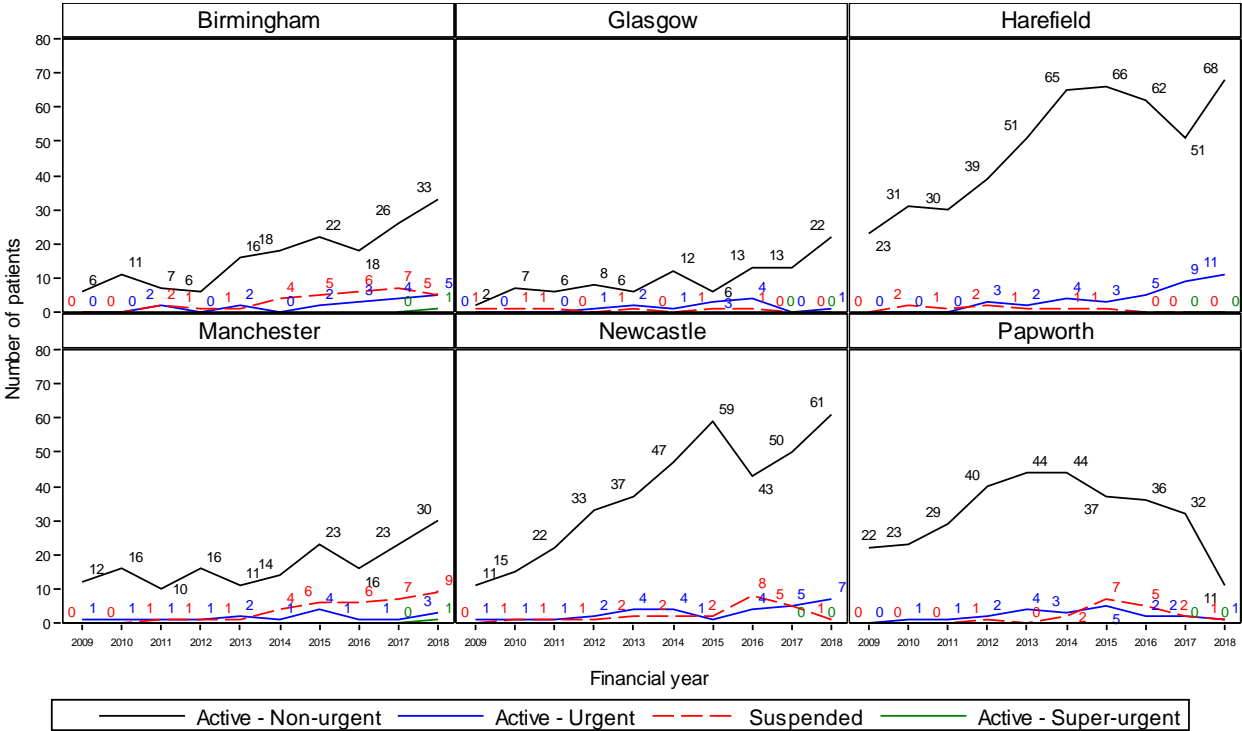


Figure 3.3 shows the trend over time in the number of adult patients on the heart transplant list at 31 March each year across centres. All centres have seen a general increase over the decade, however Papworth have seen a decreasing trend in recent years.

Figure 3.3 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 2017 – 31 March 2018

There were 290 adult patient registrations onto the heart transplant list between 1 April 2017 and 31 March 2018. Demographic characteristics of these patients are shown by centre and overall in **Table 3.1**. Nationally, 73% of patients were male and the [median](#) age was 51 years. Note that there were 49 super-urgent heart registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

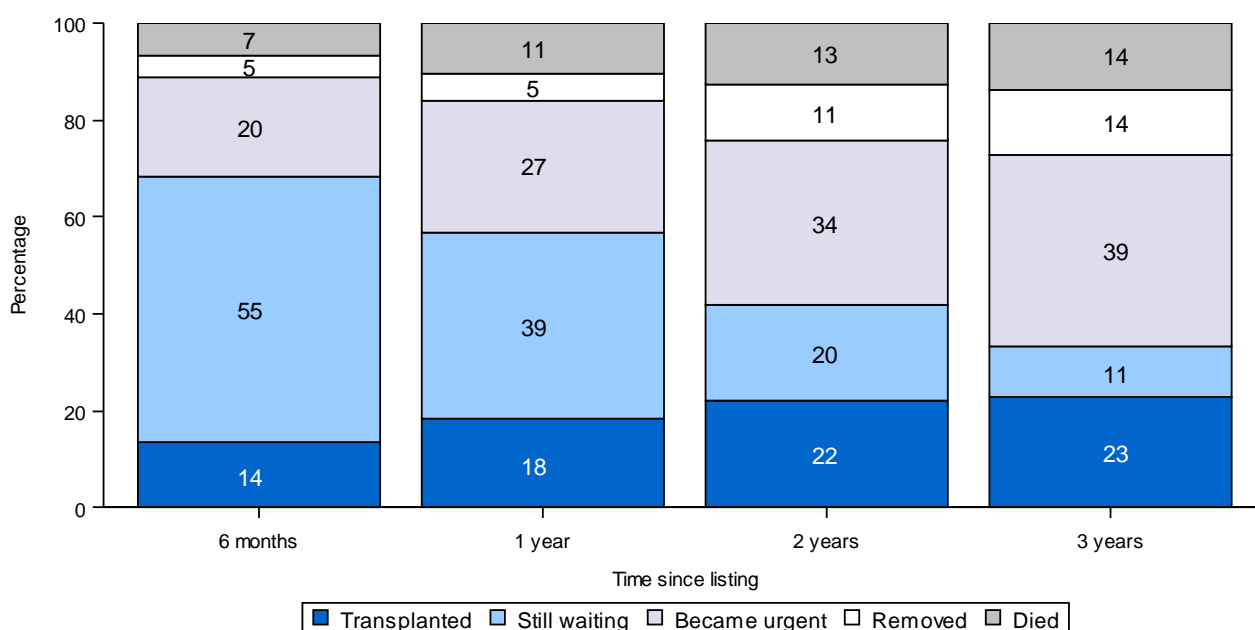
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		45 (100)	25 (100)	82 (100)	41 (100)	49 (100)	48 (100)	290 (100)
Highest urgency during registration	Non-urgent	19 (42)	11 (44)	36 (44)	20 (49)	26 (53)	18 (38)	130 (45)
	Urgent	21 (47)	5 (20)	32 (39)	13 (32)	20 (41)	20 (42)	111 (38)
	Super-urgent	5 (11)	9 (36)	14 (17)	8 (20)	3 (6)	10 (21)	49 (17)
Recipient sex	Male	31 (69)	15 (60)	52 (63)	32 (78)	40 (82)	41 (85)	211 (73)
	Female	14 (31)	10 (40)	30 (37)	9 (22)	9 (18)	7 (15)	79 (27)
Recipient ethnicity	White	36 (80)	24 (96)	58 (71)	34 (83)	47 (96)	43 (90)	242 (83)
	Non-white	8 (18)	1 (4)	24 (29)	7 (17)	2 (4)	5 (10)	47 (16)
	Missing	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0)
Recipient age (years)	Median (IQR)	54 (44, 61)	49 (40, 53)	49 (37, 55)	54 (41, 59)	51 (34, 60)	55 (42, 60)	51 (39, 58)
	Missing	0	0	0	0	0	0	0
Primary Disease	Coronary heart disease	4 (9)	6 (24)	13 (16)	15 (37)	14 (29)	9 (19)	61 (21)
	Cardiomyopathy	25 (56)	11 (44)	42 (51)	16 (39)	19 (39)	19 (40)	132 (46)
	Congenital heart disease	0 (0)	0 (0)	4 (5)	1 (2)	8 (16)	1 (2)	14 (5)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (0)
	Other	16 (36)	8 (32)	23 (28)	9 (22)	8 (16)	18 (38)	82 (28)
Previous open heart surgery	None	21 (47)	22 (88)	44 (54)	20 (49)	13 (27)	34 (71)	154 (53)
	One	18 (40)	1 (4)	27 (33)	18 (44)	26 (53)	12 (25)	102 (35)
	More than one	4 (9)	0 (0)	9 (11)	1 (2)	7 (14)	1 (2)	22 (8)
	Missing	2 (4)	2 (8)	2 (2)	2 (5)	3 (6)	1 (2)	12 (4)
Previous thoracotomy	No	44 (98)	20 (80)	70 (85)	36 (88)	42 (86)	47 (98)	259 (89)
	Yes	0 (0)	3 (12)	11 (13)	5 (12)	3 (6)	0 (0)	22 (8)
	Missing	1 (2)	2 (8)	1 (1)	0 (0)	4 (8)	1 (2)	9 (3)
Serum Bilirubin (umol/l)	Median (IQR)	14 (8, 22)	10 (7, 13)	16 (11, 21)	19 (14, 27)	14 (9, 23)	20 (12, 27)	16 (10, 23)
	Missing	0	4	2	0	3	3	12
Serum Creatinine (umol/l)	Median (IQR)	108 (93, 135)	88 (78, 100)	89 (70, 114)	94 (70, 124)	121 (100, 178)	119 (92, 144)	103 (80, 132)
	Missing	0	4	1	1	3	0	9

3.3 Post-registration outcomes, 1 April 2014 – 31 March 2015

The transplant list outcomes of adult patients listed for a non-urgent heart transplant between 1 April 2014 and 31 March 2015 are summarised in **Figure 3.4**. The same information is presented in **Figure 3.5** for those listed for an urgent heart transplant between 1 April 2014 and 31 March 2015 (including those previously on the non-urgent list). These charts show the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two year and three years after joining the list.

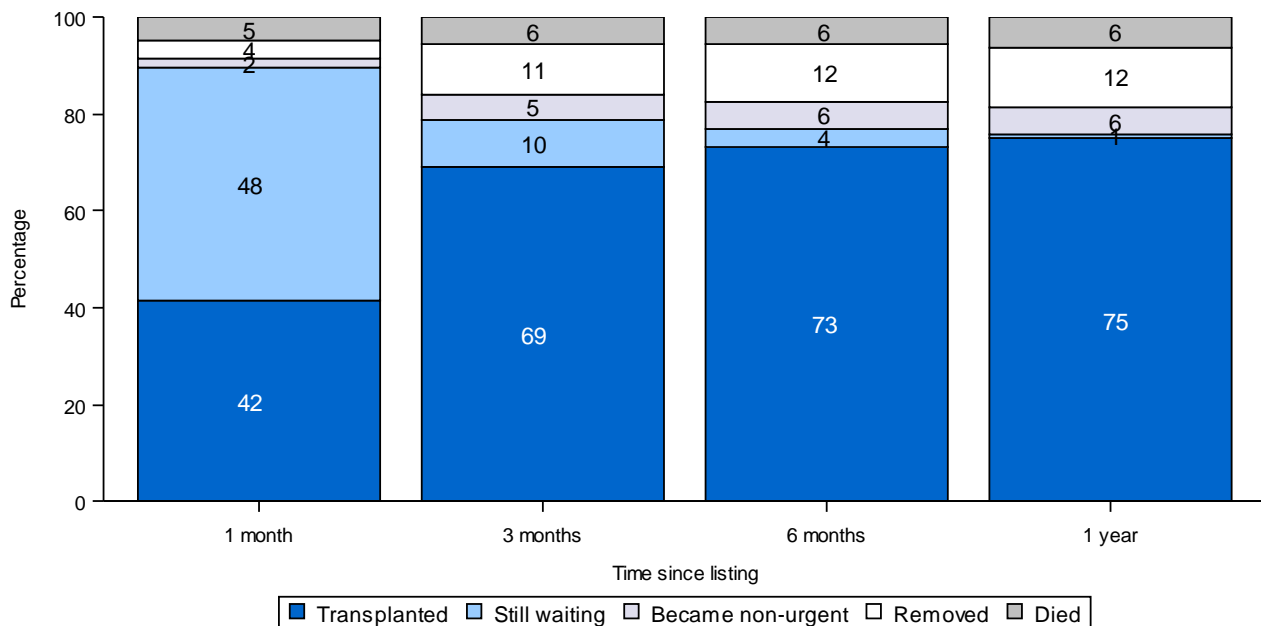
Within six months of listing 14% of non-urgent heart patients had been transplanted and 7% had died, while after three years 23% had been transplanted and 14% had died. Also, 20% had been moved to the urgent heart list within 6 months, reaching 39% by three years. About half of removals from the list were due to improved condition and the other half due to deteriorating condition.

Figure 3.4 Post-registration outcome for 132 non-urgent heart only registrations made in the UK, 1 April 2014 to 31 March 2015



The chance of transplant is much higher from the urgent heart transplant list compared with the non-urgent transplant list, as shown below in **Figure 3.5**; within 6 months, 73% have been transplanted, 6% had died and 11% removed. Removals from the list were for a variety of reasons including improved condition, deteriorating condition and no longer meeting the necessary criteria for urgent listing.

Figure 3.5 Post-registration outcome for 161 urgent heart only registrations made in the UK, 1 April 2014 to 31 March 2015



3.4 Median waiting time to transplant, 1 April 2012 - 31 March 2015

The [median](#) waiting time to heart transplant from listing for adult patients is shown in **Figure 3.6** and **Table 3.2**. This is estimated for patients registered on the heart only transplant list between 1 April 2012 and 31 March 2015 using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. This is split by the urgency of the patient at 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 overall national [median](#) waiting time from non-urgent registration is 502 days (1.4 years) and ranges from 338 days at Manchester to 960 days at Harefield. For urgent registrations, the national [median](#) waiting time is 26 days, and ranges from 19 days at Birmingham and Papworth to 42 days at Glasgow.

Figure 3.6 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2012 and 31 March 2015, by centre and urgency status at registration

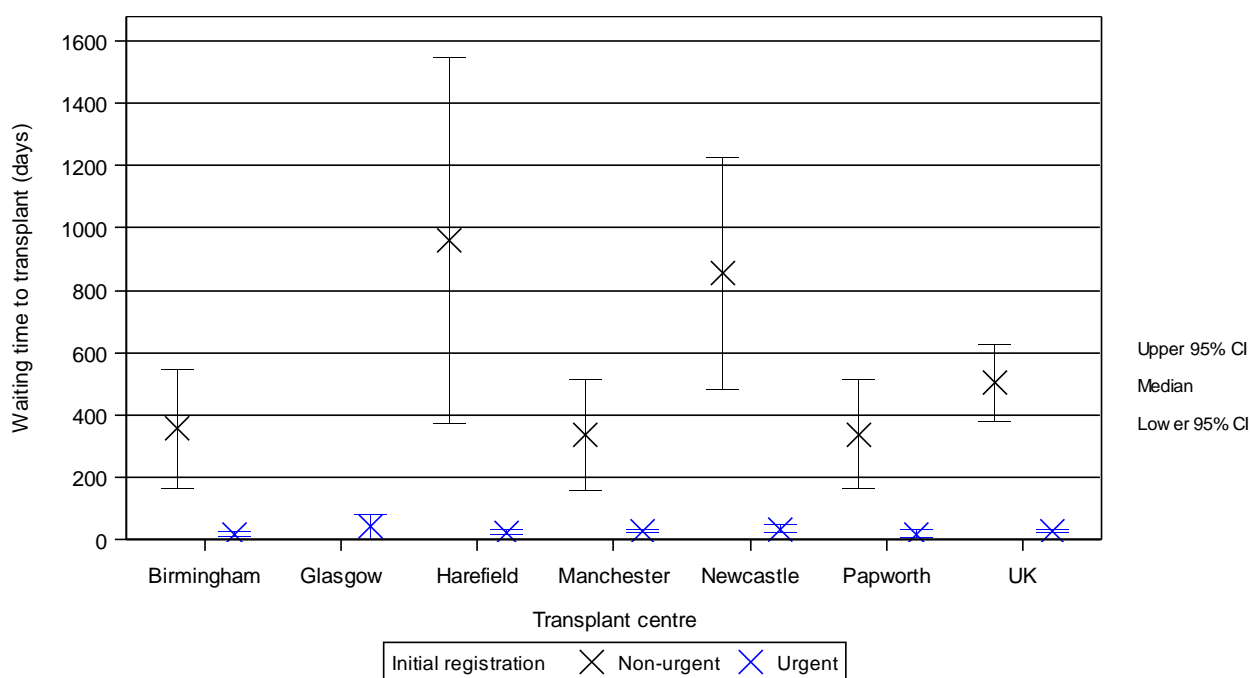


Table 3.2 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and centre, 1 April 2012 to 31 March 2015

Transplant centre	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Overall			
Birmingham	117	115	58 - 172
Glasgow	72	99	0 - 198
Harefield	133	457	156 - 758
Manchester	113	73	22 - 124
Newcastle	139	595	332 - 858
Papworth	145	172	84 - 260
UK	719	180	127 - 233
Non-urgent at initial registration			
Birmingham	72	355	165 - 545
Glasgow ¹	30	497	-
Harefield	98	960	374 - 1546
Manchester	57	338	160 - 516
Newcastle	96	855	483 - 1227
Papworth	101	339	162 - 516
UK	454	502	379 - 625
Urgent at initial registration			
Birmingham	45	19	13 - 25
Glasgow	42	42	3 - 81
Harefield	35	24	15 - 33
Manchester	56	27	22 - 32
Newcastle	43	35	22 - 48
Papworth	44	19	4 - 34
UK	265	26	21 - 31

¹ a 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 3.7** and **Table 3.3** by both blood group and urgency status at registration. For urgent registrations, blood group O patients have the longest average wait (54 days) compared with the other groups.

Figure 3.7 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2012 and 31 March 2015, by blood group and urgency status at registration

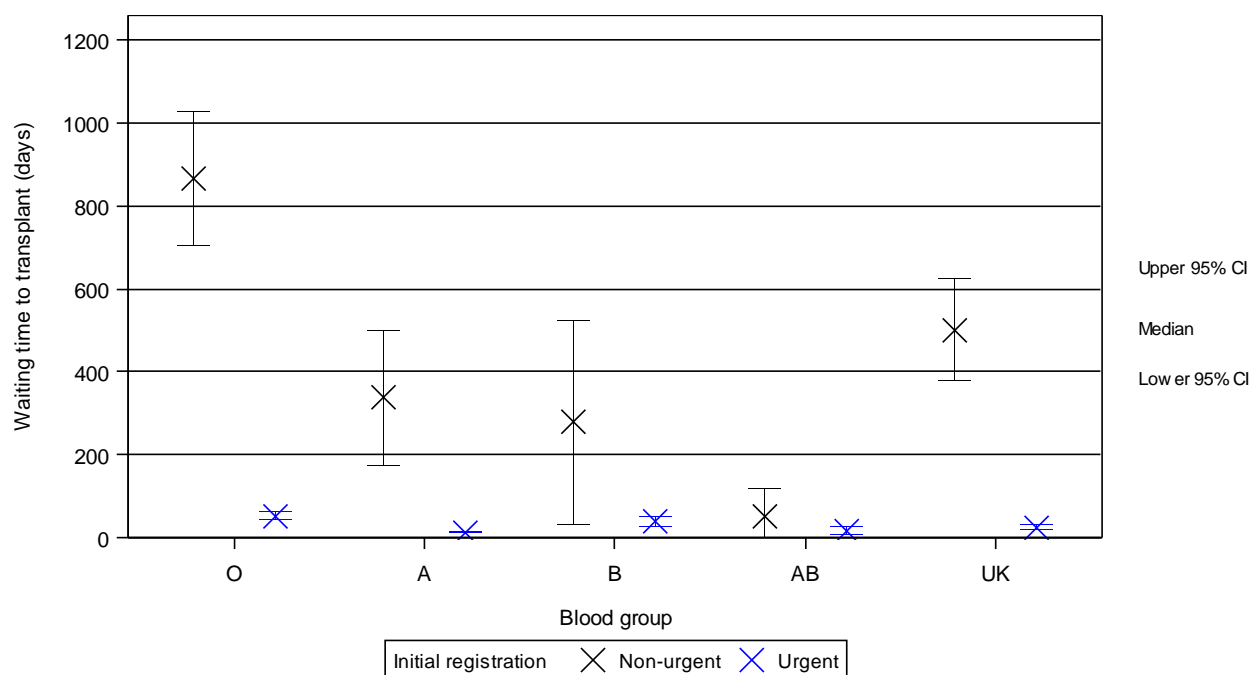


Table 3.3 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2012 to 31 March 2015

Blood group	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Overall			
O	299	479	275 - 683
A	310	87	58 - 116
B	81	150	19 - 281
AB	29	24	19 - 29
UK	719	180	127 - 233
Non-urgent at initial registration			
O	201	867	706 - 1028
A	196	338	175 - 501
B	44	279	33 - 525
AB	13	53	0 - 119
UK	454	502	379 - 625
Urgent at initial registration			
O	98	54	43 - 65
A	114	14	11 - 17
B	37	41	28 - 54
AB	16	18	8 - 28
UK	265	26	21 - 31

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 between 1 April 2015 and 31 March 2018 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a cardiac block are considered, as are all super-urgent, urgent and non-urgent patient offers. 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 rates for Harefield and Glasgow are 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 Birmingham and Papworth are below the lower 99.8% [confidence limit](#), indicating that they have a significantly lower decline rate than the national rate. There is also some evidence that the decline rate for Manchester may be significantly low, as their decline rate is between the 95% and 99.8% confidence limits.

Figure 4.1 UK adult DBD donor heart offer decline rates by centre, 1 April 2015 to 31 March 2018

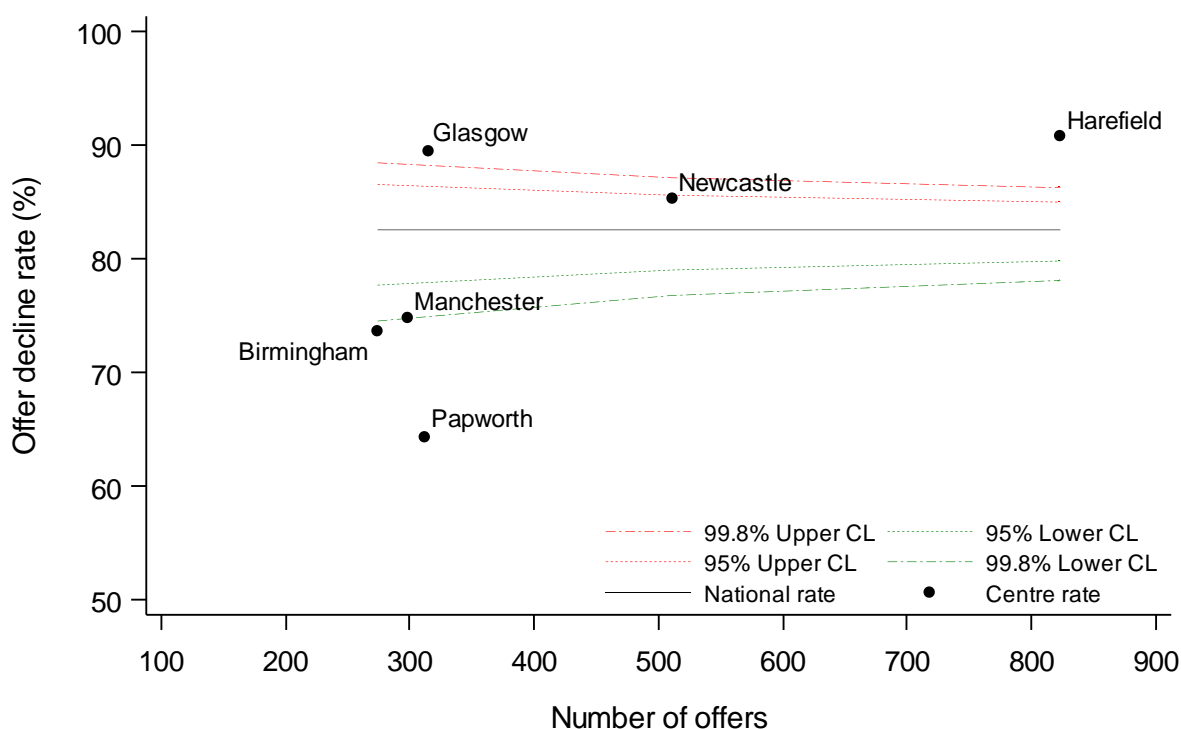


Table 4.1 shows a breakdown of each centre's decline rate across the three years analysed. Nationally, the number of offers has decreased (for hearts that are eventually transplanted) and so has the offer decline rate, from 84.4% to 78.3%.

Table 4.1 UK adult DBD donor heart offer decline rates by transplant centre and year, between 1 April 2015 and 31 March 2018								
Centre	2015/16		2016/17		2017/18		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	98	(73.5)	116	(78.4)	60	(65.0)	274	(73.7)
Glasgow	118	(94.1)	93	(83.9)	103	(89.3)	314	(89.5)
Harefield	262	(92.0)	356	(94.4)	205	(82.9)	823	(90.8)
Manchester	116	(73.3)	93	(68.8)	89	(83.1)	298	(74.8)
Newcastle	213	(89.2)	178	(84.8)	119	(79.0)	510	(85.3)
Papworth	127	(70.1)	92	(62.0)	93	(59.1)	312	(64.4)
UK	934	(84.4)	928	(83.7)	669	(78.3)	2531	(82.5)
	Centre has reached the upper 99.8% confidence limit							
	Centre has reached the upper 95% confidence limit							
	Centre has reached the lower 95% confidence limit							
	Centre has reached the lower 99.8% confidence limit							

ADULT HEART TRANSPLANTATION

Transplants



5.1 Adult heart transplants, 1 April 2008 – 31 March 2018

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 162 adult heart transplants nationally; three lower than the previous year, and five less than the most active year over the last decade, which was 2013/2014. However, compared with 2008/2009, activity has increased by 72%.

Figure 5.1 Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2008 to 31 March 2018

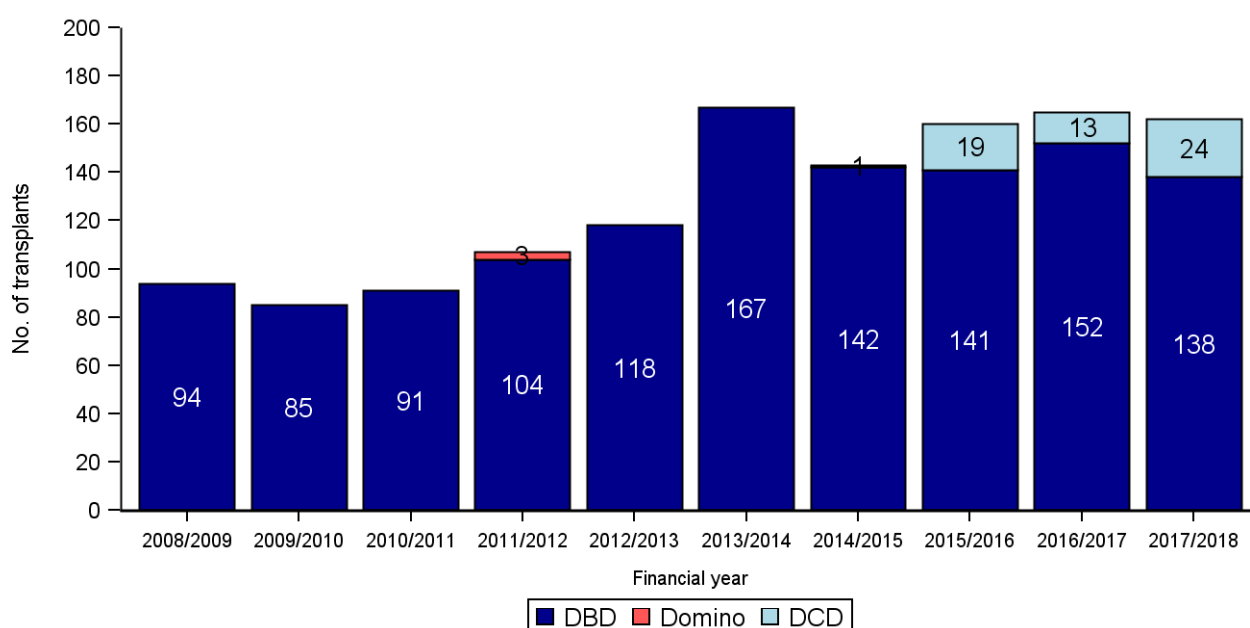
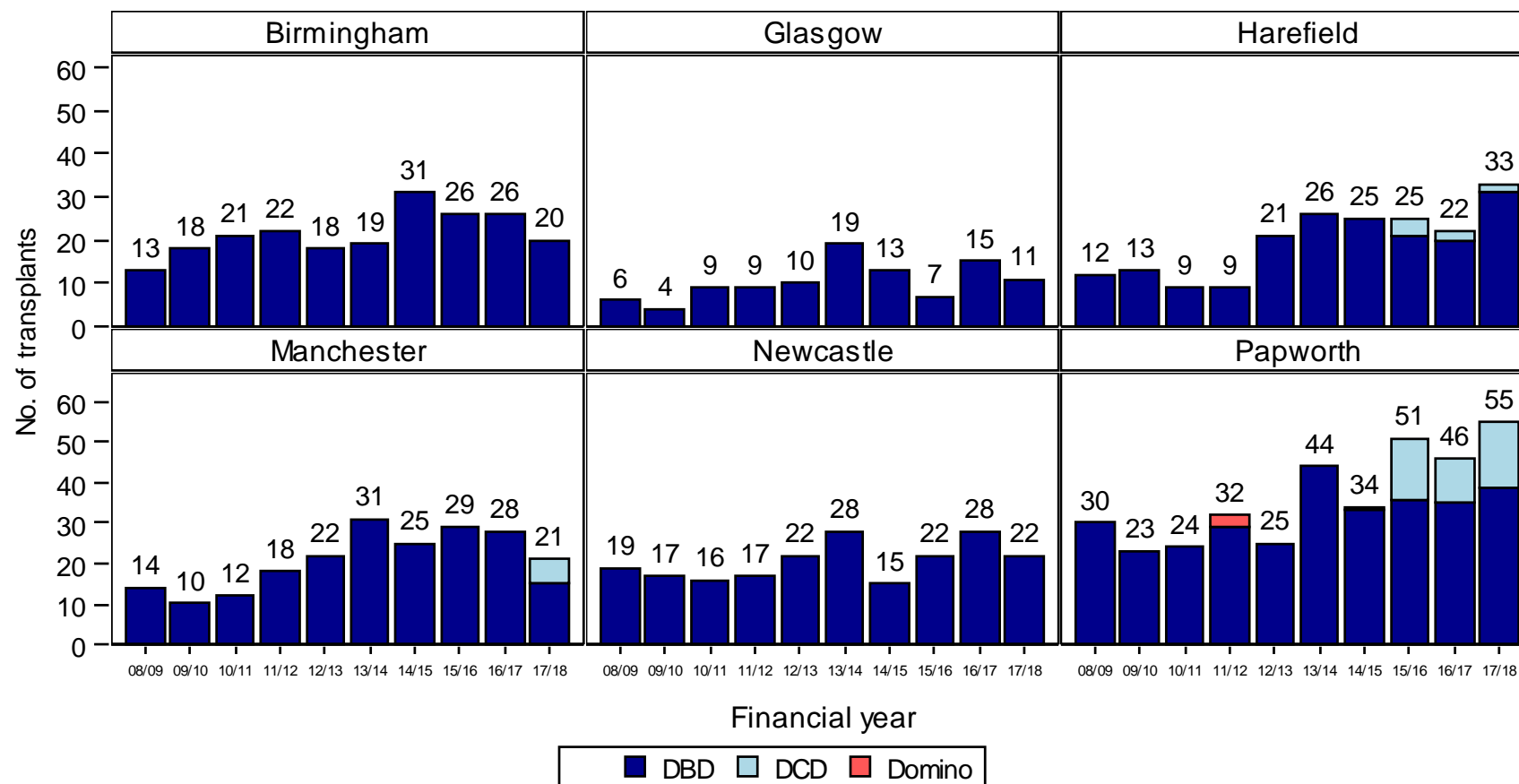


Figure 5.2 shows the number of adult heart transplants performed per centre, per year, over the last ten years, by donor type. Harefield and Papworth have had a steady increase in their heart transplant numbers over the decade.

Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2008 to 31 March 2018



Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants, performed by three centres in this time period, represented 15% of last year's adult heart transplants. 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 2017 to 31 March 2018

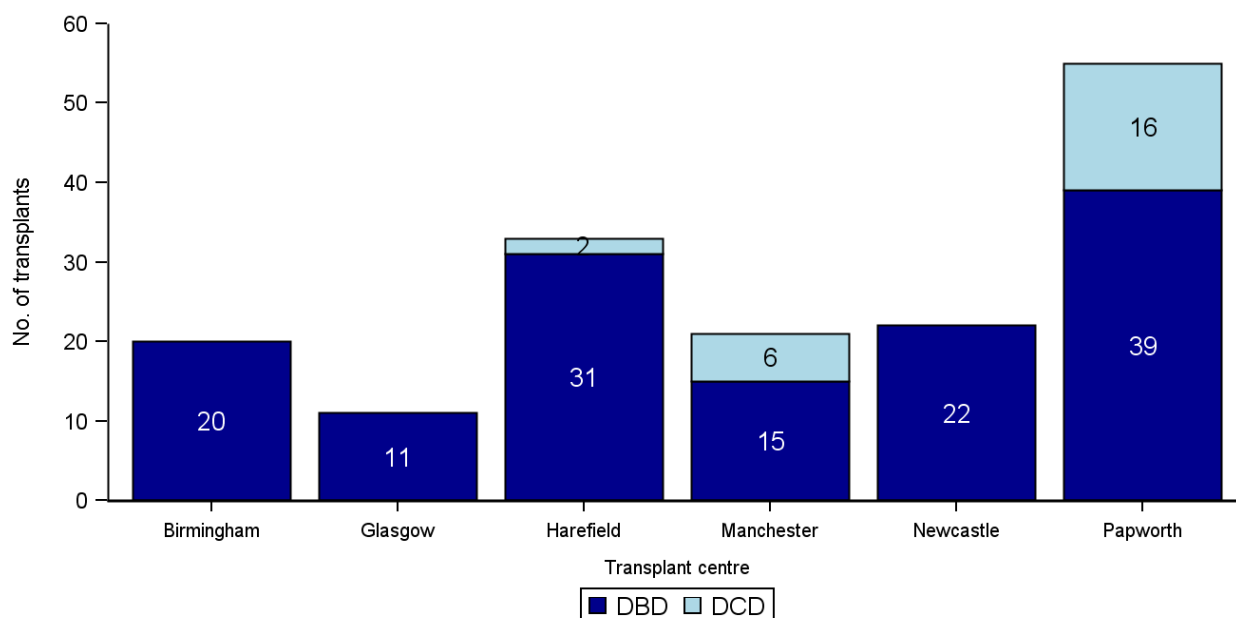


Figure 5.4 and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time, the proportion of urgent transplants has increased; from 45% in 2008/2009 to 80% in 2017/2018, including 35 super-urgent transplants.

Figure 5.4 Number of adult heart transplants in the UK, by financial year and urgency status, 1 April 2008 to 31 March 2018

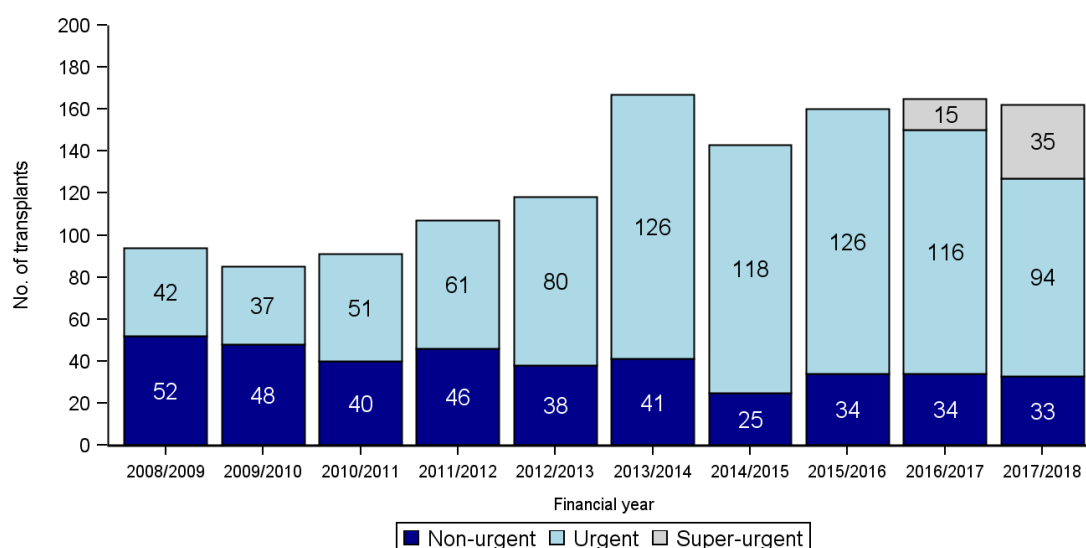
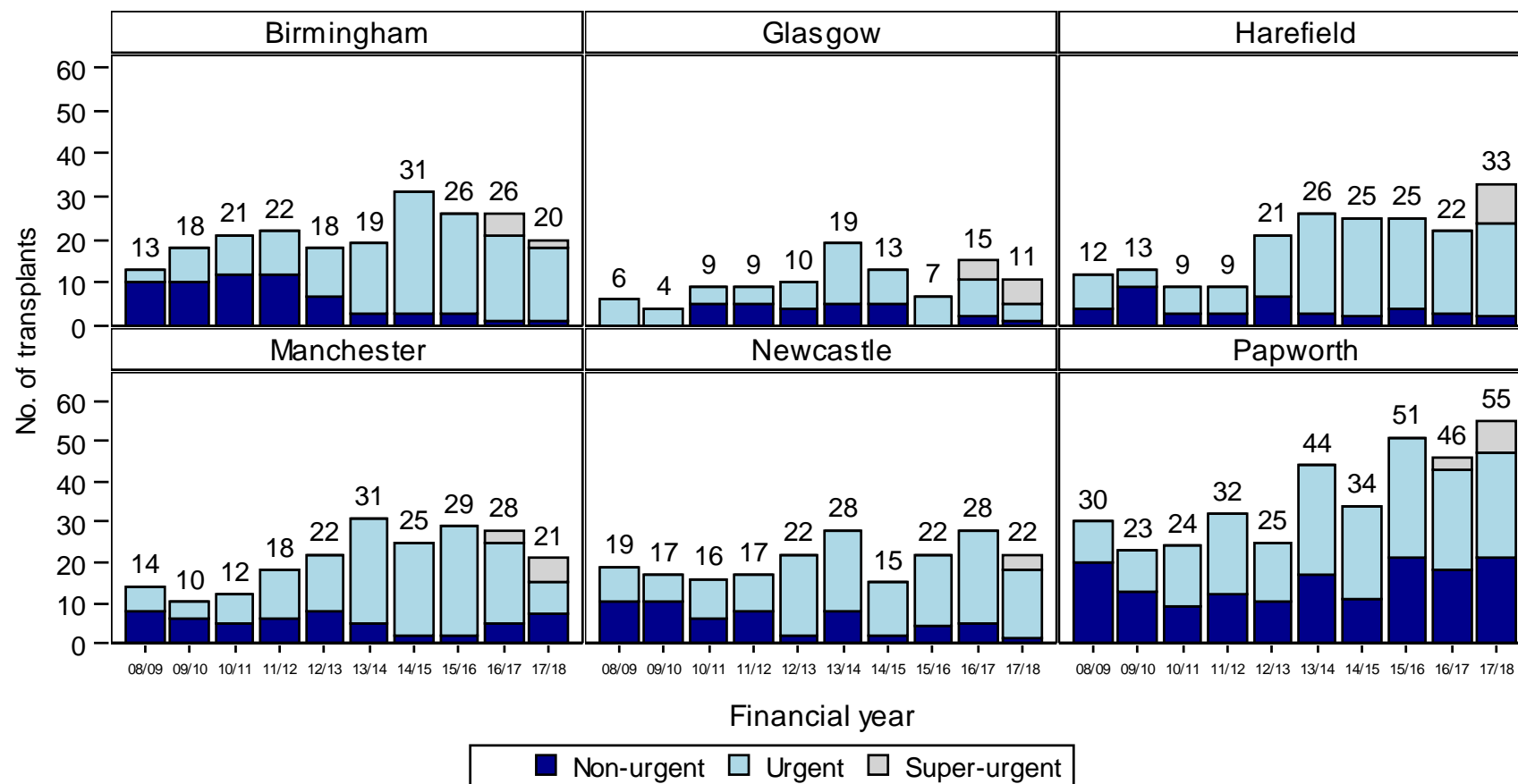
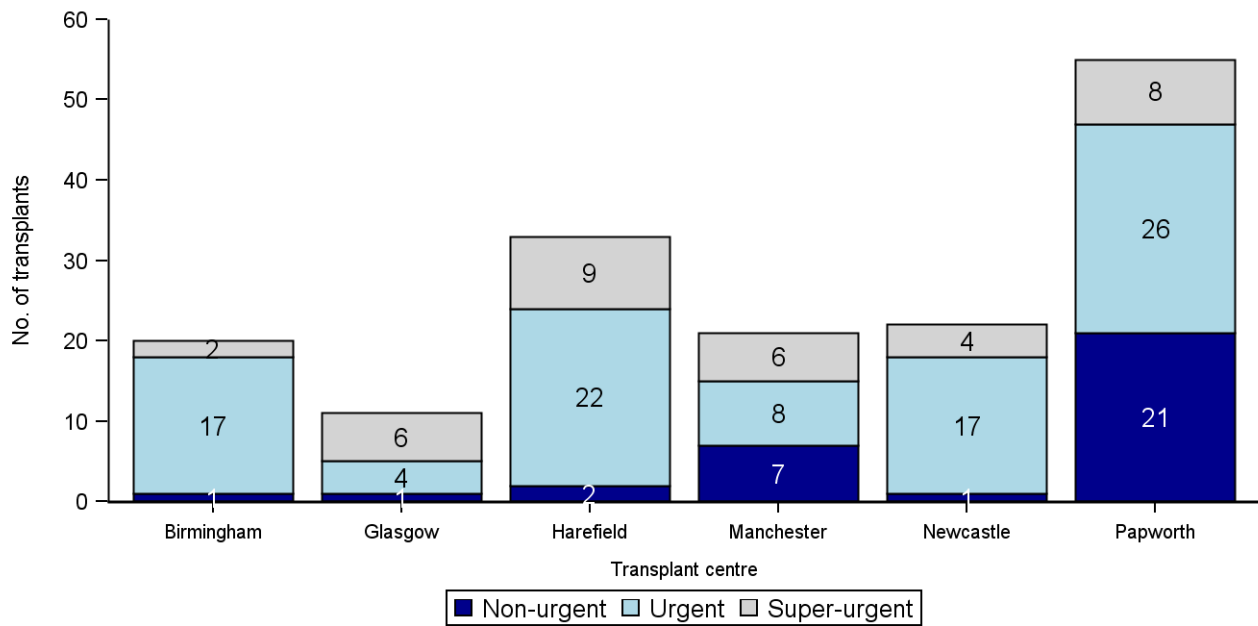


Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2008 to 31 March 2018



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 64% of all non-urgent transplants performed in 2017/2018. Of the 33 non-urgent transplants, 14 (42%) were from DCD donors.

Figure 5.6 Number of adult heart transplants in the UK, by centre and urgency status, 1 April 2017 to 31 March 2018



5.2 Demographic characteristics of transplants, 1 April 2017 – 31 March 2018

The demographic characteristics of the 162 adult heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 73% of heart recipients were male and the [median](#) age was 52 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 2017 to 31 March 2018, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		20 (100)	11 (100)	33 (100)	21 (100)	22 (100)	55 (100)	162 (100)
Urgency status at transplant	Non-urgent	1 (5)	1 (9)	2 (6)	7 (33)	1 (5)	21 (38)	33 (20)
	Urgent	17 (85)	4 (36)	22 (67)	8 (38)	17 (77)	26 (47)	94 (58)
	Super-urgent	2 (10)	6 (55)	9 (27)	6 (29)	4 (18)	8 (15)	35 (22)
Recipient sex	Male	13 (65)	7 (64)	21 (64)	18 (86)	13 (59)	47 (85)	119 (73)
	Female	7 (35)	4 (36)	12 (36)	3 (14)	9 (41)	8 (15)	43 (27)
Recipient ethnicity	White	14 (70)	11 (100)	27 (82)	20 (95)	20 (91)	45 (82)	137 (85)
	Non-white	5 (25)	0 (0)	6 (18)	1 (5)	2 (9)	10 (18)	24 (15)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient age (years)	Median (IQR)	51 (42, 59)	48 (44, 50)	52 (38, 58)	54 (49, 59)	46 (32, 59)	52 (43, 61)	52 (39, 59)
	Missing	0	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	81 (66, 87)	75 (69, 85)	73 (57, 84)	78 (67, 87)	69 (60, 84)	78 (67, 89)	76 (65, 86)
	Missing	0	0	0	0	0	0	0
Recipient primary disease	Coronary heart disease	1 (5)	4 (36)	2 (6)	8 (38)	2 (9)	11 (20)	28 (17)
	Cardiomyopathy	7 (35)	3 (27)	20 (61)	6 (29)	6 (27)	26 (47)	68 (42)
	Congenital heart disease	1 (5)	0 (0)	2 (6)	0 (0)	6 (27)	2 (4)	11 (7)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (1)
	Other	11 (55)	4 (36)	9 (27)	7 (33)	8 (36)	15 (27)	54 (33)
NYHA class	II	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	3 (5)	4 (3)
	III	2 (10)	4 (36)	16 (48)	9 (43)	10 (45)	25 (45)	66 (41)
	IV	15 (75)	6 (55)	17 (52)	11 (52)	8 (36)	27 (49)	84 (52)
	Missing	2 (10)	1 (9)	0 (0)	1 (5)	4 (18)	0 (0)	8 (5)
Recipient in hospital pre-transplant	No	2 (10)	1 (9)	1 (3)	6 (29)	3 (14)	27 (49)	40 (25)
	Yes	18 (90)	10 (91)	32 (97)	15 (71)	16 (73)	28 (51)	119 (74)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	3 (14)	0 (0)	3 (2)

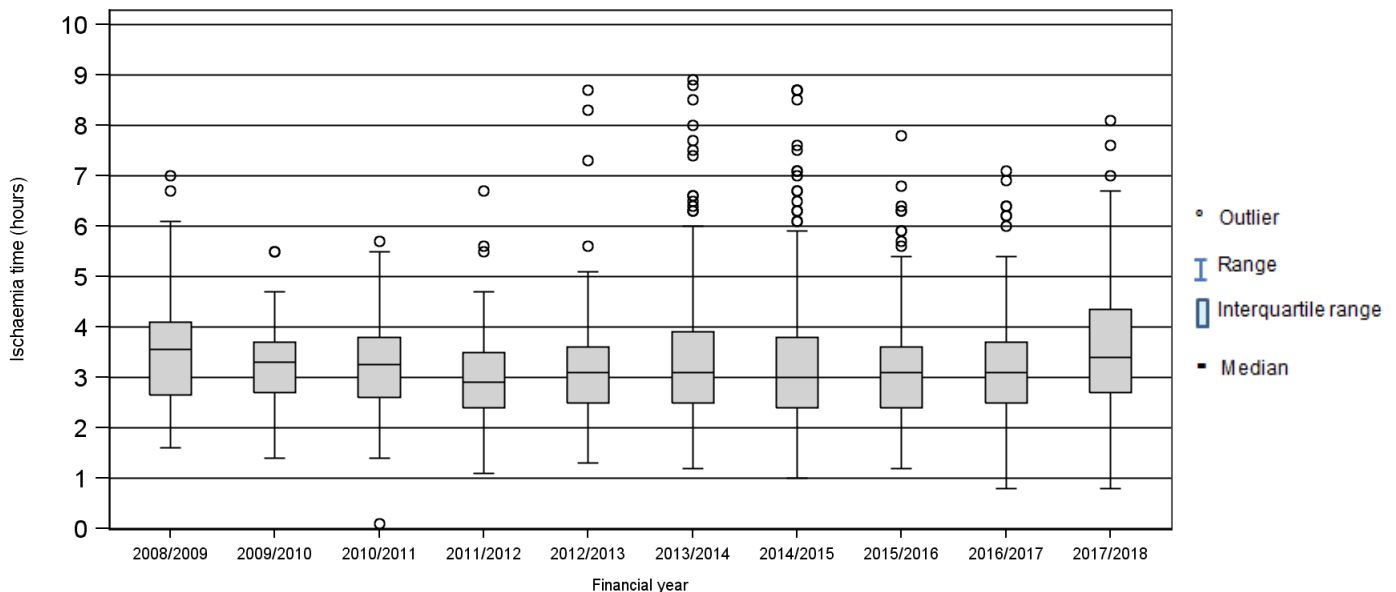
Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2017 to 31 March 2018, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
If in hospital, recipient on ventilator	No	17 (94)	10 (100)	30 (94)	15 (100)	16 (100)	27 (96)	115 (97)
	Yes	1 (6)	0 (0)	2 (6)	0 (0)	0 (0)	1 (4)	4 (3)
If in hospital, recipient on VAD	None	16 (89)	8 (80)	24 (75)	9 (60)	16 (100)	20 (71)	93 (78)
	Left	0 (0)	1 (10)	7 (22)	3 (20)	0 (0)	2 (7)	13 (11)
	Right	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)	1 (1)
	Both	2 (11)	1 (10)	0 (0)	3 (20)	0 (0)	6 (21)	12 (10)
If in hospital, recipient on TAH	No	18 (100)	10 (100)	29 (91)	15 (100)	16 (100)	28 (100)	116 (98)
	Yes	0 (0)	0 (0)	3 (9)	0 (0)	0 (0)	0 (0)	3 (3)
If in hospital, recipient on ECMO	No	18 (100)	10 (100)	31 (97)	15 (100)	14 (88)	27 (96)	115 (97)
	Yes	0 (0)	0 (0)	1 (3)	0 (0)	1 (6)	1 (4)	3 (3)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	1 (1)
If in hospital, recipient on inotropes	No	3 (17)	2 (20)	7 (22)	7 (47)	12 (75)	8 (29)	39 (33)
	Yes	15 (83)	8 (80)	25 (78)	8 (53)	4 (25)	20 (71)	80 (67)
If in hospital, recipient on IABP	No	18 (100)	4 (40)	30 (94)	13 (87)	16 (100)	27 (96)	108 (91)
	Yes	0 (0)	5 (50)	2 (6)	2 (13)	0 (0)	1 (4)	10 (8)
	Missing	0 (0)	1 (10)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient CMV status	No	10 (50)	7 (64)	18 (55)	11 (52)	11 (50)	35 (64)	92 (57)
	Yes	9 (45)	4 (36)	15 (45)	10 (48)	11 (50)	20 (36)	69 (43)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient HCV status	No	19 (95)	11 (100)	33 (100)	21 (100)	22 (100)	55 (100)	161 (99)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient HBV status	No	19 (95)	11 (100)	33 (100)	21 (100)	22 (100)	55 (100)	161 (99)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient HIV status	No	19 (95)	11 (100)	33 (100)	21 (100)	22 (100)	55 (100)	161 (99)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient serum creatinine (umol/l)	Median (IQR)	109 (85, 147)	93 (85, 113)	85 (69, 109)	103 (77, 123)	137 (95, 176)	111 (86, 137)	106 (82, 133)
	Missing	2	2	0	0	4	0	8
Donor sex	Male	15 (75)	7 (64)	18 (55)	14 (67)	15 (68)	40 (73)	109 (67)
	Female	5 (25)	4 (36)	15 (45)	7 (33)	7 (32)	15 (27)	53 (33)
Donor ethnicity	White	20 (100)	11 (100)	28 (85)	19 (90)	21 (95)	49 (89)	148 (91)
	Non-white	0 (0)	0 (0)	4 (12)	2 (10)	1 (5)	4 (7)	11 (7)
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	2 (4)	3 (2)

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2017 to 31 March 2018, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor age (years)	Median (IQR)	38 (29, 51)	34 (32, 49)	44 (30, 51)	28 (23, 41)	34 (21, 46)	37 (27, 48)	37 (26, 48)
	Missing	0	0	0	0	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	27 (24, 31)	26 (24, 30)	26 (24, 31)	26 (23, 28)	25 (23, 26)	26 (23, 28)	26 (23, 28)
	Missing	0	0	0	0	0	0	0
Donor cause of death	CVA	15 (75)	9 (82)	27 (82)	17 (81)	13 (59)	40 (73)	121 (75)
	Trauma	1 (5)	0 (0)	0 (0)	3 (14)	4 (18)	5 (9)	13 (8)
	Others	4 (20)	2 (18)	6 (18)	1 (5)	5 (23)	10 (18)	28 (17)
Donor hypotension	No	9 (45)	7 (64)	28 (85)	17 (81)	11 (50)	45 (82)	117 (72)
	Yes	10 (50)	3 (27)	5 (15)	4 (19)	5 (23)	10 (18)	37 (23)
	Missing	1 (5)	1 (9)	0 (0)	0 (0)	6 (27)	0 (0)	8 (5)
Donor past diabetes	No	20 (100)	11 (100)	33 (100)	21 (100)	22 (100)	53 (96)	160 (99)
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (4)	2 (1)
Donor past cardiothoracic disease	No	19 (95)	11 (100)	32 (97)	20 (95)	21 (95)	53 (96)	156 (96)
	Yes	1 (5)	0 (0)	1 (3)	0 (0)	1 (5)	0 (0)	3 (2)
	Missing	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	2 (4)	3 (2)
Donor past hypertension	No	16 (80)	10 (91)	28 (85)	21 (100)	20 (91)	48 (87)	143 (88)
	Yes	4 (20)	1 (9)	5 (15)	0 (0)	2 (9)	7 (13)	19 (12)
Donor past tumour	No	20 (100)	8 (73)	32 (97)	20 (95)	22 (100)	52 (95)	154 (95)
	Yes	0 (0)	3 (27)	0 (0)	1 (5)	0 (0)	3 (5)	7 (4)
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)	1 (1)
Donor past smoker	No	7 (35)	6 (55)	19 (58)	6 (29)	9 (41)	19 (35)	66 (41)
	Yes	13 (65)	5 (45)	14 (42)	15 (71)	13 (59)	36 (65)	96 (59)
Total ischaemia time (hours)	Median (IQR)	3.3 (2.5, 3.6)	2.8 (2.5, 3.1)	5.5 (4.6, 6.2)	3.4 (3.0, 4.7)	3.7 (3.4, 4.7)	3.3 (2.5, 4.1)	3.6 (2.9, 5.0)
	Missing	1	1	0	1	8	0	11

5.3 Total ischaemia time, 1 April 2008 – 31 March 2018

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 (12%) not all of this time duration is ischaemic, and no adjustment has been made for this. The national [median](#) total ischaemia time has reduced from 3.6 hours to 3.4 hours 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 2008 to 31 March 2018



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 (2017/2018) and over the last 10 years, respectively. The increase in observed [median](#) total ischaemia time at Harefield over the decade is explained by their increasing use of the organ care system (OCS); in 2017/2018, 100% of hearts transplanted by Harefield used OCS compared with 0%-32% for other centres, who have a median of between 2.5 and 4 hours.

Figure 5.8 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre, 1 April 2017 to 31 March 2018

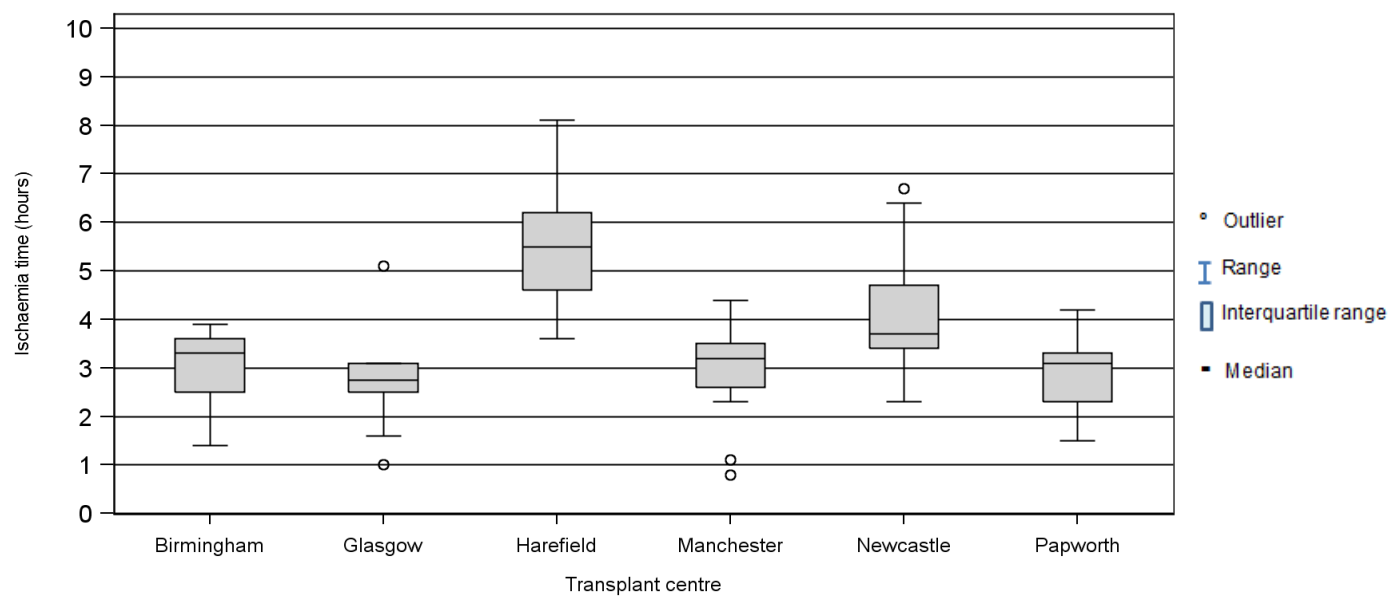
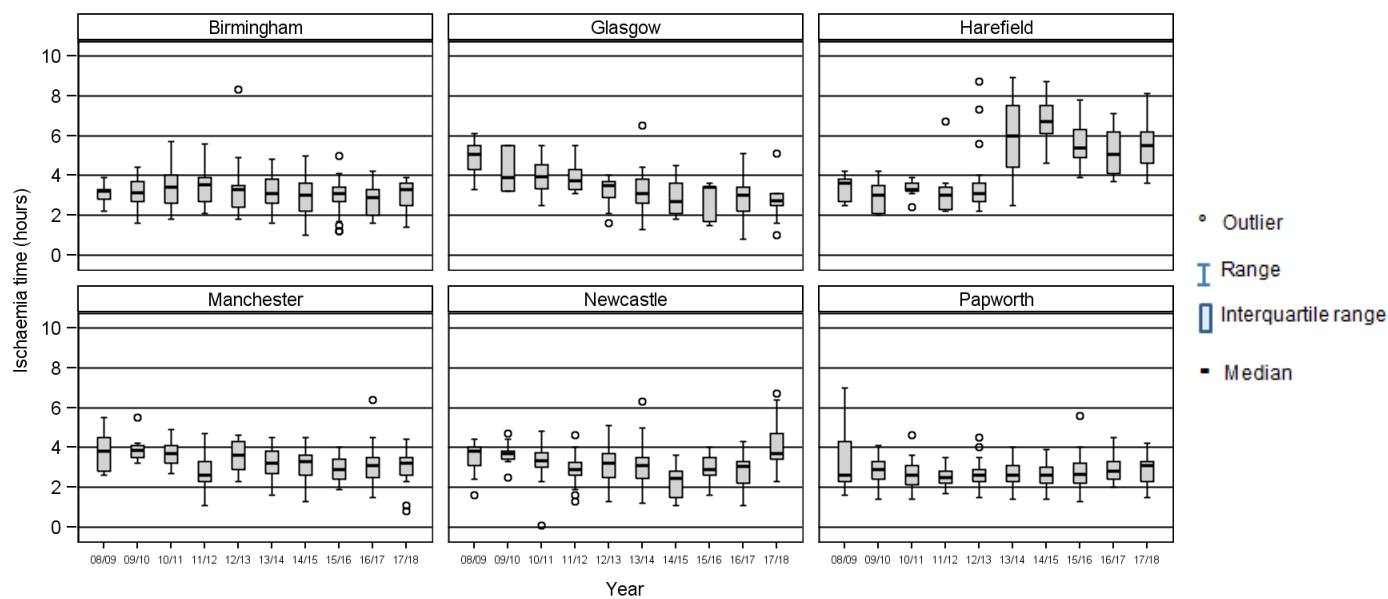


Figure 5.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre and financial year, 1 April 2008 to 31 March 2018



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 and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2013 to 31 March 2017 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2009 to 31 March 2013. [Survival rates](#) are presented by transplant centre in **Tables 6.1-6.3** and **Figures 6.1-6.3** as well as disease group in **Tables 6.4-6.6**. 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 2013 and 31 March 2017.

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 595 first adult heart only transplants in the period 1 April 2013 to 31 March 2017. All of the centres, apart from Papworth, were statistically consistent with the national rate of survival which was 90.8%. The rate for Papworth lies between the upper 95% and 99.8% [confidence limits](#) providing some evidence of a significantly high 30-day survival rate.

Table 6.1 30 day patient survival rates after first adult heart transplant, by centre, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 30 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	102	89.2	(81.4 - 93.9)	88.3	(78.8 - 93.5)
Glasgow	53	86.8	(74.3 - 93.5)	83.6	(65.5 - 92.2)
Harefield	90	86.7	(77.7 - 92.2)	90.2	(82.8 - 94.4)
Manchester	113	94.7	(88.6 - 97.6)	93.1	(84.6 - 96.9)
Newcastle	91	86.8	(77.9 - 92.3)	88.1	(79.0 - 93.2)
Papworth	146	95.2	(90.2 - 97.7)	95.3	(90.1 - 97.8)
UK	595	90.8	(88.1 - 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 6.1 Risk-adjusted 30 day patient survival rates for adult heart transplants, by centre , 1 April 2013 to 31 March 2017

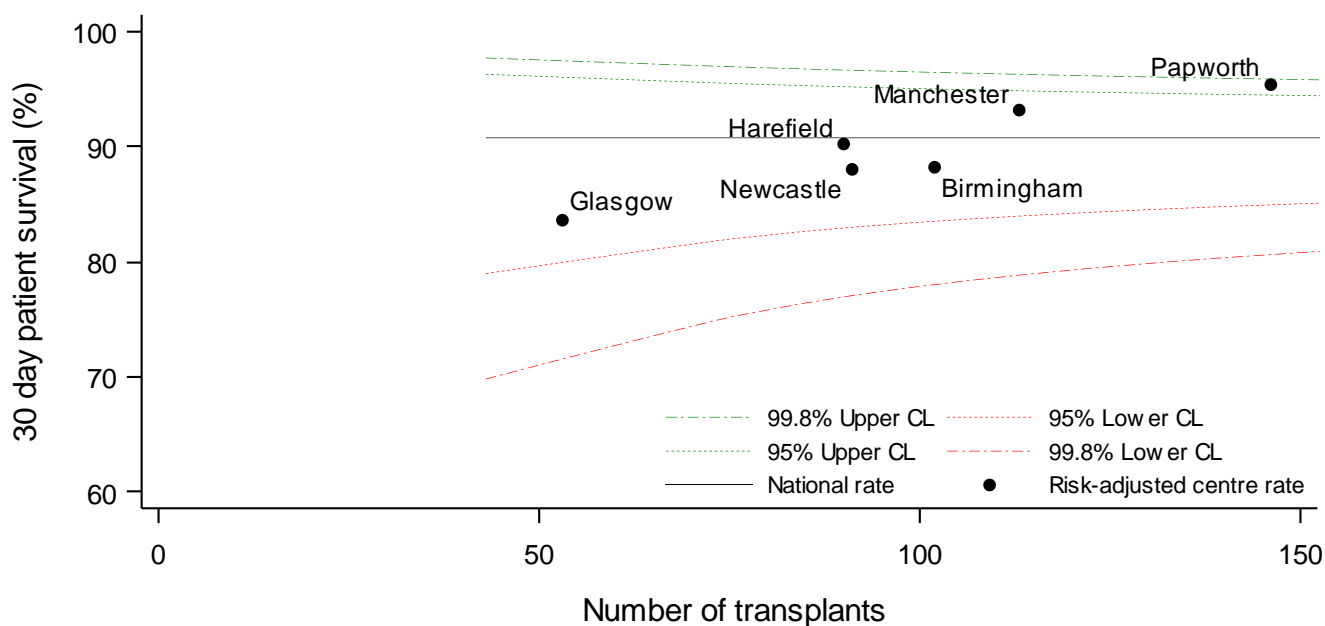


Table 6.2 and **Figure 6.2** show the 1-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 595 first adult heart only transplants in the period 1 April 2013 to 31 March 2017. The national rate of survival was 83.2%. None of the centres were statistically significantly different to the national rate, as their rates lie within the funnel, except Papworth whose rate lies between the upper 95% and 99.8% [confidence limits](#) providing some evidence of a significantly high 1-year survival rate.

Table 6.2 1 year patient survival rates after first adult heart transplant, by centre, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 1 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	102	81.0	(71.8 - 87.5)	78.8	(66.8 - 86.5)
Glasgow	53	80.4	(66.5 - 89.0)	76.3	(55.9 - 87.2)
Harefield	90	75.6	(65.3 - 83.2)	82.1	(72.9 - 88.2)
Manchester	113	86.6	(78.7 - 91.7)	83.8	(73.2 - 90.3)
Newcastle	91	80.2	(70.4 - 87.0)	79.9	(68.2 - 87.4)
Papworth	146	89.6	(83.4 - 93.6)	90.0	(83.5 - 94.0)
UK	595	83.2	(79.9 - 86.0)		

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 one-year patient survival rates for adult heart transplants, by centre, 1 April 2013 to 31 March 2017

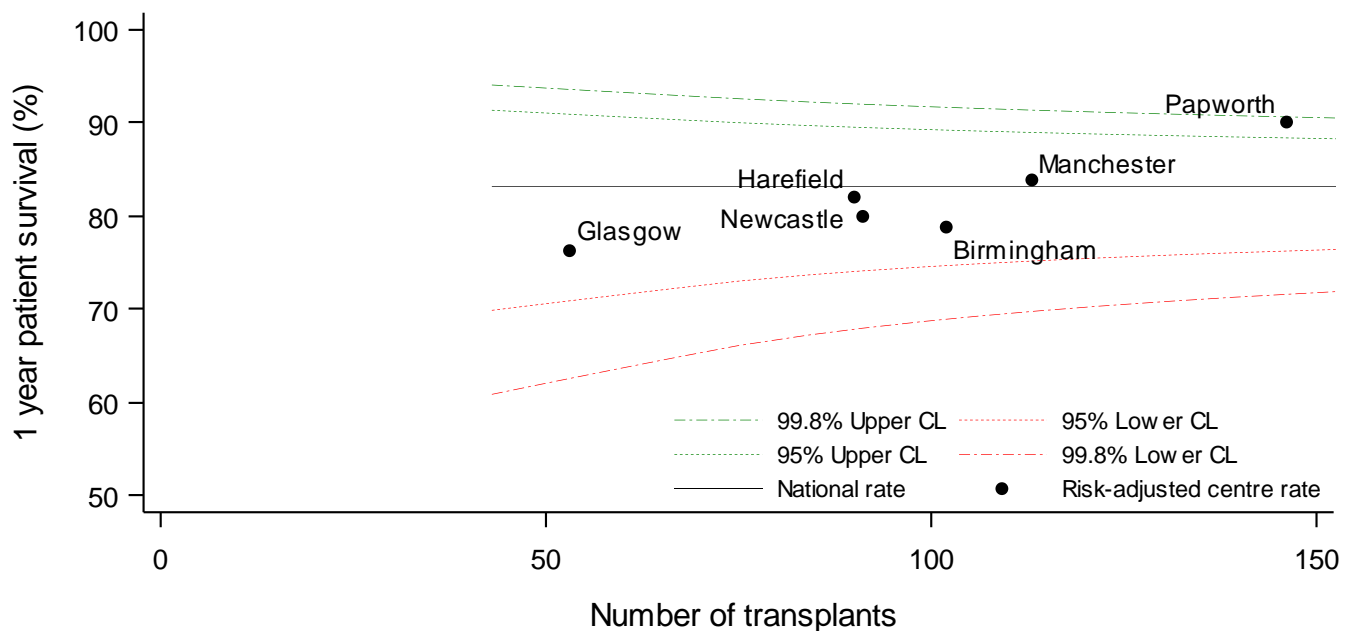
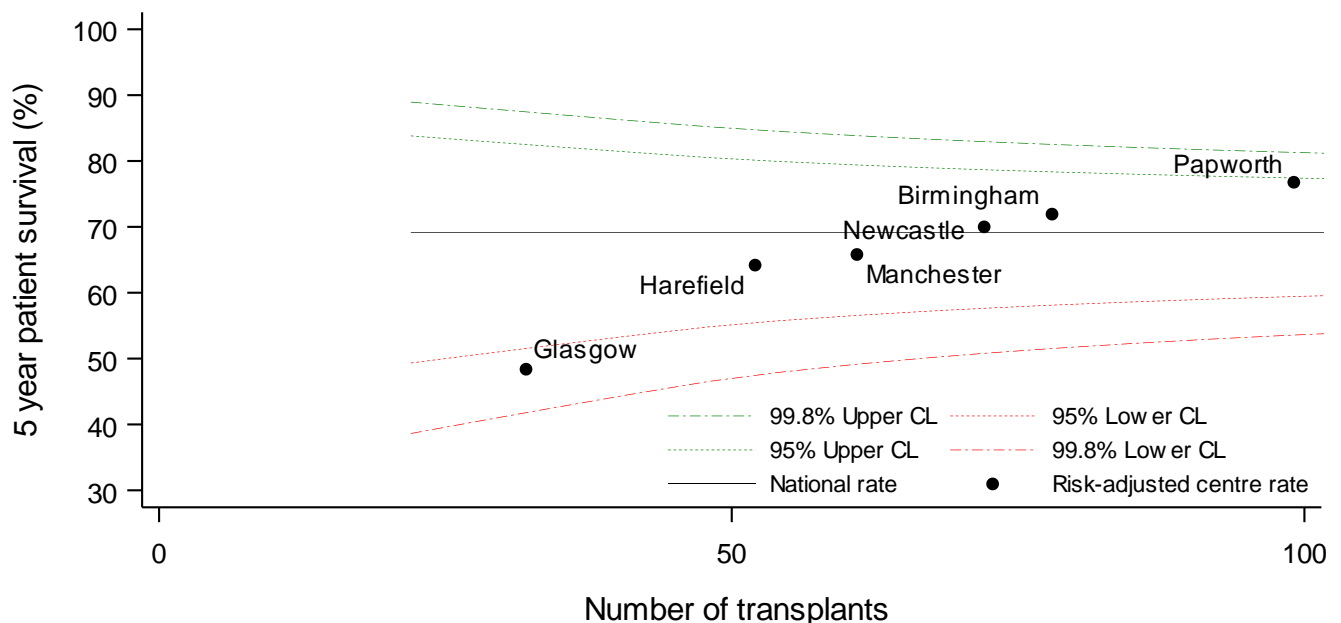


Table 6.3 and **Figure 6.3** show the 5-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 394 first adult heart only transplants in the period 1 April 2009 to 31 March 2013. The national rate of survival was 69.2%. The rate for Glasgow lies between the lower 95% and 99.8% [confidence limits](#), indicating that it may be significantly lower than the national rate.

Table 6.3 5 year patient survival rates after first adult heart transplant, by centre, 1 April 2009 to 31 March 2013					
Centre	Number of transplants	% 5 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	78	68.9	(57.3 – 78.0)	71.8	(57.9 - 81.1)
Glasgow	32	54.8	(35.5 - 70.5)	48.5	(13.0 - 69.5)
Harefield	52	68.9	(54.2 - 79.7)	64.2	(41.5 - 78.0)
Manchester	61	62.1	(48.7 – 73.0)	65.8	(48.6 - 77.3)
Newcastle	72	70.4	(58.3 - 79.6)	69.9	(53.9 - 80.4)
Papworth	99	77.7	(68.2 - 84.7)	76.8	(64.8 - 84.7)
UK	394	69.2	(64.3 - 73.5)		

	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 6.3 Risk-adjusted five year patient survival rates for adult heart transplants, by centre, 1 April 2009 to 31 March 2013



6.2 Survival by disease group

Tables 6.4, 6.5 and 6.6 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 30 days, 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; however, coronary heart disease had the highest 30-day and 1-year survival rate while congenital heart disease had the highest 5-year survival rate.

Table 6.4 30 day patient survival rates after first adult heart transplant, by disease group, 1 April 2013 and 31 March 2017

Disease group	Number of transplants	% 30 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Congenital heart disease	38	84.2	(68.2 - 92.6)	85.6	(68.1 - 93.6)
Coronary heart disease	83	94.0	(86.1 - 97.4)	94.6	(87.1 - 97.8)
Dilated cardiomyopathy	366	90.4	(86.9 - 93.0)	90.1	(86.3 - 92.9)
Other	108	91.7	(84.6 - 95.6)	91.4	(83.5 - 95.5)
UK	595	90.8	(88.1 - 92.8)		

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

Table 6.5 1 year patient survival rates after first adult heart transplant, by disease group, 1 April 2013 and 31 March 2017

Disease group	Number of transplants	% 1 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Congenital heart disease	38	73.7	(56.6 - 84.9)	74.5	(52.6 - 86.3)
Coronary heart disease	83	83.0	(73.0 - 89.6)	84.3	(73.5 - 90.7)
Dilated cardiomyopathy	366	84.5	(80.3 - 87.8)	84.2	(79.5 - 87.9)
Other	108	82.3	(73.6 - 88.3)	81.9	(71.6 - 88.4)
UK	595	83.2	(79.9 - 86.0)		

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

Table 6.6 5 year patient survival rates after first adult heart transplant, by disease group, 1 April 2009 and 31 March 2013

Disease group	Number of transplants	% 5 year survival (95% CI)			
		<u>Unadjusted</u>		<u>Risk-adjusted</u>	
Congenital heart disease	33	77.5	(58.2 - 88.6)	75.2	(48.0 - 88.2)
Coronary heart disease	61	70.1	(56.8 – 80.0)	72.1	(55.7 - 82.4)
Dilated cardiomyopathy	222	69.0	(62.4 - 74.7)	69.6	(61.4 - 76.0)
Other	78	65.2	(53.5 - 74.7)	62.9	(45.9 - 74.6)
UK	394	69.2	(64.3 - 73.5)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: red; margin-right: 5px;"></div> <div>Group has reached the lower 99.8% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: #f08080; margin-right: 5px;"></div> <div>Group has reached the lower 95% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: #90ee90; margin-right: 5px;"></div> <div>Group has reached the upper 95% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 15px; background-color: green; margin-right: 5px;"></div> <div>Group has reached the upper 99.8% confidence limit</div> </div>					

6.3 Survival post DCD heart transplant

Table 6.7 and **Table 6.8** present short-term patient [survival rates](#) following DCD heart only transplant, by centre and nationally. During the time period 1 April 2013 to 31 March 2017 a small number of transplants were performed, by two centres only, and there were five deaths within 1 year.

Table 6.7 30 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2013 and 31 March 2017

Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Harefield ¹	5	0	-	-
Papworth	27	0	100.0	-
UK	32	0	100.0	-

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

Table 6.8 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2013 and 31 March 2017

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Harefield ¹	5	1	-	-
Papworth	27	4	84.9	(64.5 - 94.0)
UK	32	5	84.2	(66.0 – 93.1)

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 2006 and 31 December 2017. 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, five and ten year [risk-adjusted survival rates](#) from the point of heart transplant listing are shown as [funnel plots](#) in **Figures 7.1, 7.2 and 7.3** respectively. These rates are also shown in **Table 7.1**. Note that all rates (at 1, 5 and 10 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 one and five year survival rates fell above the upper 99.8% [confidence limits](#), indicating significantly high survival from listing at these time points; at 10 years, there remained some evidence of higher survival with the rate falling between the upper 95% and 99.8% [confidence limits](#). Newcastle's five and ten year survival rates fell below the lower 99.8% [confidence limits](#), indicating significantly low survival from listing at these time points. There was also some evidence of lower survival at one year at Birmingham and a higher survival at five and ten years at Papworth, compared with the national rates.

Table 7.1 Risk-adjusted 1, 5 and 10 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2006 to 31 December 2017							
Centre	Number at risk ¹ at day 0	Survival rate at 1 year (%)	Number at risk ¹ at 1 year	Survival rate at 5 years (%)	Number at risk ¹ at 5 years	Survival rate at 10 years (%)	Number at risk ¹ at 10 years
Birmingham	325	75.6	(203)	61.5	(77)	50.1	(10)
Glasgow	186	82.1	(106)	63.8	(30)	53.5	(5)
Harefield	391	84.6	(256)	66.8	(84)	55.9	(23)
Manchester	307	89.1	(223)	73.4	(77)	62.6	(22)
Newcastle	397	77.8	(265)	54.2	(83)	44.6	(15)
Papworth	498	85.2	(357)	70.7	(163)	61.5	(32)
UK	2104	82.7	(1410)	65.6	(514)	55.4	(107)
<div> <div></div> Centre has reached the lower 99.8% confidence limit </div> <div> <div></div> Centre has reached the lower 95% confidence limit </div> <div> <div></div> Centre has reached the upper 95% confidence limit </div> <div> <div></div> Centre has reached the upper 99.8% confidence limit </div>							
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 2006 – 31 December 2017

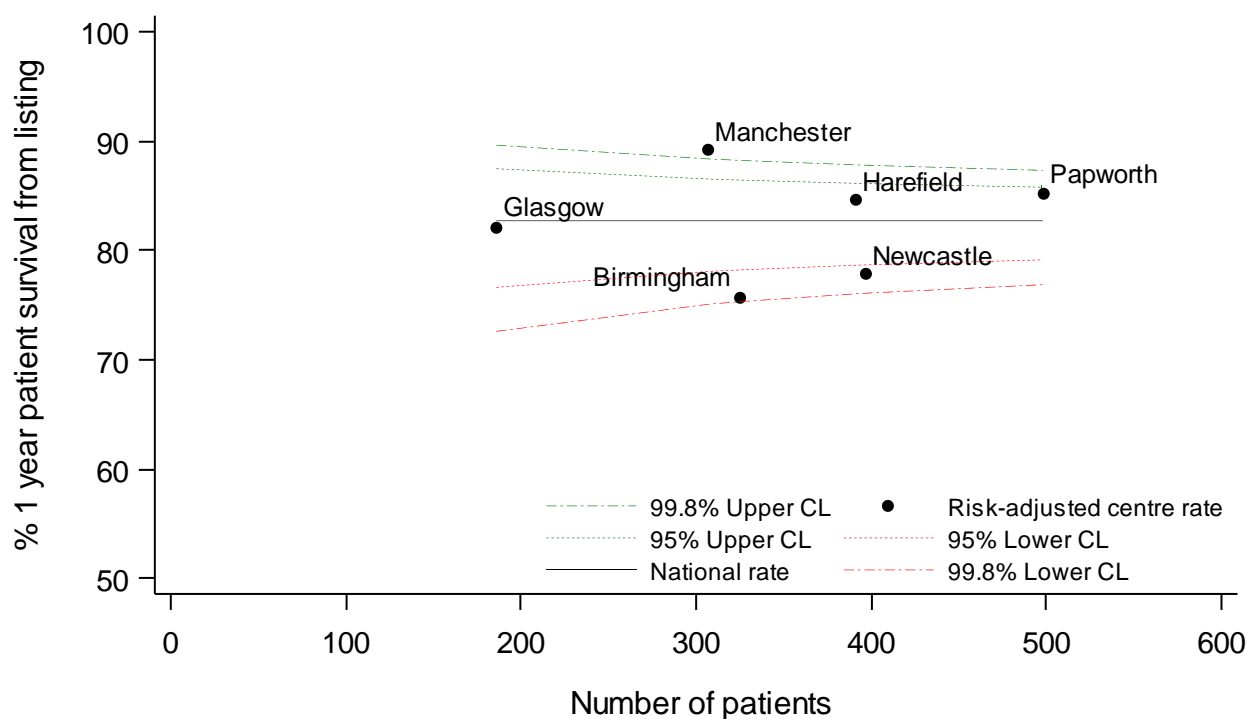
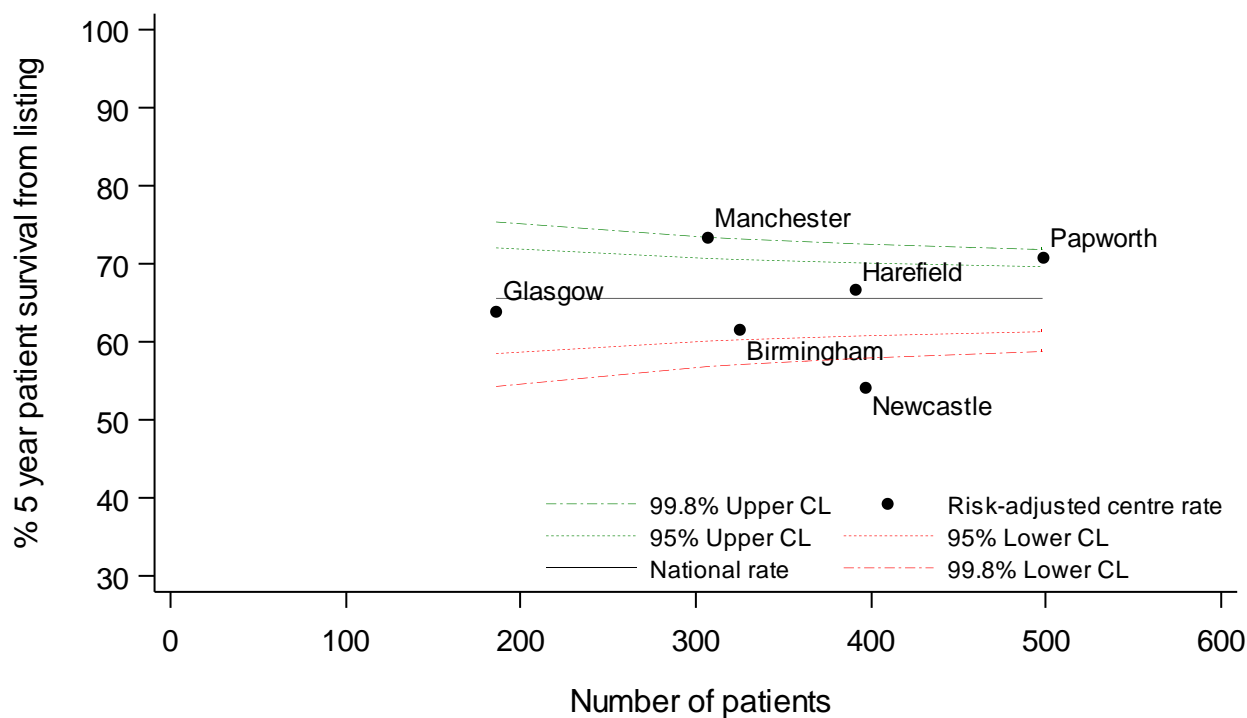
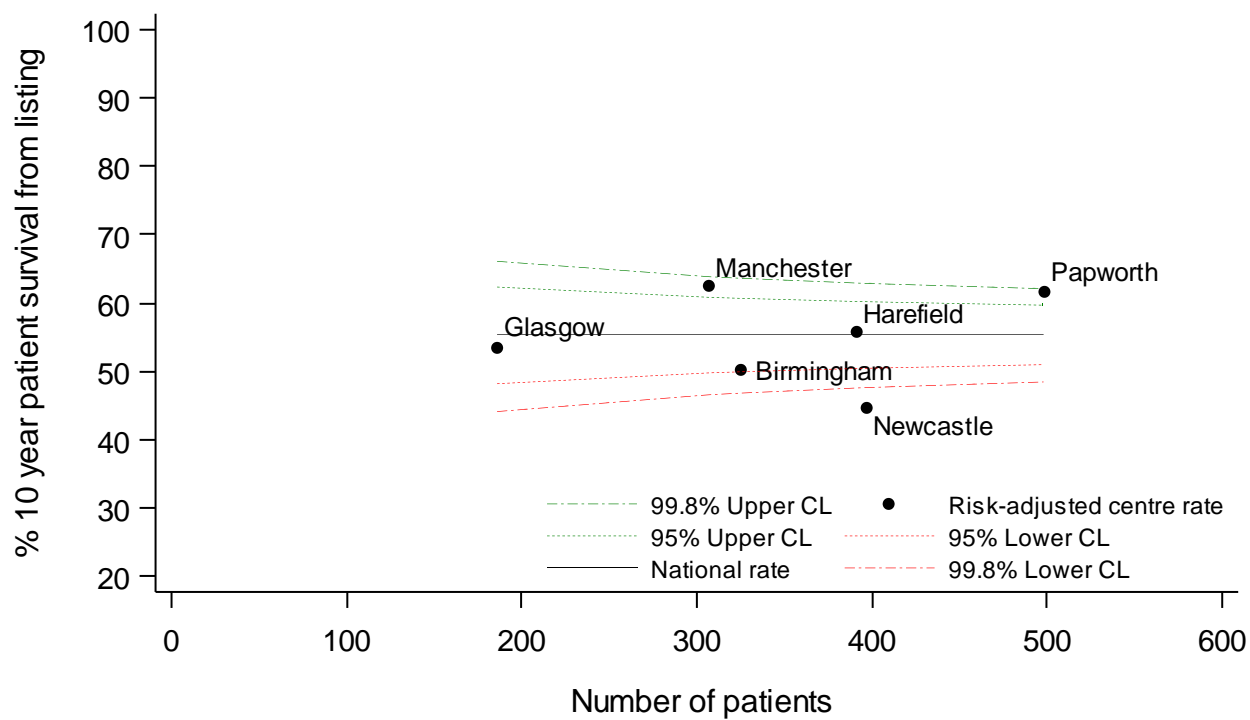


Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2006 – 31 December 2017



**Figure 7.3 Risk-adjusted ten year patient survival rates from listing by centre,
1 January 2006 – 31 December 2017**



ADULT HEART TRANSPLANTATION

Form Return Rates



8. Adult heart form return rates, 1 January – 31 December 2017

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 (more than 2 years). These include all adult heart transplants between 1 January and 31 December 2017 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 number of forms outstanding for this period.

Table 8.1 Form return rates for adult heart transplants, 1 January 2017 to 31 December 2017

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
Aberdeen Royal Infirmary	-	-	-	-	-	-	1	0
Birmingham Queen Elizabeth Hospital	22	100	22	100	23	91	219	68
Royal Bournemouth General Hospital	-	-	-	-	-	-	1	100
Glasgow Golden Jubilee Hospital	11	100	14	100	12	83	139	62
Harefield Hospital	31	100	31	100	16	100	535	94
Manchester Wythenshawe Hospital	19	100	20	100	30	100	238	98
Newcastle Freeman Hospital	21	95	25	100	25	100	292	85
Royal Papworth Hospital	52	100	48	100	40	100	554	96
Sheffield Northern General Hospital	-	-	-	-	-	-	56	86
Overall	156	99	160	100	146	97	2035	88

ADULT LUNG TRANSPLANTATION

Transplant List



9.1 Adult lung and heart-lung transplant list as at 31 March, 2009 – 2018

Figure 9.1 shows the number of adult patients on the lung and heart-lung transplant lists at 31 March each year between 2009 and 2018 split by urgency status of the patient. The number of patients on the active non-urgent lung transplant list has increased since 2011, reaching 339 on 31 March 2018. The number of patients on the heart-lung list has remained stable throughout the period. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2018, there were no patients on the super-urgent list and 1 patient active on the urgent list.

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

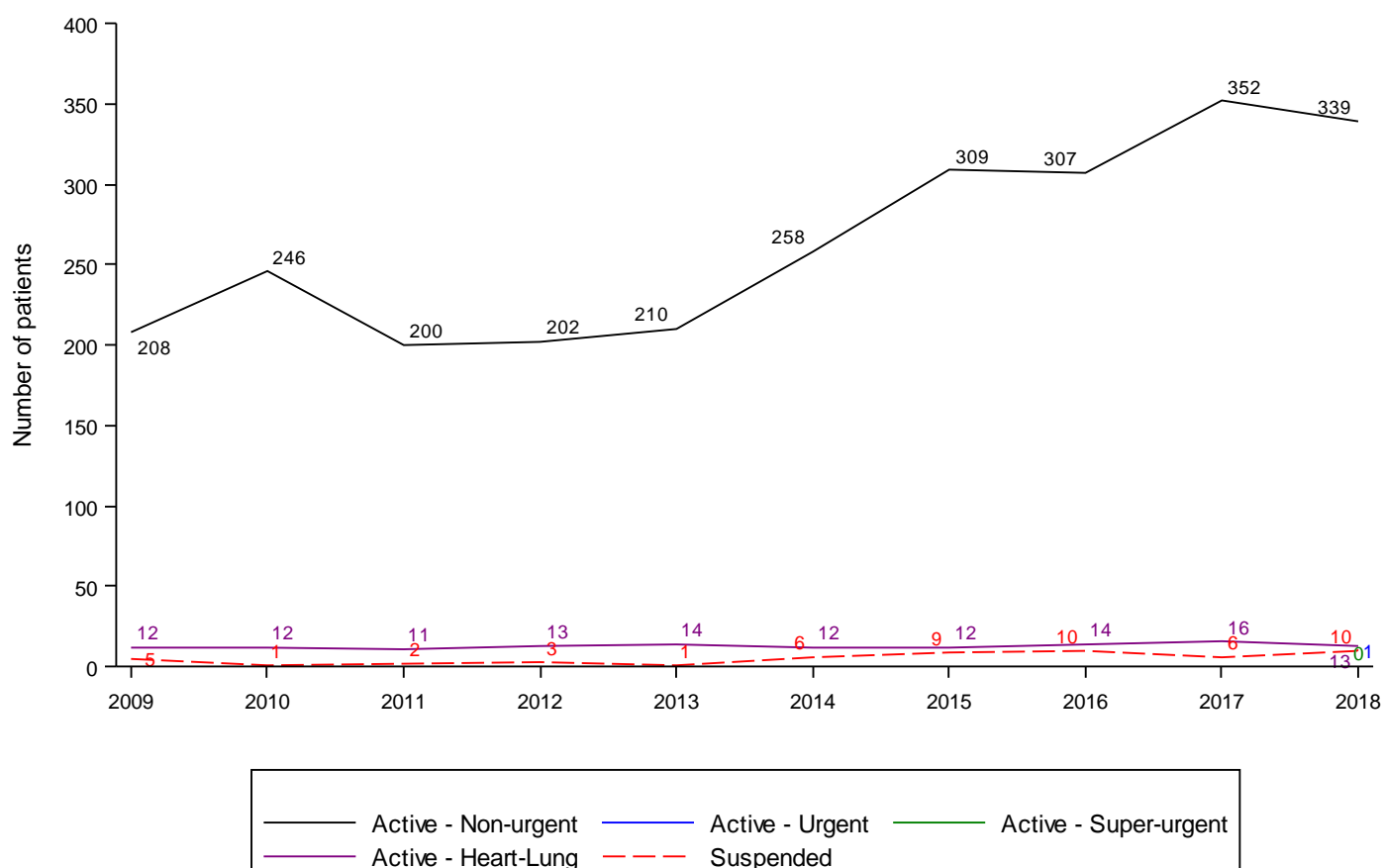


Figure 9.2 shows the number of adult patients on the [active lung transplant list](#) on 31 March 2018 by centre. In total, there were 353 adult patients waiting. Harefield had the highest number of patients on the transplant list while Papworth had the lowest. There was one patient on the urgent list, at Papworth, and no patients at any centre on the super-urgent list on this date.

Figure 9.2 Number of adult patients on the active lung transplant list at 31 March 2018, by centre

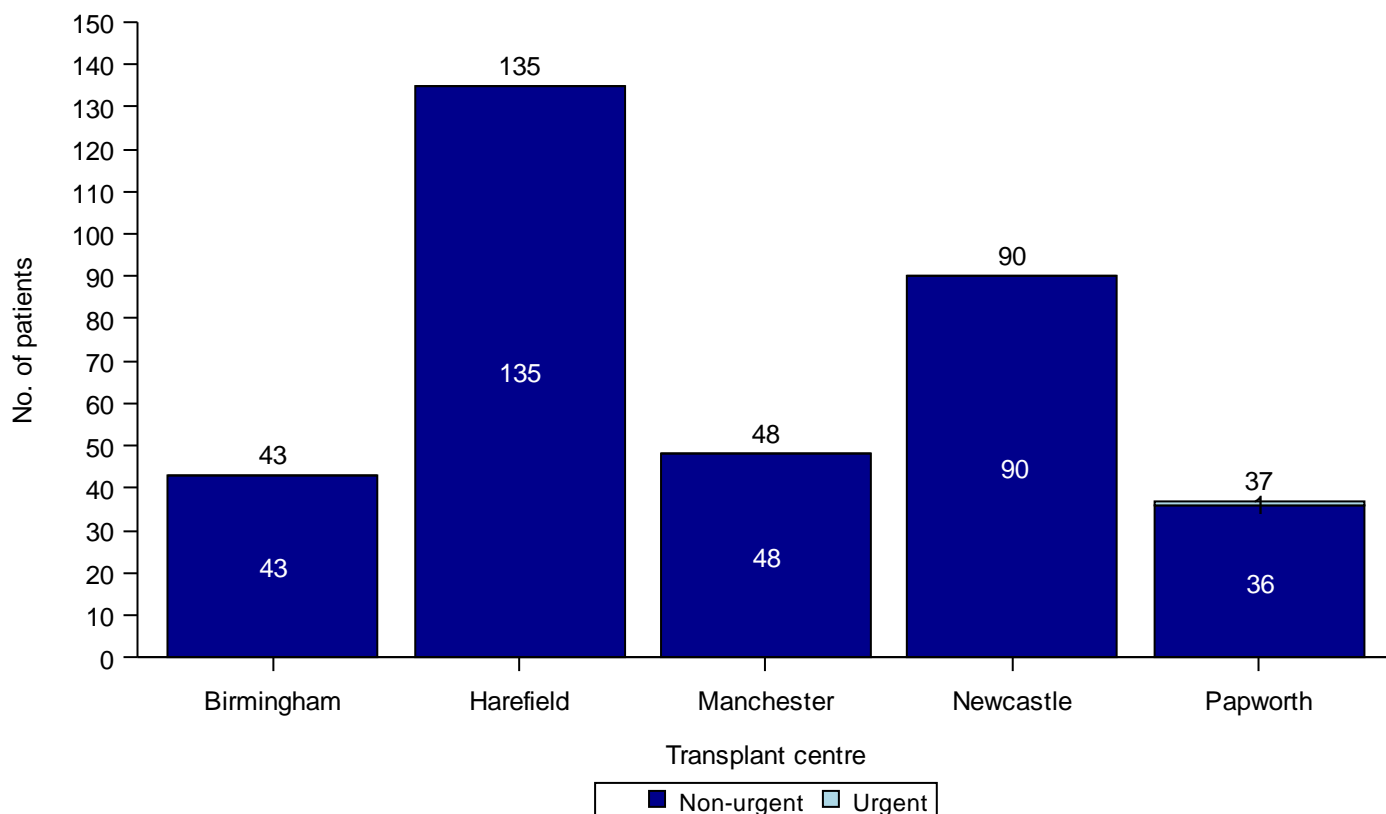
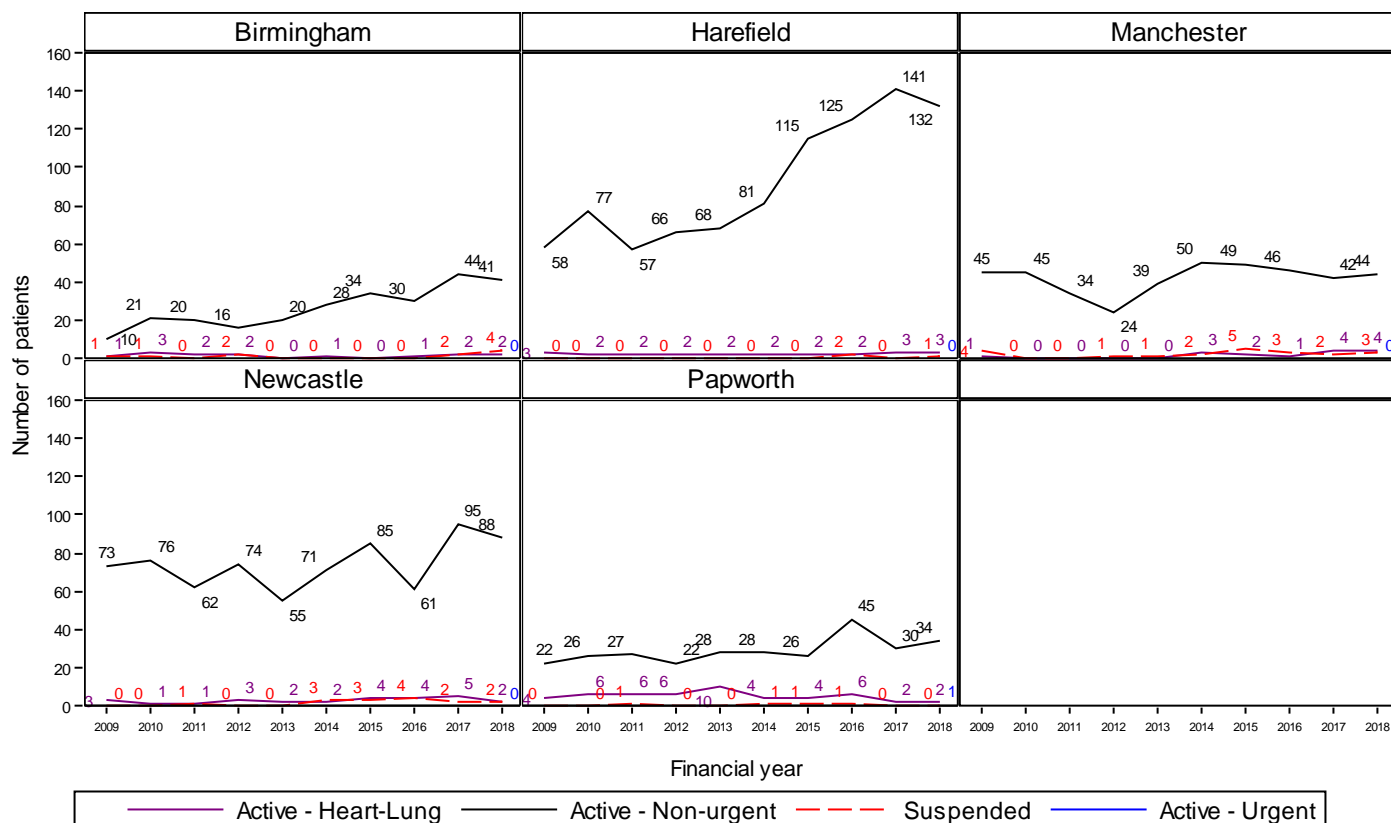


Figure 9.3 shows the trend over time in the number of adult patients on the lung transplant list at 31 March each year across centre. Harefield have experienced a marked increase in their lung list since 2011 compared with other centres.

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 2017 – 31 March 2018

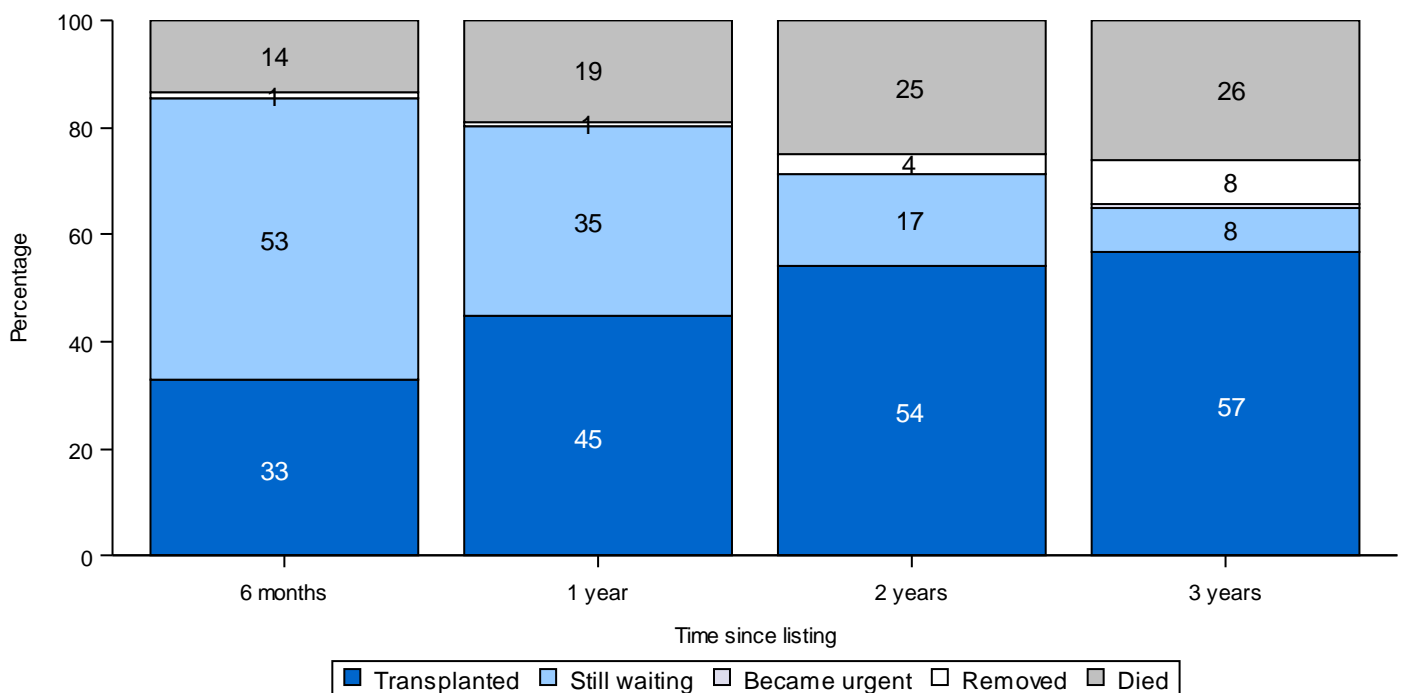
There were 290 adult patient registrations onto the lung or heart-lung transplant lists between 1 April 2017 and 31 March 2018. Demographic characteristics of these patients are shown by centre and overall in **Table 9.1**. Nationally, 55% of patients were male and the [median](#) age was 53 years. Note that there were 33 urgent lung registrations and 7 super-urgent lung registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		39 (100)	87 (100)	44 (100)	62 (100)	58 (100)	290 (100)
Highest urgency on the lung list during registration	Non-urgent	35 (90)	80 (92)	39 (89)	48 (77)	48 (83)	250 (86)
	Urgent	3 (8)	3 (3)	5 (11)	12 (19)	10 (17)	33 (11)
	Super-urgent	1 (3)	4 (5)	0 (0)	2 (3)	0 (0)	7 (2)
Recipient sex	Male	19 (49)	50 (57)	29 (66)	30 (48)	30 (52)	158 (55)
	Female	20 (51)	37 (43)	15 (34)	30 (48)	28 (48)	130 (45)
	Missing	0 (0)	0 (0)	0 (0)	2 (3)	0 (0)	2 (1)
Recipient ethnicity	White	34 (87)	83 (95)	42 (95)	60 (97)	55 (95)	274 (95)
	Non-white	5 (13)	4 (5)	2 (5)	2 (3)	3 (5)	16 (6)
Recipient age (years)	Median (IQR)	54 (45, 59)	51 (32, 59)	53 (38, 59)	56 (46, 61)	55 (36, 60)	53 (38, 60)
	Missing	0	0	0	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	6 (15)	29 (33)	11 (25)	9 (15)	13 (22)	68 (23)
	Fibrosing lung disease	12 (31)	23 (26)	12 (27)	37 (60)	18 (31)	102 (35)
	COPD and emphysema	12 (31)	24 (28)	13 (30)	10 (16)	11 (19)	70 (24)
	Primary pulmonary hypertension	1 (3)	2 (2)	4 (9)	2 (3)	3 (5)	12 (4)
	Other	8 (21)	9 (10)	4 (9)	4 (6)	13 (22)	38 (13)
Smoker	No	38 (97)	87 (100)	44 (100)	61 (98)	58 (100)	288 (99)
	Yes	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0)
	Missing	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)	1 (0)
Lung function - FEV1 (litres)	Median (IQR)	0.96 (0.61, 1.28)	0.92 (0.69, 1.35)	1.19 (0.72, 2.19)	1.27 (1.05, 2.02)	1.13 (0.82, 1.57)	1.08 (0.75, 1.72)
	Missing	1	4	5	5	1	16
Lung function – FVC (litres)	Median (IQR)	2.12 (1.54, 2.64)	1.97 (1.41, 2.75)	2.61 (1.95, 3.32)	1.99 (1.42, 2.58)	1.96 (1.45, 2.55)	2.06 (1.51, 2.78)
	Missing	1	4	5	4	1	15

9.3 Post-registration outcomes, 1 April 2014 – 31 March 2015

The transplant list outcomes of adult patients listed for a lung only transplant between 1 April 2014 and 31 March 2015 are summarised in **Figure 9.4**. This shows the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two year and three years after joining the list. Within six months of listing, 33% of lung patients had been transplanted and 14% had died. Three years after listing, 57% have been transplanted and 26% had died. Removals from the list were mainly due to deteriorating condition.

Figure 9.4 Post-registration outcome for 296 lung only registrations made in the UK, 1 April 2014 to 31 March 2015



9.4 Median waiting time to transplant, 1 April 2012 - 31 March 2015

The [median](#) waiting time to lung transplant from listing for adult patients is shown in **Figure 9.5** and **Table 9.2**. This is estimated for patients registered on the lung only transplant list between 1 April 2012 and 31 March 2015 using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. The national [median](#) waiting time was 282 days and ranged from 221 days at Birmingham to 377 days at Manchester. The variation in waiting times between centres was found to be significant (log-rank $p=0.02$).

Figure 9.5 Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2012 and 31 March 2015, by centre

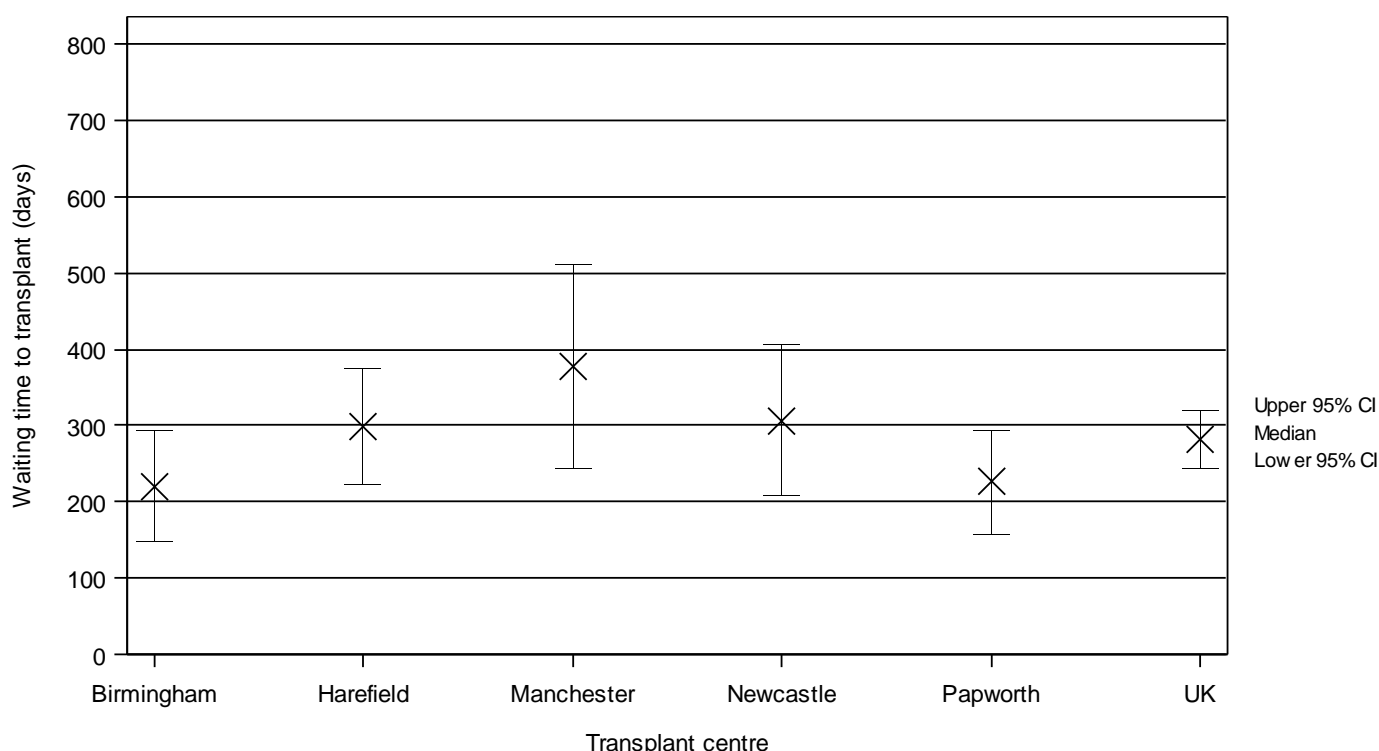
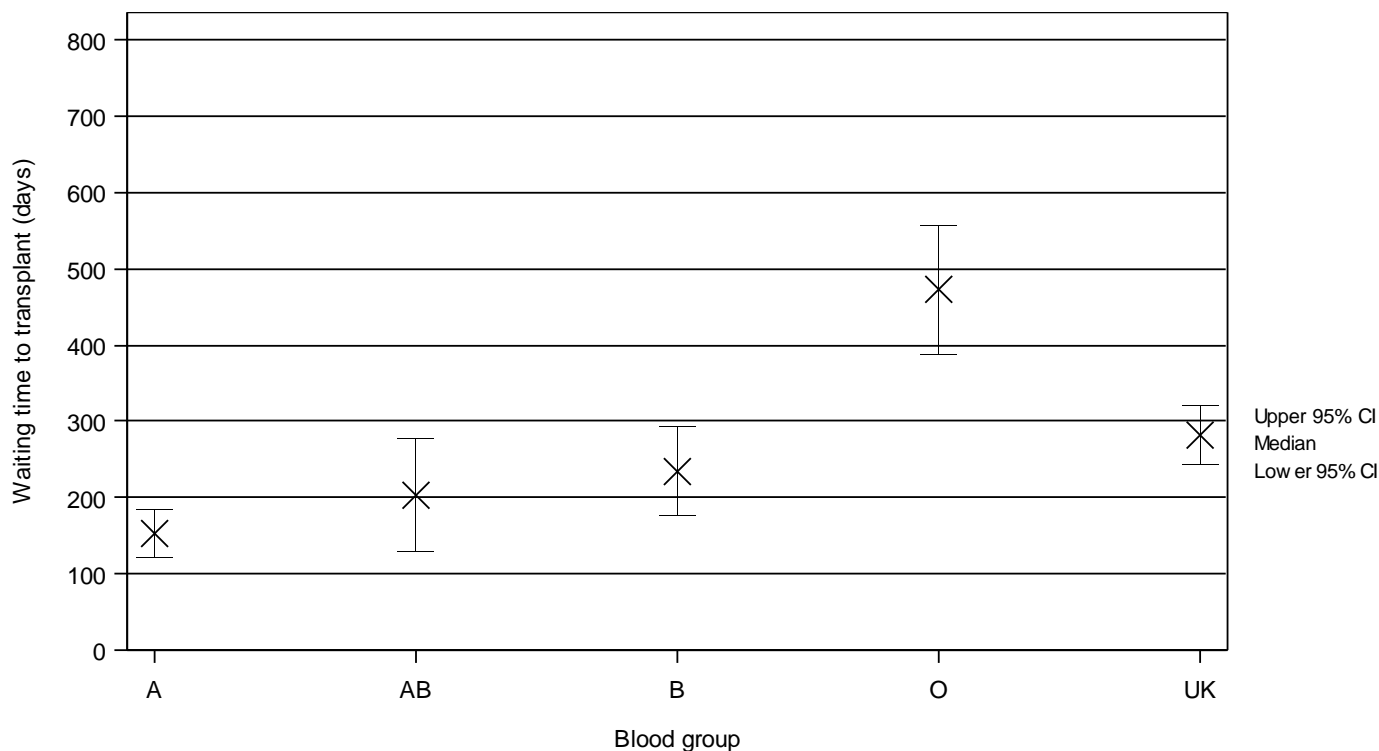


Table 9.2 Median active waiting time to lung transplant for adult patients registered on the transplant list, by centre, 1 April 2012 to 31 March 2015

Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Birmingham	102	221	149 - 293
Harefield	247	299	223 - 375
Manchester	144	377	244 - 510
Newcastle	209	307	208 - 406
Papworth	149	226	159 - 293
UK	851	282	243 - 321

The [median](#) waiting time to lung transplant for adult patients is also considered by blood group. This is shown in **Figure 9.6** and **Table 9.3**. Blood group O patients have the longest average wait (472 days) compared with the other blood groups (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 2012 and 31 March 2015, by blood group



Blood group	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
A	360	153	121 - 185
AB	21	203	129 - 277
B	89	235	176 - 294
O	381	472	387 - 557
UK	851	282	243 - 321

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 2015 and 31 March 2018 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 included and 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.

Figures 10.1 compares individual centre decline rates with the national rate using [funnel plots](#). The offer decline rate for Papworth is below the lower 99.8% [confidence limit](#), indicating a significantly low decline rate compared with the national rate. The offer decline rate for Birmingham is between the upper 95% and 99.8% [confidence limit](#), indicating some evidence of a significantly high decline rate compared with the national rate.

Figure 10.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2015 to 31 March 2018

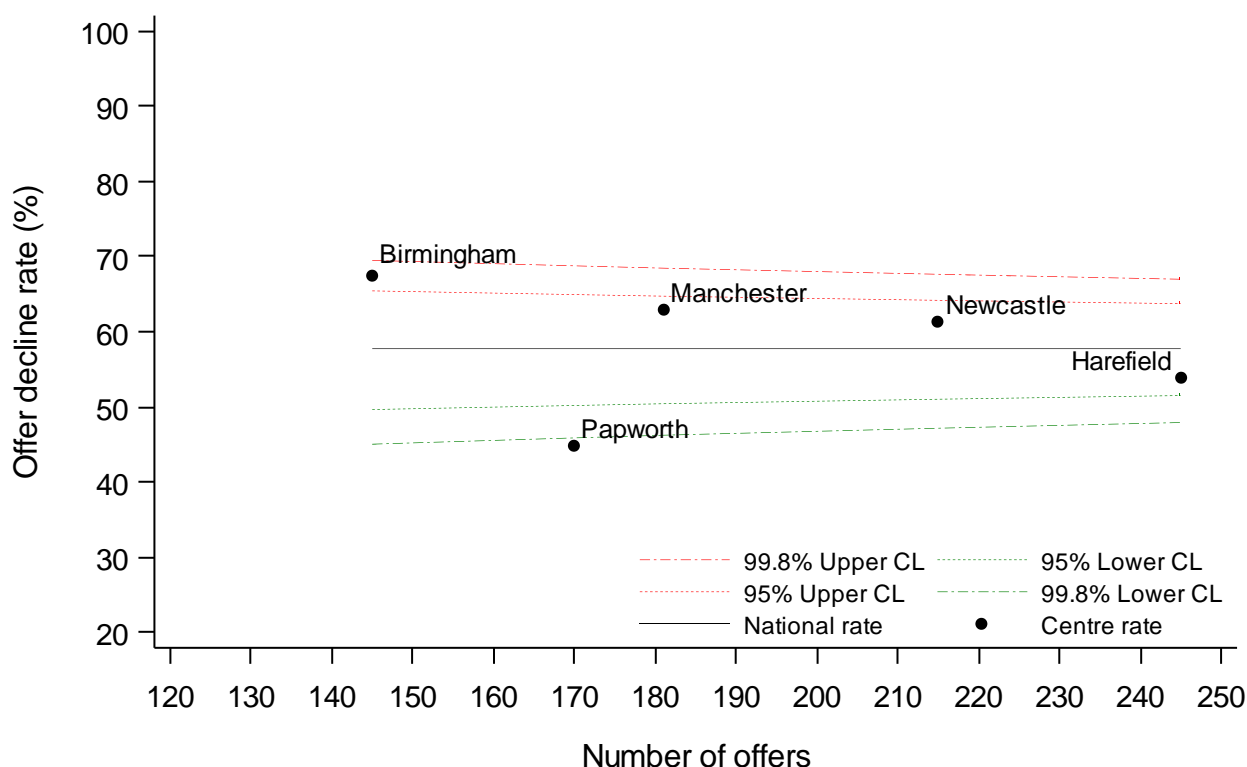


Table 10.1 shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the number of offers has increased and so has the offer decline rate, from 48.8% to 65.8%. This may be due to several reasons; the introduction of patient-specific offers in May 2017, an increase in transplant activity (as this analysis only considers lungs that were eventually transplanted), and a broadening of the lung offering criteria up to 74 years in January 2018.

Table 10.1 UK adult DBD donor bilateral lung offer decline rates by transplant centre and year, between 1 April 2015 and 31 March 2018								
Centre	2015/16		2016/17		2017/18		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	44	(56.8)	42	(76.2)	59	(69.5)	145	(67.6)
Harefield	54	(37.0)	74	(54.1)	117	(61.5)	245	(53.9)
Manchester	49	(57.1)	54	(55.6)	78	(71.8)	181	(63.0)
Newcastle	64	(57.8)	54	(51.9)	97	(69.1)	215	(61.4)
Papworth	49	(34.7)	45	(31.1)	76	(59.2)	170	(44.7)
UK	260	(48.8)	269	(53.5)	427	(65.8)	956	(57.7)
<div> <div></div>Centre has reached the upper 99.8% confidence limit </div> <div> <div></div>Centre has reached the upper 95% confidence limit </div> <div> <div></div>Centre has reached the lower 95% confidence limit </div> <div> <div></div>Centre has reached the lower 99.8% confidence limit </div>								

ADULT LUNG TRANSPLANTATION

Transplants



11.1 Adult lung and heart-lung transplants, 1 April 2008 – 31 March 2018

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 then fell to 167 in 2016/2017 but has since risen to 207 in 2017/2018. In recent years DCD lung transplantation has represented approximately 20% 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 Harefield.

Figure 11.1 Number of adult lung transplants in the UK, by financial year and donor type, 1 April 2008 to 31 March 2018

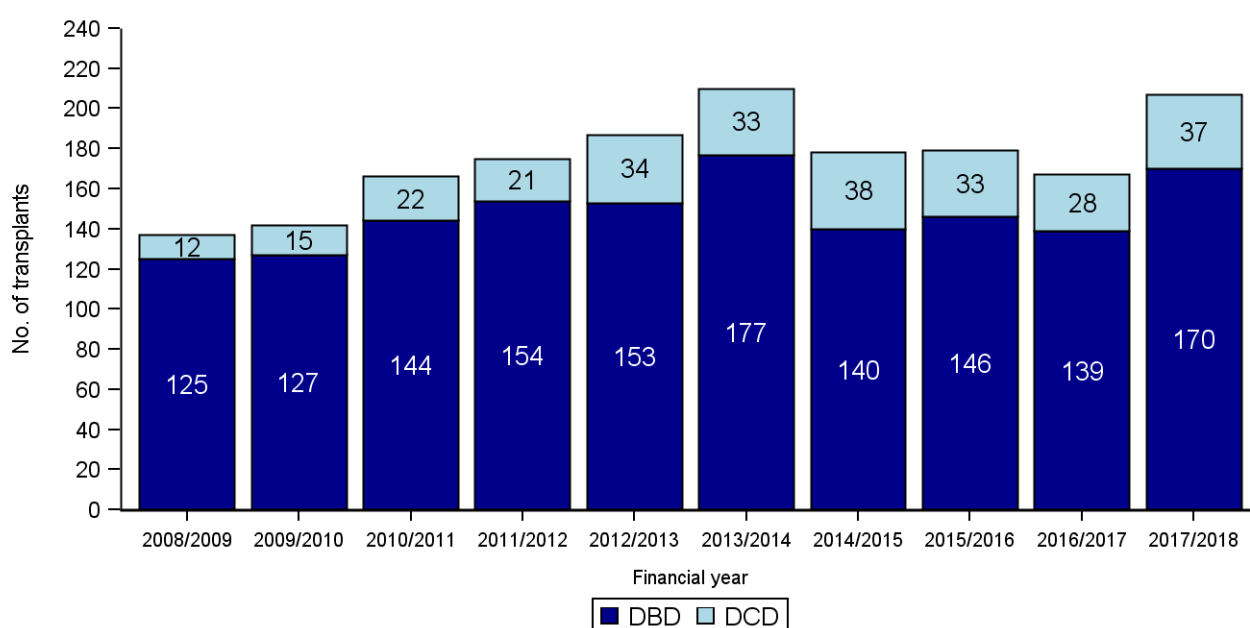


Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2008 to 31 March 2018

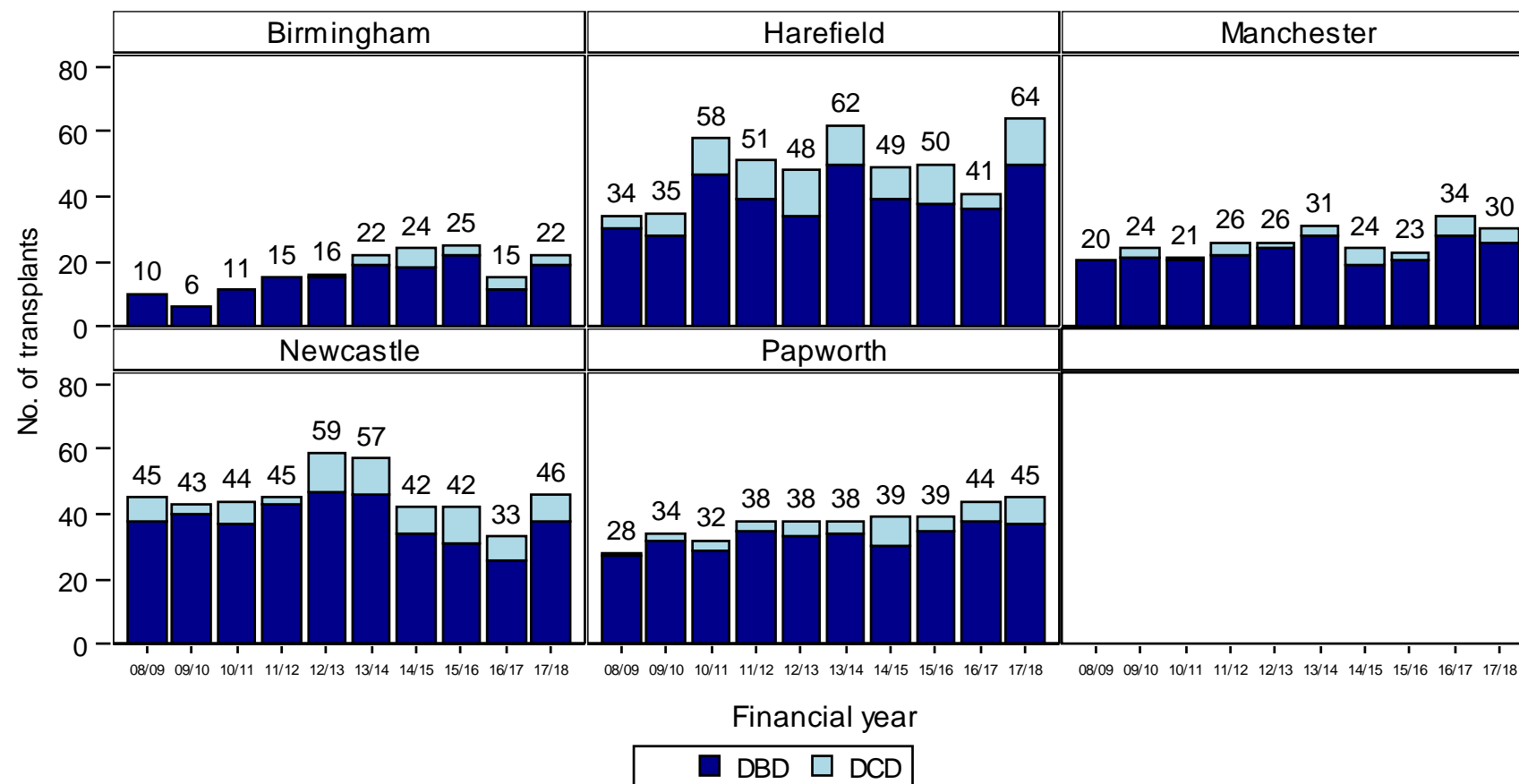


Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2017 to 31 March 2018

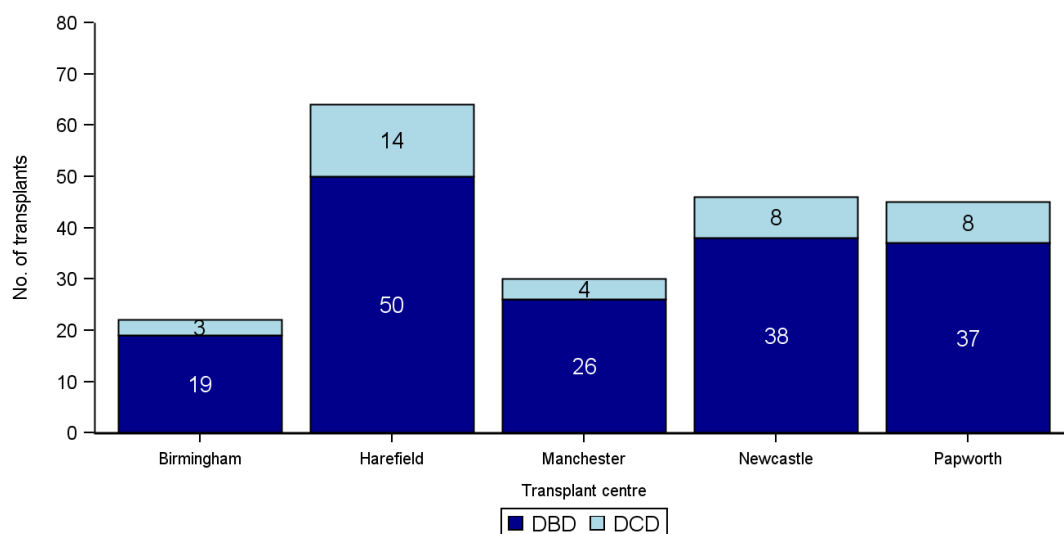


Figure 11.4 and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. The number of transplants by transplant type in the latest financial year (2017/2018) is shown by centre in **Figure 11.6**. There was a total of 46 heart-lung block transplants, and no partial lung transplants, over the decade. The overall proportion of single lung transplants has decreased from 23% in 2008/2009 to 11% in 2017/2018. When broken down by centre, it can be seen that Harefield, Newcastle and Birmingham have reduced their use of single lungs. In the last financial year Papworth was the highest user of single lungs for transplantation and Harefield of heart-lung blocks (**Figure 11.6**).

Figure 11.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2008 to 31 March 2018

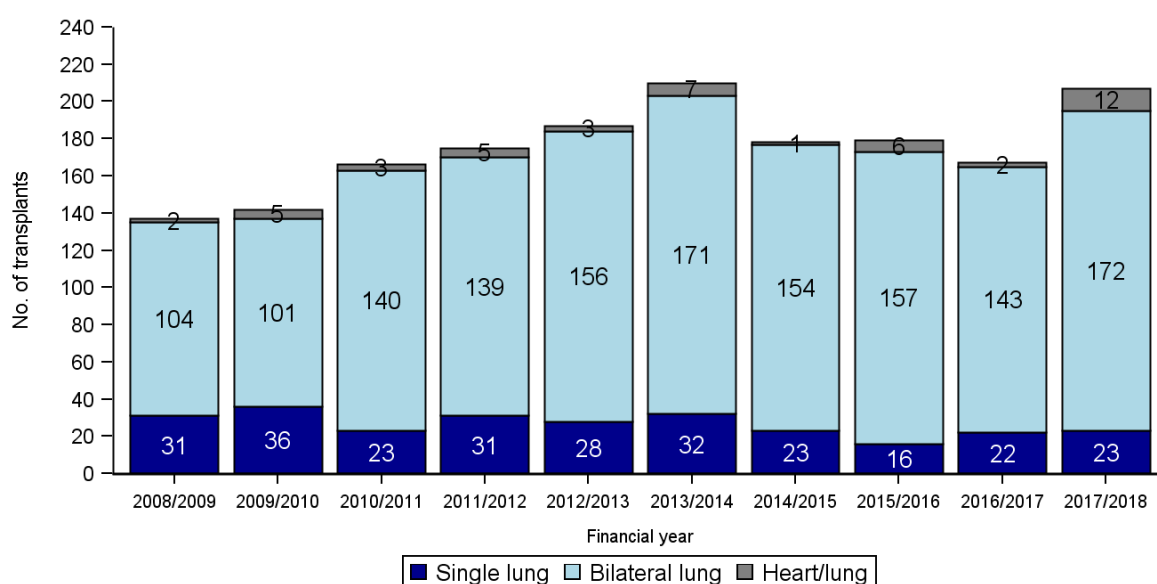


Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2008 to 31 March 2018

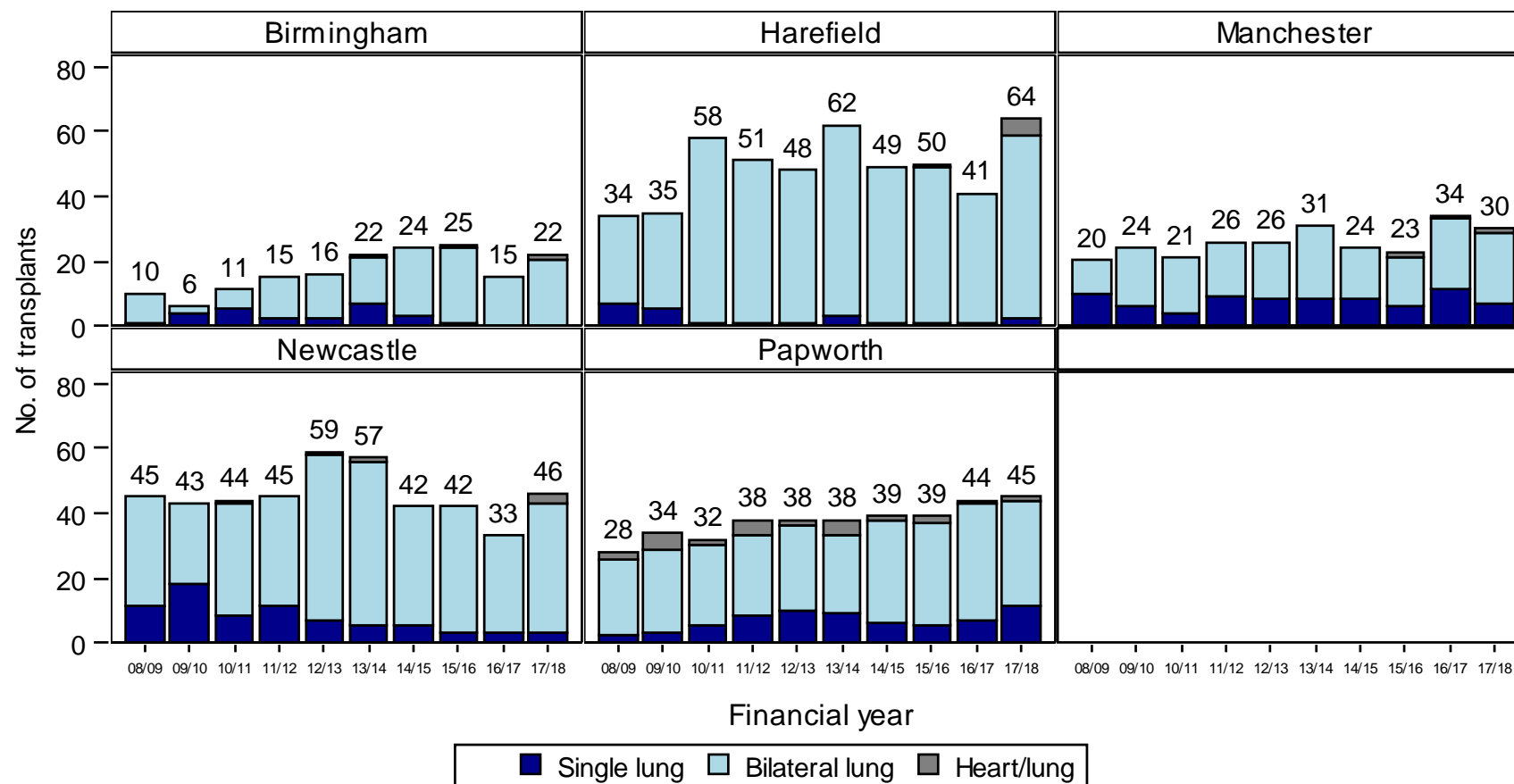
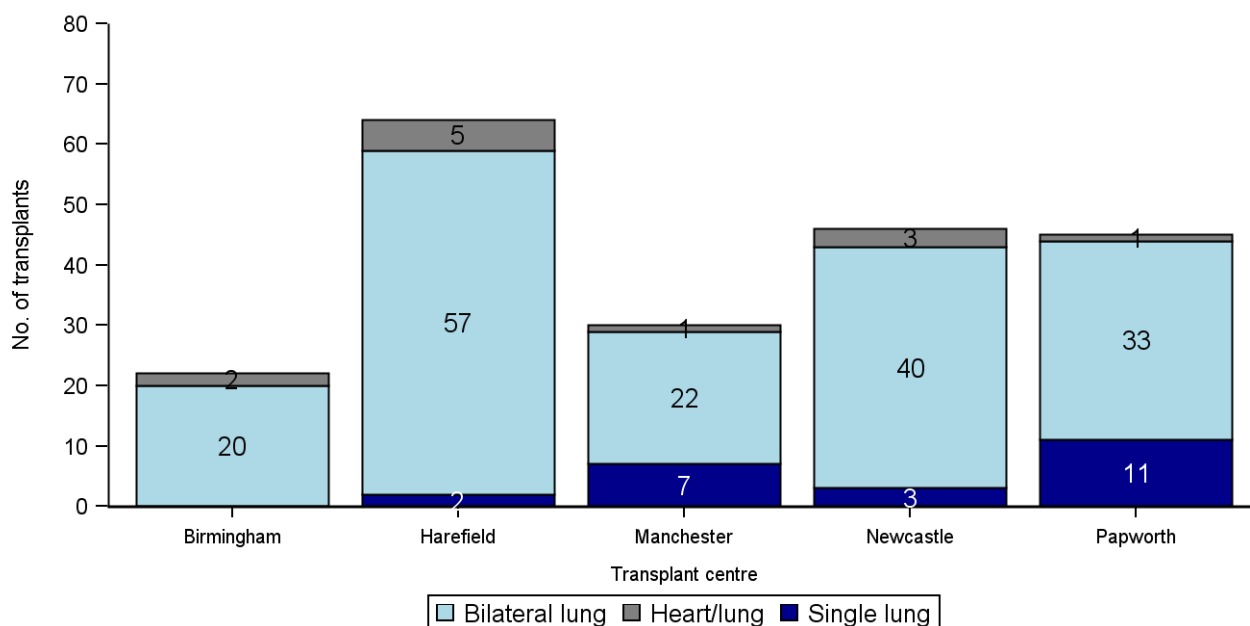


Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2017 to 31 March 2018



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. Heart-lung patients have access to urgent transplants through the heart allocation scheme. The number of lung only transplants by urgency status in the latest financial year (2017/2018) is shown by centre in **Figure 11.7**, and for heart-lung transplants in **Figure 11.8**. In 2017/2018, there were 46 urgent lung only transplants, ranging from 5 at Birmingham and Harefield to 18 at Newcastle. There were 5 super-urgent lung only transplants in the year, performed by Birmingham and Harefield. Of the 12 heart-lung transplants in 2017/2018, 5 were urgent transplants and 2 were super-urgent (outwith policy).

Figure 11.7 Number of adult lung only transplants in the UK, by centre and urgency status, 1 April 2017 to 31 March 2018

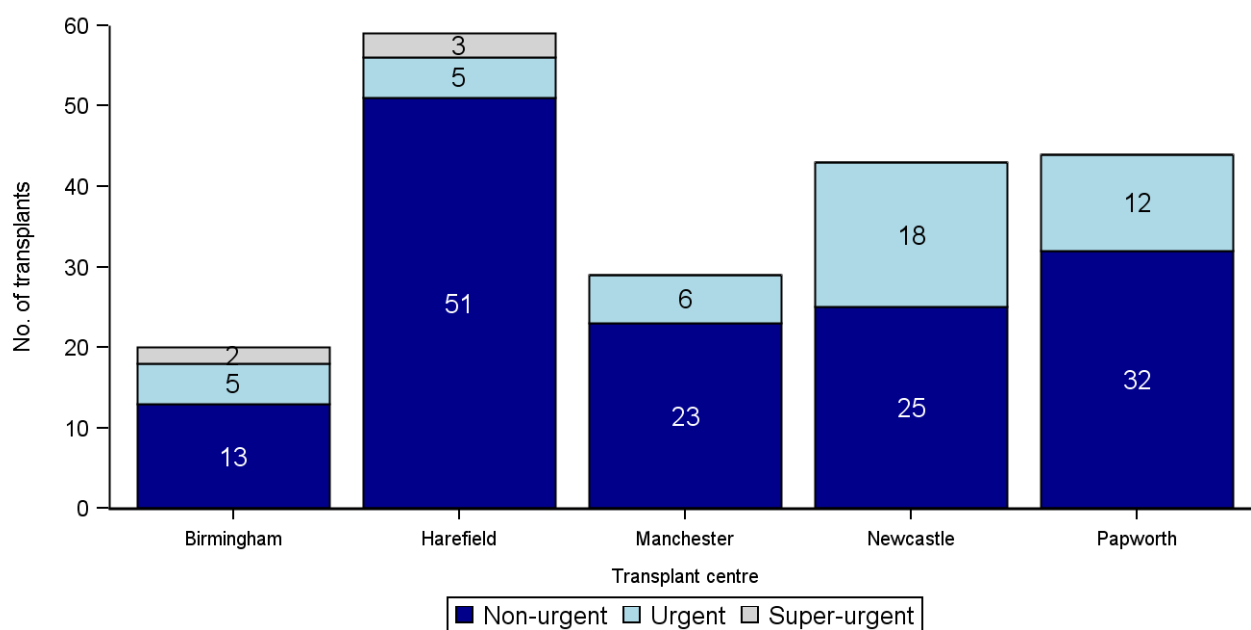
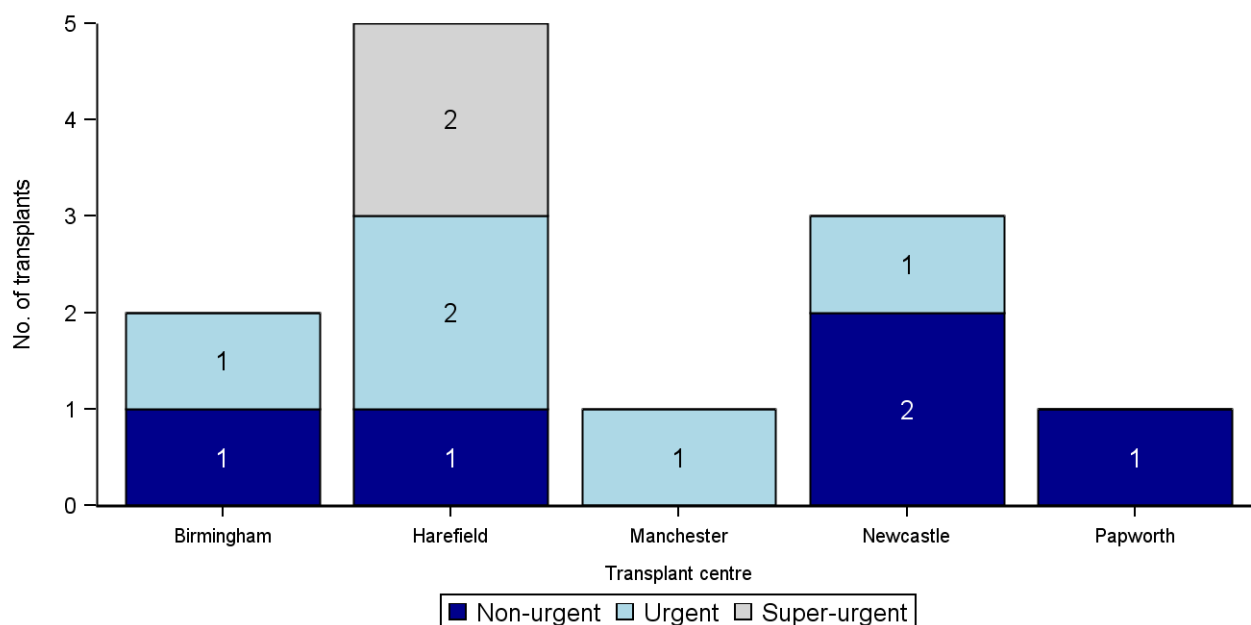


Figure 11.8 Number of adult heart-lung transplants in the UK, by centre and urgency status, 1 April 2017 to 31 March 2018



11.2 Demographic characteristics of transplants, 1 April 2017 – 31 March 2018

The demographic characteristics of the 207 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 56% of lung recipients were male and the [median](#) age was 52 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 2017 to 31 March 2018, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		22 (100)	64 (100)	30 (100)	46 (100)	45 (100)	207 (100)
Urgency status at transplant	Non-urgent	14 (64)	52 (81)	23 (77)	27 (59)	33 (73)	149 (72)
	Urgent	6 (27)	7 (11)	7 (23)	19 (41)	12 (27)	51 (25)
	Super-urgent	2 (9)	5 (8)	0 (0)	0 (0)	0 (0)	7 (3)
Transplant type	Single lung	0 (0)	2 (3)	7 (23)	3 (7)	11 (24)	23 (11)
	Bilateral lung	20 (91)	57 (89)	22 (73)	40 (87)	33 (73)	172 (83)
	Heart-lung	2 (9)	5 (8)	1 (3)	3 (7)	1 (2)	12 (6)
Recipient sex	Male	12 (55)	36 (56)	18 (60)	26 (57)	24 (53)	116 (56)
	Female	10 (45)	28 (44)	12 (40)	20 (43)	21 (47)	91 (44)
Recipient ethnicity	White	20 (91)	60 (94)	27 (90)	45 (98)	41 (91)	193 (93)
	Non-white	2 (9)	4 (6)	3 (10)	1 (2)	4 (9)	14 (7)
Recipient age (years)	Median (IQR)	49 (35, 59)	47 (30, 58)	54 (34, 61)	54 (46, 60)	54 (36, 60)	52 (35, 60)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	66 (57, 75)	61 (54, 69)	72 (57, 84)	73 (62, 83)	64 (54, 80)	65 (55, 79)
	Missing	0	0	0	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	7 (32)	25 (39)	9 (30)	6 (13)	12 (27)	59 (29)
	Fibrosing lung disease	0 (0)	4 (6)	8 (27)	24 (52)	13 (29)	49 (24)
	COPD and emphysema	10 (45)	27 (42)	8 (27)	9 (20)	7 (16)	61 (30)
	Primary pulmonary hypertension	0 (0)	1 (2)	2 (7)	2 (4)	5 (11)	10 (5)
	Other	5 (23)	7 (11)	3 (10)	5 (11)	8 (18)	28 (14)
NYHA class	I	6 (27)	0 (0)	0 (0)	0 (0)	0 (0)	6 (3)
	II	7 (32)	25 (39)	0 (0)	0 (0)	2 (4)	34 (16)
	III	1 (5)	28 (44)	28 (93)	4 (9)	28 (62)	89 (43)
	IV	1 (5)	11 (17)	2 (7)	0 (0)	15 (33)	29 (14)
	Missing	7 (32)	0 (0)	0 (0)	42 (91)	0 (0)	49 (24)

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2017 to 31 March 2018, by centre		Birmingham	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Recipient in hospital pre-transplant	No	15 (68)	48 (75)	27 (90)	36 (78)	41 (91)	167 (81)
	Yes	7 (32)	16 (25)	3 (10)	5 (11)	4 (9)	35 (17)
	Missing	0 (0)	0 (0)	0 (0)	5 (11)	0 (0)	5 (2)
If in hospital, recipient on ventilator	No	5 (71)	15 (94)	2 (67)	4 (80)	4 (100)	30 (86)
	Yes	2 (29)	1 (6)	0 (0)	1 (20)	0 (0)	4 (11)
	Missing	0 (0)	0 (0)	1 (33)	0 (0)	0 (0)	1 (3)
If in hospital, recipient on inotropes	No	5 (71)	12 (75)	2 (67)	3 (60)	3 (75)	25 (71)
	Yes	2 (29)	4 (25)	1 (33)	2 (40)	1 (25)	10 (29)
If in hospital, recipient on ECMO	No	5 (71)	10 (63)	3 (100)	4 (80)	4 (100)	26 (74)
	Yes	2 (29)	6 (38)	0 (0)	1 (20)	0 (0)	9 (26)
Recipient CMV status	No	14 (64)	32 (50)	19 (63)	25 (54)	26 (58)	116 (56)
	Yes	8 (36)	32 (50)	11 (37)	21 (46)	19 (42)	91 (44)
Recipient HCV status	No	22 (100)	64 (100)	30 (100)	46 (100)	45 (100)	207 (100)
Recipient HBV status	No	22 (100)	64 (100)	30 (100)	46 (100)	45 (100)	207 (100)
Recipient HIV status	No	22 (100)	64 (100)	30 (100)	46 (100)	45 (100)	207 (100)
Recipient serum creatinine (umol/l)	Median (IQR)	67 (58, 89)	57 (51, 77)	66 (59, 74)	77 (66, 92)	63 (50, 79)	66 (53, 80)
	Missing	0	1	0	7	0	8
Donor sex	Male	6 (27)	27 (42)	13 (43)	18 (39)	16 (36)	80 (39)
	Female	16 (73)	37 (58)	17 (57)	28 (61)	29 (64)	127 (61)
Donor ethnicity	White	21 (95)	55 (86)	27 (90)	44 (96)	44 (98)	191 (92)
	Non-white	1 (5)	8 (13)	3 (10)	1 (2)	1 (2)	14 (7)
	Missing	0 (0)	1 (2)	0 (0)	1 (2)	0 (0)	2 (1)
Donor age (years)	Median (IQR)	51 (44, 58)	46 (30, 57)	46 (40, 53)	49 (27, 55)	37 (28, 54)	46 (30, 56)
	Missing	0	0	0	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	24 (21, 29)	26 (22, 29)	27 (24, 29)	26 (23, 28)	25 (22, 29)	26 (22, 29)
	Missing	0	0	0	0	0	0
Donor cause of death	CVA	17 (77)	56 (88)	27 (90)	36 (78)	40 (89)	176 (85)
	Trauma	0 (0)	1 (2)	0 (0)	2 (4)	2 (4)	5 (2)
	Others	5 (23)	7 (11)	3 (10)	8 (17)	3 (7)	26 (13)

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2017 to 31 March 2018, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor hypotension	No	9 (41)	56 (88)	22 (73)	24 (52)	29 (64)	140 (68)
	Yes	13 (59)	7 (11)	8 (27)	14 (30)	16 (36)	58 (28)
	Missing	0 (0)	1 (2)	0 (0)	8 (17)	0 (0)	9 (4)
Donor past cardiothoracic disease	No	21 (95)	58 (91)	30 (100)	44 (96)	41 (91)	194 (94)
	Yes	1 (5)	5 (8)	0 (0)	2 (4)	2 (4)	10 (5)
	Missing	0 (0)	1 (2)	0 (0)	0 (0)	2 (4)	3 (1)
Donor past hypertension	No	17 (77)	50 (78)	20 (67)	34 (74)	33 (73)	154 (74)
	Yes	5 (23)	14 (22)	10 (33)	12 (26)	12 (27)	53 (26)
Donor past tumour	No	20 (91)	62 (97)	29 (97)	42 (91)	45 (100)	198 (96)
	Yes	2 (9)	2 (3)	1 (3)	4 (9)	0 (0)	9 (4)
Donor past smoker	No	13 (59)	32 (50)	16 (53)	24 (52)	26 (58)	111 (54)
	Yes	9 (41)	32 (50)	14 (47)	22 (48)	19 (42)	96 (46)
Total ischaemia time (hours)	Median (IQR)	6.4 (5.6, 7.0)	8.3 (6.8, 10.6)	5.8 (4.6, 6.5)	7.2 (5.9, 7.9)	6.1 (5.1, 7.1)	6.8 (5.3, 8.0)
	Missing	1	5	0	5	0	11

11.3 Total ischaemia time, 1 April 2008 – 31 March 2018

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 (4%) 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 5.3 hours to 6.4 hours over the last decade.

Figure 11.9 Boxplots of total ischaemia time in adult DBD donor lung transplants, by financial year, 1 April 2008 to 31 March 2018

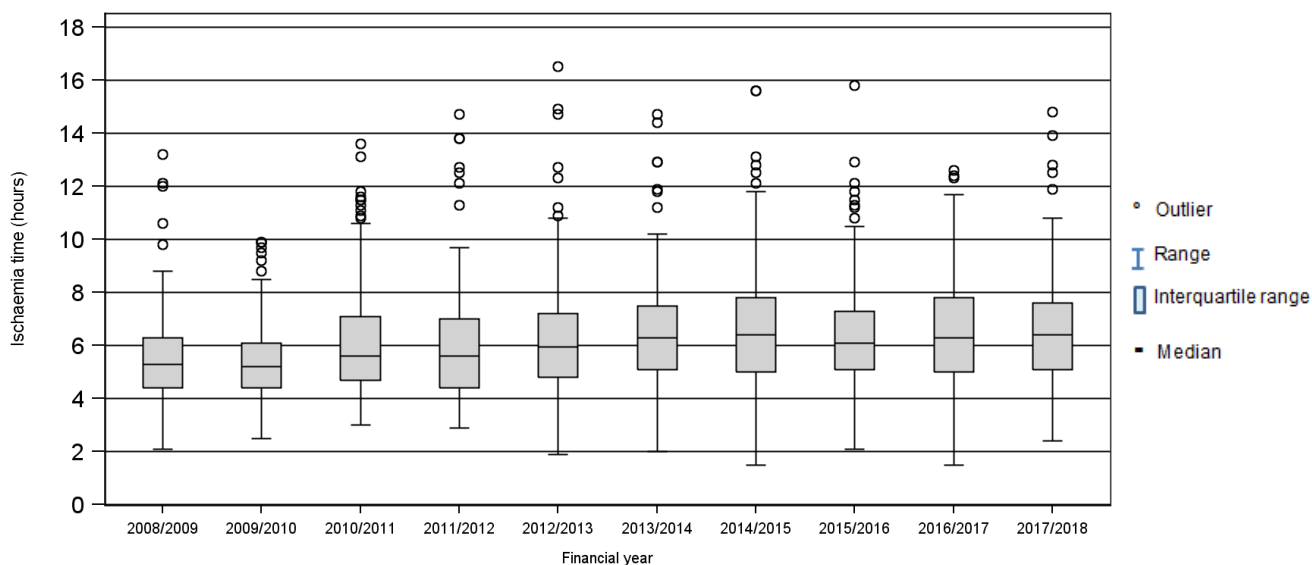


Figure 11.10 and **Figure 11.11** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2017/2018) and over the last 10 years, respectively. Ischaemia times were longest in 2017/2018 for lungs transplanted by Harefield and Newcastle and shortest for Manchester and Papworth. Harefield have seen the most noticeable increase in ischaemia times over the decade, whilst Manchester have seen a general decrease, and other centres have seen no clear upward or downward trend.

Figure 11.10 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2017 to 31 March 2018

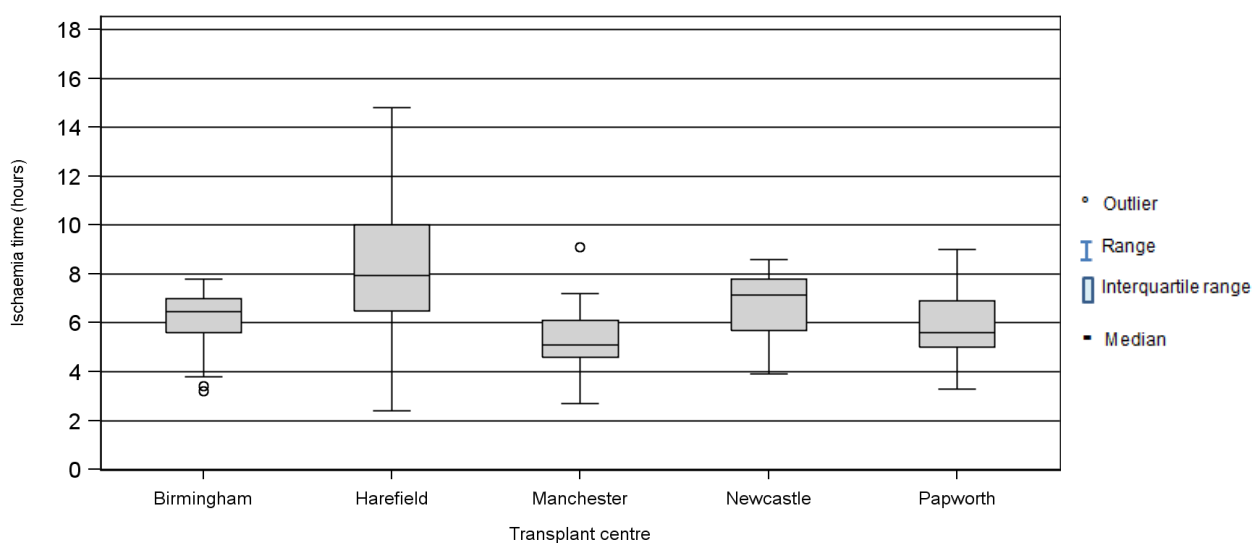
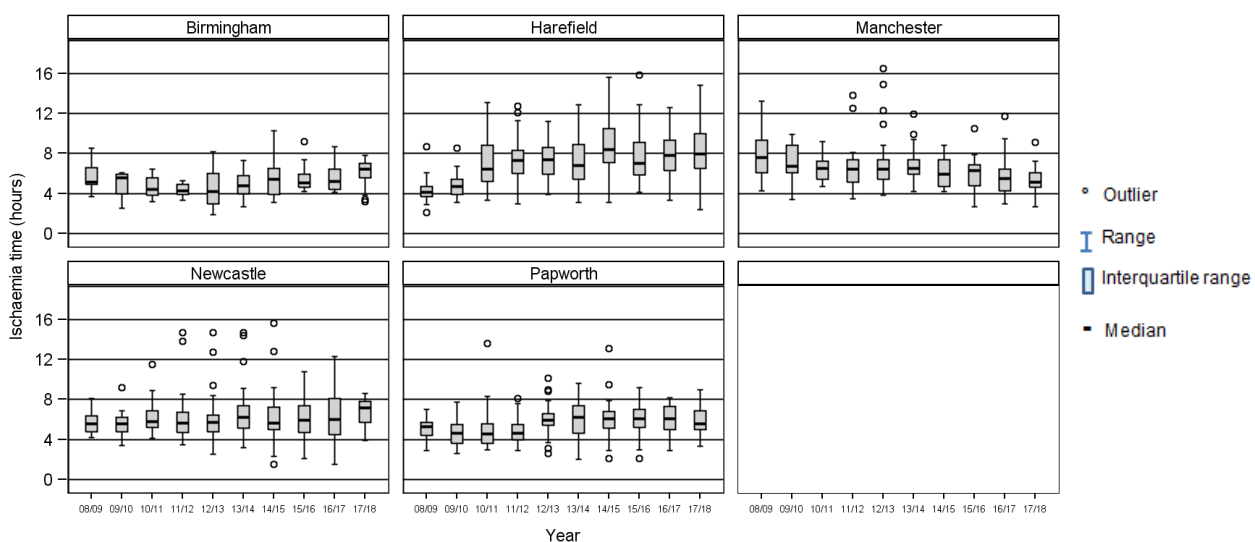


Figure 11.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2008 to 31 March 2018



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 2013 to 31 March 2017 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2009 to 31 March 2013. 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 12.4-12.6**. Heart-lung transplants are excluded but separate tables (**Table 12.7** and **12.8**) at the end of this section provide [unadjusted survival rates](#) for the small number of heart-lung transplant recipients between 1 April 2013 and 31 March 2017.

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 706 first adult lung only transplants in the period 1 April 2013 to 31 March 2017. All of the centres were statistically consistent with the national rate of survival which was 89.4%.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 90 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	84	81.0	(70.8 - 87.9)	81.6	(70.0 - 88.7)
Harefield	191	91.6	(86.7 - 94.8)	90.1	(83.9 - 93.9)
Manchester	109	91.7	(84.7 - 95.6)	92.8	(86.1 - 96.2)
Newcastle	173	86.7	(80.7 - 91.0)	87.1	(80.6 - 91.4)
Papworth	149	92.6	(87.1 - 95.8)	92.9	(87.1 - 96.1)
UK	706	89.4	(86.9 - 91.4)		

	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 2013 to 31 March 2017

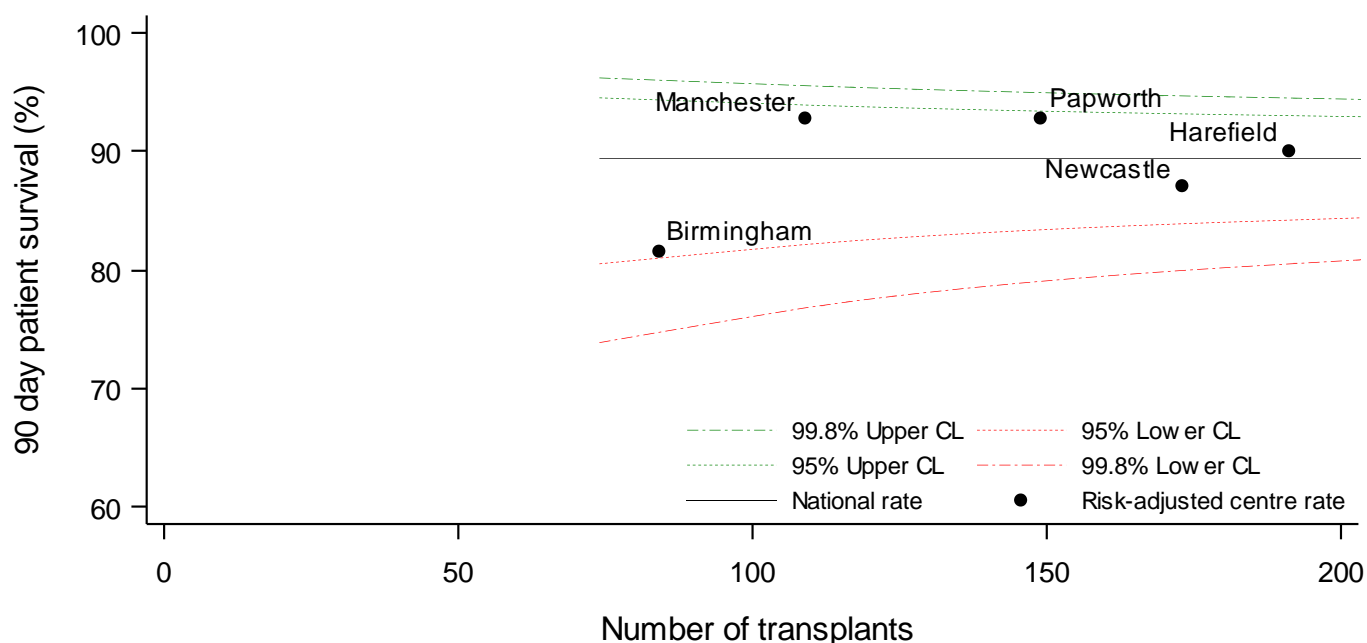


Table 12.2 and **Figure 12.2** show the 1-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 706 first adult lung only transplants in the period 1 April 2013 to 31 March 2017. The national rate of survival was 80.0%. The rates for all centres lie with the funnel, except Birmingham whose risk-adjusted survival rate is between the lower 95% and 99.8% [confidence limits](#), providing some evidence of lower than average survival.

Table 12.2 1 year patient survival rates after first adult lung transplant, by centre, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 1 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	84	69.9	(58.7 - 78.5)	68.6	(53.6 - 78.8)
Harefield	191	83.1	(77.0 - 87.8)	81.9	(74.4 - 87.2)
Manchester	109	83.1	(74.6 - 89.0)	85.1	(76.3 - 90.6)
Newcastle	173	80.1	(73.3 - 85.4)	79.9	(71.9 - 85.7)
Papworth	149	79.1	(71.6 - 84.8)	79.8	(71.3 - 85.8)
UK	706	80.0	(76.8 - 82.8)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> <div>Centre has reached the lower 99.8% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> <div>Centre has reached the lower 95% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> <div>Centre has reached the upper 95% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> <div>Centre has reached the upper 99.8% confidence limit</div> </div>					

Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2013 to 31 March 2017

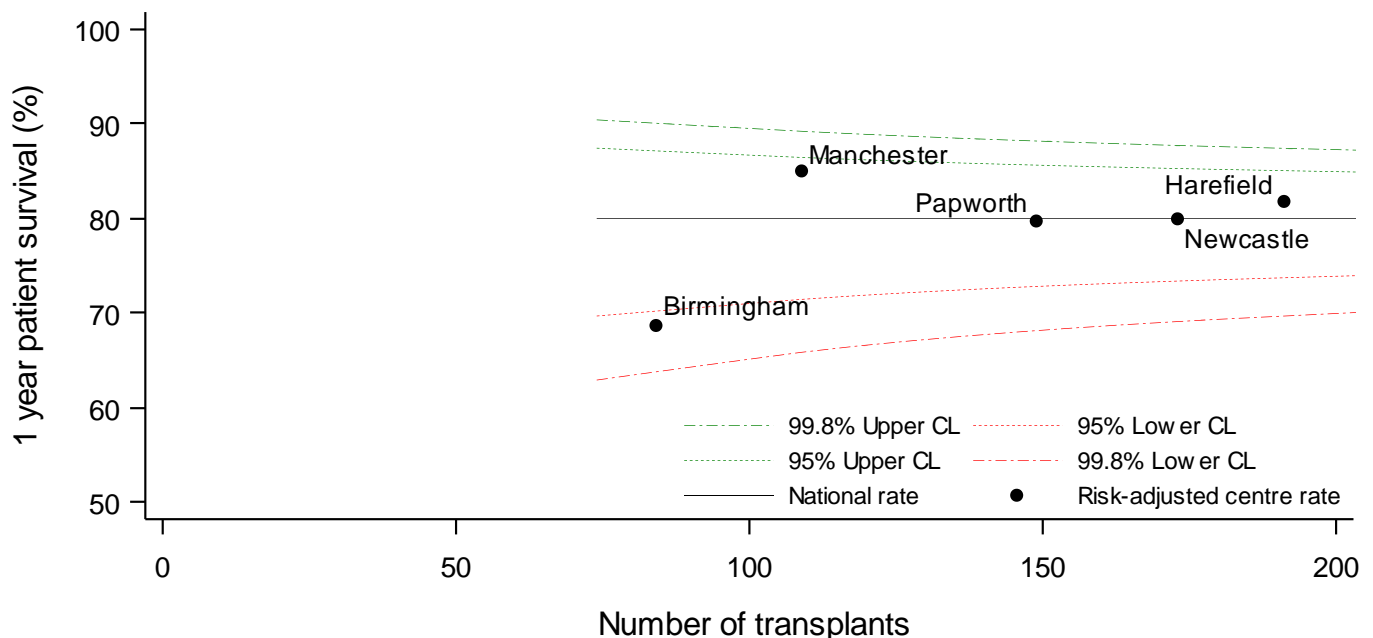
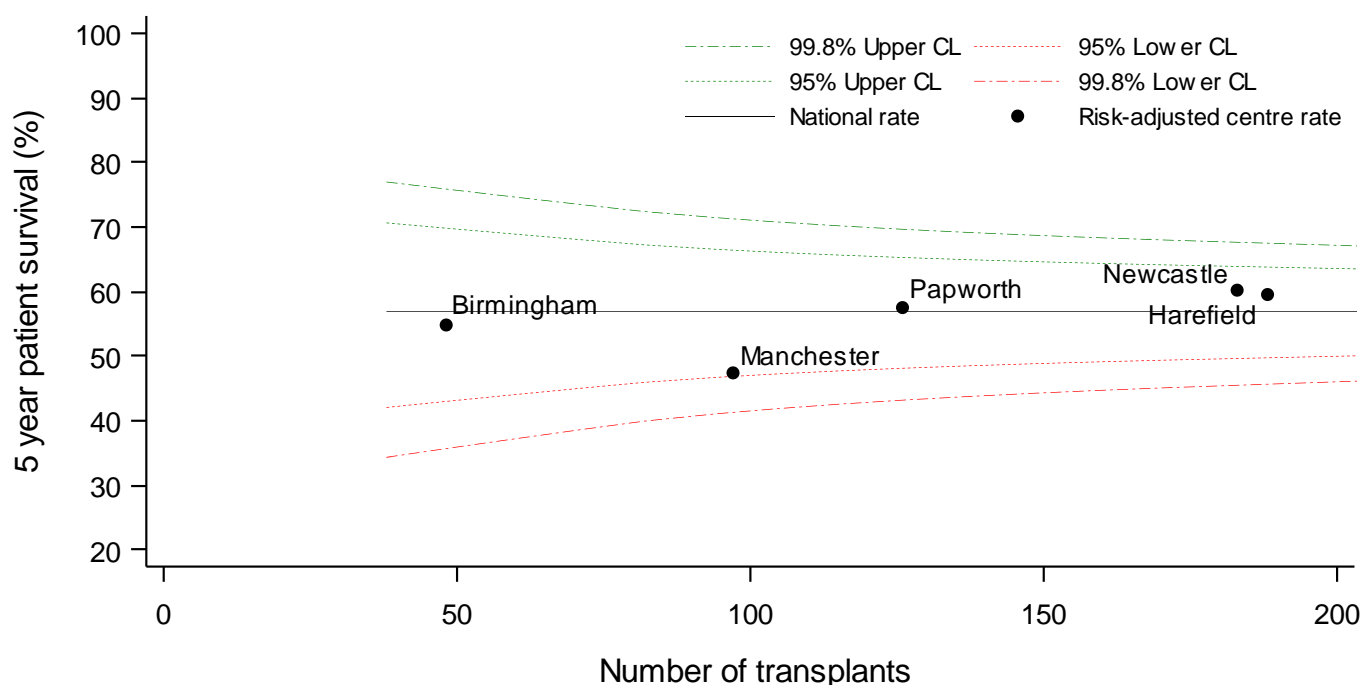


Table 12.3 and **Figure 12.3** show the 5-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 642 first adult lung only transplants in the period 1 April 2009 to 31 March 2013. All centres were statistically consistent with the national rate of survival which was 56.9%.

Table 12.3 5 year patient survival rates after first adult lung transplant, by centre, 1 April 2009 to 31 March 2013					
Centre	Number of transplants	% 5 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Birmingham	48	50.8	(35.6 - 64.1)	54.7	(31.8 - 69.9)
Harefield	188	61.3	(53.9 - 67.9)	59.5	(49.0 - 67.8)
Manchester	97	44.2	(34.1 - 53.8)	47.4	(31.3 - 59.7)
Newcastle	183	62.0	(54.3 - 68.8)	60.0	(49.1 - 68.6)
Papworth	126	56.0	(46.9 - 64.2)	57.6	(44.8 - 67.5)
UK	642	56.9	(52.9 - 60.7)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> Centre has reached the lower 99.8% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> Centre has reached the lower 95% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> Centre has reached the upper 95% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> Centre has reached the upper 99.8% confidence limit </div>					

Figure 12.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2009 to 31 March 2013



12.2 Survival by disease group

Tables 12.4, 12.5 and 12.6 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 30 days, 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 90 day, 1 year or 5 years.

Table 12.4 90 day patient survival rates after first adult lung transplant, by disease group, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 90 day survival (95% CI)			
		Unadjusted		Risk-adjusted	
Cystic fibrosis and bronchiectasis	209	91.4	(86.7 - 94.5)	91.0	(85.7 - 94.3)
COPD and emphysema	190	91.6	(86.6 - 94.8)	90.4	(84.4 - 94.1)
Fibrosing lung disease	169	87.6	(81.6 - 91.7)	89.6	(84.1 - 93.2)
Other	138	85.5	(78.4 - 90.4)	85.4	(77.4 - 90.6)
UK	706	89.4	(86.9 - 91.4)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> Group has reached the lower 99.8% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> Group has reached the lower 95% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> Group has reached the upper 95% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> Group has reached the upper 99.8% confidence limit </div>					

Table 12.5 1 year patient survival rates after first adult lung transplant, by disease group, 1 April 2013 to 31 March 2017					
Centre	Number of transplants	% 1 year survival (95% CI)			
		Unadjusted		Risk-adjusted	
Cystic fibrosis and bronchiectasis	209	80.2	(74.0 – 85.0)	80.5	(73.5 - 85.6)
COPD and emphysema	190	85.5	(79.6 - 89.8)	82.7	(74.8 - 88.2)
Fibrosing lung disease	169	78.0	(71.0 - 83.6)	80.3	(72.8 - 85.7)
Other	138	74.6	(66.5 - 81.1)	75.9	(66.4 - 82.7)
UK	706	80.0	(76.8 - 82.8)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> Group has reached the lower 99.8% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> Group has reached the lower 95% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> Group has reached the upper 95% confidence limit </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> Group has reached the upper 99.8% confidence limit </div>					

Table 12.6 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2009 to 31 March 2013

Centre	Number of transplants	% 5 year survival (95% CI)			
			<u>Unadjusted</u>		<u>Risk-adjusted</u>
Cystic fibrosis and bronchiectasis	184	64.2	(56.6 - 70.8)	59.6	(48.3 - 68.5)
COPD and emphysema	251	58.6	(52.1 - 64.5)	58.4	(49.5 - 65.7)
Fibrosing lung disease	112	48.1	(38.5 - 57.1)	56.2	(43.2 - 66.2)
Other	95	49.2	(38.7 - 58.8)	49.4	(32.9 - 61.9)
UK	642	56.9	(52.9 - 60.7)		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> Group has reached the lower 99.8% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> Group has reached the lower 95% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> Group has reached the upper 95% confidence limit </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> Group has reached the upper 99.8% confidence limit </div>					

12.3 Survival post heart-lung transplant

Table 12.7 and **Table 12.8** present short-term patient [survival rates](#) following combined heart-lung transplant, by centre and nationally. During the time period 1 April 2013 to 31 March 2018, 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 80% at 90 days and 76.7% at one year.

Table 12.7 90 day patient survival after first adult heart-lung transplant, by centre, 1 April 2013 and 31 March 2017

Centre	Number of transplants	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Birmingham ¹	2	0	-	-
Harefield ¹	1	1	-	-
Manchester ¹	3	0	-	-
Newcastle ¹	3	2	-	-
Papworth	21	3	85.7	(62.0 - 95.2)
UK	30	6	80.0	(60.8 - 90.5)

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

Table 12.8 1 year patient survival after first adult heart-lung transplant, by centre, 1 April 2013 and 31 March 2017

Centre	Number of transplants	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Birmingham ¹	2	0	-	-
Harefield ¹	1	1	-	-
Manchester ¹	3	1	-	-
Newcastle ¹	3	2	-	-
Papworth	21	3	85.7	(62.0 - 95.2)
UK	30	7	76.7	(57.2 - 88.1)

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 2006 and 31 December 2017. 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, five and ten year [risk-adjusted survival rates](#) from the point of lung transplant listing are shown as [funnel plots](#) in **Figures 13.1, 13.2 and 13.3** respectively. These rates are also shown in **Table 13.1**. Note that all rates (at 1, 5 and 10 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 rates for Harefield and Manchester fell outside the upper 95% [confidence limit](#) but within the 99.8% [confidence limit](#), providing some evidence of higher than average [survival rates](#). The five and ten year [survival rates](#) from listing for Harefield were above the 99.8% [confidence limit](#) indicating higher than average survival. The one, five and ten year [survival rates](#) from listing for Birmingham all fell below the 99.8% [confidence limits](#) indicating lower than average survival.

Table 13.1 Risk-adjusted 1, 5 and 10 year patient survival rates from listing for first lung only transplant in patients registered between 1 January 2006 and 31 December 2017							
Centre	Number at risk ¹ at day 0	Survival rate at 1 year (%)	Number at risk ¹ at 1 year	Survival rate at 5 years (%)	Number at risk ¹ at 5 years	Survival rate at 10 years (%)	Number at risk ¹ at 10 years
Birmingham	302	67.7	(178)	30.1	(33)	6.3	(3)
Harefield	813	81.6	(583)	52.8	(163)	34.2	(19)
Manchester	451	82.4	(317)	48.7	(81)	29.4	(17)
Newcastle	746	75.0	(507)	47.1	(145)	29.4	(21)
Papworth	493	77.4	(327)	44.2	(98)	25.3	(7)
UK	2805	77.8	(1912)	46.9	(520)	27.9	(67)
<div> <div></div> Centre has reached the lower 99.8% confidence limit <div></div> Centre has reached the lower 95% confidence limit <div></div> Centre has reached the upper 95% confidence limit <div></div> Centre has reached the upper 99.8% confidence limit </div>							
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 2006 – 31 December 2017

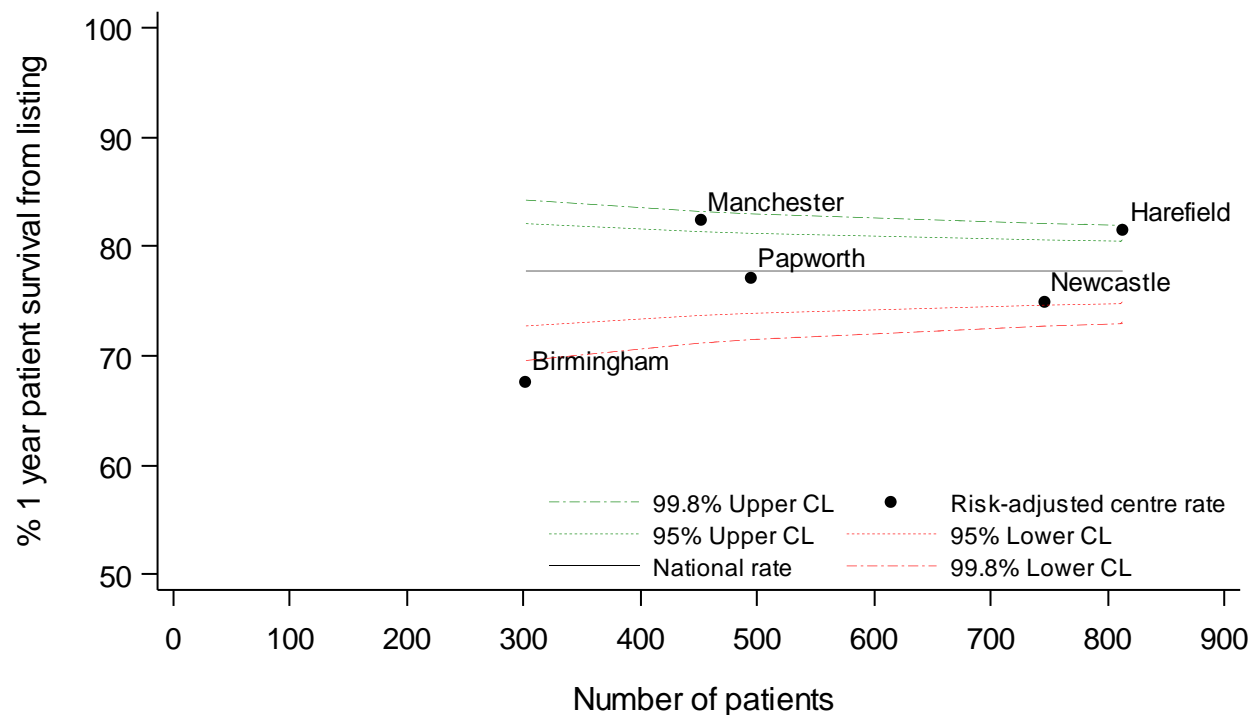
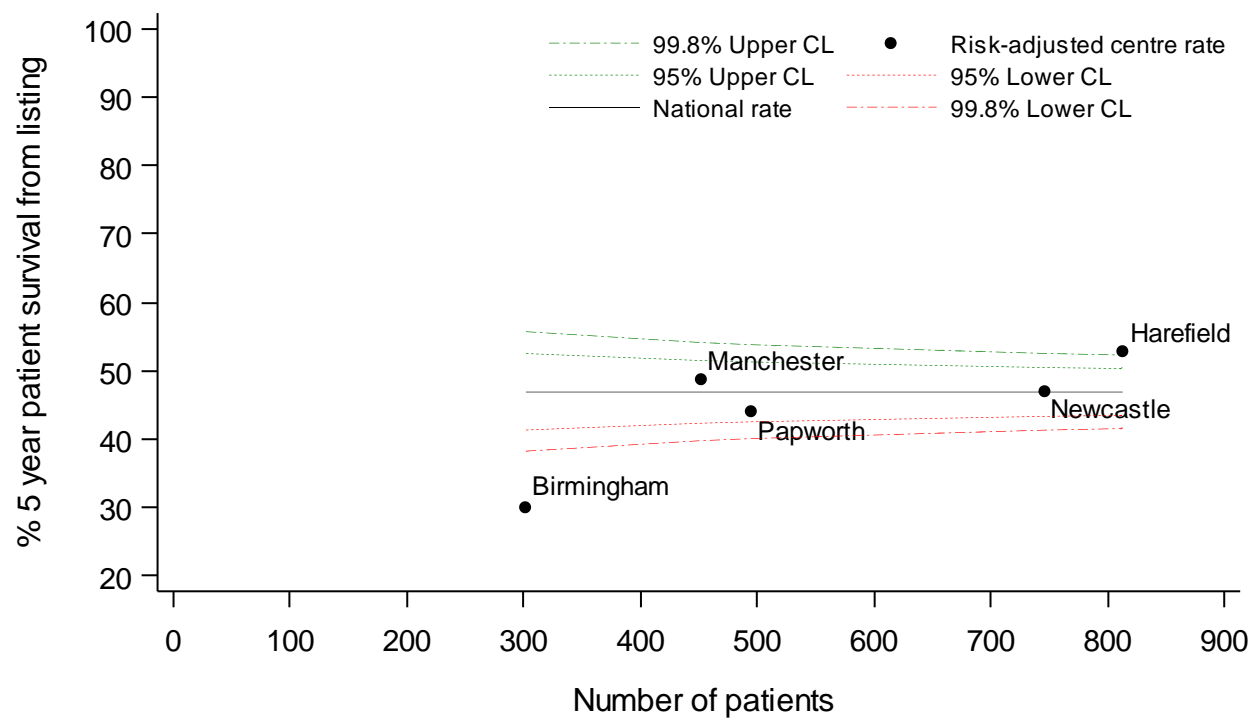
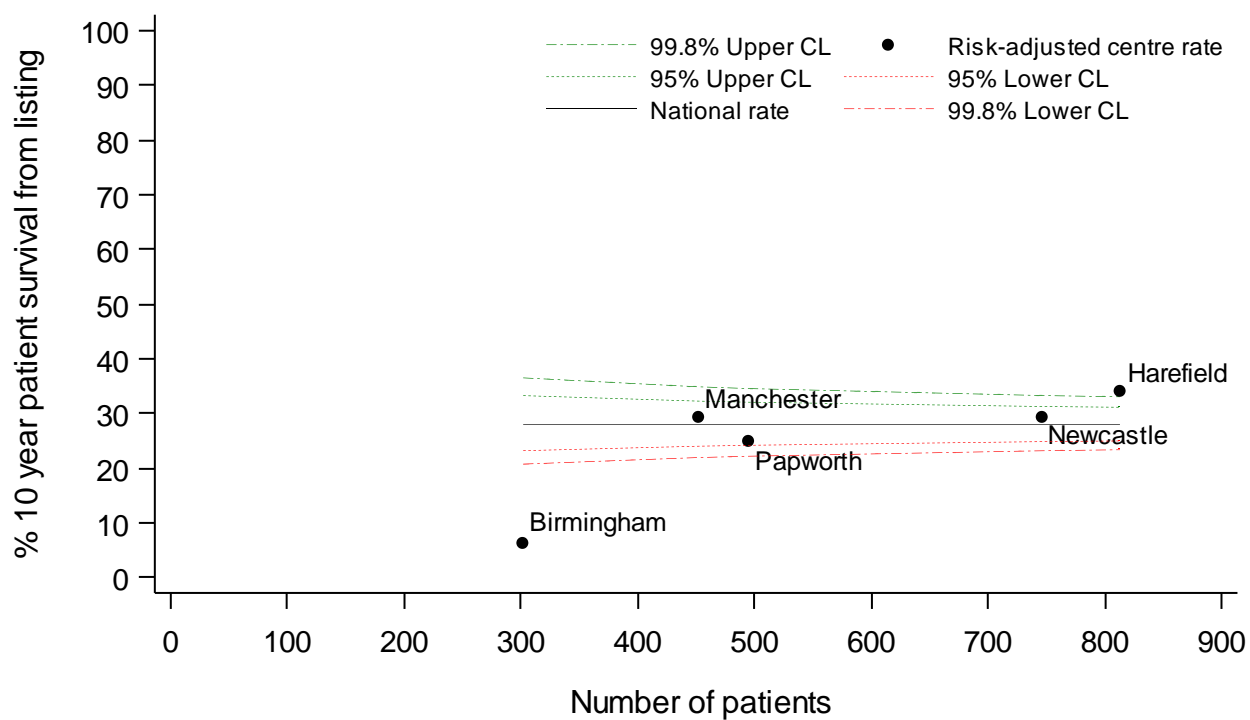


Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2006 – 31 December 2017



**Figure 13.3 Risk-adjusted ten year patient survival rates from listing by centre,
1 January 2006 – 31 December 2017**



ADULT LUNG TRANSPLANTATION

Form Return Rates



14. Adult lung form return rates, 1 January – 31 December 2017

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 (more than 2 years). These include all adult lung and heart-lung transplants between 1 January and 31 December 2017 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. A small number of transplant record and lifetime follow-up forms are outstanding for this period.

Table 14.1 Form return rates for adult lung transplants, 1 January 2017 to 31 December 2017

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	16	100	17	100	16	100	94	62
Harefield Hospital	61	100	57	100	36	100	389	95
Manchester Wythenshawe Hospital	30	100	33	100	30	100	160	99
Newcastle Freeman Hospital	40	98	34	100	27	100	338	89
Royal Papworth Hospital	45	100	51	100	32	100	282	97
Sheffield Northern General Hospital	-	-	-	-	-	-	4	100
Overall	192	99	192	100	141	100	1267	92

PAEDIATRIC HEART TRANSPLANTATION

Transplant List



15.1 Paediatric heart only transplant list as at 31 March, 2009 – 2018

Figure 15.1 shows the number of paediatric patients on the heart transplant list at 31 March each year between 2009 and 2018 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased significantly over the period to a peak of 26 in 2015, but in 2018 it has fallen to 16. The number of patients on the urgent transplant list has varied between 3 in 2009 and 12 in 2016 and was 10 in 2018. The number of patients on the urgent transplant list has varied between 3 in 2009 and 12 in 2016 and was 10 in 2018.

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

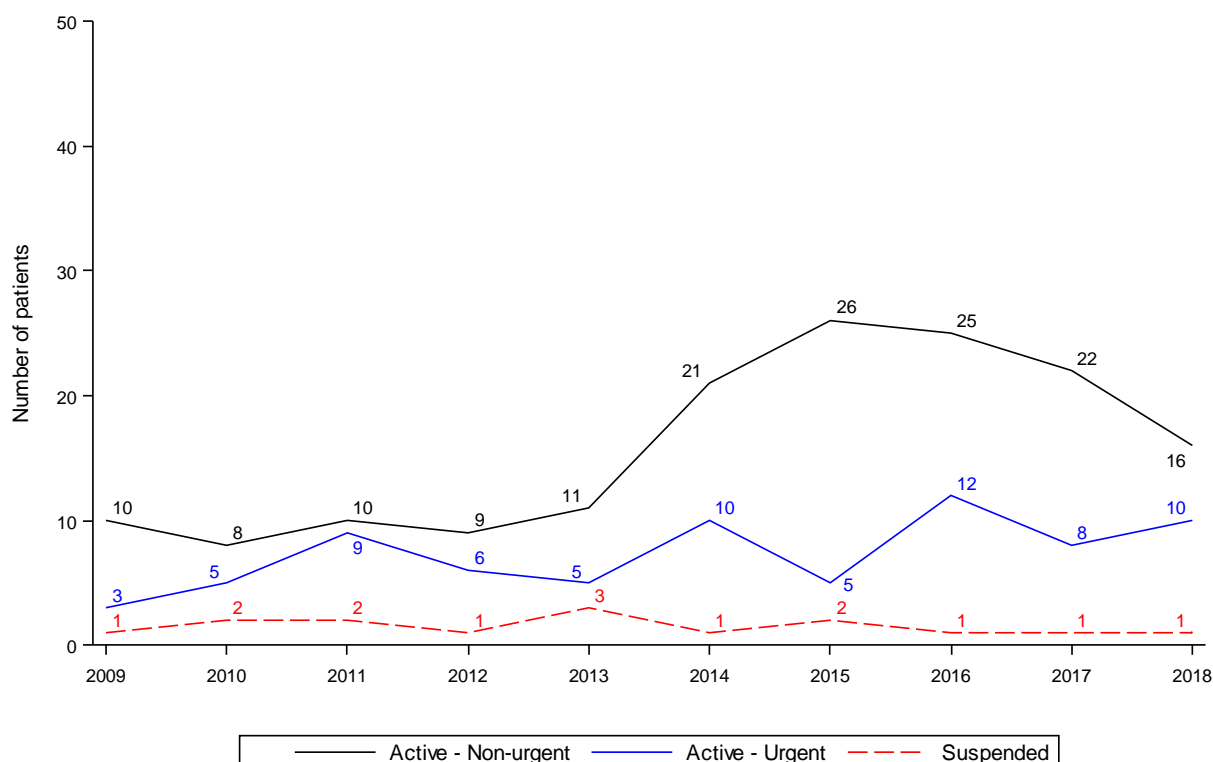


Figure 15.2 shows the number of paediatric patients on the [active heart transplant list](#) at 31 March 2018 by centre. In total, there were 26 paediatric patients waiting. Great Ormond Street Hospital had the largest overall number of paediatric patients on the transplant list, with more non-urgent than urgent.

Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2018, by centre

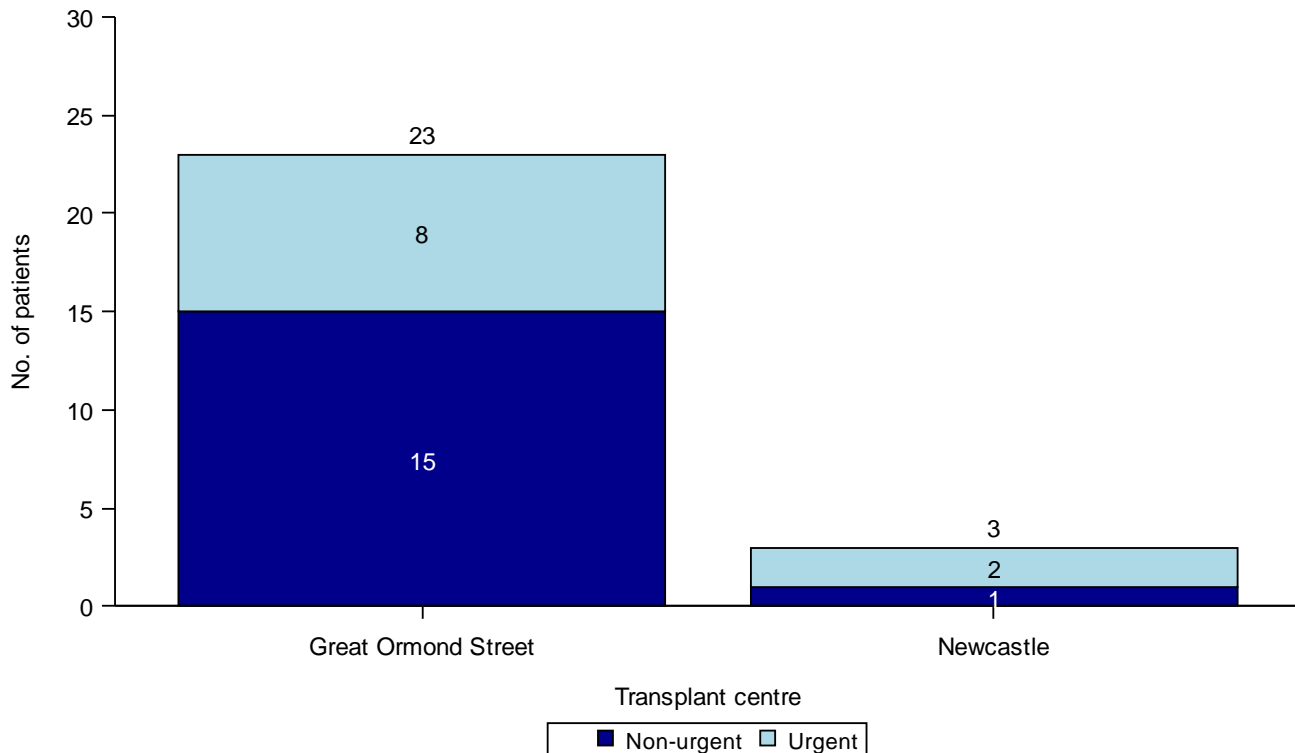
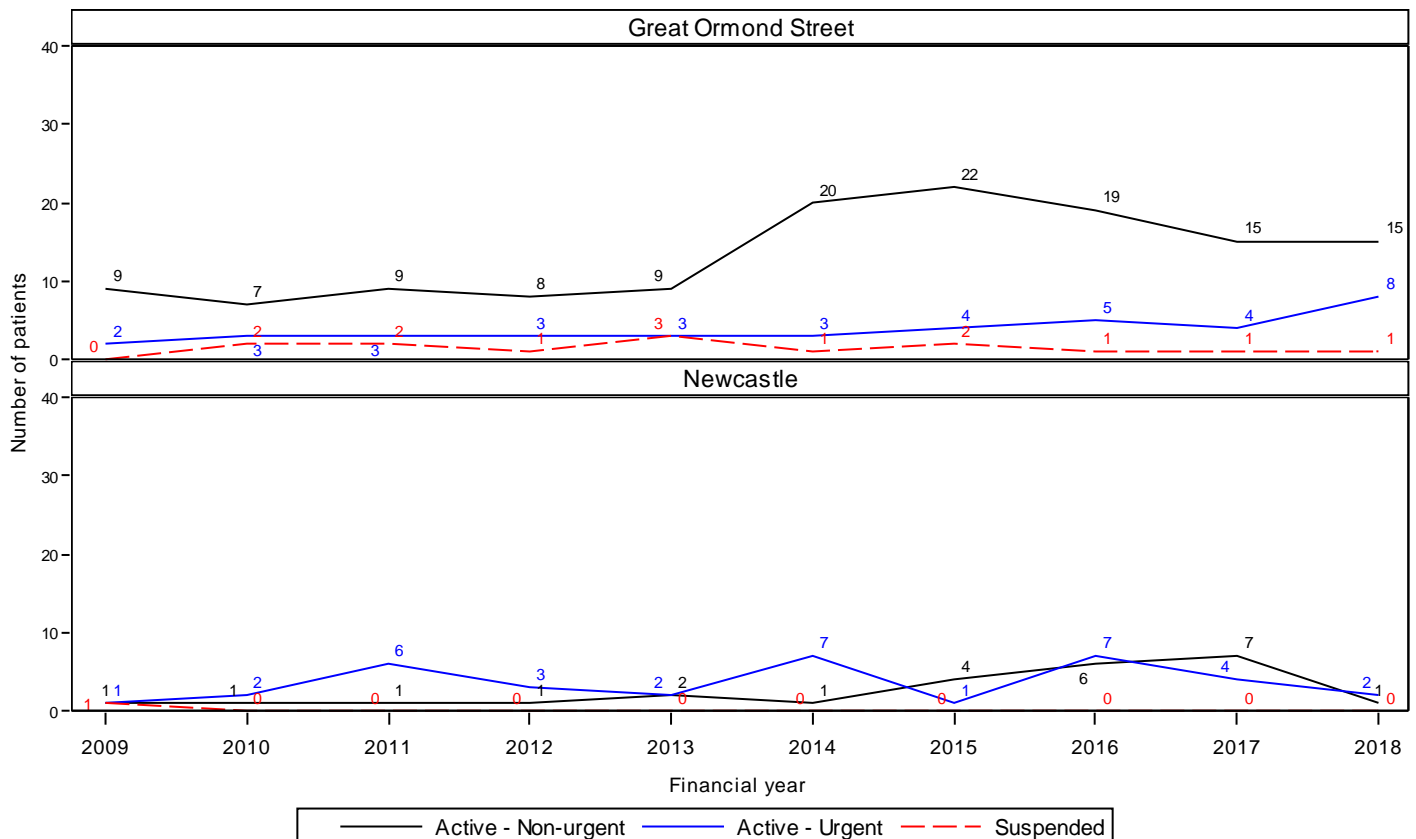


Figure 15.3 shows the trend over time in the number of paediatric patients on the heart transplant list at 31 March each year across each centre. Great Ormond Street Hospital experienced a substantial increase in their non-urgent list in 2014 and since then it has only decreased slightly whilst their urgent list has increased recently. Likewise, Newcastle's non-urgent list has increased in recent years, but has fallen this year to 1, and there has been no clear upward or downward trend in their urgent list.

Figure 15.3 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 2017 – 31 March 2018

There were 44 paediatric patient registrations onto the heart transplant list between 1 April 2017 and 31 March 2018. Demographic characteristics of these patients are shown by centre and overall in **Table 15.1**. Nationally, 48% of the patients were male and the [median](#) age was 5 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 2017 and 31 March 2018, by centre

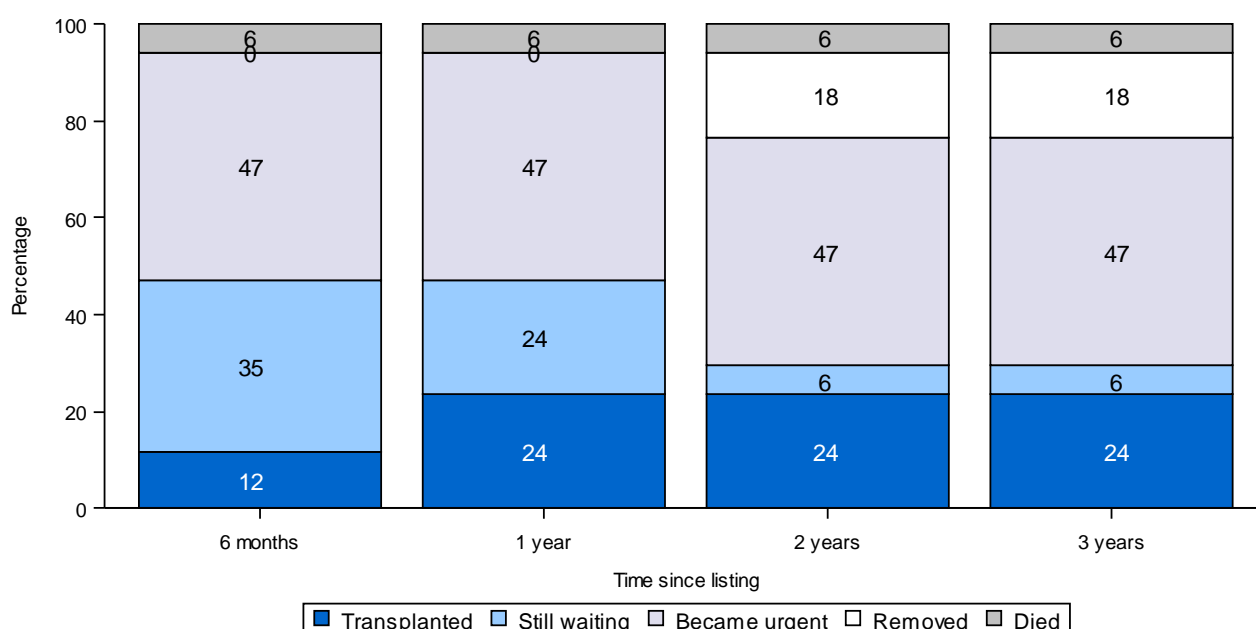
		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		25 (100)	19 (100)	44 (100)
Highest urgency during registration	Non-urgent	11 (44)	3 (16)	14 (32)
	Urgent	13 (52)	16 (84)	29 (66)
	Super-urgent ¹	1 (4)	0 (0)	1 (2)
Recipient sex	Male	12 (48)	9 (47)	21 (48)
	Female	13 (52)	10 (53)	23 (52)
Recipient ethnicity	White	17 (68)	17 (89)	34 (77)
	Non-white	8 (32)	2 (11)	10 (23)
Recipient age (years)	Median (IQR)	4 (3, 10)	6 (1, 10)	5 (2, 10)
	Missing	0	0	0
Recipient height (cm)	Median (IQR)	101 (85, 137)	110 (74, 151)	102 (83, 140)
	Missing	1	0	1
Recipient weight (kg)	Median (IQR)	17 (12, 34)	19 (9, 40)	18 (10, 35)
	Missing	0	0	0
Primary Disease	Coronary heart disease	0 (0)	1 (5)	1 (2)
	Cardiomyopathy	8 (32)	6 (32)	14 (32)
	Congenital heart disease	6 (24)	6 (32)	12 (27)
	Others	11 (44)	6 (32)	17 (39)
Previous open heart surgery	None	12 (48)	4 (21)	16 (36)
	One	2 (8)	9 (47)	11 (25)
	More than one	3 (12)	6 (32)	9 (21)
	Missing	8 (32)	0 (0)	8 (18)
Previous thoracotomy	No	19 (76)	17 (89)	36 (82)
	Yes	1 (4)	2 (11)	3 (7)
	Missing	5 (20)	0 (0)	5 (11)
Serum Bilirubin (umol/l)	Median (IQR)	16 (13, 24)	10 (6, 15)	13 (9, 23)
	Missing	12	0	12
Serum Creatinine (umol/l)	Median (IQR)	32 (27, 42)	46 (29, 68)	40 (28, 52)
	Missing	10	0	10

¹ The Super Urgent Heart Offering Scheme is not available to paediatric patients and this was a registration in error

15.3 Post-registration outcomes, 1 April 2014 – 31 March 2015

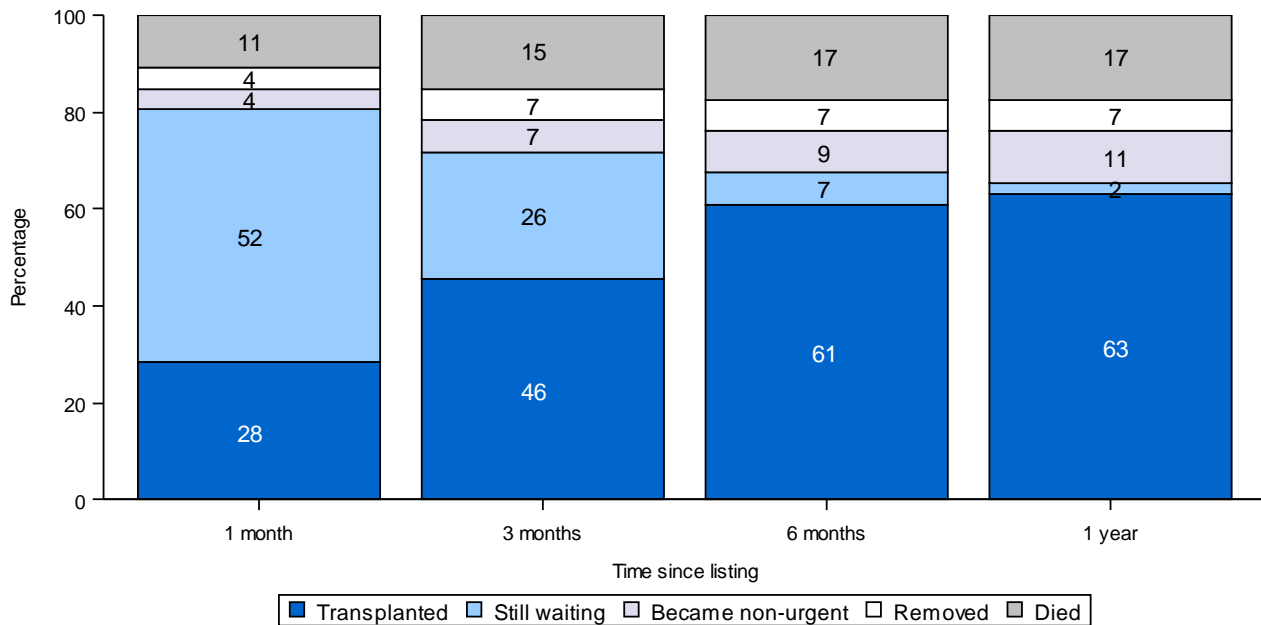
The transplant list outcomes of paediatric patients listed for a non-urgent heart transplant between 1 April 2014 and 31 March 2015 are summarised in **Figure 15.4**. The same information is presented in **Figure 15.5** for those listed for an urgent heart transplant between 1 April 2014 and 31 March 2015 (including those previously on the non-urgent list). These charts show the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one, two and three years after joining the list. Within 6 months of listing, 12% of non-urgent heart patients had been transplanted and 6% had died, while after three years, 24% had been transplanted and 6% had died. Also, 47% had been moved to the urgent heart list within 6 months.

Figure 15.4 Post-registration outcome for 17 new non-urgent heart only registrations made in the UK, 1 April 2014 to 31 March 2015



The chance of transplant is much higher from the urgent heart transplant list compared with the non-urgent transplant list, as shown below in **Figure 15.5**; within 6 months, 61% have been transplanted, 17% had died and 7% removed. Removals from the list were mainly due to improving condition.

Figure 15.5 Post-registration outcome for 46 new urgent heart only registrations made in the UK, 1 April 2014 to 31 March 2015



15.4 Median waiting time to transplant, 1 April 2012 - 31 March 2015

Table 15.2 shows the [median](#) waiting time to heart transplant from listing for paediatric patients registered between 1 April 2012 and 31 March 2015. This is estimated using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. This is split by the urgency of the patient at 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 is 312 days from non-urgent registration and 63 days from urgent registration. The [median](#) waiting time to heart transplant for paediatric patients is also considered by blood group and is shown 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 2012 to 31 March 2015			
Transplant centre	Number of patients registered	Median	Waiting time (days) 95% Confidence interval
Overall			
Great Ormond Street Hospital	76	187	78 - 296
Newcastle	73	96	44 - 148
UK	149	124	106 - 142
Non-urgent at initial registration			
Great Ormond Street Hospital	38	414	235 - 593
Newcastle	13	122	84 - 160
UK	51	312	230 - 394
Urgent at initial registration			
Great Ormond Street Hospital	38	70	32 - 108
Newcastle	60	60	15 - 105
UK	98	63	48 - 78

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 2012 to 31 March 2015

Blood group	Number of patients registered	Waiting time (days)	
		<u>Median</u>	95% <u>Confidence interval</u>
Overall			
O	61	124	87 - 161
A	48	123	100 - 146
B	32	180	39 - 321
AB ¹	8	-	-
UK	149	124	106 - 142
Non-urgent at initial registration			
O	19	414	37 - 791
A	18	269	12 - 526
B	13	320	220 - 420
AB ¹	1	-	-
UK	51	312	230 - 394
Urgent at initial registration			
O	42	58	49 - 67
A	30	121	0 - 265
B	19	138	43 - 233
AB ¹	7	57	34 - 80
UK	98	63	48 - 78

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 2015 and 31 March 2018. 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 offer are considered, as are all urgent and non-urgent patient offers. 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 offers received per year has varied considerably which is due to a number of factors including how many urgent patients each centre had on their list during the year. Generally, Newcastle declined fewer offers than Great Ormond Street Hospital (GOSH).

Table 16.1 UK paediatric DBD donor heart offer decline rates by transplant centre and year, 1 April 2015 to 31 March 2018								
Centre	2015/16		2016/17		2017/18		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
GOSH	51	(88.2)	7	(57.1)	15	(73.3)	73	(82.2)
Newcastle	49	(85.7)	18	(55.6)	11	(27.3)	78	(70.5)
UK	100	(87.0)	25	(56.0)	26	(53.8)	151	(76.2)

PAEDIATRIC HEART TRANSPLANTATION

Transplants



17.1 Paediatric heart transplants, 1 April 2008 – 31 March 2018

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 second highest in 2014/2015 but has not reached over 40 per year. Last year's activity is shown by centre and donor type in **Figure 17.3**. In 2017/2018, there were 35 transplants, comprising 19 at Newcastle and 14 at Great Ormond Street Hospital, with Newcastle performing one DCD heart transplant.

Figure 17.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2008 to 31 March 2018

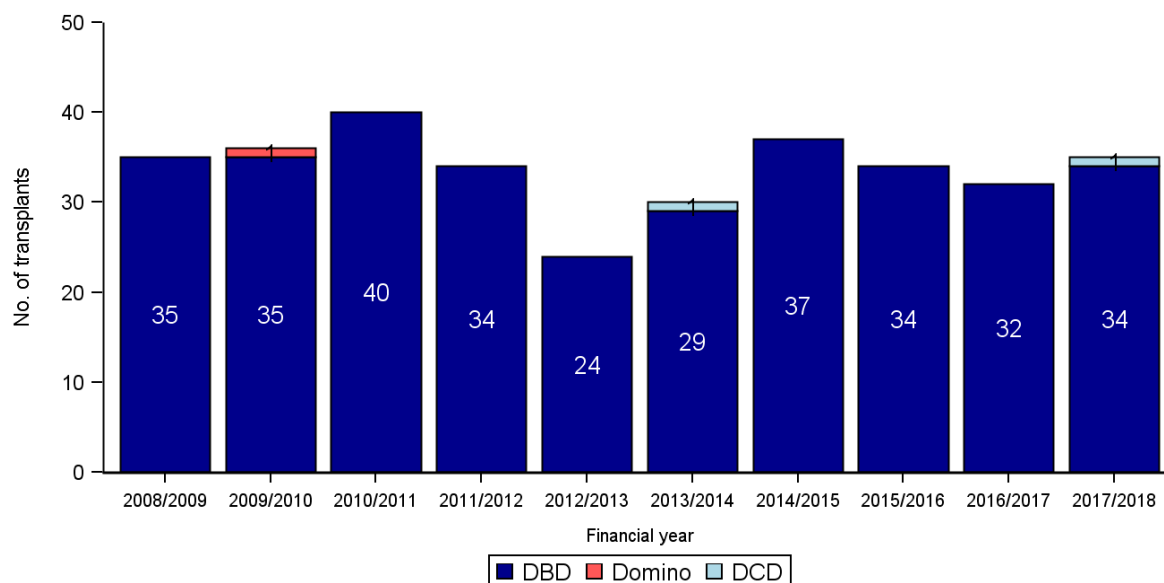


Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2008 to 31 March 2018

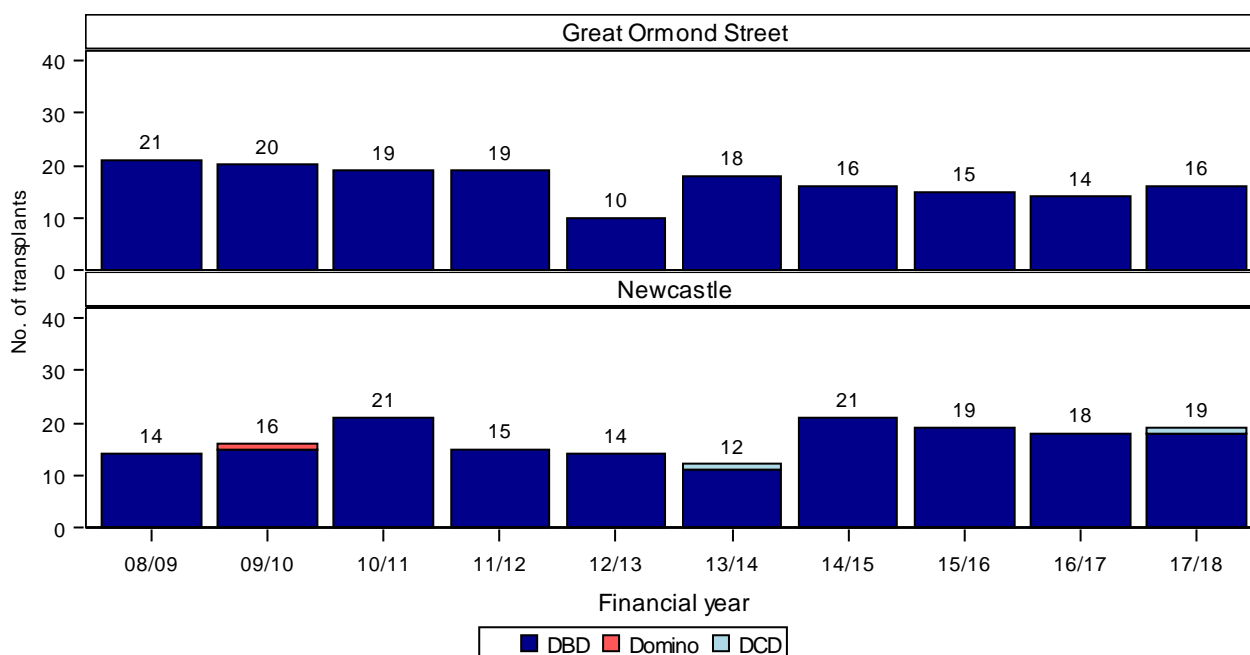


Figure 17.3 Number of paediatric heart transplants in the UK, by centre and donor type, 1 April 2017 to 31 March 2018

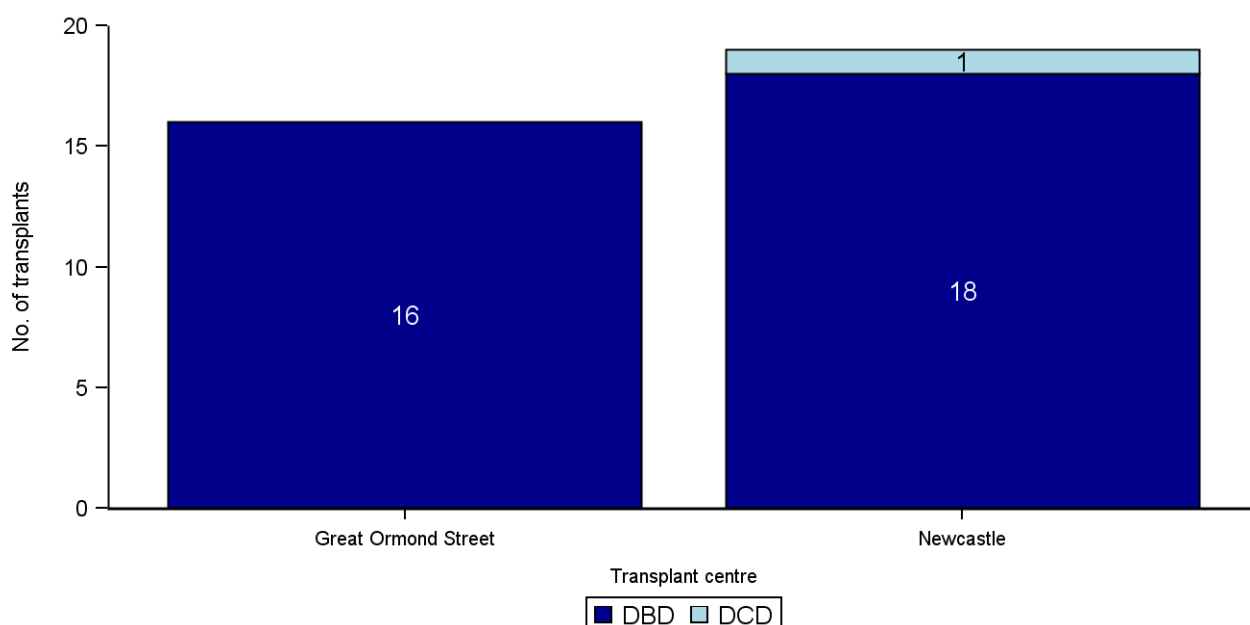


Figure 17.4 and 17.5 show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time the proportion of urgent transplants has increased; from 49% in 2008/2009 to 89% in 2014/2015 but has fallen in the most recent year to 69%. 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 2008 to 31 March 2018

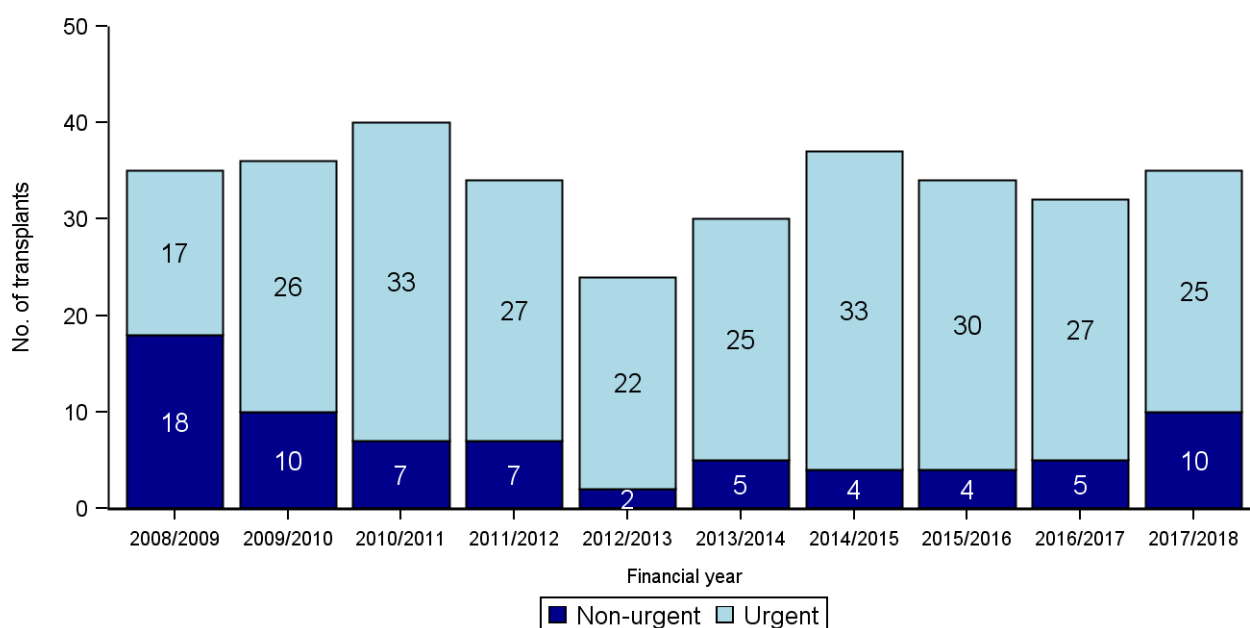


Figure 17.5 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2008 to 31 March 2018

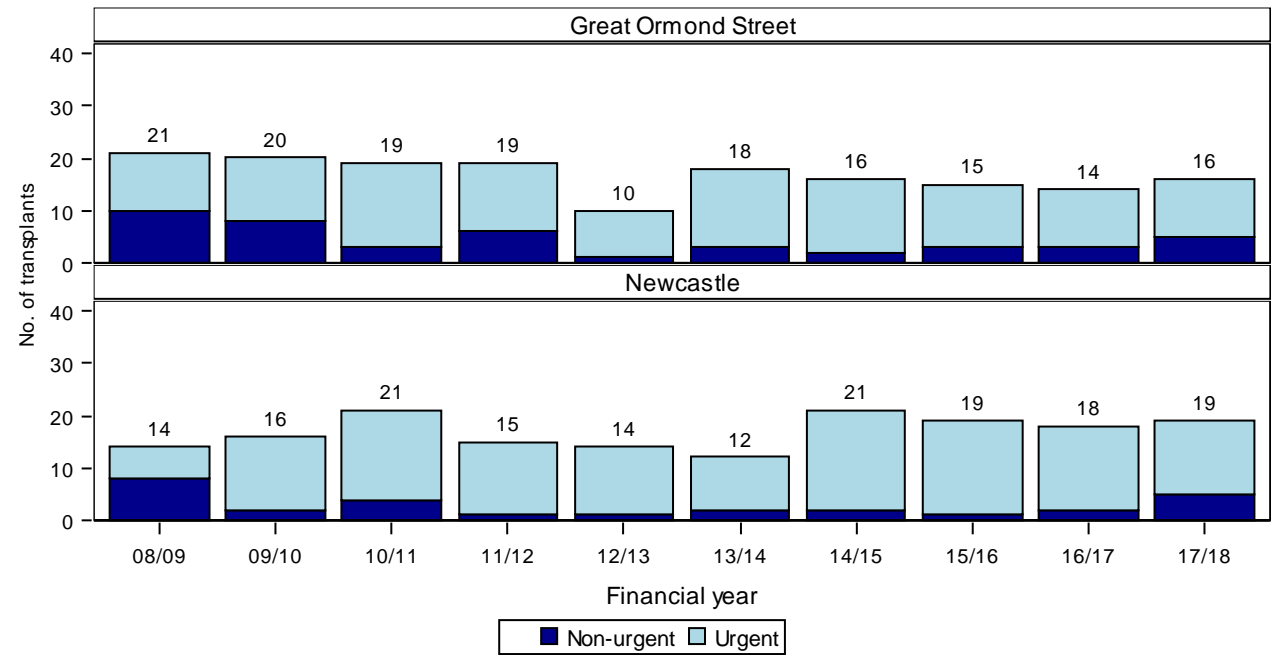
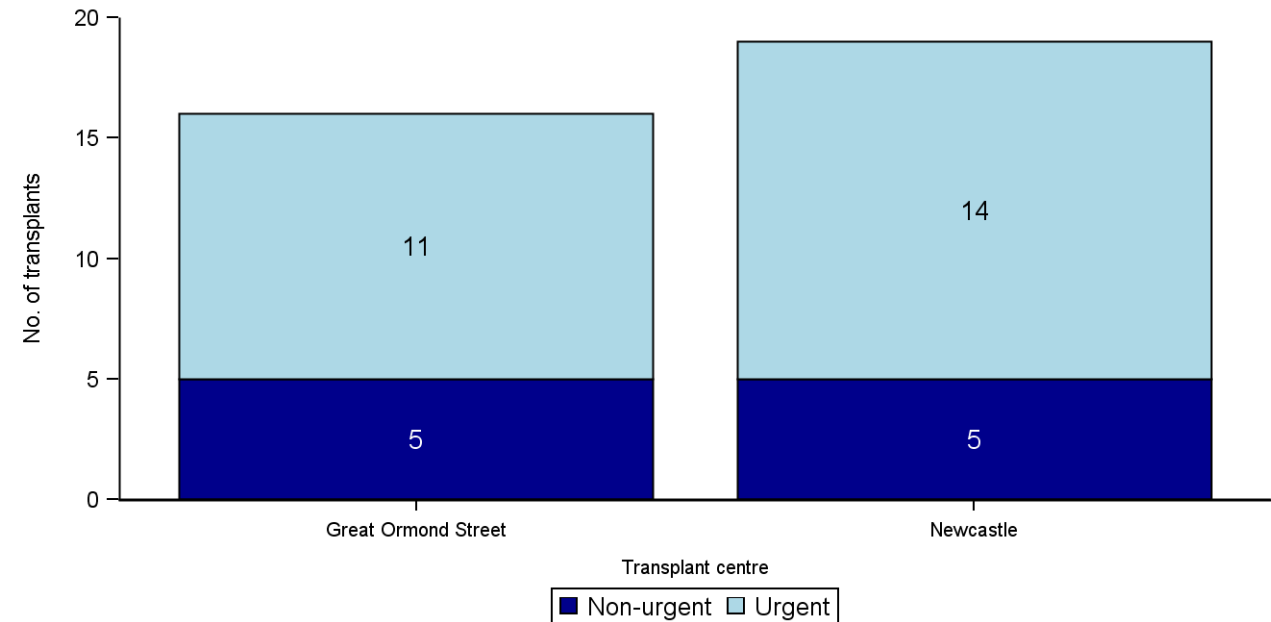


Figure 17.6 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2017 to 31 March 2018



17.2 Demographic characteristics of transplants, 1 April 2017 – 31 March 2018

The demographic characteristics of the 35 paediatric heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 17.1**. Nationally, 60% of heart recipients were male and the [median](#) age was 9 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 2017 to 31 March 2018, by centre				
		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of transplants		16 (100)	19 (100)	35 (100)
Urgency status at transplant	Non-urgent	5 (31)	5 (26)	10 (29)
	Urgent	11 (69)	14 (74)	25 (71)
Recipient sex	Male	7 (44)	14 (74)	21 (60)
	Female	9 (56)	5 (26)	14 (40)
Recipient ethnicity	White	9 (56)	17 (89)	26 (74)
	Non-white	7 (44)	2 (11)	9 (26)
Recipient age (years)	Median (IQR)	12 (8, 14)	7 (1, 10)	9 (3, 13)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	35 (20, 44)	19 (10, 38)	22 (14, 40)
	Missing	0	0	0
Recipient primary disease	Cardiomyopathy	4 (25)	7 (37)	11 (31)
	Congenital heart disease	5 (31)	10 (53)	15 (43)
	Others	7 (44)	2 (11)	9 (26)
NYHA class	III	0 (0)	15 (79)	15 (43)
	IV	14 (88)	3 (16)	17 (49)
	Missing	2 (13)	1 (5)	3 (9)
Recipient in hospital pre-transplant	No	6 (38)	5 (26)	11 (31)
	Yes	9 (56)	13 (68)	22 (63)
	Missing	1 (6)	1 (5)	2 (6)
If in hospital, recipient on ventilator	No	8 (89)	9 (69)	17 (77)
	Yes	1 (11)	4 (31)	5 (23)
If in hospital, recipient on VAD	None	3 (33)	5 (38)	8 (36)
	Left	4 (44)	8 (62)	12 (55)
	Right	1 (11)	0 (0)	1 (5)
	Both	1 (11)	0 (0)	1 (5)
If in hospital, recipient on TAH	No	9 (100)	13 (100)	22 (100)
If in hospital, recipient on ECMO	No	9 (100)	11 (85)	20 (91)
	Yes	0 (0)	1 (8)	1 (5)
	Missing	0 (0)	1 (8)	1 (5)
If in hospital, recipient on inotropes	No	6 (67)	6 (46)	12 (55)
	Yes	3 (33)	7 (54)	10 (46)
If in hospital, recipient on IABP	No	9 (100)	13 (100)	22 (100)

Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2017 to 31 March 2018, by centre

		Great Ormond Street Hospital	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Recipient CMV status	No	8 (50)	9 (47)	17 (49)
	Yes	5 (31)	6 (32)	11 (31)
	Missing	3 (19)	4 (21)	7 (20)
Recipient HCV status	No	14 (88)	15 (79)	29 (83)
	Missing	2 (13)	4 (21)	6 (17)
Recipient HBV status	No	14 (88)	14 (74)	28 (80)
	Missing	2 (13)	5 (26)	7 (20)
Recipient HIV status	No	14 (88)	15 (79)	29 (83)
	Missing	2 (13)	4 (21)	6 (17)
Recipient serum creatinine (umol/l)	Median (IQR)	48 (39, 67)	39 (30, 51)	43 (33, 53)
	Missing	1	1	2
Donor sex	Male	2 (13)	8 (42)	10 (29)
	Female	14 (88)	10 (53)	24 (69)
	Missing	0 (0)	1 (5)	1 (3)
Donor ethnicity	White	13 (81)	14 (74)	27 (77)
	Non-white	1 (6)	0 (0)	1 (3)
	Missing	2 (13)	5 (26)	7 (20)
Donor age (years)	Median (IQR)	22 (12, 40)	10 (4, 18)	13 (7, 34)
	Missing	0	1	1
Donor BMI (kg/m ²)	Median (IQR)	20 (19, 23)	17 (15, 21)	19 (16, 22)
	Missing	0	0	0
Donor cause of death	CVA	10 (63)	10 (53)	20 (57)
	Trauma	3 (19)	0 (0)	3 (9)
	Others	3 (19)	9 (47)	12 (34)
Donor hypotension	No	8 (50)	9 (47)	17 (49)
	Yes	5 (31)	6 (32)	11 (31)
	Missing	3 (19)	4 (21)	7 (20)
Donor past diabetes	No	16 (100)	19 (100)	35 (100)
Donor past cardiothoracic disease	No	13 (81)	15 (79)	28 (80)
	Yes	1 (6)	0 (0)	1 (3)
	Missing	2 (13)	4 (21)	6 (17)
Donor past hypertension	No	14 (88)	19 (100)	33 (94)
	Yes	2 (13)	0 (0)	2 (6)
Donor past tumour	No	15 (94)	19 (100)	34 (97)
	Yes	1 (6)	0 (0)	1 (3)
Donor past smoker	No	11 (69)	15 (79)	26 (74)
	Yes	5 (31)	4 (21)	9 (26)
Total ischaemia time (hours)	Median (IQR)	4.3 (3.2, 4.5)	3.3 (3.1, 4.2)	3.7 (3.1, 4.3)
	Missing	0	2	2

17.3 Total ischaemia time, 1 April 2008 – 31 March 2018

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 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 2008 to 31 March 2018

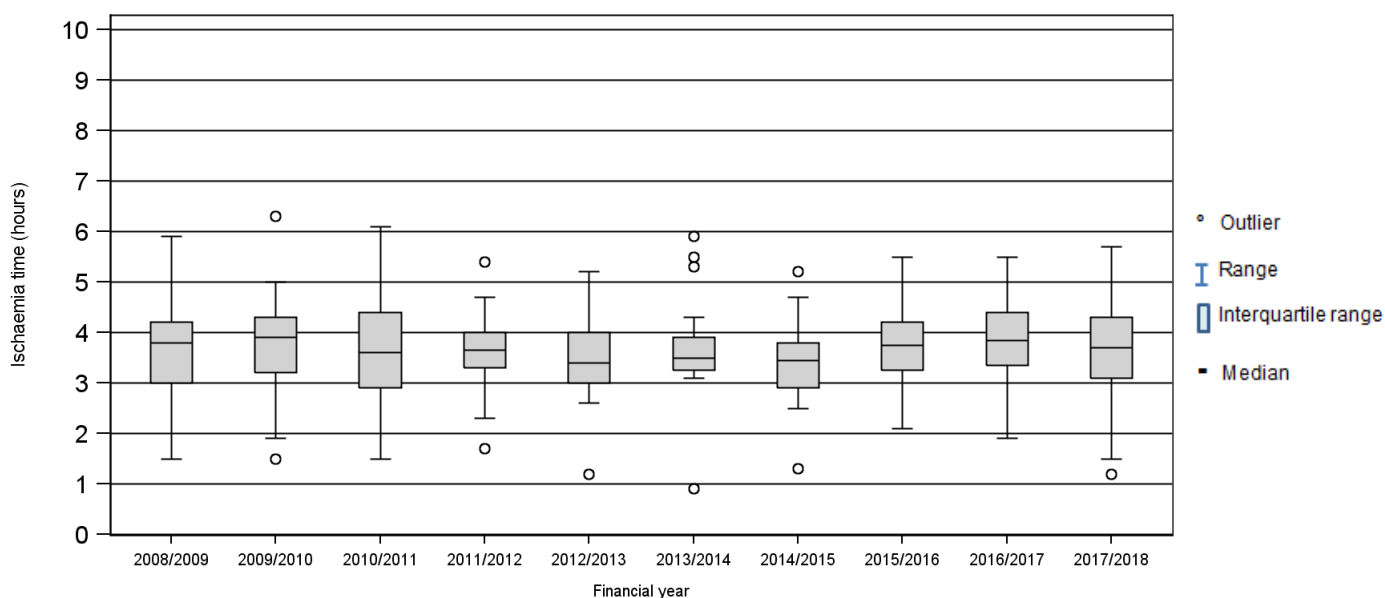


Figure 17.8 and **Figure 17.9** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2017/2018) and over the last 10 years, respectively. Generally, the median ischaemia times for Newcastle were slightly lower than the median ischaemia times for Great Ormond Street Hospital.

Figure 17.8 Boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients, by transplant centre, 1 April 2017 to 31 March 2018

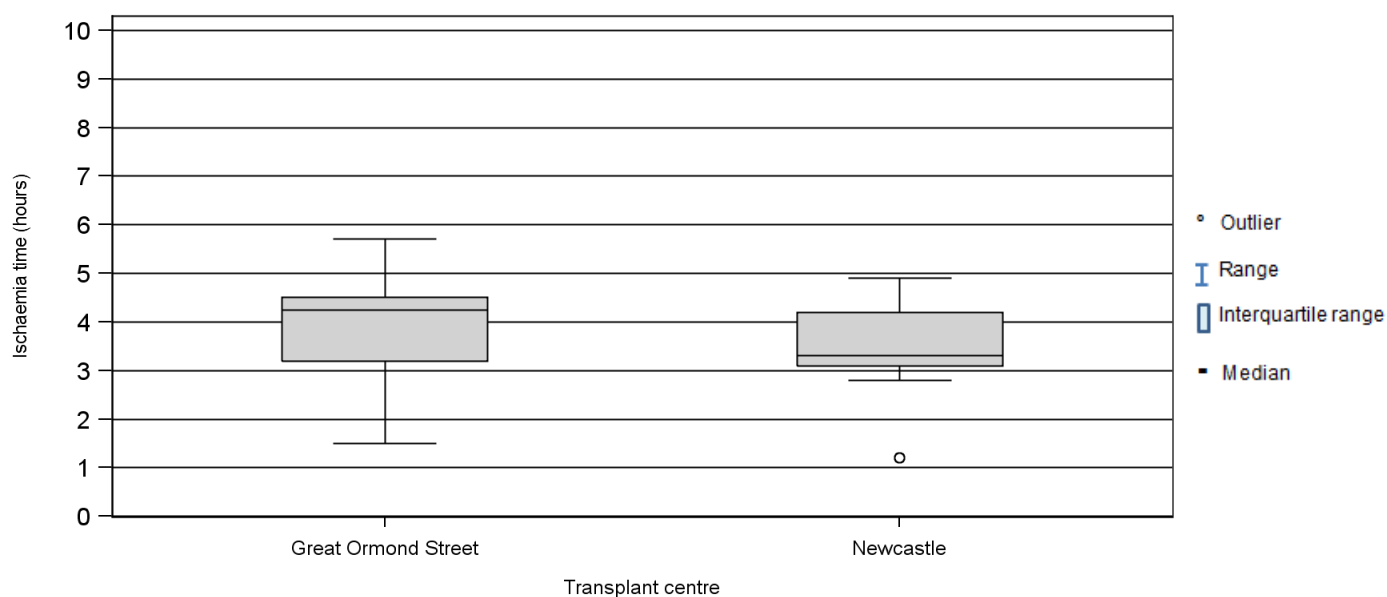
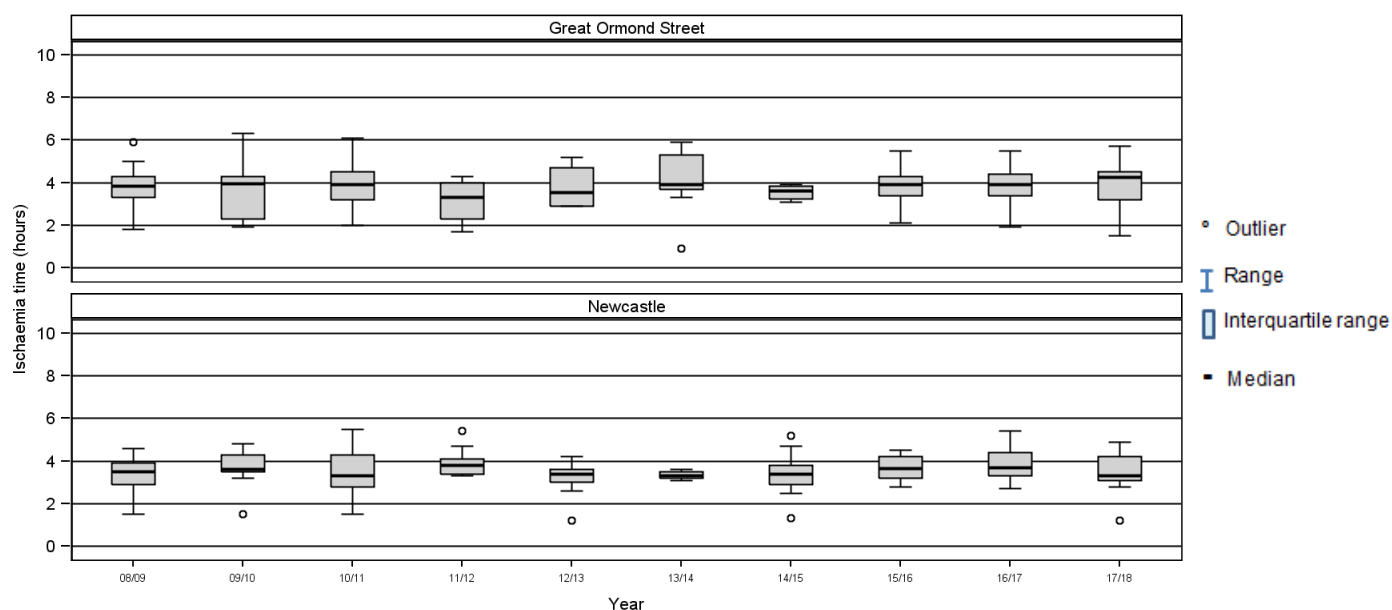


Figure 17.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2008 to 31 March 2018



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 and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2013 to 31 March 2017 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2009 to 31 March 2013.

The 30-day post-transplant [unadjusted](#) patient survival rate for each centre and nationally are shown in **Table 18.1** for the 128 first paediatric heart only transplants in the period 1 April 2013 to 31 March 2017. 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 2013 to 31 March 2017				
Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	63	2	96.8	(87.9 - 99.2)
Newcastle	65	5	92.3	(82.5 - 96.7)
UK	128	7	94.5	(88.9 - 97.4)

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

Table 18.2 1 year patient survival rates after first paediatric heart only transplant, by centre, 1 April 2013 to 31 March 2017				
Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	63	4	93.3	(82.9 - 97.4)
Newcastle	65	7	89.1	(78.5 - 94.7)
UK	128	11	91.1	(84.5 - 95.0)

Five year [survival rates](#) were estimated from the 130 first paediatric heart only transplants performed in the period 1 April 2009 to 31 March 2013. The [unadjusted](#) patient [survival rates](#) are shown in **Table 18.3**. There is no statistically significant difference between the two centres' rates.

**Table 18.3 5 year patient survival after first paediatric heart only transplant, by centre,
1 April 2009 to 31 March 2013**

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	67	12	81.3	(69.3 – 89.0)
Newcastle	63	10	83.8	(71.9 - 90.9)
UK	130	22	82.5	(74.7 - 88.2)

PAEDIATRIC HEART TRANSPLANTATION

Form Return Rates



19. Paediatric heart form return rates, 1 January – 31 December 2017

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 (more than 2 years). These include all paediatric heart transplants between 1 January and 31 December 2017 for the transplant record, and all follow up forms issued in this time period. A number of forms are outstanding for this period, in particular for Great Ormond Street Hospital.

Table 19.1 Form return rates for paediatric heart transplants, 1 January 2017 to 31 December 2017

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	12	100	11	55	15	13	133	19
Newcastle, Freeman Hospital	15	100	13	100	16	100	186	88
Overall	27	100	24	79	31	58	319	59

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List



20.1 Paediatric lung and heart/lung transplant list as at 31 March, 2008 – 2018

Figure 20.1 shows the number of paediatric patients on the lung transplant list at 31 March each year between 2009 and 2018 split by urgency status. The number of patients on the active lung transplant list was highest in 2013. It has since decreased to 3 as at 31 March 2018. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2018, there were no patients on the super-urgent list and one patient on the urgent list. There are usually 3 or fewer patients active for a heart-lung transplant.

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

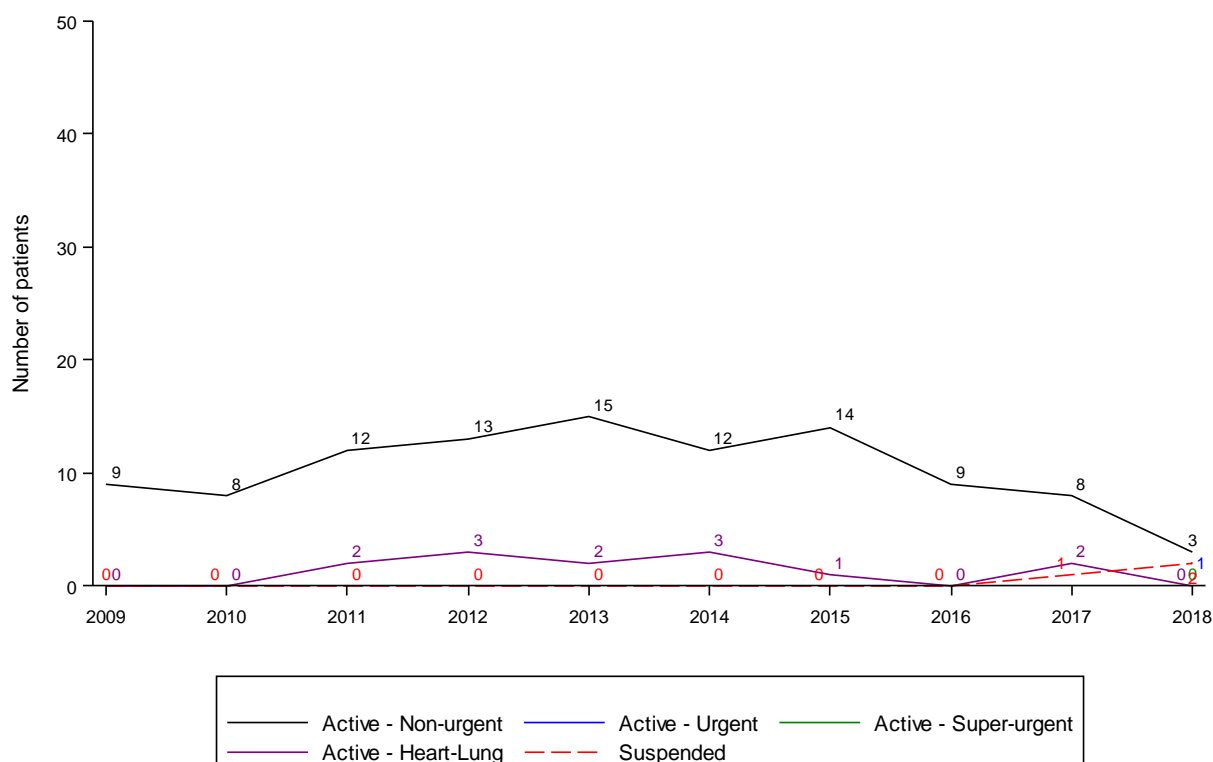


Figure 20.2 shows the number of paediatric patients on the [active lung transplant list](#) at 31 March 2018 by centre. In total, there were 4 paediatric patients waiting. Each centre had two patients on the list. One patient at Great Ormond Street Hospital was on the urgent list and no patients were on the super-urgent list at either centre.

Figure 20.2 Number of paediatric patients on the active lung transplant list at 31 March 2018, by centre

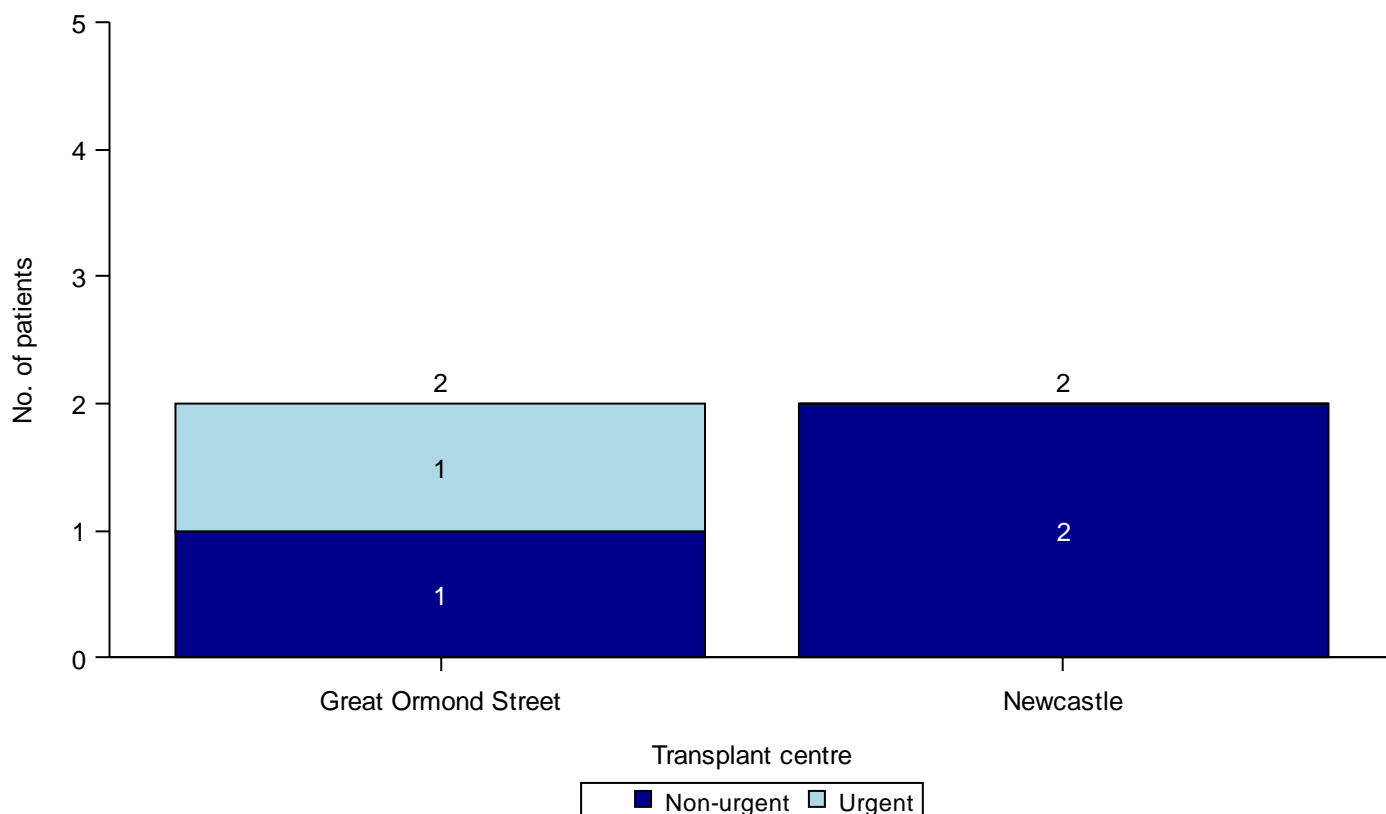
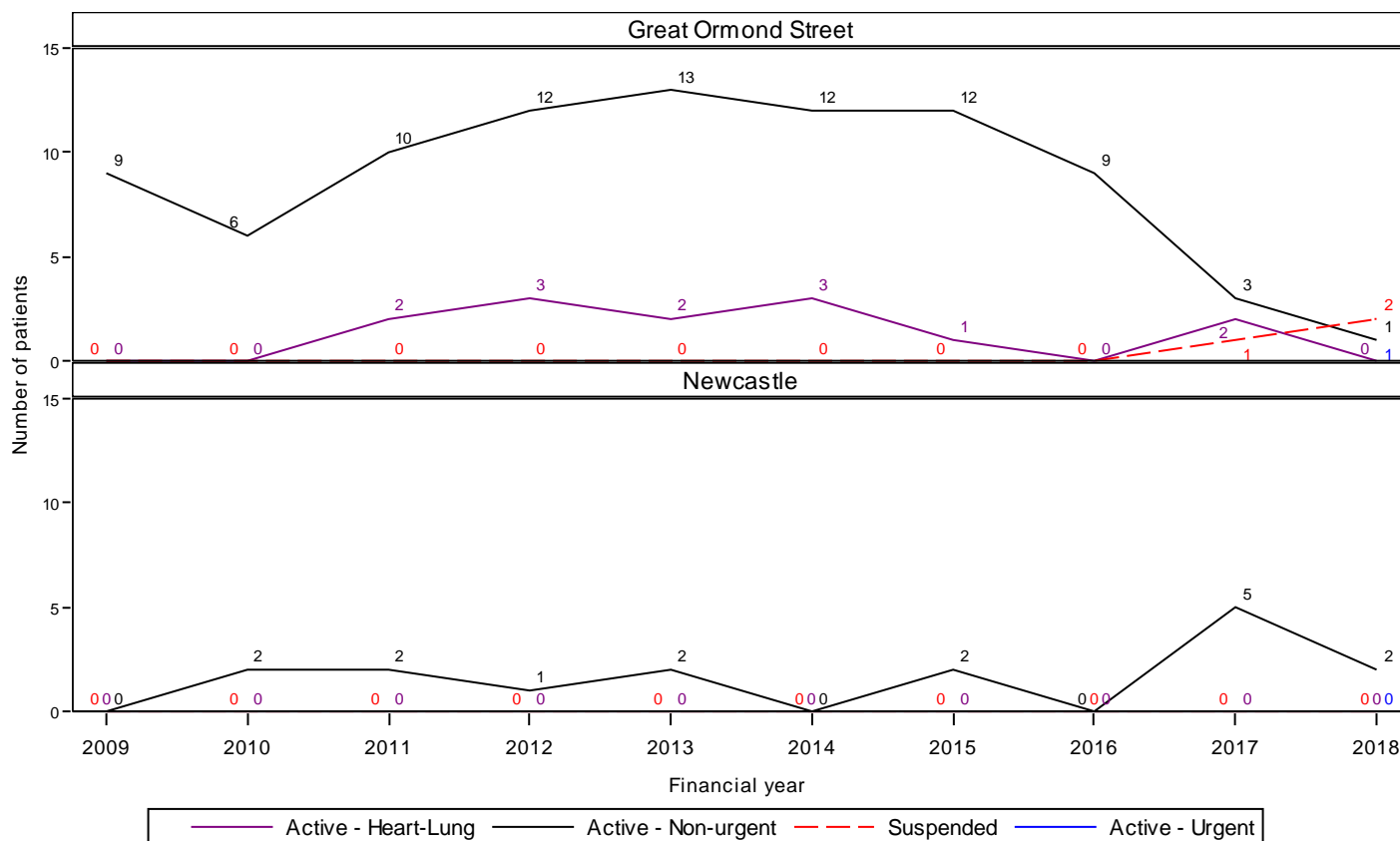


Figure 20.3 shows the trend over time in the number of paediatric patients on the lung transplant list at each centre at 31 March each year between 2009 and 2018. Great Ormond Street Hospital experienced an increase in their non-urgent list between 2010 and 2012 but after remaining high for several years it has now decreased to just one on 31 March 2018. Newcastle had a peak of five patients on their non-urgent list last year, but this has decreased to two.

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 2016 – 31 March 2018

There were 13 paediatric registrations onto the lung transplant list between 1 April 2016 and 31 March 2018 (two years analysed due to small numbers). Newcastle registered no patients in 2017/2018. Demographic characteristics of these patients are shown by centre and overall in **Table 20.1**. Nationally, 41% of the patients were male and the [median](#) age was 11 years. For some characteristics, due to rounding, percentages may not add up to 100.

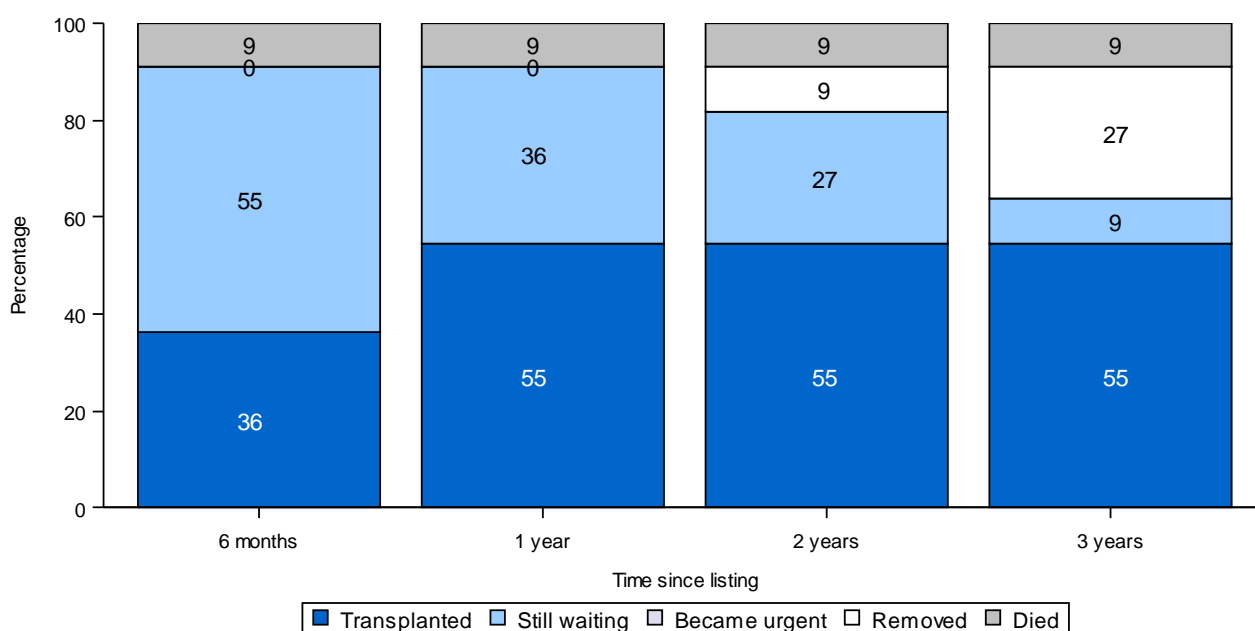
Table 20.1 Demographic characteristics of paediatric patients registered onto the lung transplant list between 1 April 2016 and 31 March 2018, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		11 (100)	6 (100)	17 (100)
Year of registration	2016/2017	7 (64)	6 (100)	13 (76)
	2017/2018	4 (36)	0 (0)	4 (24)
Highest urgency during registration	Non-urgent	9 (82)	5 (83)	14 (82)
	Urgent	2 (18)	1 (17)	3 (18)
Recipient sex	Male	4 (36)	3 (50)	7 (41)
	Female	7 (64)	3 (50)	10 (59)
Recipient ethnicity	White	11 (100)	6 (100)	17 (100)
Recipient age (years)	Median (IQR)	8 (5, 14)	13 (10, 14)	11 (7, 14)
	Missing	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	5 (45)	5 (83)	10 (59)
	Fibrosing lung disease	1 (9)	0 (0)	1 (6)
	Primary pulmonary hypertension	2 (18)	1 (17)	3 (18)
	Other heart/lung disease	3 (27)	0 (0)	3 (18)
Lung function - FEV1 (litres)	Median (IQR)	-	0.74 (0.63, 1.02)	0.83 (0.65, 0.86)
	Missing	10	2	12
Lung function – FVC (litres)	Median (IQR)	-	1.40 (1.13, 1.57)	1.52 (1.35, 1.69)
	Missing	9	2	11

20.3 Post-registration outcomes, 1 April 2014 – 31 March 2015

The transplant list outcomes of paediatric patients listed for a lung transplant between 1 April 2014 and 31 March 2015 are summarised in **Figure 20.4**. This shows the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two years and three years after joining the list. Within six months of listing, 36% of patients were transplanted and 9% had died, whilst after three years, the transplant rate had increased to 55%, with no change in the death rate. Please note this is only based on 11 patients.

Figure 20.4 Post-registration outcome for 11 new lung only registrations made in the UK, 1 April 2014 to 31 March 2015



20.4 Median waiting time to transplant, 1 April 2012 - 31 March 2015

The [median](#) waiting time to lung transplant from listing for paediatric patients registered between 1 April 2012 and 31 March 2015 is shown in **Table 20.2**. This is estimated using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. Any suspended time is discounted. The national median waiting time to paediatric lung transplant is 436 days.

Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the transplant list, by centre, 1 April 2012 to 31 March 2015

Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Great Ormond Street Hospital	18	296	188 - 404
Newcastle ¹	5	-	-
UK	23	436	96 - 776

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

PAEDIATRIC LUNG TRANSPLANTATION

Response to Offers



21. Response to Offers

Table 21.1 compares individual centre paediatric bilateral lung offer decline rates over the three years between 1 April 2015 and 31 March 2018. 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 offer are included and 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 number of offers received (for lungs eventually transplanted) per year has fallen considerably. Overall, Great Ormond Street Hospital (GOSH) had a slightly higher decline rate than Newcastle.

Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre and year, 1 April 2015 to 31 March 2018								
Centre	2015/16		2016/17		2017/18		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
GOSH	14	(85.7)	5	(60.0)	3	(100.0)	22	(81.8)
Newcastle	9	(66.7)	7	(71.4)	4	(75.0)	20	(70.0)
UK	23	(78.3)	12	(66.7)	7	(85.7)	42	(76.2)

PAEDIATRIC LUNG TRANSPLANTATION

Transplants



22.1 Paediatric lung and heart-lung transplants, 1 April 2008 – 31 March 2018

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 in the last year decreased to 6. 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 (2017/2018) is shown by centre in **Figure 22.3**. All but one transplant used DBD donor lungs.

Figure 22.1 Number of paediatric lung transplants in the UK, by financial year and donor type, 1 April 2008 to 31 March 2018

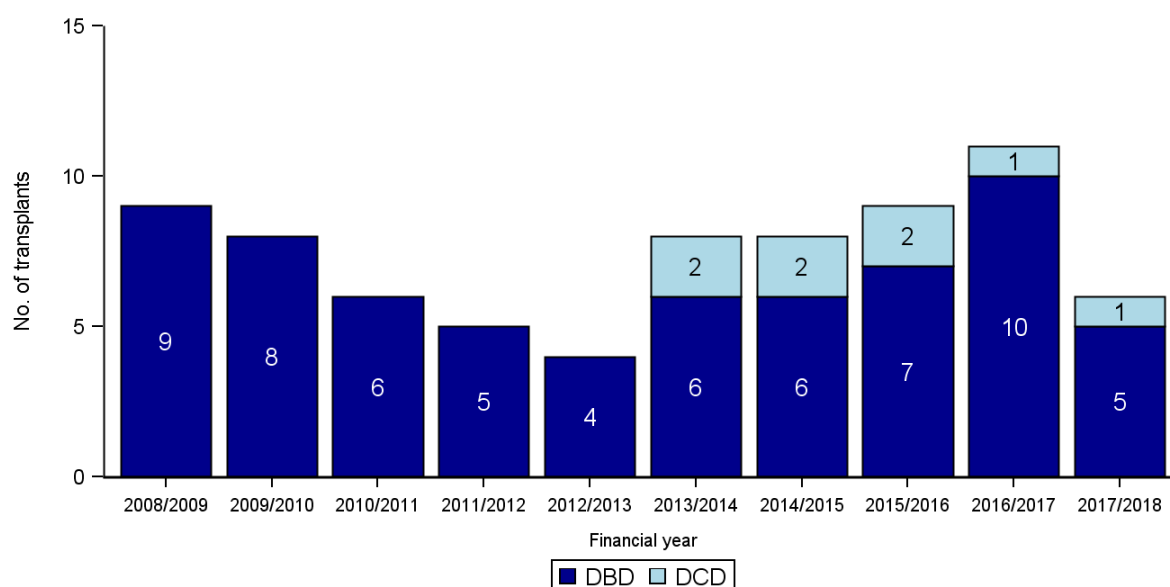


Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2008 to 31 March 2018

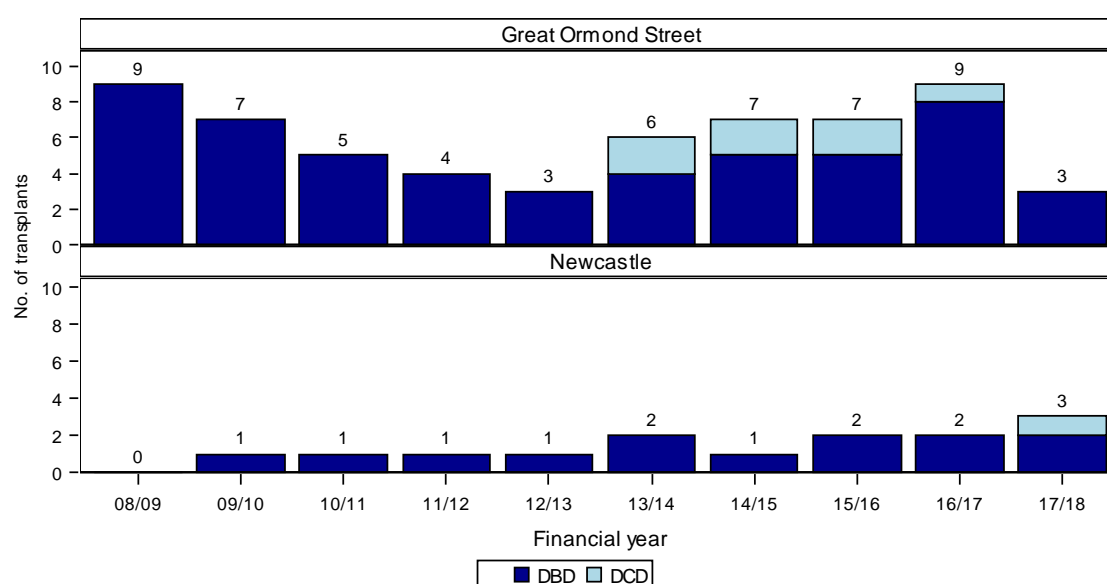


Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2017 to 31 March 2018

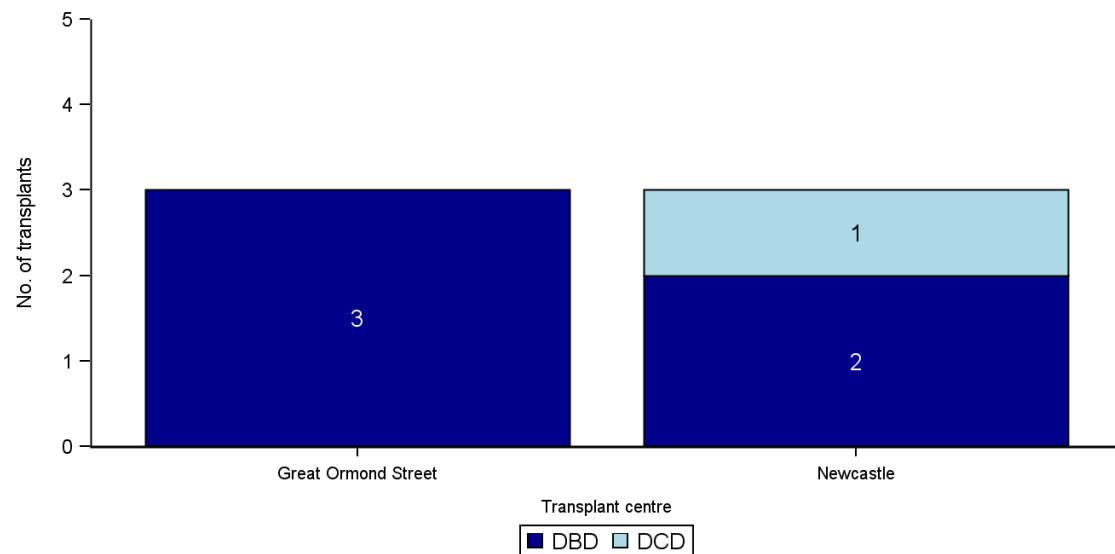


Figure 22.4 and 22.5 show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period, there have been two paediatric heart-lung block transplants; one performed by each centre. Newcastle performed one partial lung transplant in 2013/2014.

Figure 22.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2008 to 31 March 2018

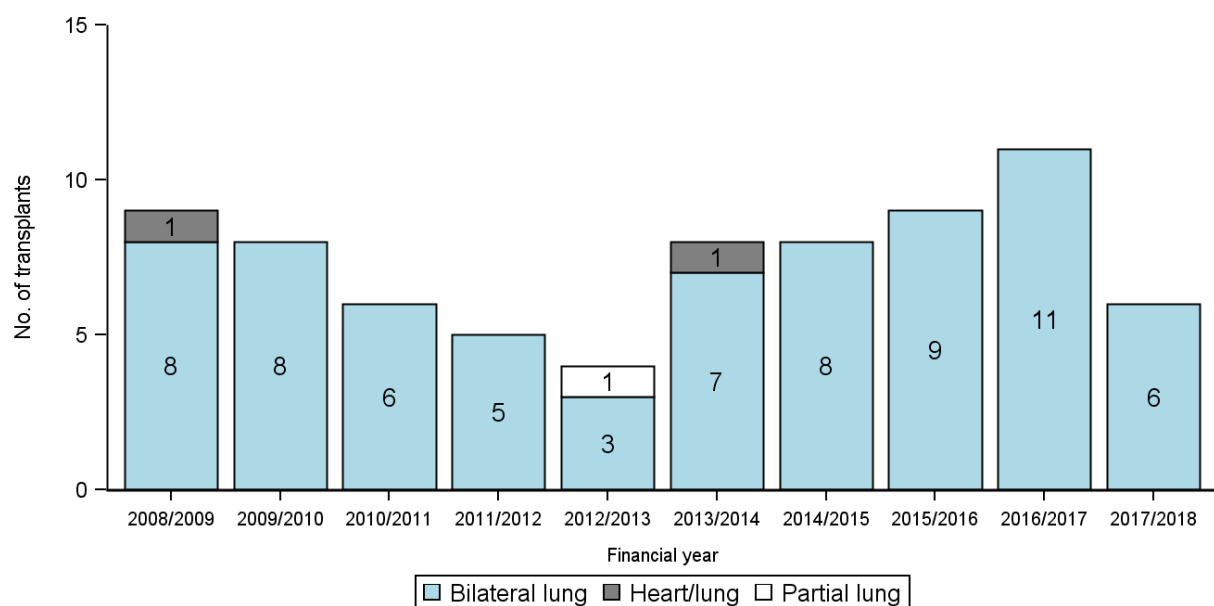
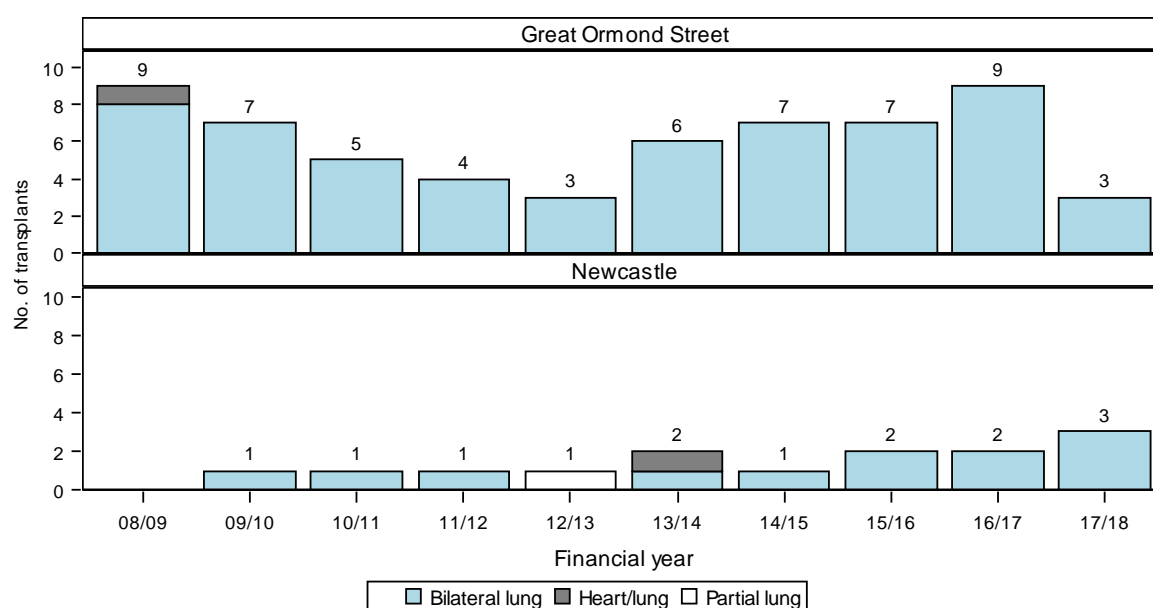
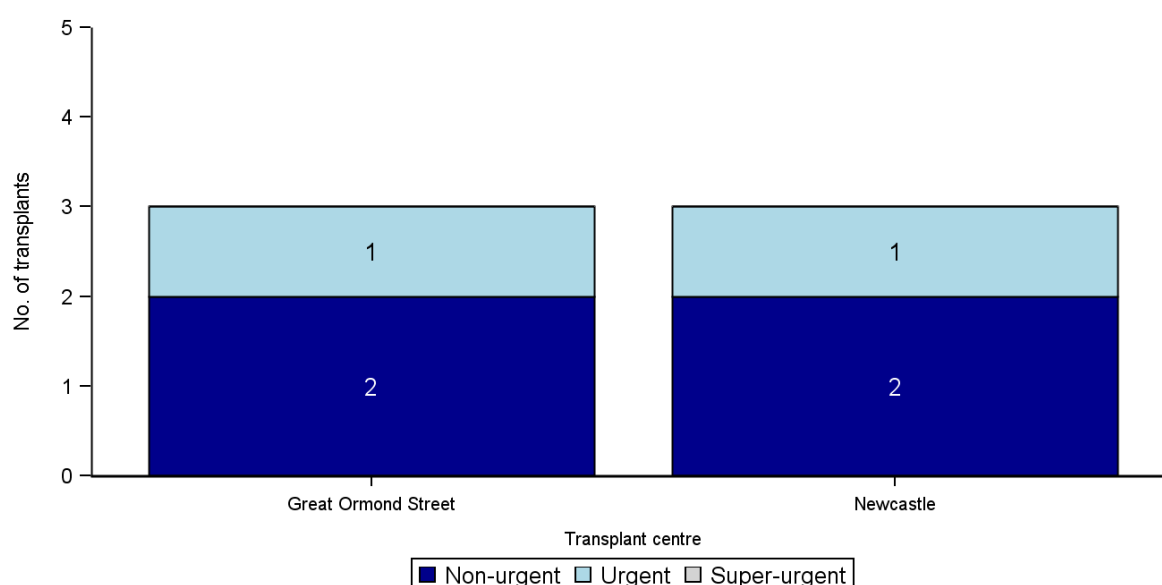


Figure 22.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2008 to 31 March 2018



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. Heart-lung patients have access to urgent transplants through the heart allocation scheme. The number of lung only transplants by urgency status in the latest financial year (2017/2018) is shown by centre in **Figure 22.6**. There were two urgent lung only transplants, one at each centre. Neither centre performed a super-urgent lung only transplant.

Figure 22.6 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2017 to 31 March 2018



22.2 Demographic characteristics of transplants, 1 April 2016 – 31 March 2018

The demographic characteristics of the 17 paediatric lung transplant recipients and donors in the last two years are shown by centre and overall in **Table 22.1**. Nationally, 47% of lung recipients were male and the [median](#) age was 12 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 2016 to 31 March 2018, by centre				
		Great Ormond Street Hospital	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		12 (100)	5 (100)	17 (100)
Year of transplant	2016/2017	9 (75)	2 (40)	11 (65)
	2017/2018	3 (25)	3 (60)	6 (35)
Urgency status at transplant	Non-urgent	11 (92)	4 (80)	15 (88)
	Urgent	1 (8)	1 (20)	2 (12)
Recipient sex	Male	5 (42)	3 (60)	8 (47)
	Female	7 (58)	2 (40)	9 (53)
Recipient ethnicity	White	12 (100)	5 (100)	17 (100)
Recipient age (years)	Median (IQR)	11 (5, 15)	15 (14, 15)	12 (7, 15)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	25 (13, 32)	41 (40, 43)	29 (21, 41)
	Missing	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	4 (33)	4 (80)	8 (47)
	Primary pulmonary hypertension	4 (33)	1 (20)	5 (29)
	Other heart/lung disease	4 (33)	0 (0)	4 (24)
NYHA class	III	0 (0)	1 (20)	1 (6)
	IV	10 (83)	0 (0)	10 (59)
	Missing	2 (17)	4 (80)	6 (35)
Recipient in hospital pre-transplant	No	7 (58)	2 (40)	9 (53)
	Yes	4 (33)	2 (40)	6 (35)
	Missing	1 (8)	1 (20)	2 (12)
If in hospital, recipient on ventilator	No	4 (100)	2 (100)	6 (100)
If in hospital, recipient on inotropes	No	4 (100)	1 (50)	5 (83)
	Yes	0 (0)	1 (50)	1 (17)
Recipient CMV status	No	3 (25)	4 (80)	7 (41)
	Yes	6 (50)	1 (20)	7 (41)
	Missing	3 (25)	0 (0)	3 (18)
Recipient HCV status	No	9 (75)	5 (100)	14 (82)
	Missing	3 (25)	0 (0)	3 (18)
Recipient HBV status	No	9 (75)	5 (100)	14 (82)
	Missing	3 (25)	0 (0)	3 (18)

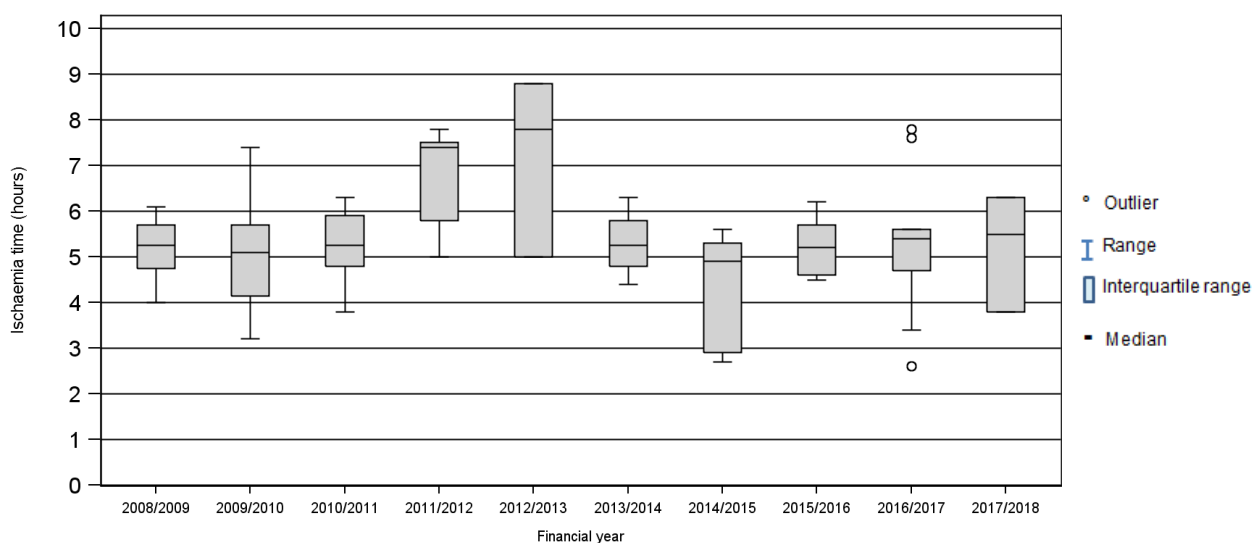
Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2016 to 31 March 2018, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	TOTAL N (%)
Recipient HIV status	No	9 (75)	5 (100)	14 (82)
	Missing	3 (25)	0 (0)	3 (18)
Recipient serum creatinine (umol/l)	Median (IQR)	31 (27, 36)	53 (50, 55)	35 (28, 50)
	Missing	2	1	3
Donor sex	Male	5 (42)	1 (20)	6 (35)
	Female	7 (58)	4 (80)	11 (65)
Donor ethnicity	White	7 (58)	4 (80)	11 (65)
	Non-white	1 (8)	1 (20)	2 (12)
	Missing	4 (33)	0 (0)	4 (24)
Donor age (years)	Median (IQR)	14 (4, 34)	13 (10, 14)	13 (6, 23)
	Missing	0	0	0
Donor BMI (kg/m ²)	Median (IQR)	22 (15, 25)	21 (20, 22)	21 (18, 24)
	Missing	0	0	0
Donor cause of death	CVA	5 (42)	4 (80)	9 (53)
	Trauma	1 (8)	0 (0)	1 (6)
	Others	6 (50)	1 (20)	7 (41)
Donor hypotension	No	1 (33)	2 (67)	3 (50)
	Yes	2 (67)	0 (0)	2 (33)
	Missing	0 (0)	1 (33)	1 (17)
Donor past cardiothoracic disease	No	8 (67)	5 (100)	13 (77)
	Missing	4 (33)	0 (0)	4 (24)
Donor past hypertension	No	9 (75)	5 (100)	14 (82)
	Missing	3 (25)	0 (0)	3 (18)
Donor past tumour	No	8 (67)	5 (100)	13 (77)
	Yes	1 (8)	0 (0)	1 (6)
	Missing	3 (25)	0 (0)	3 (18)
Donor past smoker	No	4 (33)	5 (100)	9 (53)
	Yes	5 (42)	0 (0)	5 (29)
	Missing	3 (25)	0 (0)	3 (18)
Total ischaemia time (hours)	Median (IQR)	5.2 (3.8, 6.3)	5.5 (5.5, 5.8)	5.5 (4.7, 6.0)
	Missing	2	1	3

22.3 Total ischaemia time, 1 April 2008 – 31 March 2018

Figure 22.7 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 has varied quite substantially over the decade, however these are based on a very small number of transplants per year (≤ 11). No further breakdown by centre is shown due to small numbers.

Figure 22.7 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2008 to 31 March 2018



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. Ninety-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2013 to 31 March 2017 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2009 to 31 March 2013.

The 90-day post-transplant [unadjusted](#) patient [survival rates](#) are shown in **Table 23.1** for the 35 first paediatric lung only transplants in the period 1 April 2013 to 31 March 2017. Only 6 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 94.1%.

Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre, 1 April 2013 to 31 March 2017

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	29	2	93.1	(75.1 - 98.2)
Newcastle ¹	6	0	-	-
UK	35	2	94.1	(78.5 - 98.5)

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

There were no additional deaths between 90 days and 1 year for the 35 paediatric lung only transplants performed in the period 1 April 2013 to 31 March 2017, therefore the 1-year [survival rates](#) in **Table 23.2** are identical to those in **Table 23.1**.

Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2013 to 31 March 2017

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	29	2	93.1	(75.1 - 98.2)
Newcastle ¹	6	0	-	-
UK	35	2	94.1	(78.5 - 98.5)

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 21 first lung only transplants performed in the period 1 April 2009 to 31 March 2013. 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 2009 to 31 March 2013

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	18	5	72.2	(45.6 - 87.4)
Newcastle ¹	3	0	-	-
UK	21	5	76.2	(51.9 - 89.3)

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 2017

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 (more than 2 years). These include all paediatric lung and heart-lung transplants between 1 January and 31 December 2017 for the transplant record, and all follow up forms issued in this time period. A number of forms are outstanding for this period for both centres.

Table 24.1 Form return rates for paediatric lung transplants, 1 January 2017 to 31 December 2017

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	4	100	5	80	6	0	19	37
Newcastle, Freeman Hospital	3	67	3	100	2	100	15	93
Overall	7	86	8	88	8	25	34	62

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 2008 – 31 March 2018	• Introduction	None	1301	1751
1 April 2008 – 31 March 2018	• Transplants	• Multi-organ transplants	1292	1748
1 April 2013 – 31 March 2017	Post-transplant survival – • 30/90-day • 1-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	595	706
1 April 2009 – 31 March 2013	Post-transplant survival – • 5-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	394	642

Table A1.2 Paediatric transplants analysed				
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2008 – 31 March 2018	• Introduction	None	337	74
1 April 2008 – 31 March 2018	• Transplants	• Multi-organ transplants	337	74
1 April 2013 – 31 March 2017	Post-transplant survival – • 30/90-day • 1-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	128	35
1 April 2009 – 31 March 2013	Post-transplant survival – • 5-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	130	21

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 2017 and 31 March 2018 were extracted from the UK Transplant Registry on 6 June 2018 (numerator). Patients registered for a heart-lung block were included in the lung numbers. Patients were assigned to Strategic Health Authorities (SHA) in England using their postcode of residence, as reported at registration. The number of registrations per million population (pmp) by SHA was obtained using mid-2016 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No SHA 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 or lung transplants on NHS group 1 recipients between 1 April 2017 and 31 March 2018 (numerator), divided by the mid-2016 population estimates from the ONS (denominator). Patients who received a heart-lung block transplant were included in the lung numbers. 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 2017 and 31 March 2018 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 or lung 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 0% for several variables to 8.3% for respiratory arrest, and for lung transplants ranged from 0% for several variables to 9.1% for recipient cholesterol at registration. 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 English Strategic Health Authority (SHA), 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 2006 and 31 December 2017. 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 1 May 2018 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, five and ten 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, five and ten 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)

A donor whose heart is still beating when their entire brain has stopped working so that they cannot survive without the use of a ventilator. Organs for transplant are removed from the donor while their heart is still beating, but only after extensive tests determine that the brain cannot recover and they have been certified dead.

Donor after circulatory death (DCD)

A donor whose heart stops beating before their brain stops working and who is then certified dead. The organs are then removed.

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

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