NHS
Blood and Transplant

ANNUAL REPORT ON CARDIOTHORACIC ORGAN TRANSPLANTATION

REPORT FOR 2018/2019
(1 APRIL 2009 – 31 MARCH 2019)

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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 2009 to 31 March 2019. 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, 2018/2019, 183 heart transplants were performed across the UK. This is an 8% decrease from the number performed in the previous year, 2017/2018. The number of lung transplants performed was 166, which was a 22% decrease from 2017/2018 and the second lowest number over the past 10 years. These numbers, which are for adult and paediatric patients combined, represent 2.8 heart transplants per million population and 2.5 lung transplants per million population in the UK.

- On 31 March 2019, the national heart transplant list was particularly high, with 293 patients waiting for a heart transplant; 3% higher than on 31 March 2018 and 133% higher than a decade earlier. Of these, 23 adult patients and 11 paediatric patients were on the urgent heart only list and 2 adults were on the super-urgent list.

- On 18 May 2017, urgent and super-urgent lung allocation schemes were introduced in the UK. On 31 March 2019, there were 350 patients waiting for a lung or heart-lung transplant; 2% lower than on 31 March 2018 and 32% higher than a decade earlier. Of these, there were 12 adults on the heart-lung list, one paediatric patient on the urgent lung list and no patients on the super-urgent lung list at 31 March 2019.

- The national 30 day rate of **survival following adult heart transplantation** was 90.3%, which ranged from 78.6% to 94.2% across centres (risk-adjusted).The national 90 day survival rate was 86.6%, ranging from 78.4% to 91.3% across centres (risk-adjusted). The national 1 year survival rate was 82.4%, ranging from 74.4% to 88.4% across centres (risk-adjusted). The national 5 year survival rate was 69.7%, ranging from 60.5% to 79.3% across centres (risk-adjusted). At all time points analysed, there was some evidence of a significantly higher rate at Papworth in comparison to the national rate.

- The national 90 day rate of **survival following adult lung transplantation** was 88.8%, which ranged from 83.3% to 95.4% across centres (risk-adjusted), with evidence that the survival rate at Manchester was higher than the national average at this time period. The national 1 year survival rate was 80.8%, ranging from 71.6% to 87.4% across centres (risk-adjusted), with some evidence of a significantly higher rate at Manchester. The national 5 year survival rate was 56.2%, ranging from 45.7% to 60.7% across centres (risk-adjusted), with no significant outliers.

- The national rate of **survival following paediatric heart transplantation** was 95.5% at 30 days, 94.8% at 90 days, 91.8% at 1 year and 83.0% at 5 years. The unadjusted rates were similar between the two paediatric centres.

- The national rate of **survival following paediatric lung transplantation** was 91.2% at 90 days, 84.9% at 1 year, and 73.9% 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 2018/2019, 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 2009 and 31 March 2019, for all centres performing heart and/or lung transplantation in the UK. Data were obtained from the UK Transplant Registry at NHS Blood and Transplant which holds information relating to donors, recipients and outcomes for all cardiothoracic organ transplants performed in the UK.

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

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

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

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

2.1 Overview

Figure 2.1 shows the number of patients on the active transplant lists at financial year end between 2010 and 2019. 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 350 in 2019, a decrease of 2% on the previous year. The number of patients waiting for a heart transplant increased substantially over the decade, from 126 in 2010 to a peak of 293 in 2019, representing a 133% 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, 2010 to 2019

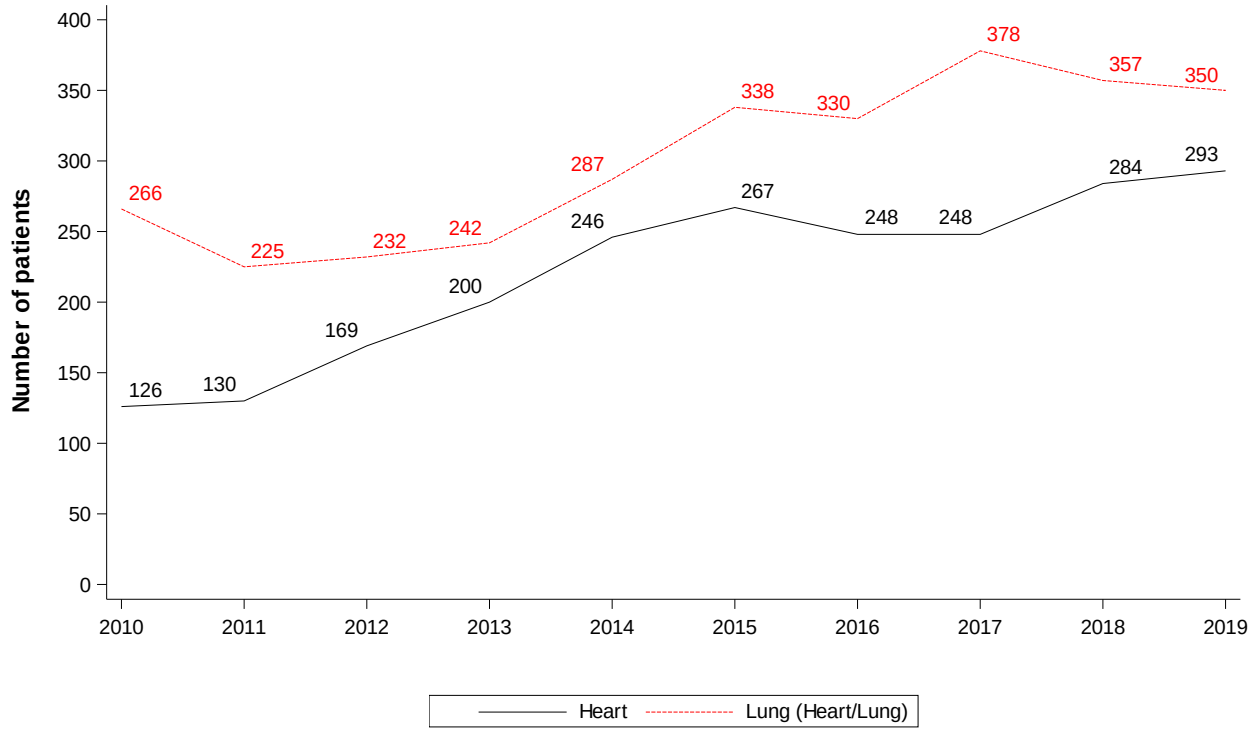


Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the active transplant lists at 31 March 2019 at each centre. In total, there were 602 adult and 41 paediatric patients waiting for a heart or lung transplant. Harefield had the highest number of adult patients on the lung transplant list whilst Newcastle has the highest number on the heart transplant list. Note that Glasgow does not perform lung transplantation. Great Ormond Street Hospital had the highest number of paediatric patients on both the heart and lung transplant lists. These numbers include 6 patients waiting for a multi-organ transplant (3 heart and kidney, 2 heart and liver and 1 lung and liver). Compared with the previous year (see Sections 3.1 and 15.1), Great Ormond Street Hospital, Newcastle and Papworth have had an increase in their heart waiting list, whilst all other centres have seen a decrease. With respect to the lung waiting list, Only Harefield and Papworth have had a decrease, whilst Newcastle's Paediatric list has remained the same and remaining centres have seen a rise (see Sections 9.1 and 20.1).

Figure 2.2 Number of adult patients on the active heart and lung transplant lists at 31 March 2019, by centre

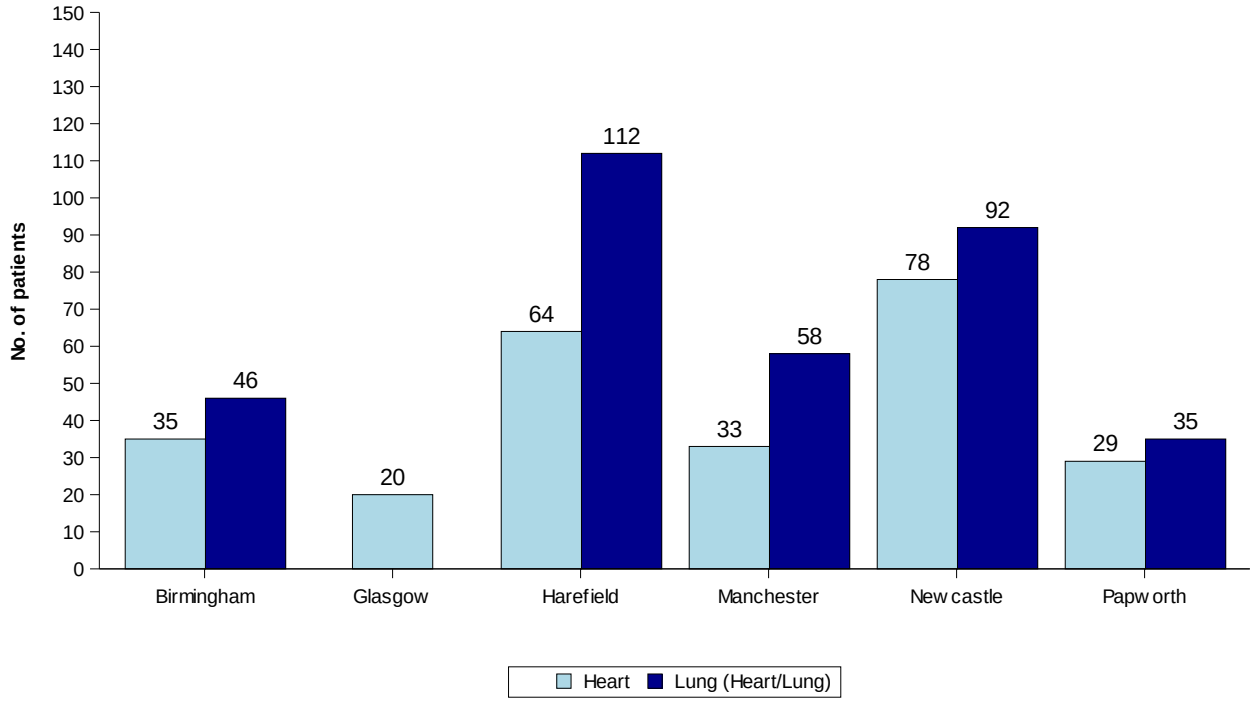


Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists at 31 March 2019, by centre

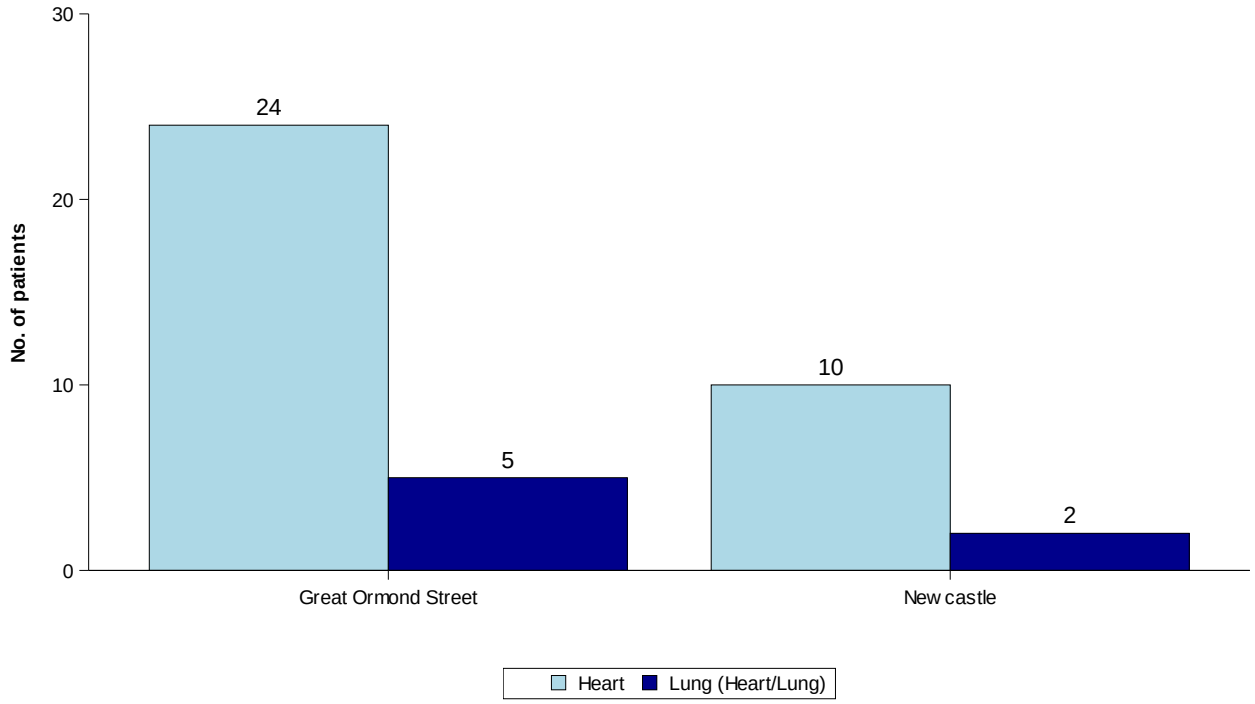


Figure 2.4 shows the total number of transplants performed in each of the last ten years. The number of heart transplants last year was 183, 8% lower than in 2017/2018. The number of lung transplants last year also fell from 2017/2018 by 22%, to 166, the lowest number since 2009/2010.

Figure 2.4 Number of cardiothoracic organ transplants in the UK, by financial year, 1 April 2009 to 31 March 2019

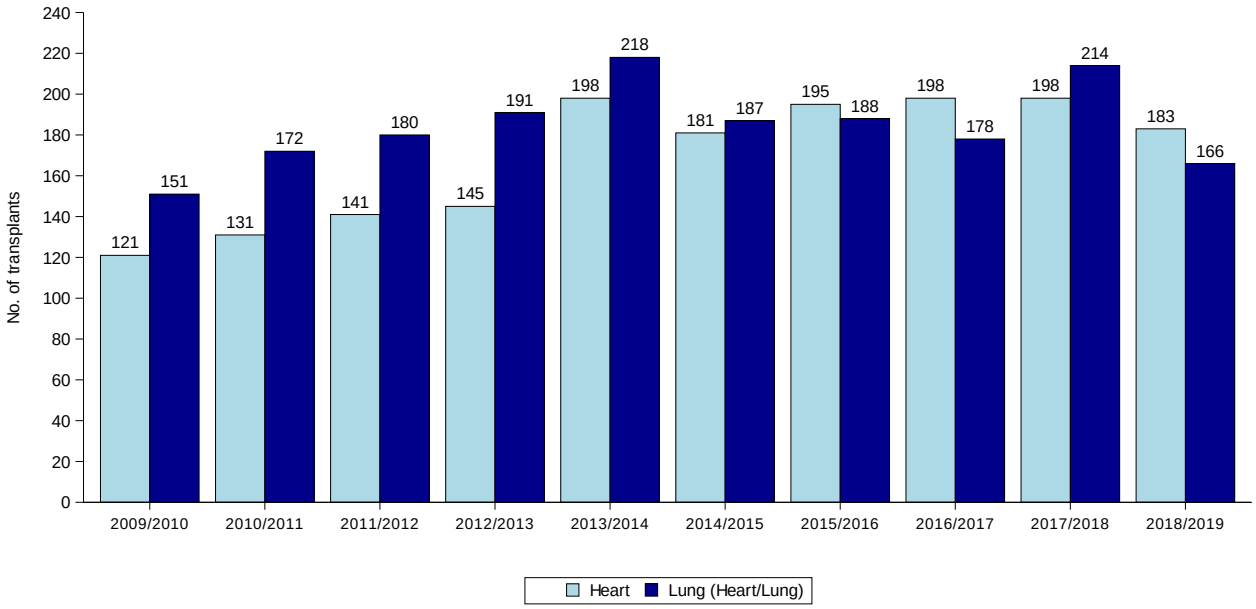


Figure 2.5 and **Figure 2.6** show the number of adult and paediatric transplants carried out in the most recent financial year at each centre. Harefield performed the highest number of lung transplants and Papworth the highest number of heart transplants. Great Ormond Street Hospital performed the highest number of paediatric heart transplants as well as the highest number of lung transplants. Compared with the previous year (see sections 5.1 and 17.1), Harefield and Birmingham performed a higher number of heart transplants. All other centres performed fewer heart transplants except Manchester whose figures remained the same. For lung transplantation, all centres performed a lower number compared with 2018/2019, except Great Ormond Street Hospital (see sections 11.1 and 22.1).

Figure 2.5 Number of adult cardiothoracic organ transplants in the UK, by centre, 1 April 2018 to 31 March 2019

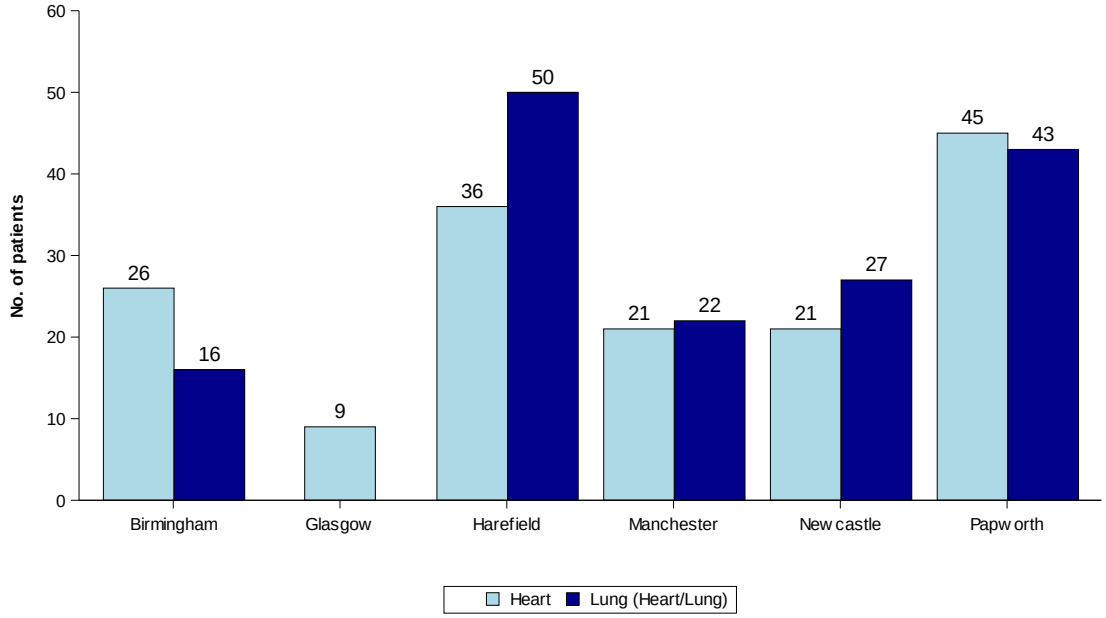


Figure 2.6 Number of paediatric cardiothoracic organ transplants in the UK, by centre, 1 April 2018 to 31 March 2019

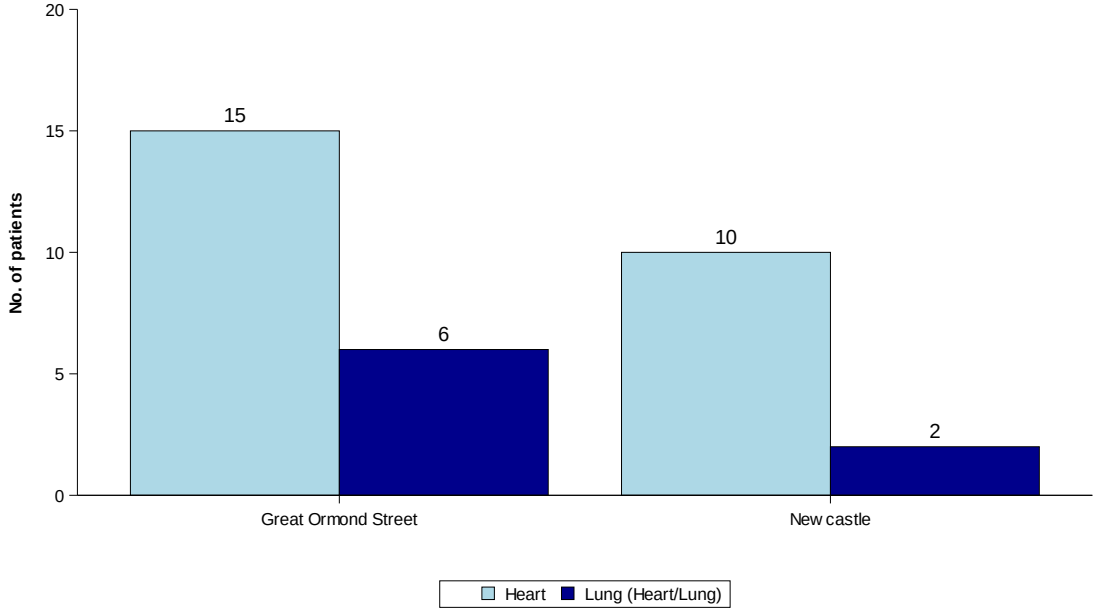
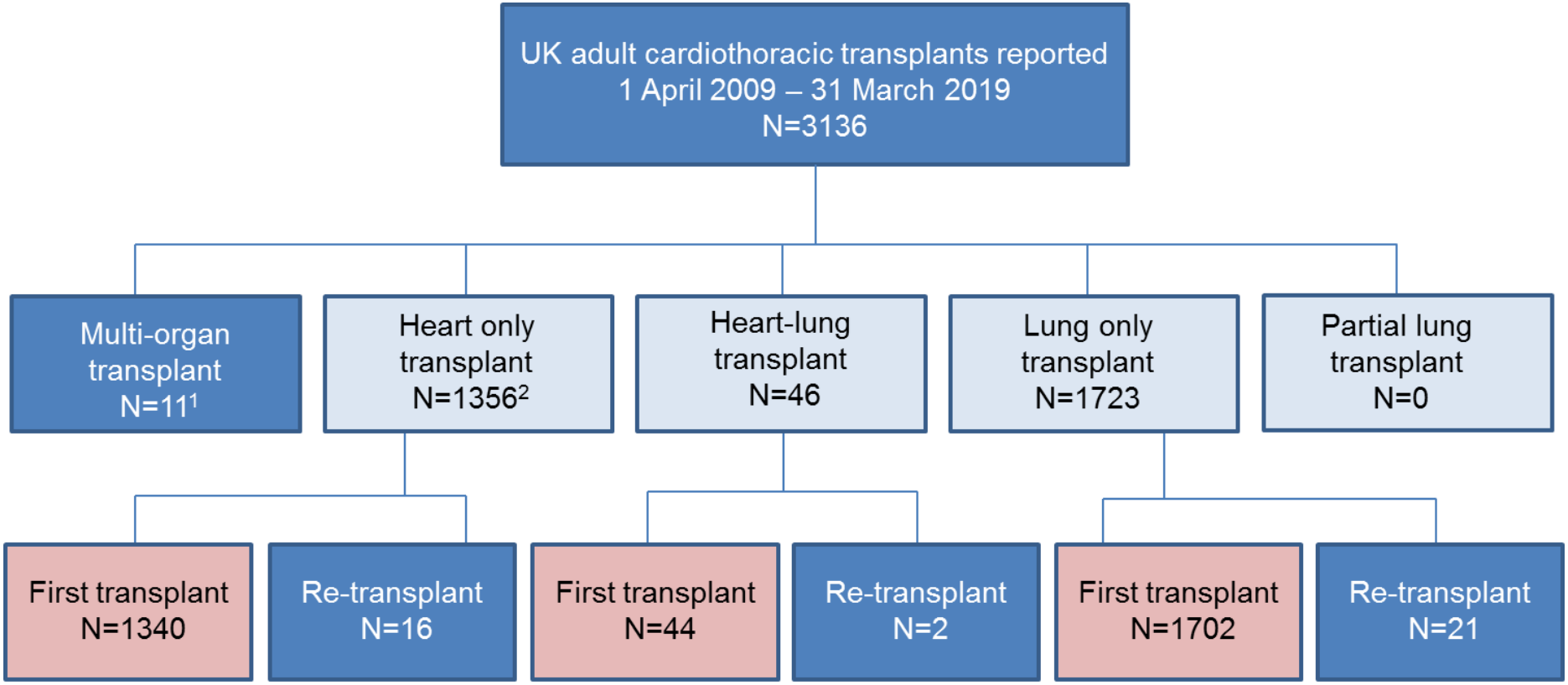


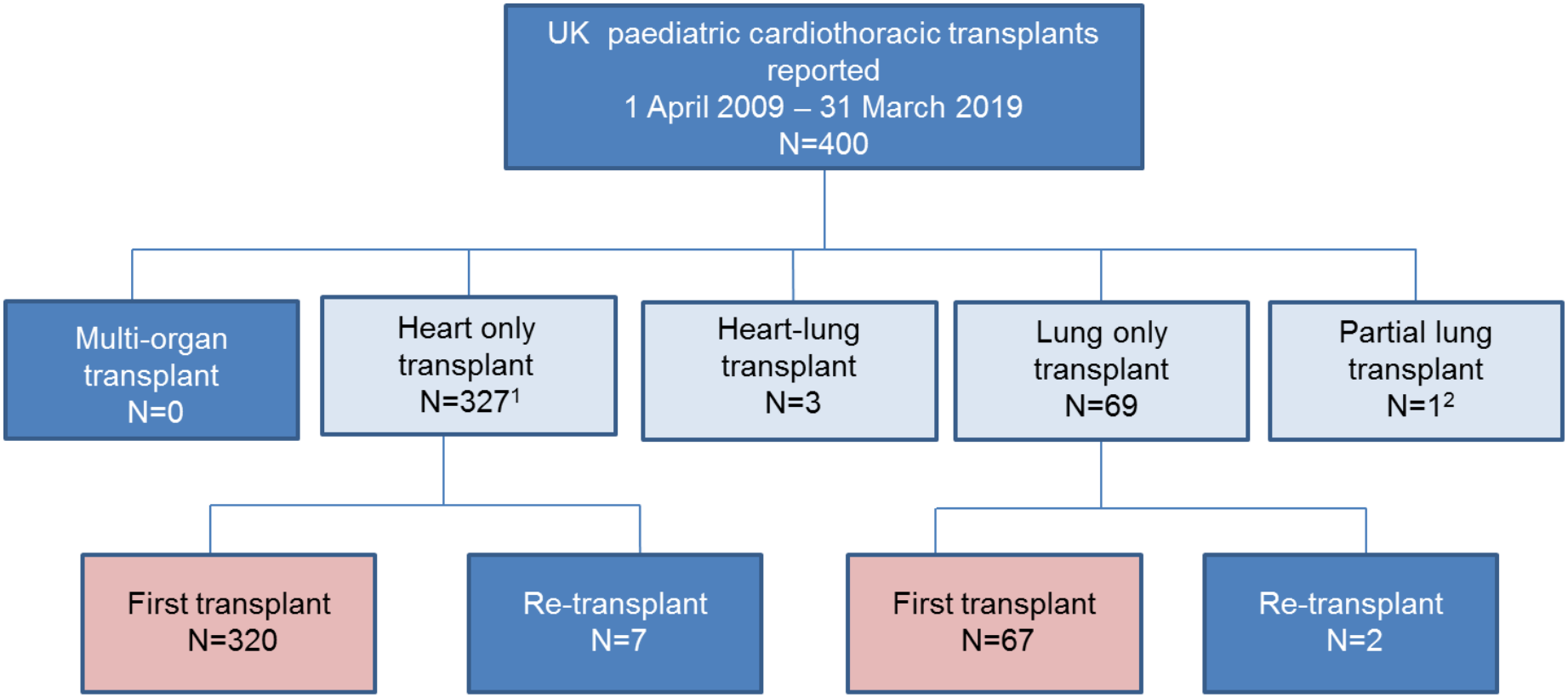
Figure 2.7 shows a breakdown of the 3,136 adult cardiothoracic organ transplants performed in the UK in the ten year period while **Figure 2.8** shows a similar breakdown for the 400 paediatric transplants performed during the same period. In the remainder of this report, multi-organ transplants are excluded, hence 3,125 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 2009 to 31 March 2019



[1] Includes 6 heart and kidney, 2 heart and liver, 2 lung and liver and 1 lung and kidney transplant
[2] Includes 88 DCD heart transplants and 3 domino donor transplants

Figure 2.8 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2009 to 31 March 2019



[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 2018 and 31 March 2019 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 4.6 pmp and 2.8 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 0.0002 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 4.2 pmp and 2.5 pmp respectively. For lungs, both registration and transplant rates yielded a SCV of 0 and 0.0141, respectively, and therefore no evidence of geographical variation beyond what would be expected at random.

Figure 2.9 Comparison of heart registration rates (pmp) with transplant rates (pmp) by recipient country/Strategic Health Authority of residence

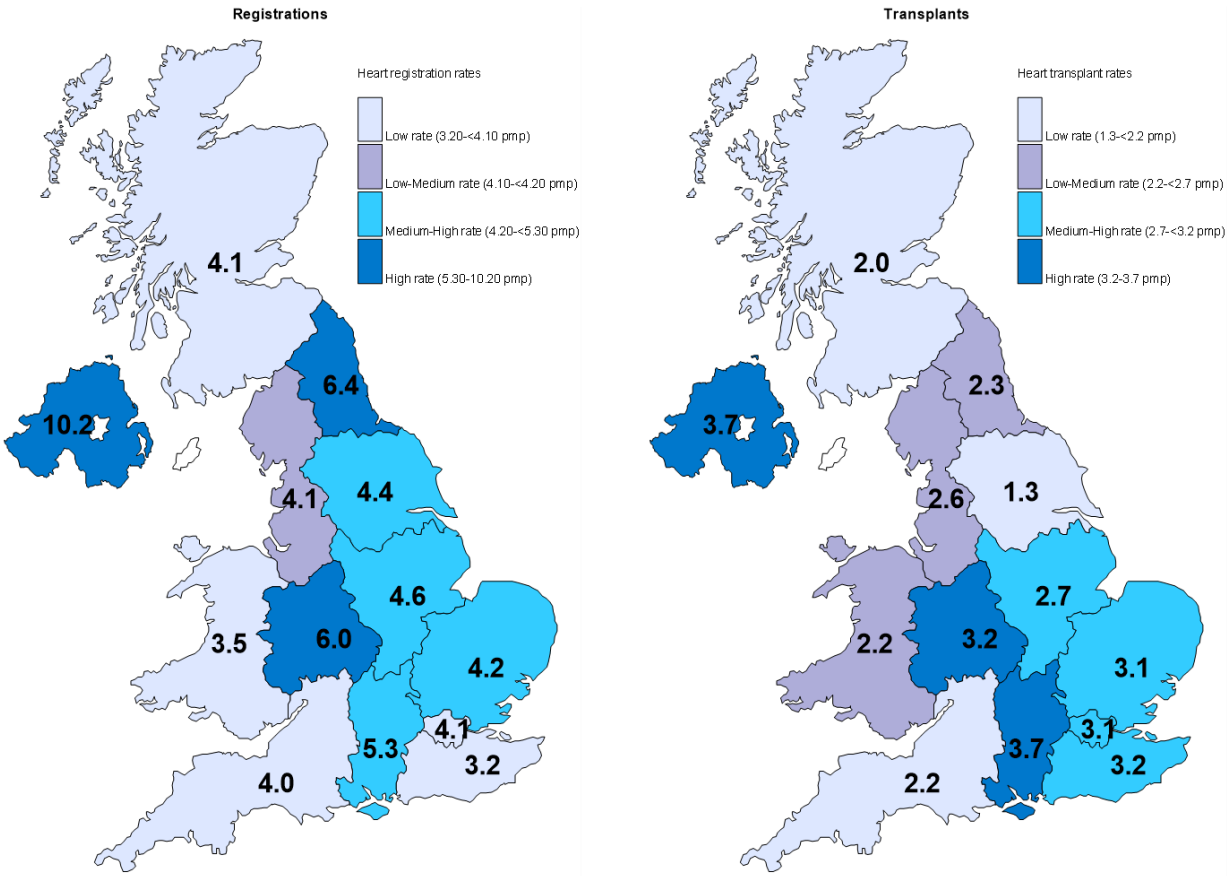


Table 2.1 Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2018 – 31 March 2019, by Country/Strategic Health Authority

Country/ Strategic Health Authority	Registrations (pmp)		Transplants (pmp)	
North East	17	(6.4)	6	(2.3)
North West	30	(4.1)	19	(2.6)
Yorkshire and The Humber	24	(4.4)	7	(1.3)
North of England	**71**	**(4.6)**	**32**	**(2.1)**
East Midlands	22	(4.6)	13	(2.7)
West Midlands	35	(6)	19	(3.2)
East of England	26	(4.2)	19	(3.1)
Midlands and East	**83**	**(4.9)**	**51**	**(3)**
London	**36**	**(4.1)**	**27**	**(3.1)**
South East Coast	15	(3.2)	15	(3.2)
South Central	23	(5.3)	16	(3.7)
South West	22	(4)	12	(2.2)
South of England	**60**	**(4.1)**	**43**	**(2.9)**
England	**250**	**(4.5)**	**153**	**(2.8)**
Isle of Man	**0**	**(0.0)**	**0**	**(0.0)**
Channel Islands	**0**	**(0.0)**	**0**	**(0.0)**
Wales	**11**	**(3.5)**	**7**	**(2.2)**
Scotland	**22**	**(4.1)**	**11**	**(2)**
Northern Ireland	**19**	**(10.2)**	**7**	**(3.7)**
TOTAL	**307[1]**	**(4.6)**	**182[2]**	**(2.8)**

[1] Registrations include 5 recipients whose postcode was unknown and excludes 2 recipients who reside in the Republic of Ireland
[2] Transplants include 4 recipients whose postcode was unknown

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

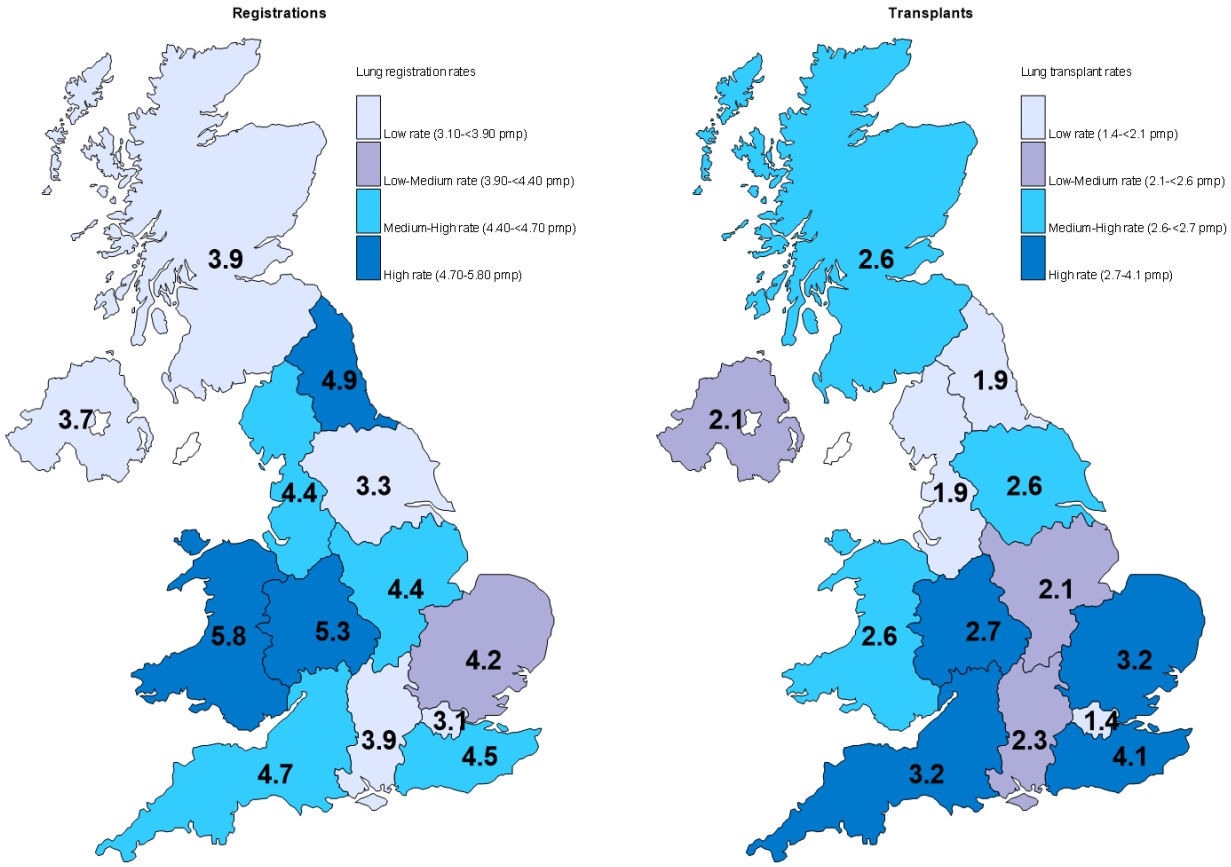


Table 2.2 Lung registration and transplant rates per million population (pmp) in the UK, 1 April 2018 – 31 March 2019, by Country/Strategic Health Authority

Country/ Strategic Health Authority	Registrations (pmp)		Transplants (pmp)	
North East	13	(4.9)	5	(1.9)
North West	32	(4.4)	14	(1.9)
Yorkshire and The Humber	18	(3.3)	14	(2.6)
North of England	**63**	**(4.1)**	**33**	**(2.1)**
East Midlands	21	(4.4)	10	(2.1)
West Midlands	31	(5.3)	16	(2.7)
East of England	26	(4.2)	20	(3.2)
Midlands and East	**78**	**(4.6)**	**46**	**(2.7)**
London	**27**	**(3.1)**	**12**	**(1.4)**
South East Coast	21	(4.5)	19	(4.1)
South Central	17	(3.9)	10	(2.3)
South West	26	(4.7)	18	(3.2)
South of England	**64**	**(4.4)**	**47**	**(3.2)**
England	**232**	**(4.2)**	**138**	**(2.5)**
Isle of Man	**1**	**(12.5)**	**0**	**(0.0)**
Channel Islands	**1**	**(6.3)**	**0**	**(0.0)**
Wales	**18**	**(5.8)**	**8**	**(2.6)**
Scotland	**21**	**(3.9)**	**14**	**(2.6)**
Northern Ireland	**7**	**(3.7)**	**4**	**(2.1)**
TOTAL	**280[1]**	**(4.2)**	**164[2]**	**(2.5)**

[1] Registrations exclude 1 recipient who resides in the Republic of Ireland
[2] Transplants exclude 1 recipient who resides in the Republic of Ireland and 1 Group 2 patient

ADULT HEART TRANSPLANTATION

Transplant List

3.1 Adult heart only transplant list as at 31 March, 2010 – 2019

Figure 3.1 shows the number of adult patients on the heart transplant list at 31 March each year between 2010 and 2019 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 103 in 2010 to 229 in 2019. The number of patients on the urgent list has increased from 3 in 2010 to 23 in 2019. There were two super-urgent patients on the list on 31 March 2019.

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

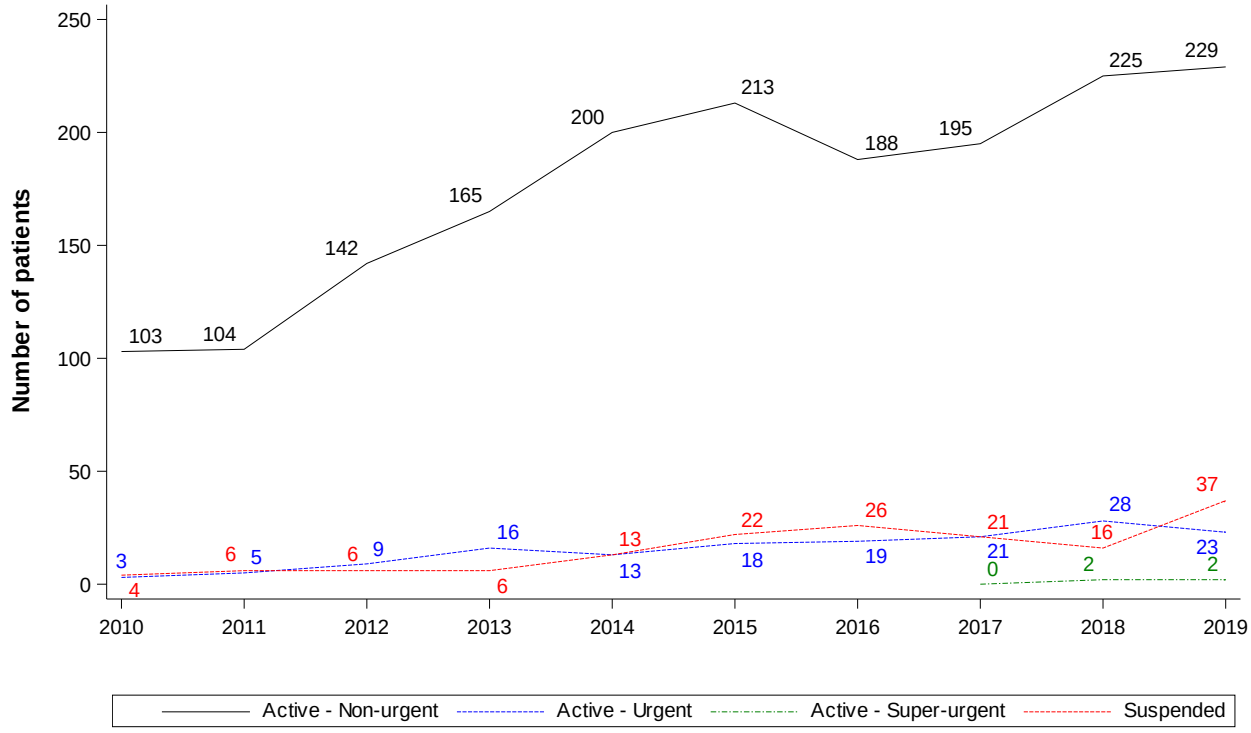


Figure 3.2 shows the number of adult patients on the active heart transplant list at 31 March 2019 by centre and urgency. **Figure 3.3** provides a similar breakdown by centre and mechanical circulatory support (MCS) status. In total, there were 254 adult patients waiting. The number of patients on the urgent transplant list at 31 March 2019 ranged from 1 at Papworth and to 6 at Newcastle. Birmingham and Papworth had one patient each on the super-urgent transplant list. A total of 145 patients were on long term MCS (including left-, right- and bi-ventricular assist devices and total artificial hearts), representing 57% of the national waiting list, but varying between 10% and 84% across centres.

Figure 3.2 Number of adult patients on the active heart transplant list at 31 March 2019, by centre and urgency

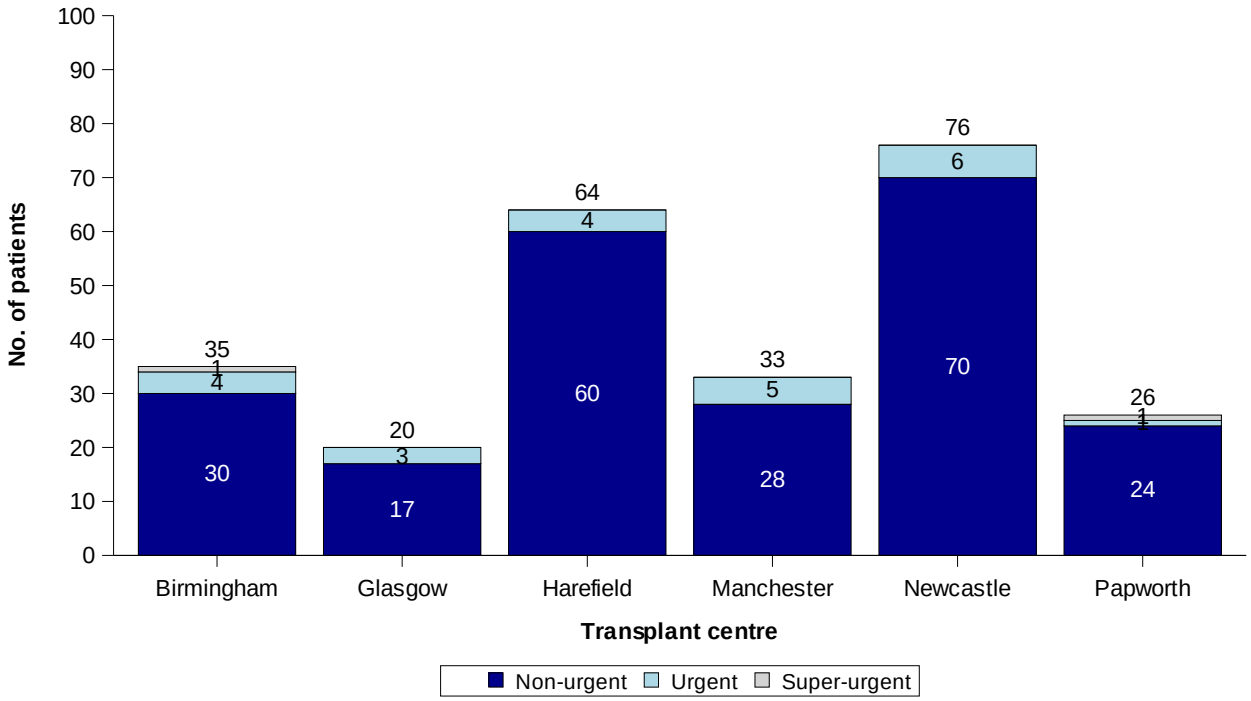


Figure 3.3 Number of adult patients on the active heart transplant list at 31 March 2019, by centre and mechanical circulatory support status

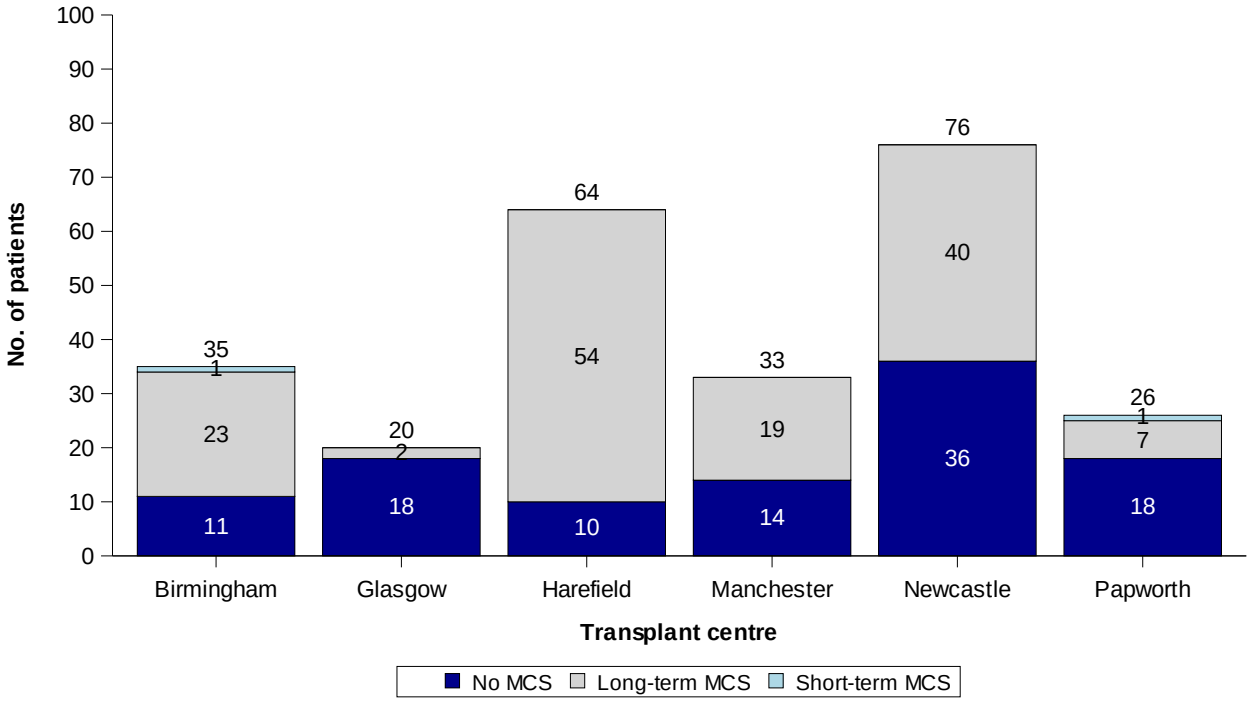
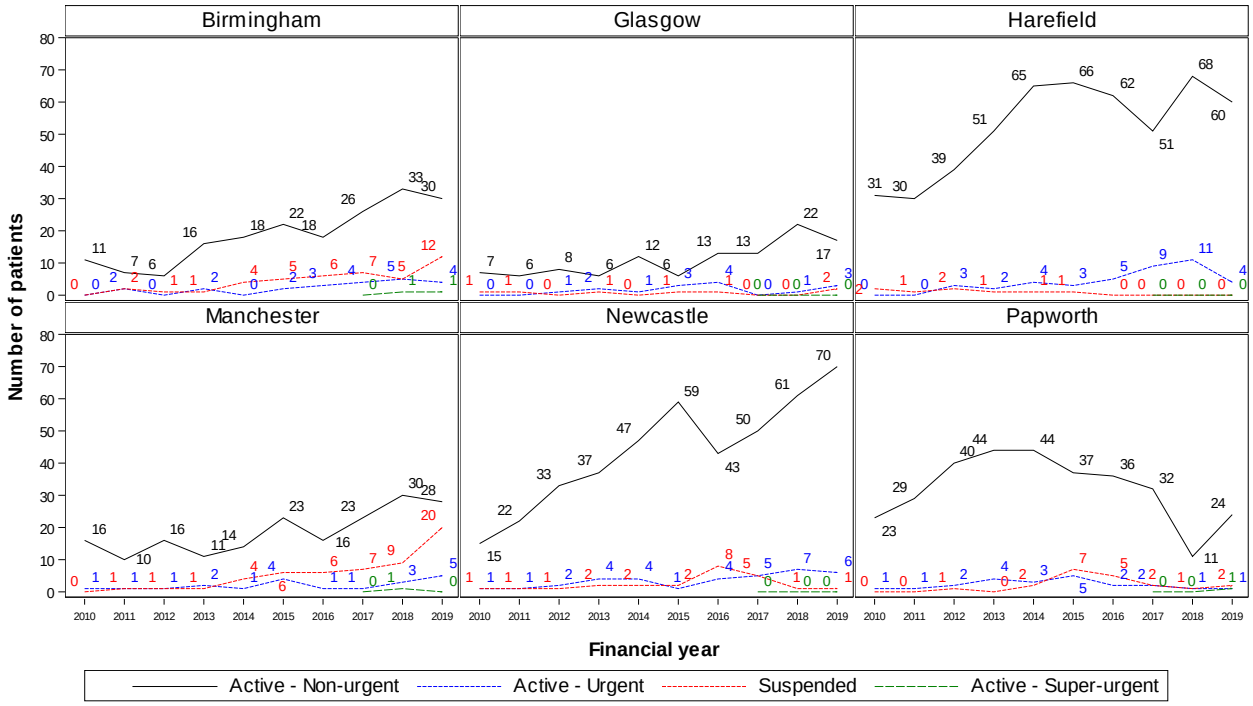


Figure 3.4 shows the trend over time in the number of adult patients on the heart transplant list at 31 March each year across centres. All centres have seen a general increase over the decade, however Papworth saw a decreasing trend between 2014 and 2018, but have had a rise in the last year.

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



3.2 Demographic characteristics, 1 April 2018 – 31 March 2019

There were 252 adult patient registrations onto the heart transplant list between 1 April 2018 and 31 March 2019. Demographic characteristics of these patients are shown by centre and overall in **Table 3.1**. Nationally, 71% of patients were male and the median age was 50 years. Note that there were 37 super-urgent heart registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

Table 3.1 Demographic characteristics of adult patients registered onto the heart transplant list between 1 April 2018 and 31 March 2019, by centre

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL** N (%)
Number of registrations		44 (100)	17 (100)	41 (100)	40 (100)	45 (100)	65 (100)	**252 (100)**
Highest urgency during registration	Non-urgent	17 (39)	7 (41)	20 (49)	21 (53)	27 (60)	32 (49)	**124 (49)**
	Urgent	21 (48)	7 (41)	12 (29)	13 (33)	13 (29)	25 (38)	**91 (36)**
	Super-urgent	6 (14)	3 (18)	9 (22)	6 (15)	5 (11)	8 (12)	**37 (15)**
Recipient sex	Male	32 (73)	14 (82)	28 (68)	30 (75)	28 (62)	47 (72)	**179 (71)**
	Female	12 (27)	3 (18)	13 (32)	10 (25)	17 (38)	18 (28)	**73 (29)**
Recipient ethnicity	White	30 (68)	15 (88)	26 (63)	35 (88)	44 (98)	54 (83)	**204 (81)**
	Non-white	14 (32)	2 (12)	15 (37)	5 (13)	1 (2)	11 (17)	**48 (19)**
Recipient age (years)	Median (IQR)	50 (42, 60)	51 (35, 59)	46 (29, 55)	53 (39, 58)	48 (36, 58)	52 (44, 59)	**50 (38, 59)**
	Missing	0	0	0	0	0	0	**0**
Primary Disease	Coronary heart disease	7 (16)	3 (18)	4 (10)	7 (18)	5 (11)	16 (25)	42 (17)
	Cardiomyopathy	28 (64)	13 (76)	28 (68)	28 (70)	27 (60)	44 (68)	168 (67)
	Congenital heart disease	3 (7)	0 (0)	2 (5)	1 (3)	11 (24)	2 (3)	19 (8)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	**0 (0)**
	Other	6 (14)	1 (6)	7 (17)	4 (10)	2 (4)	3 (5)	**23 (9)**
Previous open heart surgery	None	23 (52)	9 (53)	28 (68)	26 (65)	15 (33)	44 (68)	**145 (58)**
	One	19 (43)	5 (29)	7 (17)	13 (33)	20 (44)	18 (28)	**82 (33)**
	More than one	2 (5)	1 (6)	5 (12)	1 (3)	9 (20)	2 (3)	**20 (8)**
	Missing	0 (0)	2 (12)	1 (2)	0 (0)	1 (2)	1 (2)	**5 (2)**
Previous thoracotomy	No	43 (98)	14 (82)	30 (73)	40 (100)	44 (98)	59 (91)	**230 (91)**
	Yes	1 (2)	2 (12)	10 (24)	0 (0)	0 (0)	5 (8)	**18 (7)**
	Missing	0 (0)	1 (6)	1 (2)	0 (0)	1 (2)	1 (2)	**4 (2)**
Serum Bilirubin (umol/l)	Median (IQR)	12 (8, 22)	12 (10, 18)	13 (11, 17)	20 (12, 31)	17 (10, 26)	15 (9, 20)	**14 (10, 25)**
	Missing	0	2	1	0	4	1	**8**
Serum Creatinine (umol/l)	Median (IQR)	94 (82, 115)	90 (85, 107)	93 (66, 105)	96 (75, 112)	113 (84, 129)	107 (84, 131)	**98 (79, 119)**
	Missing	0	2	1	0	3	1	**7**

3.3 Post-registration outcomes, 1 April 2015 – 31 March 2016

The registration outcomes of adult patients listed for a heart transplant between 1 April 2015 and 31 March 2016 are summarised in **Figures 3.5** - **3.8**, nationally and by centre, for non-urgent and urgent registrations respectively. The possible outcomes for patients on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists (e.g. from the non-urgent to the urgent list), dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted".

Note that the super-urgent heart allocation scheme was introduced in October 2016 and if a patient became super-urgent this is grouped with becoming urgent, or if a patient was moved from the urgent list to the super-urgent list after October 2016 this is counted in their time on the urgent waiting list.

Figure 3.5 shows the non-urgent post-registration outcomes; within six months of listing 15% of non-urgent heart patients had been transplanted and 4% had died on the list, while after three years 24% had been transplanted and 13% had died on the list. Also, 16% had been moved to the urgent heart list within 6 months, reaching 30% by three years. Removals from the list were for a variety of reasons, mainly deteriorating condition.

Figure 3.5 Post-registration outcome for 110 non-urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016

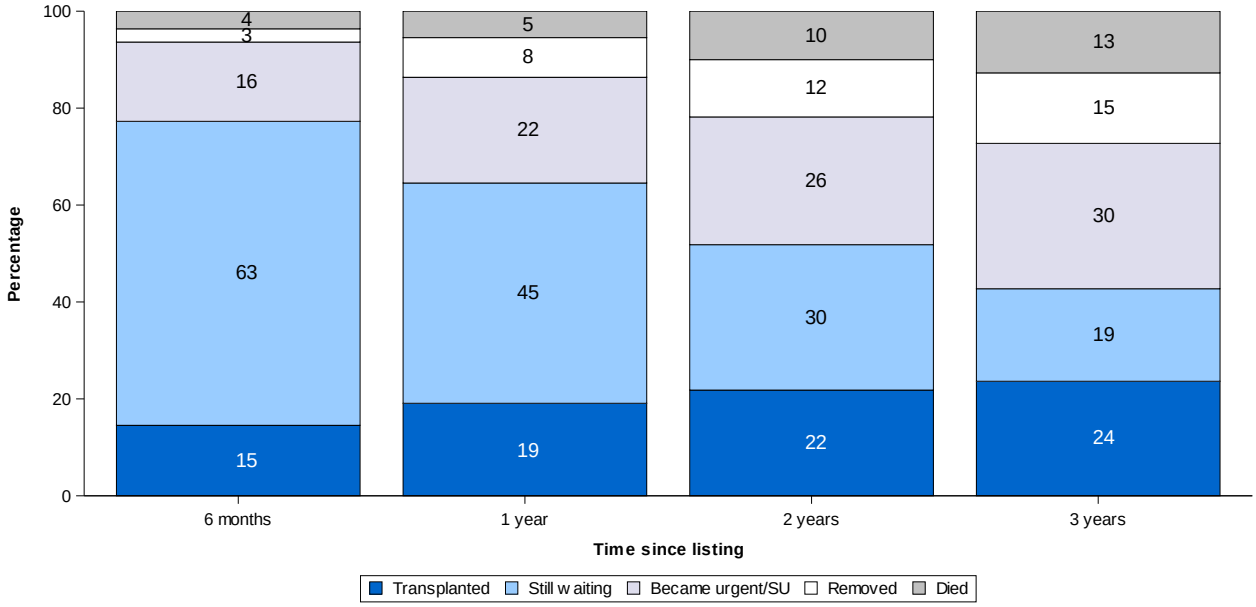


Figure 3.6 shows the three year non-urgent registration outcomes by centre. The non-urgent transplant rate at three years was highest at Papworth (50%) and lowest at Birmingham (5%). Please note that some centres had a very small number of non-urgent registrations in this time period (as shown by the numbers above the bars).

Figure 3.6 Three year registration outcomes by centre, for non-urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016

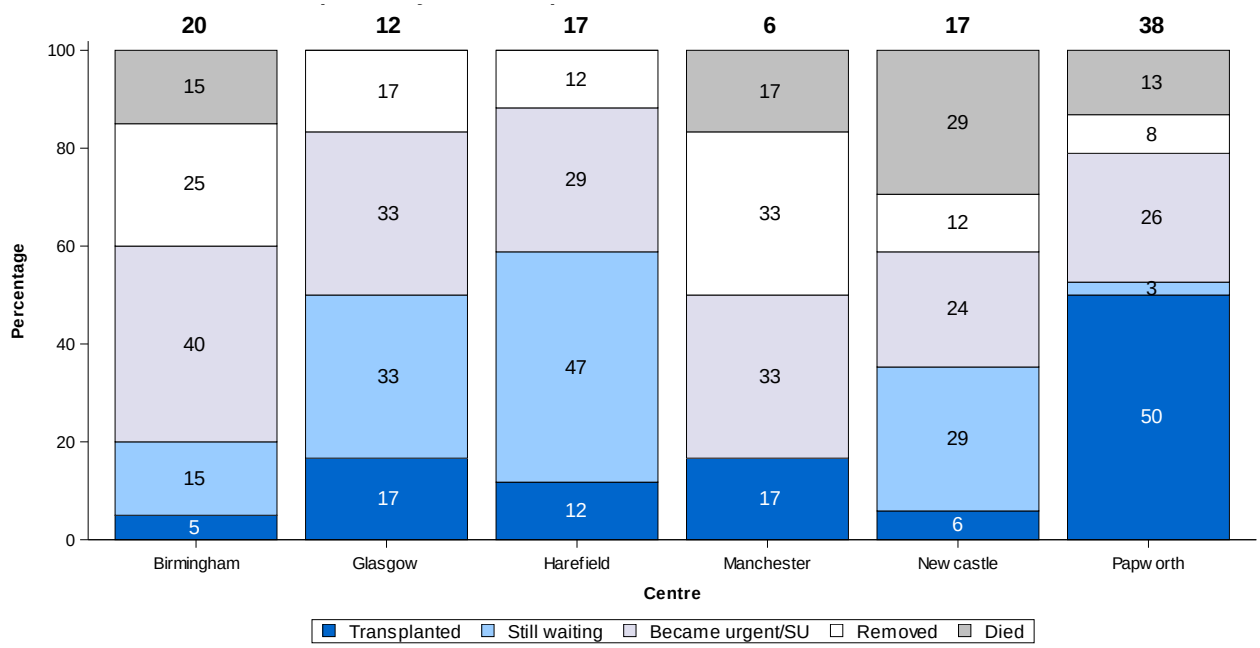


Figure 3.7 shows post-registration outcomes for urgent patients (including those previously on the non-urgent list). The chance of transplant is much higher from the urgent list compared with the non-urgent list; within 6 months, 76% had been transplanted, 5% had died on the list and 12% were removed. The most common reason for removal from the urgent heart list was due to recipients receiving a VAD. **Figure 3.8** shows the one month urgent registration outcomes by centre. The urgent transplant rate at one month was highest at Papworth (61%) and lowest at Harefield (22%).

Figure 3.7 Post-registration outcome for 158 urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016

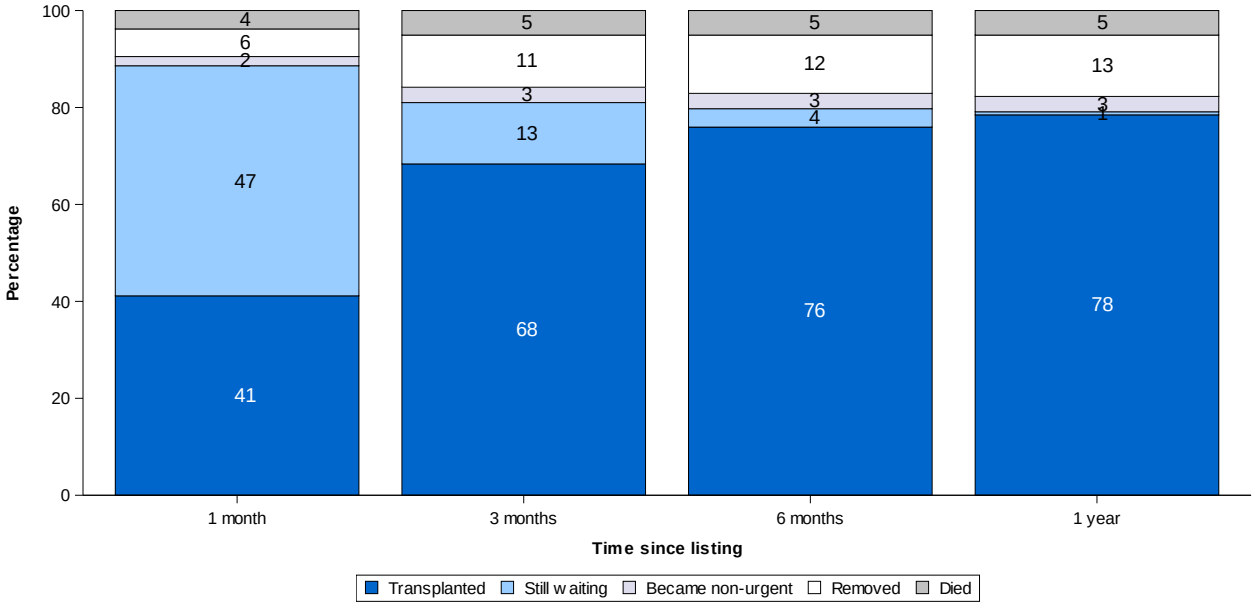
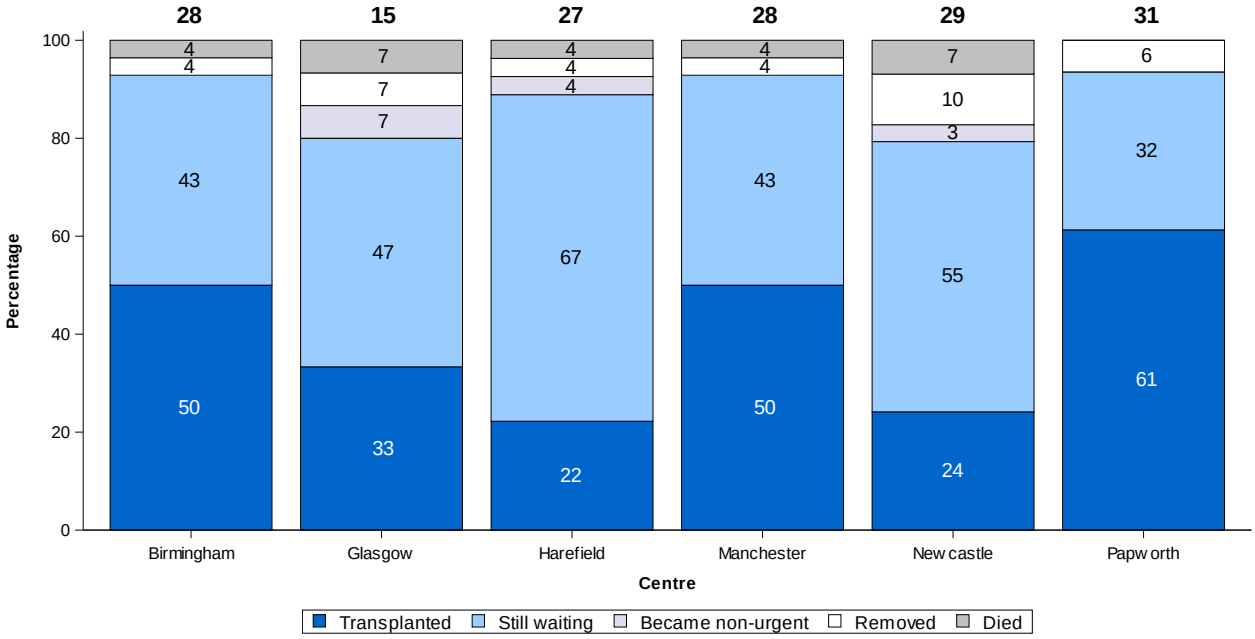


Figure 3.8 One month registration outcomes by centre, for urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016



3.4 Median waiting time to transplant, 1 April 2013 - 31 March 2016

The median waiting time to heart transplant from registration for adult patients is shown in **Figure 3.9** and **Table 3.2**. This is estimated for patients registered on the heart only transplant list between 1 April 2013 and 31 March 2016 using the Kaplan Meier method (before the introduction of the super-urgent heart allocation scheme in October 2016). This is split by the urgency of the patient at registration; non-urgent or urgent. All waiting time from initial registration is considered, regardless of any change in urgency (including time on the super-urgent heart list for any patients that became super-urgent after October 2016). Any suspended time is discounted.

The overall national median waiting time to transplant from non-urgent registration was 559 days (1.5 years) and ranged from 210 days at Papworth to 1305 days at Harefield. For urgent registrations, the national median waiting time was 30 days, and ranged from 15 days at Papworth to 54 days at Harefield. The 95% confidence intervals for some of these medians are very wide, indicating the variation in individual waiting times within groups.

Figure 3.9 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2013 and 31 March 2016, by centre and urgency status at registration

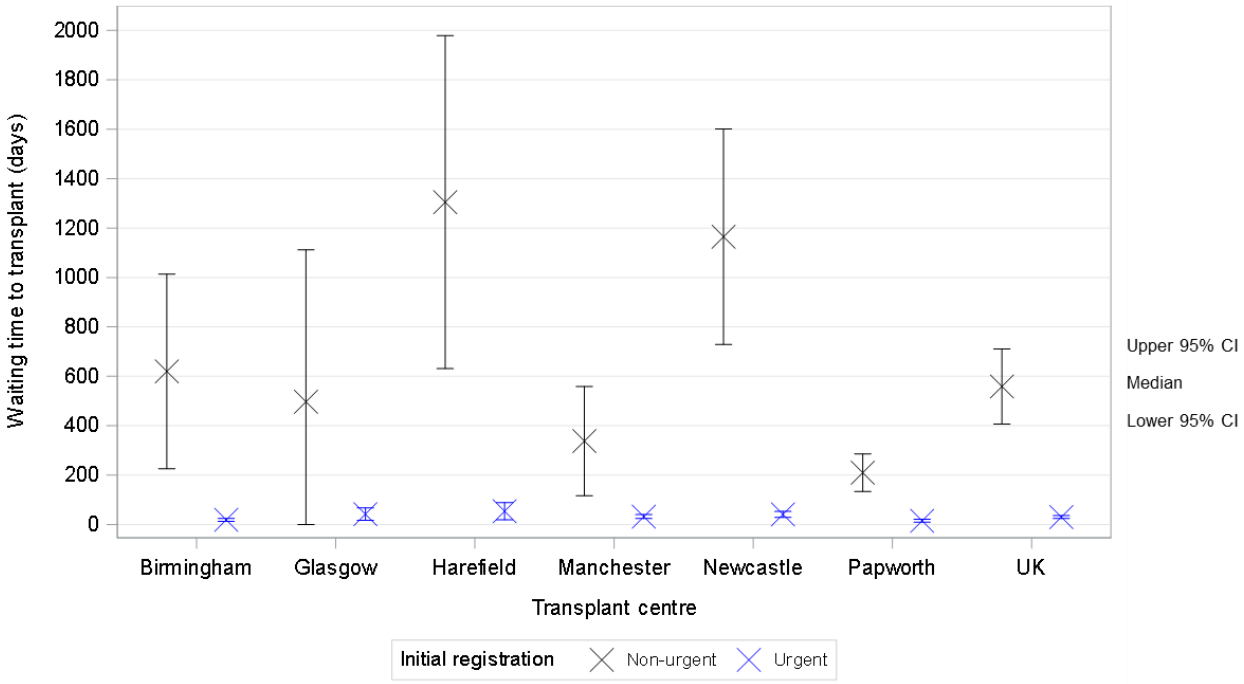


Table 3.2 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and centre, 1 April 2013 to 31 March 2016

Transplant centre	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Overall			
Birmingham	124	88	59 - 117
Glasgow	79	141	0 - 291
Harefield	122	401	182 - 620
Manchester	111	57	17 - 97
Newcastle	129	706	410 - 1002
Papworth	161	104	50 - 158
UK	**726**	**141**	**97 - 185**
Non-urgent at initial registration			
Birmingham	68	620	226 - 1014
Glasgow[1]	34	497	0 - 1112
Harefield	78	1305	631 - 1979
Manchester	46	338	117 - 559
Newcastle	81	1165	729 - 1601
Papworth	111	210	134 - 286
UK	**418**	**559**	**407 - 711**
Urgent at initial registration			
Birmingham	56	19	13 - 25
Glasgow	45	42	17 - 67
Harefield	44	54	19 - 89
Manchester	65	32	24 - 40
Newcastle	48	41	29 - 53
Papworth	50	15	9 - 21
UK	**308**	**30**	**24 - 36**

The median waiting time to heart transplant for adult patients is also considered by blood group. This is shown in **Figure 3.10** and **Table 3.3** by both blood group and urgency status at registration. For both urgent and non-urgent registrations, blood group O patients have the longest average wait compared with the other groups. The confidence intervals for blood group AB patients are particularly wide due to small numbers of patients in these groups.

Figure 3.10 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2013 and 31 March 2016, by blood group and urgency at registration

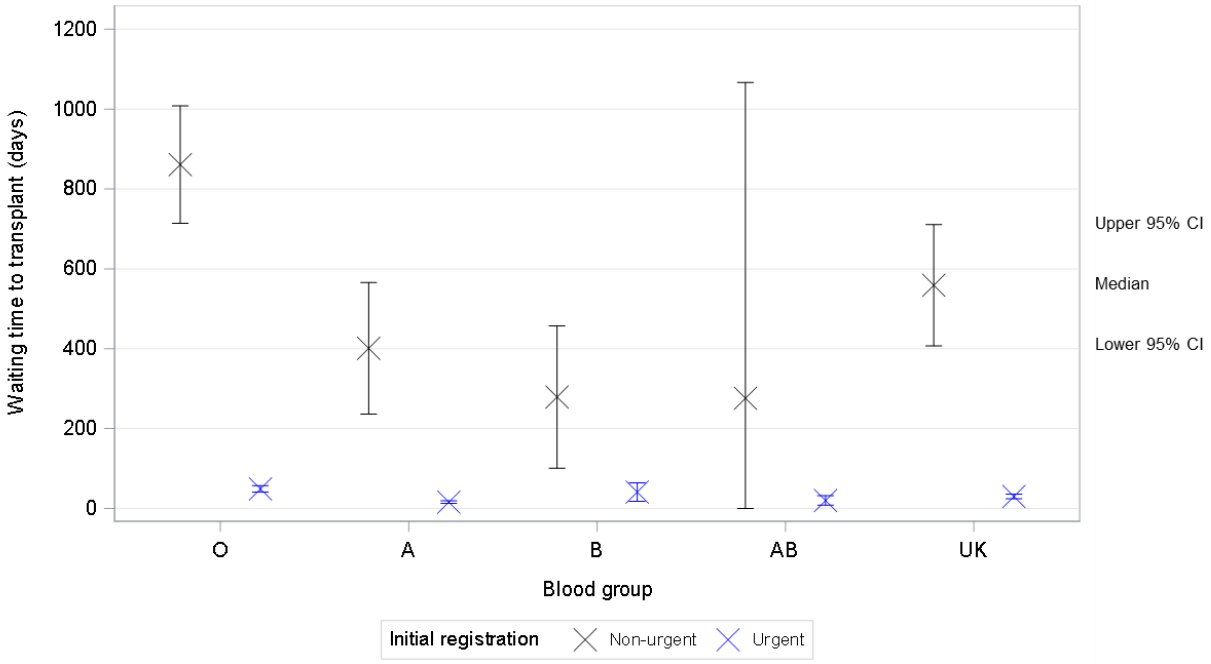
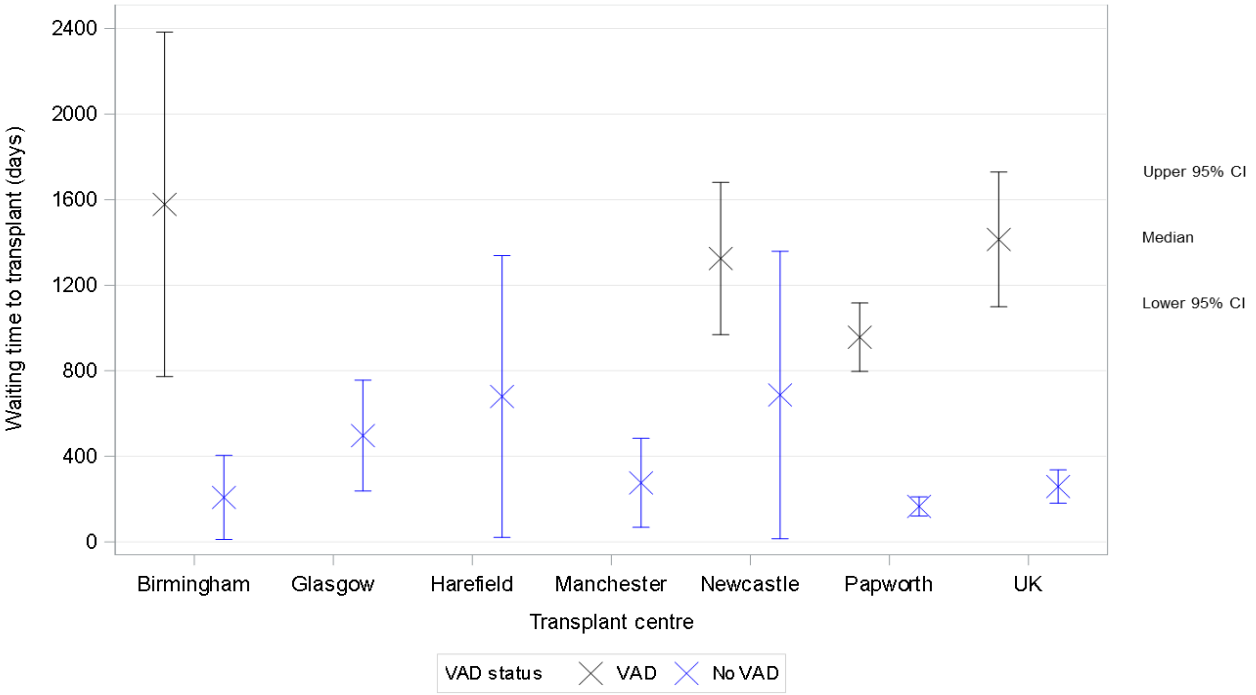


Table 3.3 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2013 to 31 March 2016

Blood group	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Overall			
O	290	339	177 - 501
A	308	82	56 - 108
B	96	155	67 - 243
AB	32	53	0 - 111
UK	**726**	**141**	**97 - 185**
Non-urgent at initial registration			
O	178	861	714 - 1008
A	171	401	236 - 566
B	56	279	101 - 457
AB	13	276	0 - 1067
UK	**418**	**559**	**407 - 711**
Urgent at initial registration			
O	112	49	41 - 57
A	137	16	13 - 19
B	40	41	18 - 64
AB	19	20	8 - 32
UK	**308**	**30**	**24 - 36**

The median waiting time to heart transplant for adult patients is shown by VAD status in **Figure 3.11** and **Table 3.4**. This considers whether a patient ever had an implantable left-ventricular assist device (LVAD) as a bridge to heart transplant compared with not, and is restricted to those who were initially non-urgent. Nationally, those ever on LVAD support wait on average 5.5 times longer (unadjusted) than those never on LVAD support (log-rank p<0.0001). Note that median waiting time estimates could not be obtained for patients on LVAD support at Glasgow and Manchester due to small numbers, while for Harefield an estimate could not be obtained as not enough patients had been transplanted at time of analysis.

Figure 3.11 Median waiting time to heart transplant for adult patients registered onto the non-urgent list between 1 April 2013 and 31 March 2016, by centre and whether the patient had an implantable left-ventricular assist device (LVAD)



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

Table 3.4 **Median active waiting time to heart transplant for adult patients registered on the non-urgent transplant list 1 April 2013 to 31 March 2016, by centre and whether the patient had an implantable left-ventricular assist device (LVAD)**

Transplant centre	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Ever on LVAD support			
Birmingham	18	1578	773 - 2383
Glasgow[1]	6	-	-
Harefield[2]	40	-	-
Manchester[1]	9	-	-
Newcastle	45	1325	969 - 1681
Papworth	23	957	797 - 1117
UK	**141**	**1414**	**1099 - 1729**
Never on LVAD support			
Birmingham	50	208	12 - 404
Glasgow	28	497	238 - 756
Harefield	38	680	21 - 1339
Manchester	37	276	68 - 484
Newcastle	36	687	15 - 1359
Papworth	88	166	121 - 211
UK	**277**	**259**	**181 - 337**

[1] Median waiting time for groups with less than 10 patients are not presented due to small numbers
[2] Median waiting time cannot be estimated as not enough patients had been transplanted by the time of analysis

ADULT HEART TRANSPLANTATION

Response to Offers

4. Response to Offers

This section presents an analysis of adult DBD donor heart offer decline rates. This only considers offers of hearts between 1 April 2016 and 31 March 2019 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

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

Figure 4.1 compares individual centre decline rates with the national rate using a funnel plot. The offer decline rate for Harefield is above the upper 99.8% confidence limit, indicating that they have a significantly higher decline rate than the national rate. The offer decline rates for both Birmingham and Papworth are below the lower 99.8% confidence limit, indicating that they have a significantly lower decline rate than the national rate. Conversely, the decline rate for Glasgow lies between the 95% and 99.8% upper confidence limits providing some evidence that this rate may be significantly high, whilst the decline rate for Harefield lies outside of the 99.8% confidence limit indicating that their rate is significantly higher than the national rate.

Figure 4.1 UK adult DBD donor heart offer decline rates by centre, 1 April 2016 to 31 March 2019

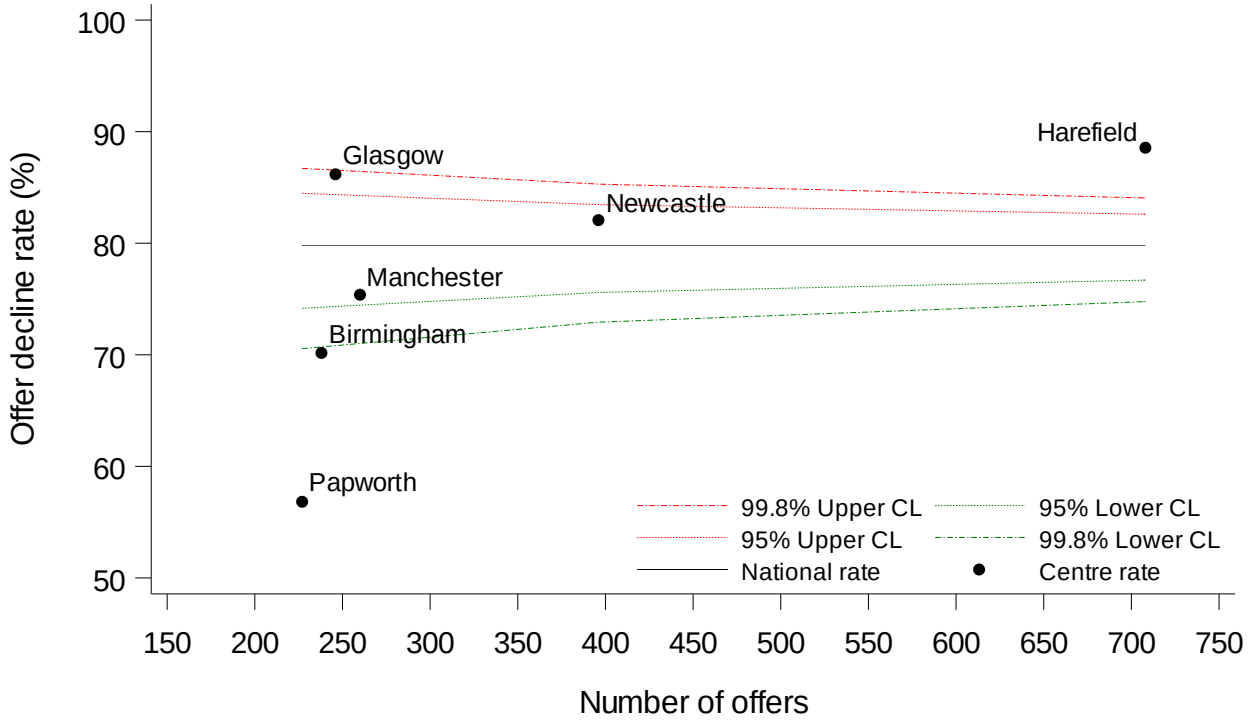


Table 4.1 shows a breakdown of each centre's decline rate across the three years analysed. Nationally, the number of offers has decreased (for hearts that were eventually transplanted) and so has the offer decline rate, from 83.7% to 74.1%.

Table 4.1 UK adult DBD donor heart offer decline rates by transplant centre and year, between 1 April 2016 and 31 March 2019

Centre	2016/17		2017/18		2018/19		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	116	(78.4)	60	(65.0)	62	(59.7)	238	(70.2)
Glasgow	93	(83.9)	103	(89.3)	50	(84.0)	246	(86.2)
Harefield	356	(94.4)	206	(83.0)	146	(82.2)	708	(88.6)
Manchester	93	(68.8)	89	(83.1)	78	(74.4)	260	(75.4)
Newcastle	178	(84.8)	122	(79.5)	96	(80.2)	396	(82.1)
Papworth	92	(62.0)	93	(59.1)	42	(40.5)	227	(56.8)
UK	**928**	**(83.7)**	**673**	**(78.5)**	**474**	**(74.1)**	**2075**	**(79.8)**

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 2009 – 31 March 2019

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 158 adult heart transplants nationally; four lower than the previous year, and nine less than the most active year over the last decade, which was 2013/2014. However, compared with 2009/2010, activity has increased by 86%.

Figure 5.1 Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2009 to 31 March 2019

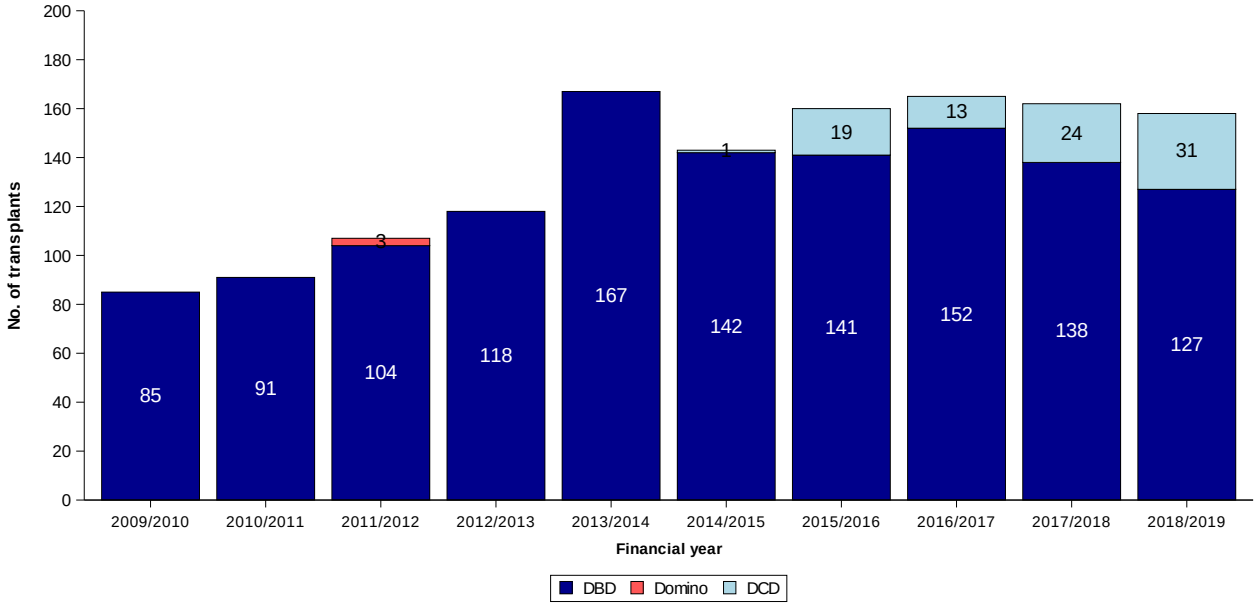
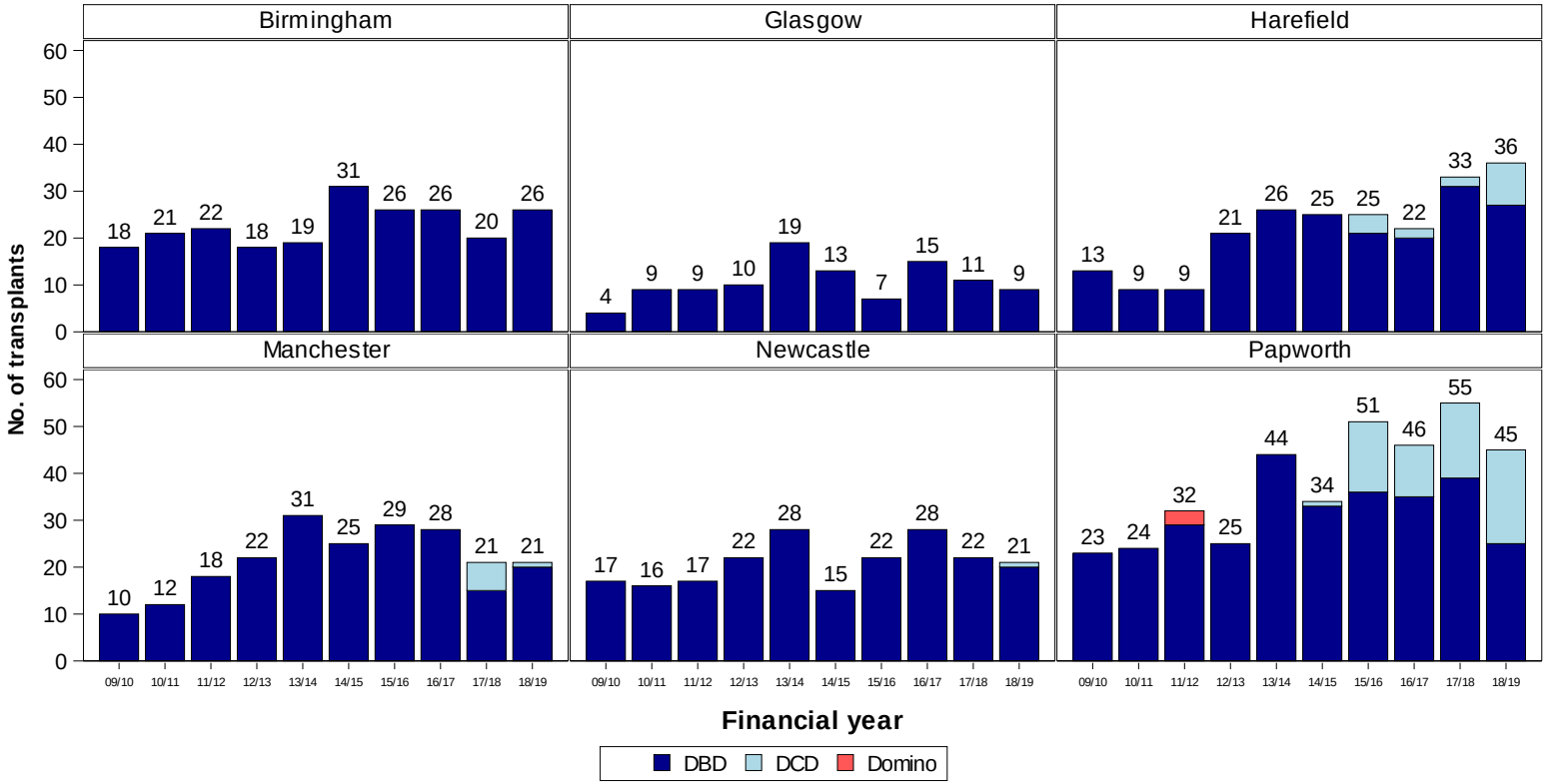


Figure 5.2 shows the number of adult heart transplants performed per centre, per year, over the last ten years, by donor type. Harefield and Papworth have had a steady increase in their heart transplant numbers over the decade.

Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2009 to 31 March 2019



Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants, performed by four centres in this time period, represented 20% of last year's adult heart transplant activity. The highest number of transplants were performed by Papworth.

Figure 5.3 Number of adult heart transplants in the UK, by centre and donor type, 1 April 2018 to 31 March 2019

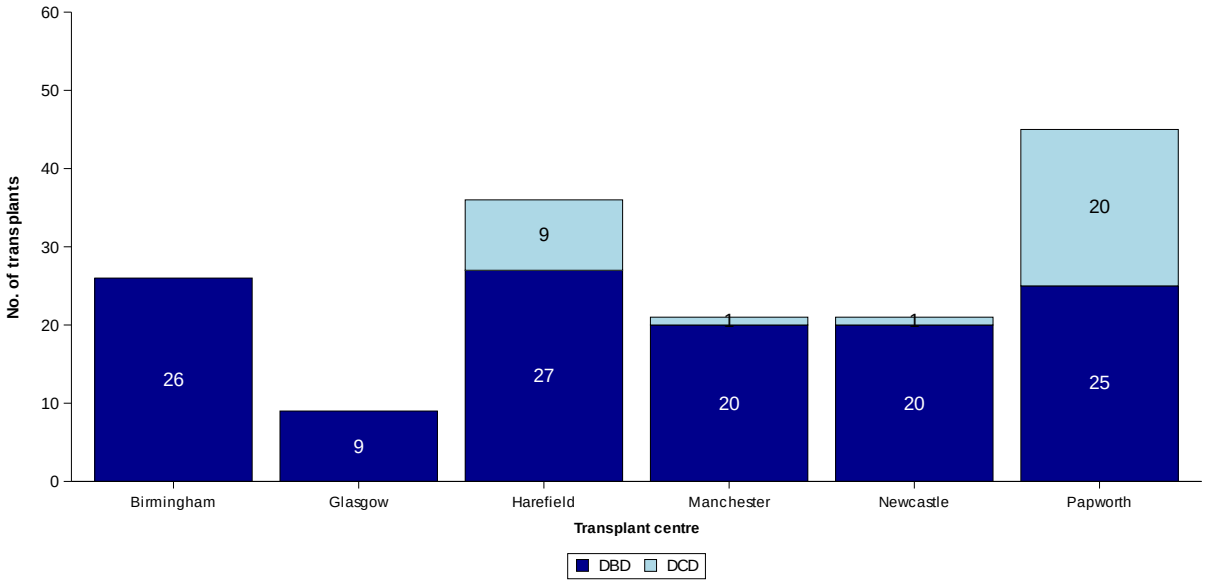


Figure 5.4 and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time, the proportion of urgent transplants has increased; from 44% in 2009/2010 to 77% in 2018/2019, including 25 super-urgent transplants. Papworth performed the highest number of non-urgent transplants over the time period.

Figure 5.4 Number of adult heart transplants in the UK, by financial year and urgency status, 1 April 2009 to 31 March 2019

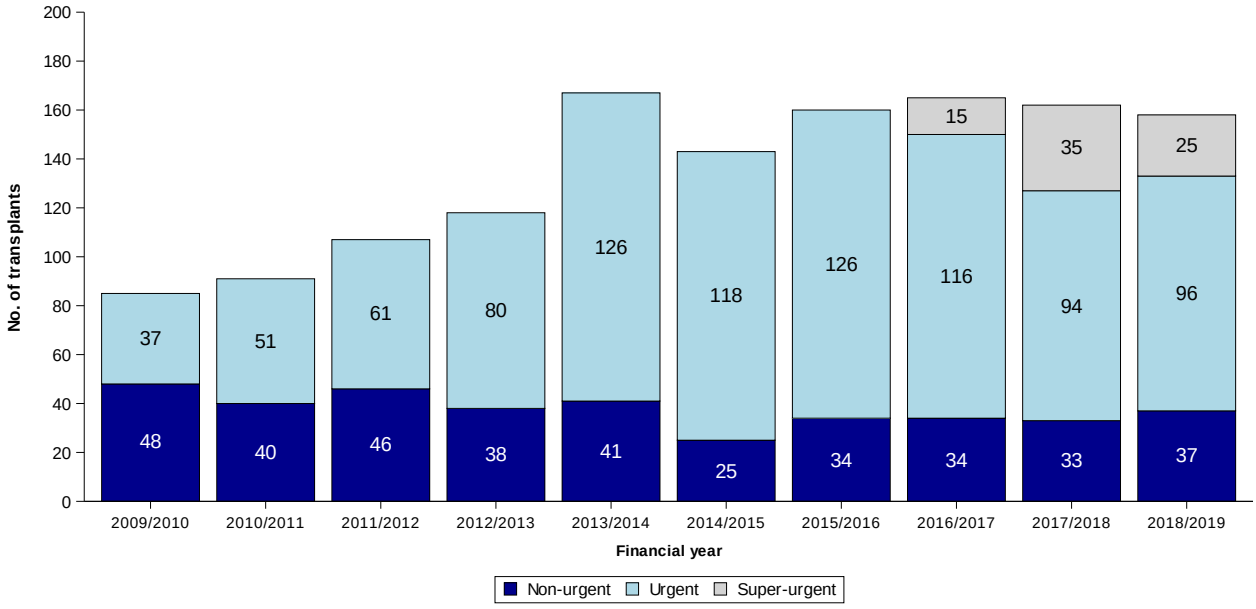
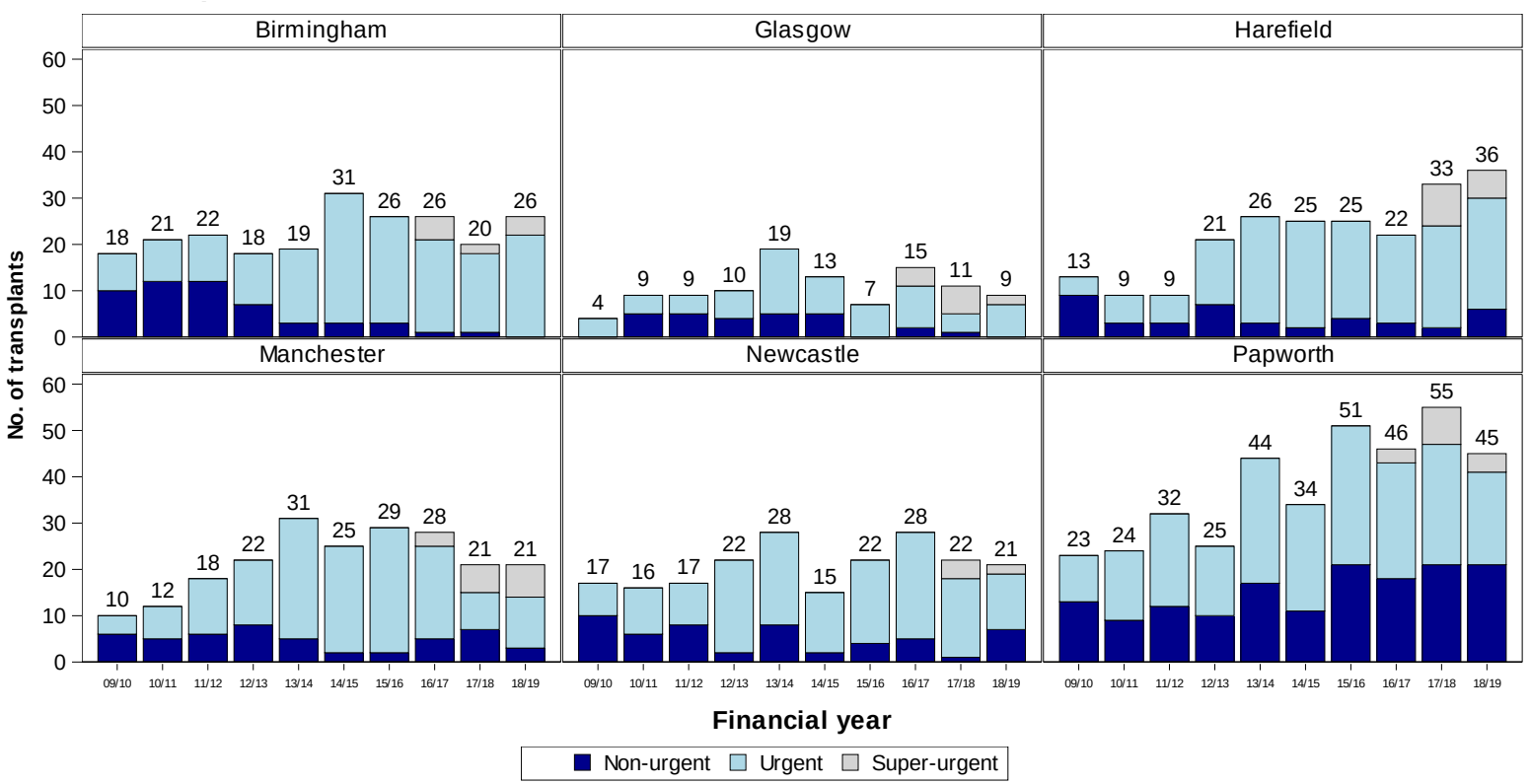
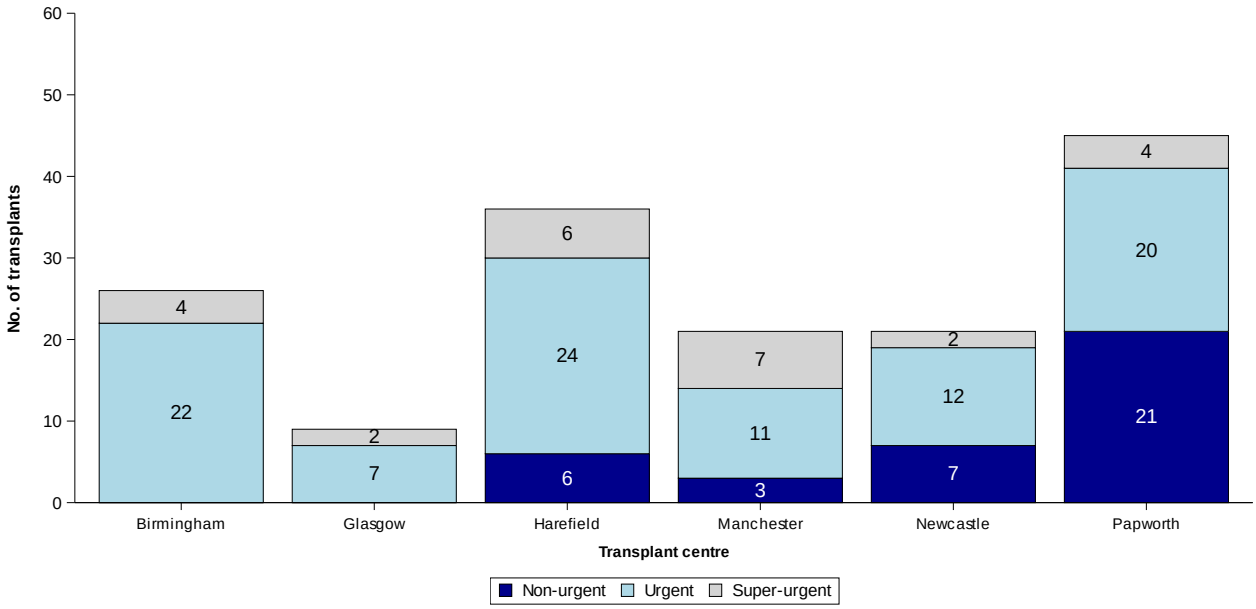


Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2009 to 31 March 2019



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 57% of all non-urgent transplants performed in 2018/2019. Of the 37 non-urgent transplants, 13 (35%) used DCD donor hearts.

Figure 5.6 Number of adult heart transplants in the UK, by centre and urgency status, 1 April 2018 to 31 March 2019



5.2 Demographic characteristics of transplants, 1 April 2018 – 31 March 2019

The demographic characteristics of the 158 adult heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 67% of heart recipients were male and the median age was 45 years while the median age for donors was 36 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 2018 to 31 March 2019, by centre

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL N (%)**
Number of transplants		26 (100)	9 (100)	36 (100)	21 (100)	21 (100)	45 (100)	**158 (100)**
Urgency status at transplant	Non-urgent	0 (0)	0 (0)	6 (17)	3 (14)	7 (33)	21 (47)	**37 (23)**
	Urgent	22 (85)	7 (78)	24 (67)	11 (52)	12 (57)	20 (44)	**96 (61)**
	Super-urgent	4 (15)	2 (22)	6 (17)	7 (33)	2 (10)	4 (9)	**25 (16)**
Recipient sex	Male	16 (62)	8 (89)	22 (61)	14 (67)	14 (67)	31 (69)	**105 (67)**
	Female	10 (38)	1 (11)	14 (39)	7 (33)	7 (33)	14 (31)	**53 (34)**
Recipient ethnicity	White	16 (62)	7 (78)	27 (75)	19 (90)	20 (95)	38 (84)	**127 (80)**
	Non-white	10 (38)	2 (22)	9 (25)	2 (10)	1 (5)	7 (16)	**31 (20)**
Recipient age (years)	Median (IQR)	46 (36, 51)	27 (26, 47)	41 (31, 50)	40 (28, 48)	44 (34, 52)	50 (43, 59)	**45 (34, 53)**
	Missing	0	0	0	0	0	0	**0**
Recipient weight (kg)	Median (IQR)	73 (66, 79)	71 (67, 81)	75 (69, 83)	72 (63, 87)	73 (62, 83)	74 (64, 85)	**74 (66, 83)**
	Missing	0	0	0	1	0	0	**1**
Recipient primary disease	Coronary heart disease	1 (4)	1 (11)	5 (14)	3 (14)	1 (5)	11 (24)	22 (14)
	Cardiomyopathy	19 (73)	8 (89)	21 (58)	15 (71)	10 (48)	32 (71)	105 (67)
	Congenital heart disease	3 (12)	0 (0)	2 (6)	0 (0)	8 (38)	0 (0)	13 (8)
	Graft failure/Rejection	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)	1 (1)
	Other	3 (12)	0 (0)	7 (19)	3 (14)	2 (10)	2 (4)	17 (11)
NYHA class	I	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	**1 (1)**
	II	1 (4)	0 (0)	3 (8)	0 (0)	0 (0)	1 (2)	**5 (3)**
	III	13 (50)	1 (11)	17 (47)	6 (29)	3 (14)	25 (56)	**65 (41)**
	IV	11 (42)	1 (11)	15 (42)	15 (71)	17 (81)	19 (42)	**78 (49)**
	Missing	1 (4)	7 (78)	1 (3)	0 (0)	0 (0)	0 (0)	**9 (6)**
Recipient in hospital pre-transplant	No	3 (12)	1 (11)	11 (31)	2 (10)	8 (38)	22 (49)	**47 (30)**
	Yes	23 (88)	3 (33)	24 (67)	18 (86)	13 (62)	23 (51)	**104 (66)**
	Missing	0 (0)	5 (56)	1 (3)	1 (5)	0 (0)	0 (0)	**7 (4)**

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2018 to 31 March 2019, by centre

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL N (%)**
If in hospital, recipient on ventilator	No	21 (91)	2 (67)	23 (96)	17 (94)	13 (100)	23 (100)	**99 (95)**
	Yes	2 (9)	0 (0)	1 (4)	1 (6)	0 (0)	0 (0)	**4 (4)**
	Missing	0 (0)	1 (33)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (1)**
If in hospital, recipient on VAD	None	17 (74)	1 (33)	19 (79)	10 (56)	8 (62)	19 (83)	**74 (71)**
	Left	1 (4)	0 (0)	5 (21)	3 (17)	4 (31)	1 (4)	**14 (14)**
	Right	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	**0 (0)**
	Both	5 (22)	1 (33)	0 (0)	5 (28)	1 (8)	3 (13)	**15 (14)**
	Missing	0 (0)	1 (33)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (1)**
If in hospital, recipient on TAH	No	23 (100)	2 (67)	22 (92)	18 (100)	13 (100)	23 (100)	**101 (97)**
	Yes	0 (0)	0 (0)	2 (8)	0 (0)	0 (0)	0 (0)	**2 (2)**
	Missing	0 (0)	1 (33)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (1)**
If in hospital, recipient on ECMO	No	22 (96)	2 (67)	22 (92)	18 (100)	13 (100)	22 (96)	**99 (95)**
	Yes	1 (4)	1 (33)	2 (8)	0 (0)	0 (0)	1 (4)	**5 (5)**
If in hospital, recipient on inotropes	No	3 (13)	2 (67)	2 (8)	8 (44)	1 (8)	8 (35)	**24 (23)**
	Yes	20 (87)	0 (0)	22 (92)	10 (56)	12 (92)	15 (65)	**79 (76)**
	Missing	0 (0)	1 (33)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (1)**
If in hospital, recipient on IABP	No	23 (100)	1 (33)	24 (100)	14 (78)	13 (100)	23 (100)	**98 (94)**
	Yes	0 (0)	2 (67)	0 (0)	4 (22)	0 (0)	0 (0)	**6 (6)**
Recipient CMV status	No	13 (50)	7 (78)	19 (53)	12 (57)	12 (57)	22 (49)	**85 (54)**
	Yes	13 (50)	2 (22)	17 (47)	9 (43)	6 (29)	23 (51)	**70 (44)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	3 (14)	0 (0)	**3 (2)**
Recipient HCV status	No	26 (100)	9 (100)	36 (100)	21 (100)	19 (90)	45 (100)	**156 (99)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (10)	0 (0)	**2 (1)**
Recipient HBV status	No	26 (100)	9 (100)	36 (100)	21 (100)	19 (90)	45 (100)	**156 (99)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (10)	0 (0)	**2 (1)**
Recipient HIV status	No	26 (100)	9 (100)	36 (100)	21 (100)	19 (90)	45 (100)	**156 (99)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (10)	0 (0)	**2 (1)**
Recipient serum creatinine (umol/l)	Median (IQR)	100 (79, 143)	-	80 (63, 108)	84 (72, 108)	94 (76, 138)	103 (88, 139)	**94 (76, 129)**
	Missing	0	7	1	0	0	1	**9**

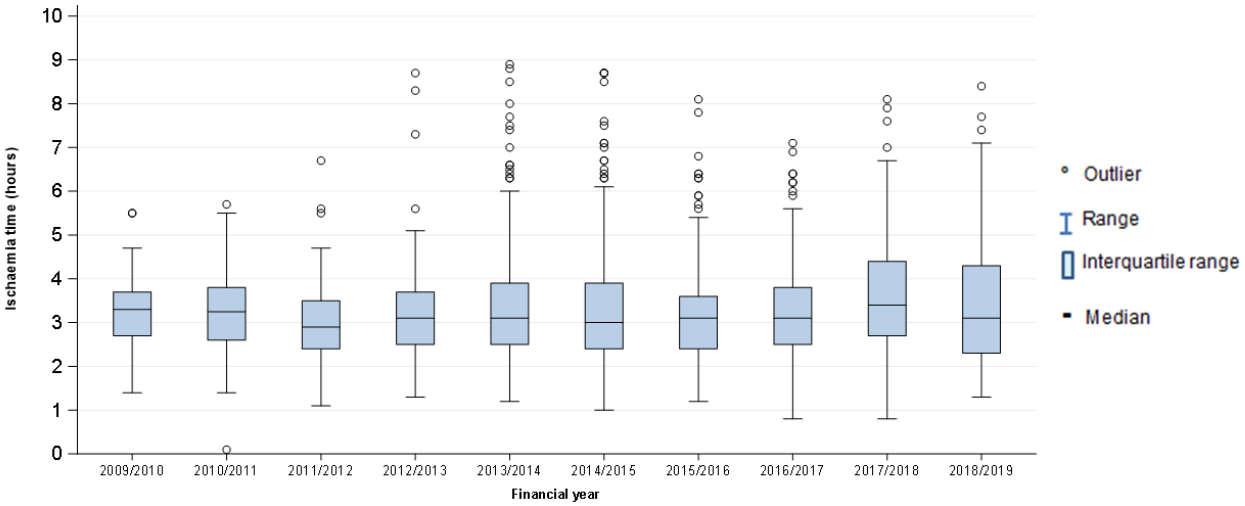
Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2018 to 31 March 2019, by centre

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL N (%)**
Donor sex	Male	15 (58)	8 (89)	20 (56)	11 (52)	18 (86)	31 (69)	**103 (65)**
	Female	11 (42)	1 (11)	16 (44)	10 (48)	3 (14)	14 (31)	**55 (35)**
Donor ethnicity	White	24 (92)	8 (89)	32 (89)	20 (95)	18 (86)	40 (89)	**142 (90)**
	Non-white	2 (8)	1 (11)	3 (8)	1 (5)	1 (5)	5 (11)	**13 (8)**
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	2 (10)	0 (0)	**3 (2)**
Donor age (years)	Median (IQR)	38 (30, 56)	35 (22, 42)	38 (27, 47)	31 (24, 42)	28 (24, 36)	40 (29, 48)	**36 (26, 47)**
	Missing	0	0	0	0	0	0	**0**
Donor BMI (kg/m^2)	Median (IQR)	26 (24, 28)	25 (21, 26)	26 (23, 28)	24 (23, 27)	26 (23, 29)	25 (23, 27)	**25 (23, 28)**
	Missing	0	0	0	0	0	0	**0**
Donor cause of death	CVA	21 (81)	7 (78)	32 (89)	19 (90)	16 (76)	39 (87)	**134 (85)**
	Trauma	1 (4)	1 (11)	3 (8)	2 (10)	4 (19)	1 (2)	**12 (8)**
	Others	4 (15)	1 (11)	1 (3)	0 (0)	1 (5)	5 (11)	**12 (8)**
Donor hypotension	No	16 (62)	1 (11)	28 (78)	14 (67)	7 (33)	35 (78)	**101 (64)**
	Yes	9 (35)	1 (11)	6 (17)	7 (33)	5 (24)	10 (22)	**38 (24)**
	Missing	1 (4)	7 (78)	2 (6)	0 (0)	9 (43)	0 (0)	**19 (12)**
Donor past diabetes	No	26 (100)	9 (100)	35 (97)	20 (95)	21 (100)	43 (96)	**154 (98)**
	Yes	0 (0)	0 (0)	1 (3)	1 (5)	0 (0)	2 (4)	**4 (3)**
Donor past cardiothoracic disease	No	25 (96)	8 (89)	35 (97)	21 (100)	19 (90)	43 (96)	**151 (96)**
	Missing	1 (4)	1 (11)	1 (3)	0 (0)	2 (10)	2 (4)	**7 (4)**
Donor past hypertension	No	23 (88)	8 (89)	33 (92)	19 (90)	20 (95)	37 (82)	**140 (89)**
	Yes	3 (12)	1 (11)	2 (6)	2 (10)	0 (0)	5 (11)	**13 (8)**
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	1 (5)	3 (7)	**5 (3)**
Donor past tumour	No	24 (92)	8 (89)	35 (97)	18 (86)	20 (95)	43 (96)	**148 (94)**
	Yes	2 (8)	1 (11)	0 (0)	3 (14)	1 (5)	1 (2)	**8 (5)**
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	1 (2)	**2 (1)**
Donor past smoker	No	11 (42)	1 (11)	15 (42)	11 (52)	6 (29)	16 (36)	**60 (38)**
	Yes	15 (58)	8 (89)	20 (56)	10 (48)	15 (71)	29 (64)	**97 (61)**
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)	**1 (1)**
Total ischaemia time (hours)	Median (IQR)	2.9 (2.3, 3.5)	-	5.3 (4.7, 5.9)	2.9 (2.4, 3.1)	3.4 (2.6, 4.2)	3.5 (2.3, 5.3)	**3.5 (2.5, 5.2)**
	Missing	1	8	3	0	1	1	**14**

5.3 Total ischaemia time, 1 April 2009 – 31 March 2019

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 (11%) not all of this time duration is ischaemic, and no adjustment has been made for this. The national median total ischaemia time has reduced slightly from 3.3 hours to 3.1 hours over the last decade.

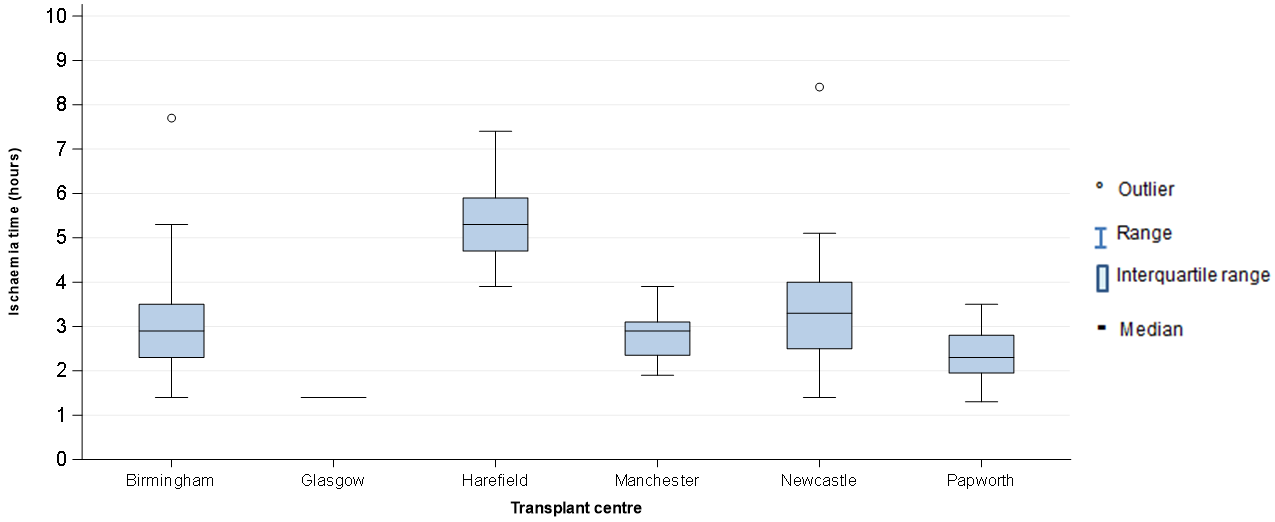
Figure 5.7 Boxplots of total ischaemia time for DBD donor hearts transplanted into adult recipients, by financial year, 1 April 2009 to 31 March 2019



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

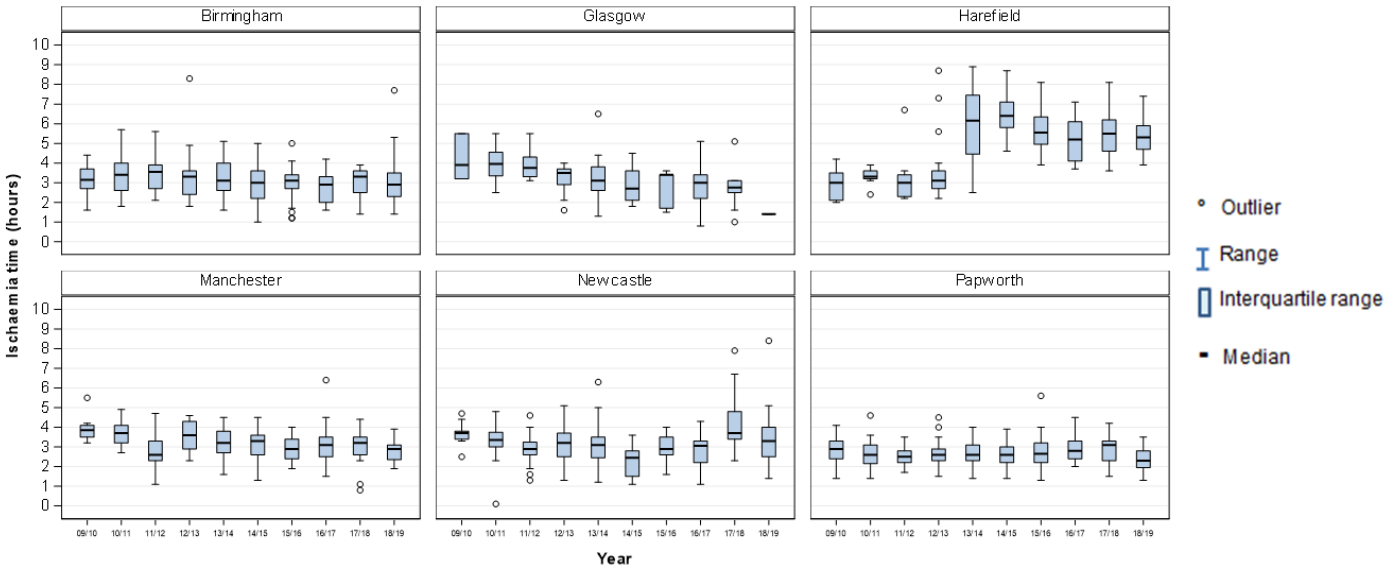
Figure 5.8 and **Figure 5.9** show boxplots of total ischaemia time by centre in the latest financial year (2018/2019) and over the last 10 years, respectively (note that total ischaemia time was not known for eight out of nine transplants performed at Glasgow during 2018/2019 which is why the boxplot in Figure 5.8 for Glasgow only has one point). 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 2018/2019, 100% of DBD hearts transplanted by Harefield used OCS compared with 0%-10% for other centres, who have a median of between 2.3 and 3.3 hours.

Figure 5.8 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre, 1 April 2018 to 31 March 2019



Includes time on the Organ Care System (OCS), where centres used the OCS in a variable proportion of transplants: Birmingham 4%, Glasgow 0%, Harefield 100%, Manchester 0%, Newcastle 10% and Papworth 0%

Figure 5.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre and financial year, 1 April 2009 to 31 March 2019



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

ADULT HEART TRANSPLANTATION

Post-Transplant Survival

6. Post-Transplant Survival

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

The survival analyses exclude multi-organ transplants and include first time transplants only. Thirty-day, 90-day and 1-year survival rates are based on transplants performed in the period 1 April 2014 to 31 March 2018 while 5-year survival rates are based on transplants performed in the period 1 April 2010 to 31 March 2014. Survival rates are presented by transplant centre in **Tables 6.1-6.4** and **Figures 6.1-6.4** as well as disease group in **Tables 6.5-6.6**. DCD heart transplants are excluded but separate tables (**Table 6.7** and **6.8**) at the end of this section provide unadjusted survival rates for the small number of DCD heart transplant recipients between 1 April 2014 and 31 March 2018.

The survival data used for these analyses is reported to NHSBT via follow-up forms. It should be noted that two centres in particular (Birmingham and Glasgow) have a large number of follow-up forms outstanding which will affect the validity of some of these survival rates, especially the 5-year survival rates. Follow-up form return rates by centre, for forms issued during the 2018 calendar year, are presented in Section 8.

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 566 first adult DBD heart only transplants in the period 1 April 2014 to 31 March 2018. All of the centres' rates, apart from Papworth, were statistically consistent with the national rate of survival which was 90.3%. 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 DBD heart transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of transplants	% 30 day survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	102	89.2	(81.4 - 93.9)	88.7	(79.6 - 93.7)
Glasgow	45	86.7	(72.7 - 93.8)	78.5	(52.2 - 90.3)
Harefield	96	83.3	(74.2 - 89.4)	88.4	(81.1 - 92.9)
Manchester	97	94.8	(88.1 - 97.8)	93.9	(85.4 - 97.5)
Newcastle	85	89.4	(80.6 - 94.3)	89.1	(79.1 - 94.3)
Papworth	141	94.3	(89.0 - 97.1)	94.2	(88.4 - 97.1)
UK	**566**	**90.3**	**(87.5 - 92.5)**		

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

Figure 6.1 Risk-adjusted 30 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2014 to 31 March 2018

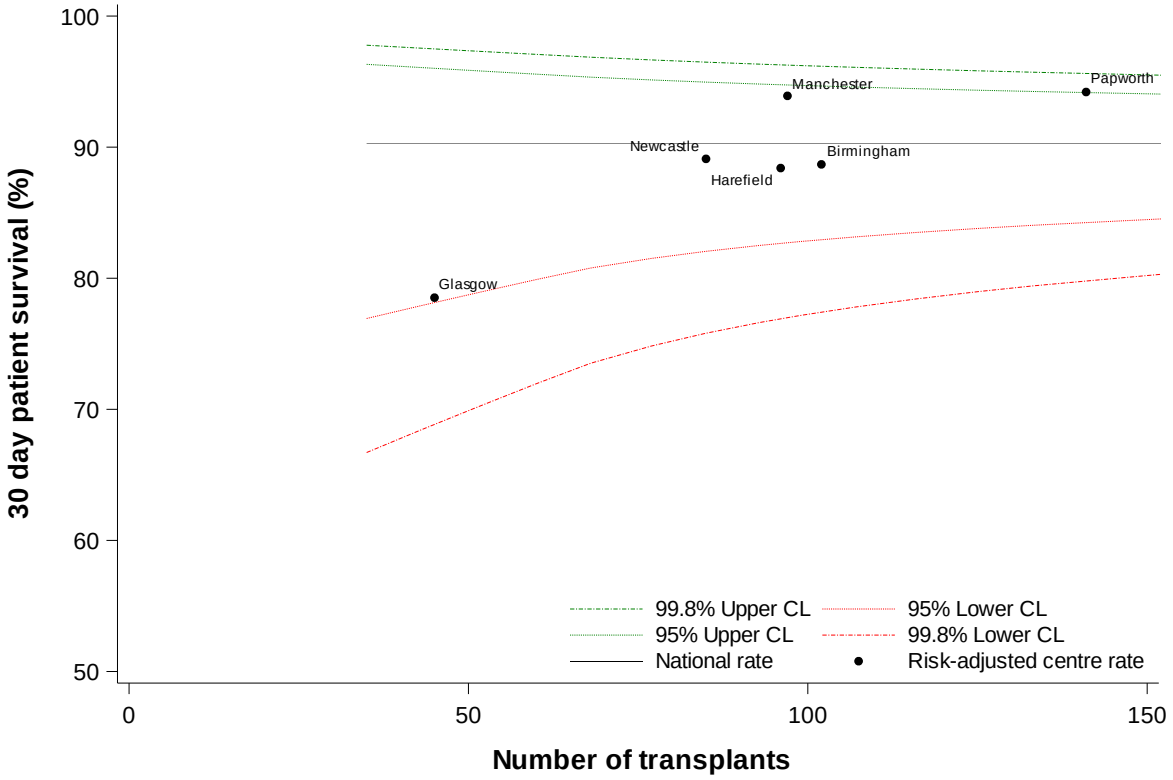


Table 6.2 and **Figure 6.2** show the 90-day post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 566 first adult DBD heart only transplants in the period 1 April 2014 to 31 March 2018. All of the centres' rates, apart from Papworth, were statistically consistent with the national rate of survival which was 86.6%. The rate for Papworth lies between the upper 95% and 99.8% confidence limits providing some evidence of a significantly high 90-day survival rate.

Table 6.2 90 day patient survival after first adult DBD heart transplant, by centre, 1 April 2014 and 31 March 2018

Centre	Number of transplants	% 90 day survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	102	85.3	(76.8 - 90.9)	84.3	(74.0 - 90.6)
Glasgow	45	84.4	(70.1 - 92.3)	78.4	(54.7 - 89.7)
Harefield	96	76.0	(66.2 - 83.4)	84.3	(76.4 - 89.6)
Manchester	97	91.8	(84.2 - 95.8)	90.6	(81.1 - 95.3)
Newcastle	85	85.9	(76.5 - 91.7)	85.1	(73.7 - 91.5)
Papworth	141	92.2	(86.4 - 95.6)	91.3	(84.2 - 95.2)
UK	**566**	**86.6**	**(83.5 - 89.1)**		

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

Figure 6.2 Risk-adjusted 90 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2014 to 31 March 2018

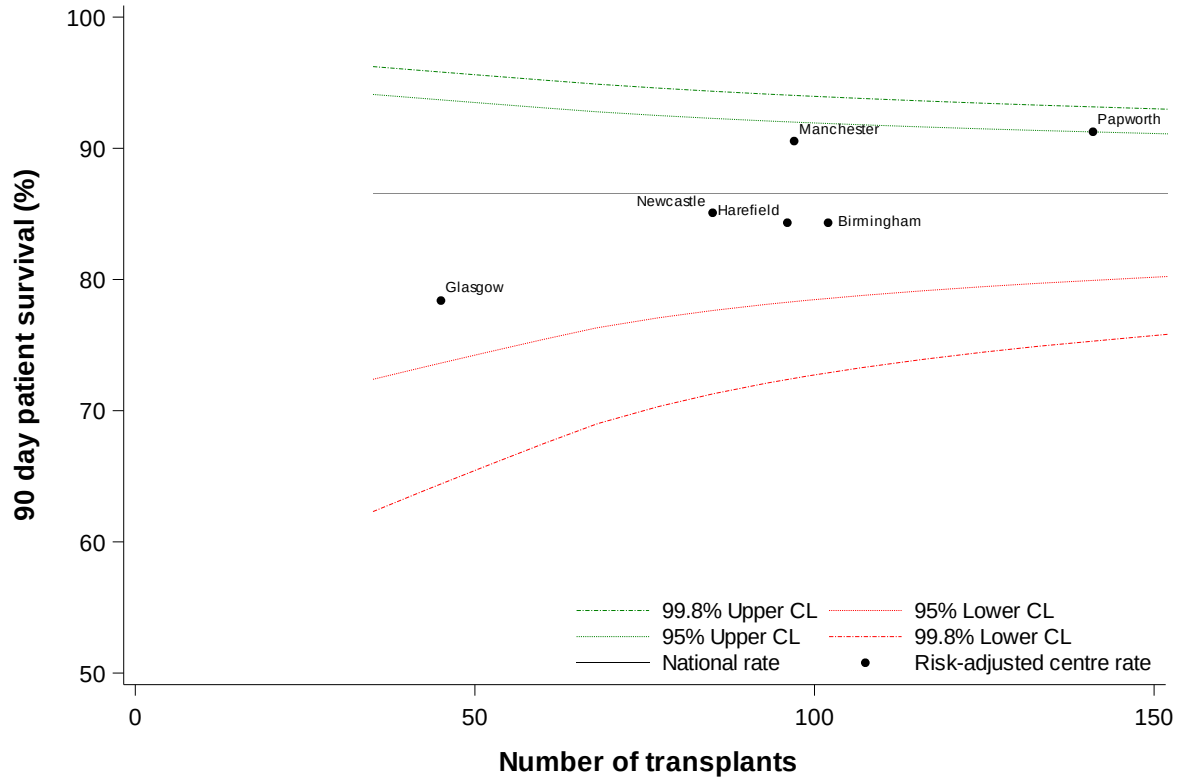


Table 6.3 and **Figure 6.3** show the 1-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 566 first adult DBD heart only transplants in the period 1 April 2014 to 31 March 2018. The national rate of survival was 82.4%. None of the centres' rates 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 6.3 1 year patient survival rates after first adult DBD heart transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of transplants	% 1 year survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	102	81.3	(72.3 - 87.6)	79.9	(68.5 - 87.2)
Glasgow	45	81.8	(66.8 - 90.5)	74.4	(48.8 - 87.2)
Harefield	96	70.7	(60.4 - 78.7)	80.1	(71.2 - 86.3)
Manchester	97	86.5	(77.9 - 91.9)	85.0	(74.1 - 91.3)
Newcastle	85	81.2	(71.1 – 88.0)	79.8	(67.0 - 87.6)
Papworth	141	89.3	(82.9 - 93.4)	88.4	(80.7 - 93.0)
UK	**566**	**82.4**	**(79.0 - 85.3)**		

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

Figure 6.3 Risk-adjusted one-year patient survival rates for adult DBD heart transplants, by centre, 1 April 2014 to 31 March 2018

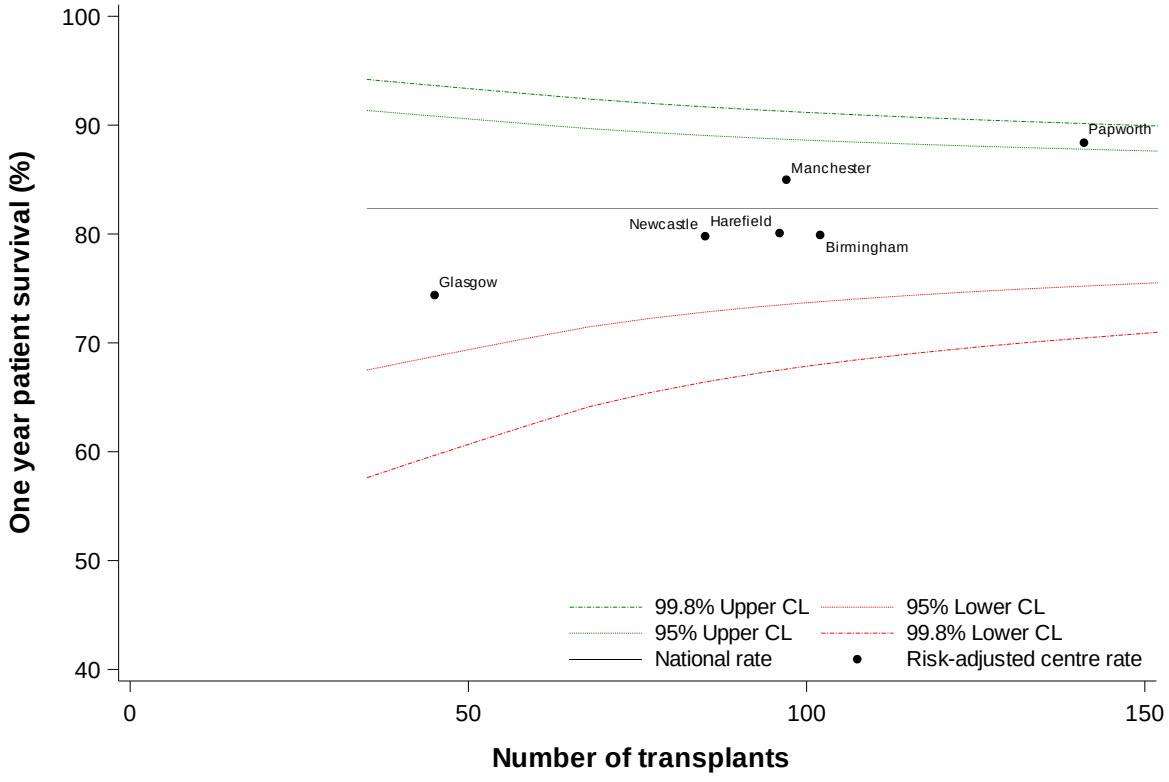


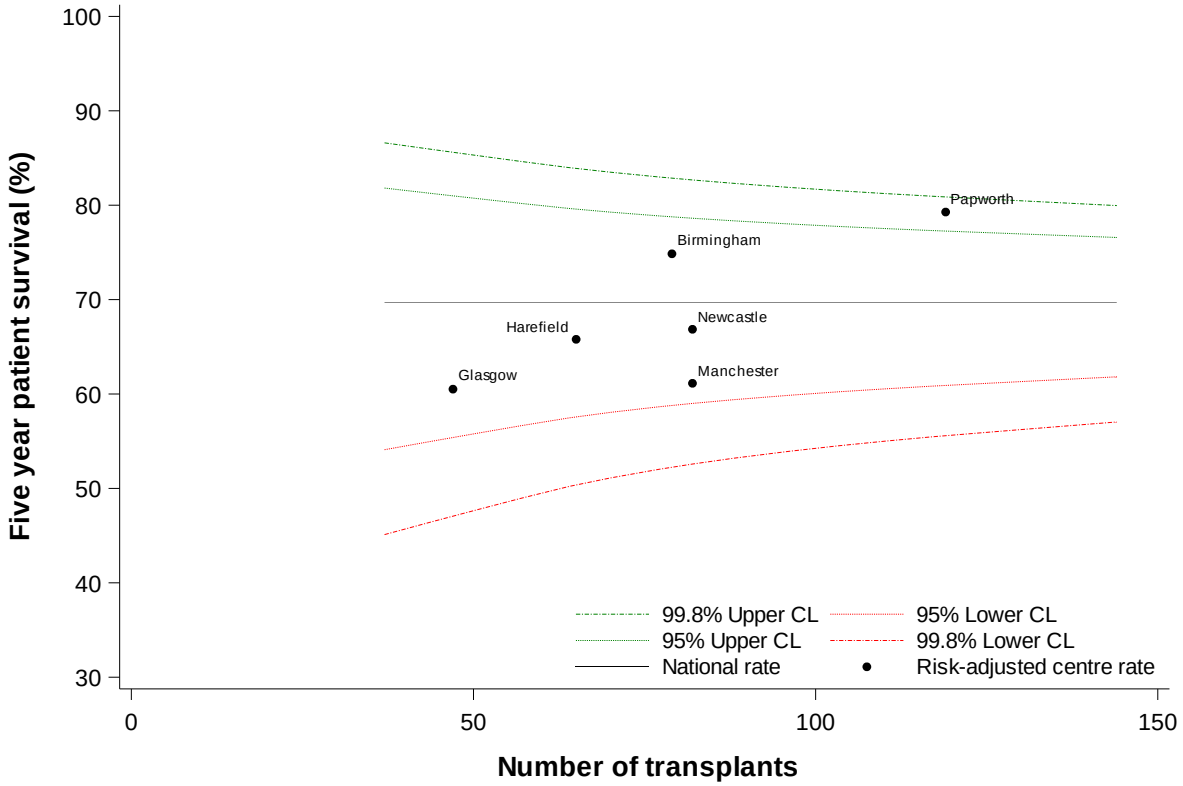
Table 6.4 and **Figure 6.4** show the 5-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 474 first adult DBD heart only transplants in the period 1 April 2010 to 31 March 2014. The national rate of survival was 69.7%. The rate for Papworth lies between the upper 95% and 99.8% confidence limits, indicating that it may be significantly higher than the national rate.

Table 6.4 5 year patient survival rates after first adult DBD heart transplant, by centre 1 April 2010 to 31 March 2014

Centre	Number of transplants	% 5 year survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	79	71.1	(59.3 – 80.0)	74.9	(61.8 - 83.4)
Glasgow	47	62.8	(46.9 - 75.2)	60.5	(36.5 - 75.5)
Harefield	65	73.7	(61.1 - 82.7)	65.8	(45.0 - 78.7)
Manchester	82	59.6	(48.1 - 69.3)	61.1	(45.3 - 72.4)
Newcastle	82	65.6	(54.2 - 74.8)	66.9	(52.0 - 77.1)
Papworth	119	79.8	(71.4 – 86.0)	79.3	(69.1 - 86.1)
UK	**474**	**69.7**	**(65.3 - 73.7)**		

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

Figure 6.4 Risk-adjusted five year patient survival rates for adult DBD heart transplants, by centre, 1 April 2010 to 31 March 2014



6.2 Survival by disease group

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

Table 6.5 1 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2014 and 31 March 2018

Disease group	Number of transplants	% 1 year survival (95% CI) Unadjusted		Risk-adjusted	
Congenital heart disease	36	77.8	(60.4 - 88.2)	76.5	(53.0 - 88.3)
Coronary heart disease	74	87.8	(77.9 - 93.5)	88.5	(77.8 - 94.0)
Dilated cardiomyopathy	338	82.4	(77.8 - 86.1)	83.4	(78.5 - 87.1)
Other	118	80.4	(72.0 - 86.5)	75.8	(63.5 - 83.9)
UK	**566**	**82.4**	**(79.0 - 85.3)**		

Table 6.6 5 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2010 and 31 March 2014

Disease group	Number of transplants	% 5 year survival (95% CI) Unadjusted		Risk-adjusted	
Congenital heart disease	41	70.3	(53.7 - 81.9)	71.4	(49.7 - 83.8)
Coronary heart disease	77	66.2	(54.1 - 75.9)	68.2	(52.9 - 78.5)
Dilated cardiomyopathy	267	71.2	(65.3 - 76.2)	70.5	(63.1 - 76.5)
Other	89	68.0	(57.1 - 76.7)	67.8	(53.4 - 77.8)
UK	**474**	**69.7**	**(65.3 - 73.7)**		

6.3 Survival by VAD status

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

Table 6.7 Unadjusted patient survival rates after first adult DBD heart transplant, by mechanical support status, 1 April 2014 and 31 March 2018

Mechanical support status	Number of transplants	% 30 day survival (95% CI) Unadjusted		% 90 day survival (95% CI) Unadjusted		% 1 year survival (95% CI) Unadjusted	
Short-term support	73	87.7	(77.6 - 93.4)	79.5	(68.3 - 87.1)	73.7	(62.0 - 82.4)
Long-term support	89	76.4	(66.1 - 83.9)	70.8	(60.1 - 79.1)	67.3	(56.4 - 76.0)
No support	404	93.8	(91.0 - 95.8)	91.3	(88.1 - 93.7)	87.2	(83.6 - 90.2)
UK	**566**	**90.3**	**(87.5 - 92.5)**	**86.6**	**(83.5 - 89.1)**	**82.4**	**(79.0 - 85.3)**

6.4 Survival post DCD heart transplant

Tables 6.8 - **6.10** present short-term patient survival rates following DCD heart only transplant, by centre and nationally. During the time period 1 April 2014 to 31 March 2018 a small number of transplants were performed, by three centres only, and there were nine deaths within 1 year.

Table 6.8 30 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2014 and 31 March 2018

Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Harefield[1]	7	0	-	-
Manchester[1]	6	0	-	-
Papworth	43	0	100.0	-
UK	**56**	**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 6.9 90 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2014 and 31 March 2018

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Harefield[1]	7	1	-	-
Manchester[1]	6	1	-	-
Papworth	43	3	93	(79.9 - 97.7)
UK	**56**	**5**	**91.1**	**(79.9 - 96.2)**

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

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

Table 6.10 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2014 and 31 March 2018

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Harefield[1]	7	2	-	-
Manchester[1]	6	2	-	-
Papworth	43	5	88.4	(74.3 – 95.0)
UK	**56**	**9**	**83.9**	**(71.4 - 91.3)**

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

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

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 2007 and 31 December 2018. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The risk factors used to produce the risk-adjusted survival rates are listed in **Appendix A2.1**.

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

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

Table 7.1 **Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2007 to 31 December 2018**

Centre	One year			Five year		
	Number at risk[1] at day 0	Survival rate (%)	(95% CI)	Number at risk[1]	Survival rate (%)	(95% CI)	Number at risk[1]
Birmingham	345	76.2	(70.2 - 81.0)	210	60.3	(52.2 - 67.1)	74
Glasgow	193	83.2	(76.8 - 87.8)	118	65.3	(56.1 - 72.6)	31
Harefield	391	84.5	(80.3 - 87.8)	279	65.3	(58.8 - 70.8)	93
Manchester	322	89.3	(85.1 - 92.3)	245	69.9	(63.2 - 75.4)	84
Newcastle	409	78.7	(73.6 - 82.8)	290	55.6	(47.6 - 62.4)	93
Papworth	501	86.4	(83.0 - 89.2)	367	71.6	(66.1 - 76.2)	161
UK	2161	83.3	(81.6 - 84.9)	1509	65.1	(62.5 - 67.5)	536

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

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

Figure 7.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2007 – 31 December 2018

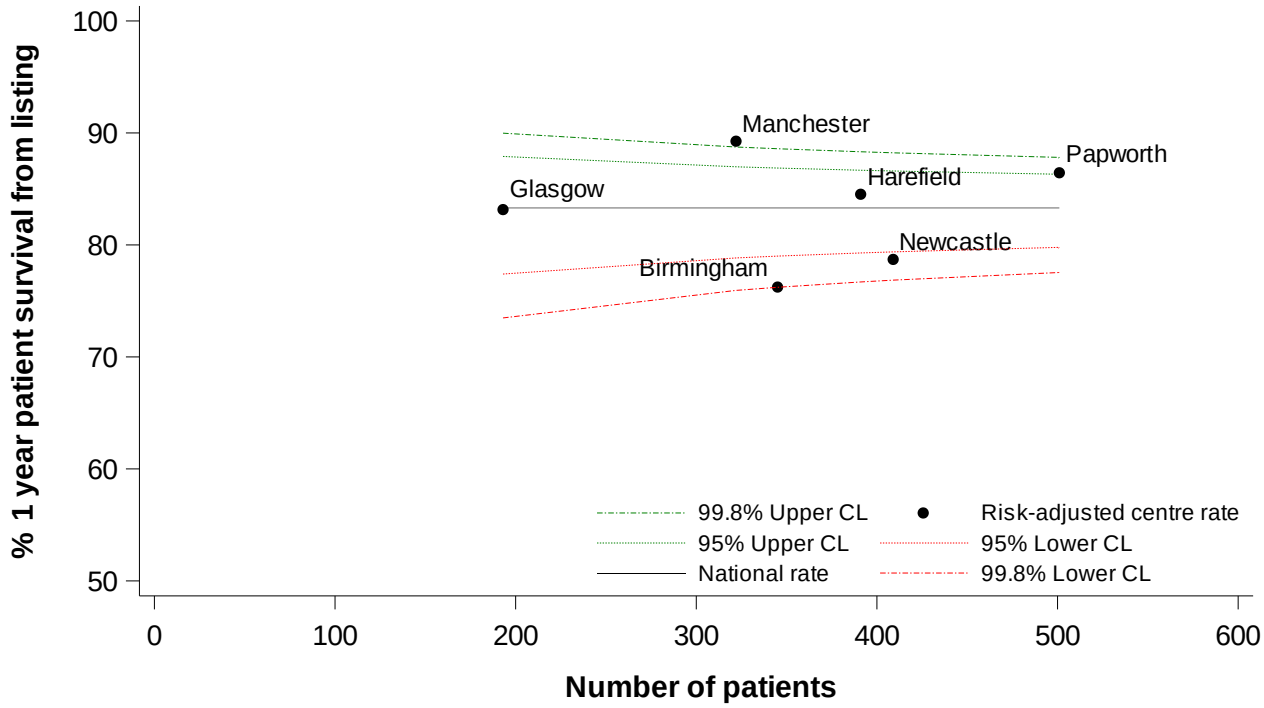
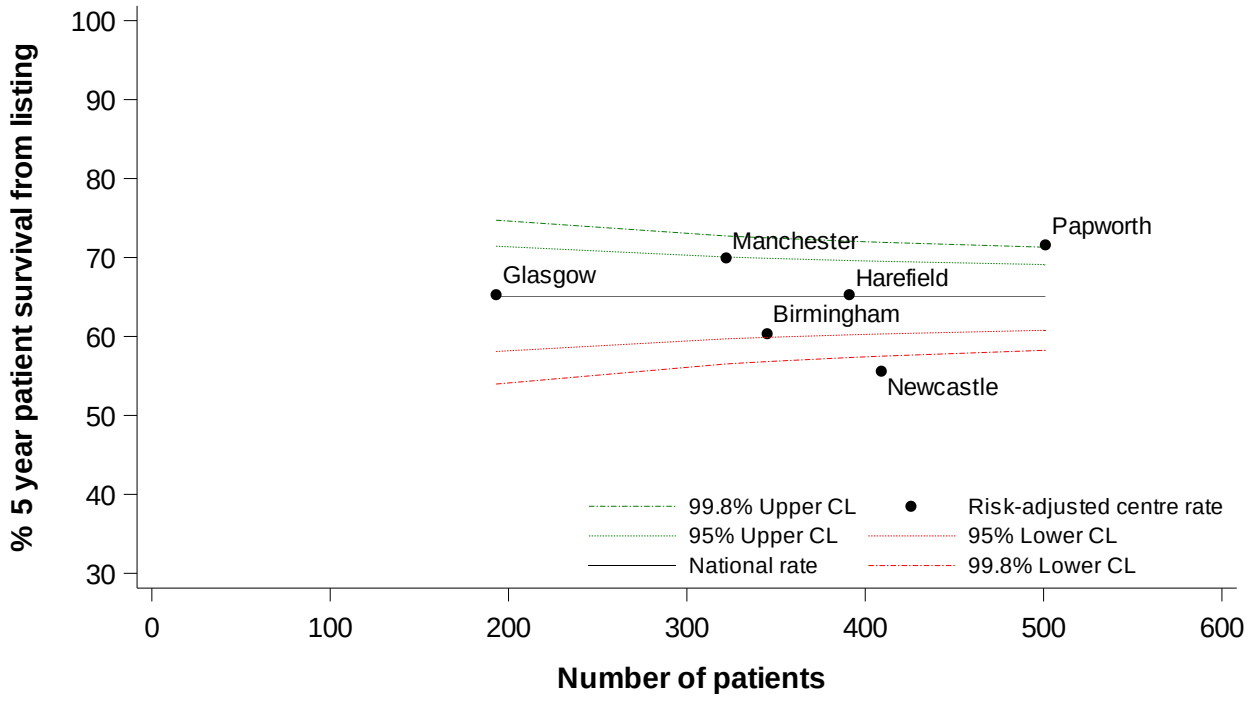


Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2007 – 31 December 2018



ADULT HEART TRANSPLANTATION

Form Return Rates

8. Adult heart form return rates, 1 January – 31 December 2018

Form return rates are reported in **Table 8.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult heart transplants between 1 January and 31 December 2018 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, especially Birmingham who have only returned 30% of lifetime follow-up forms issued.

Table 8.1 Form return rates for adult heart transplants, 1 January 2018 to 31 December 2018

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	20	80	240	30
Royal Bournemouth General Hospital	-	-	-	-	-	-	1	0
Glasgow Golden Jubilee Hospital	11	91	7	100	12	92	144	58
Harefield Hospital	39	97	30	100	26	96	508	97
Manchester Wythenshawe Hospital	24	100	25	100	18	100	255	98
Newcastle Freeman Hospital	19	100	19	100	17	100	306	96
Royal Papworth Hospital	44	100	43	100	52	100	572	97
Sheffield Northern General Hospital	-	-	-	-	-	-	51	94
Overall	159	99	146	100	145	96	2078	86

ADULT LUNG TRANSPLANTATION

Transplant List

9.1 Adult lung and heart-lung transplant list as at 31 March, 2010 – 2019

Figure 9.1 shows the number of adult patients on the lung and heart-lung transplant lists at 31 March each year between 2010 and 2019 split by urgency status of the patient. The number of patients on the active non-urgent lung transplant list has increased since 2011, reaching 331 on 31 March 2019. The number of patients on the heart-lung list has remained fairly stable throughout the period. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2019, there were no adult patients on either the urgent or super-urgent lists.

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

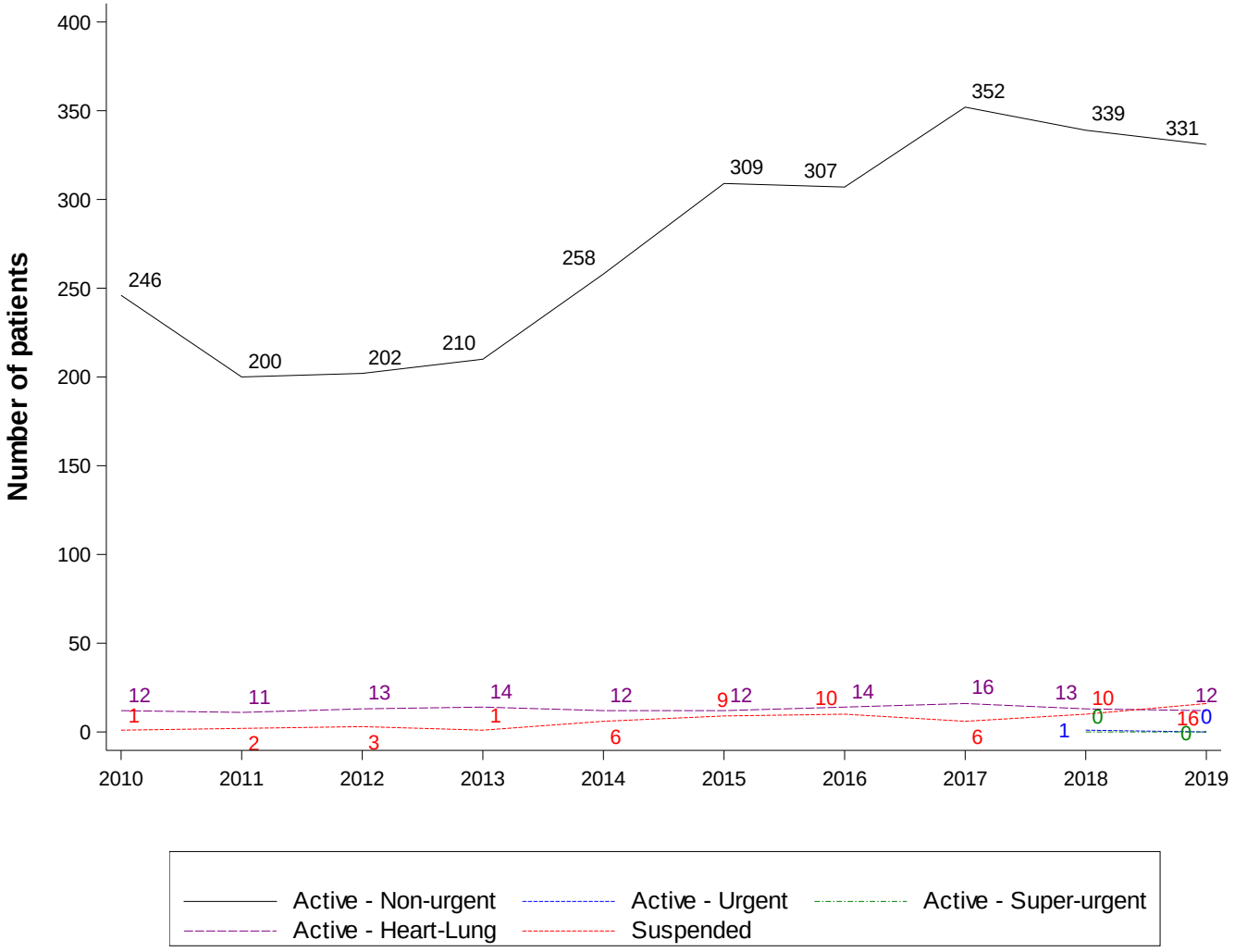


Figure 9.2 shows the number of adult patients on the active lung and heart-lung transplant lists on 31 March 2019 by centre. In total, there were 343 adult patients waiting, including 12 patients waiting for a heart-lung transplant. Harefield had the highest number of patients on the transplant list while Papworth had the lowest.

Figure 9.2 Number of adult patients on the active lung and heart-lung transplant lists at 31 March 2019, by centre

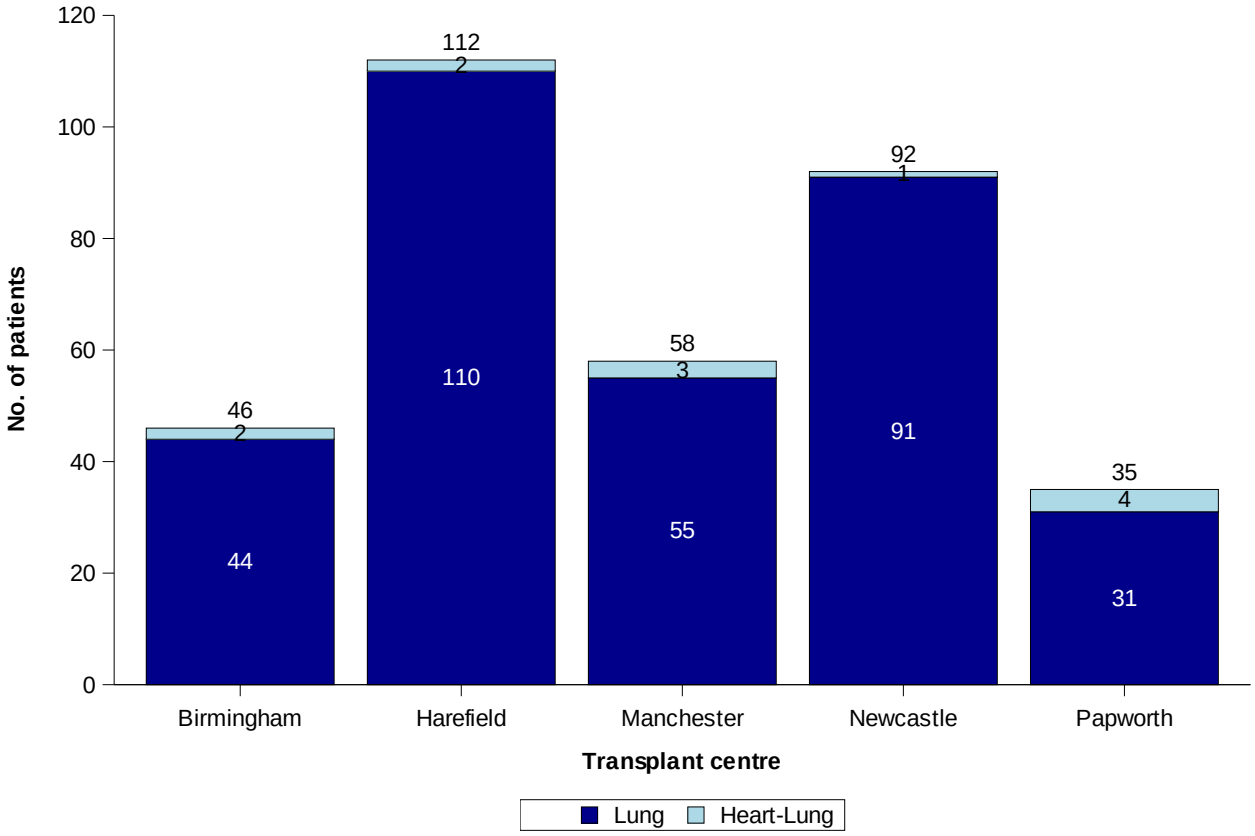
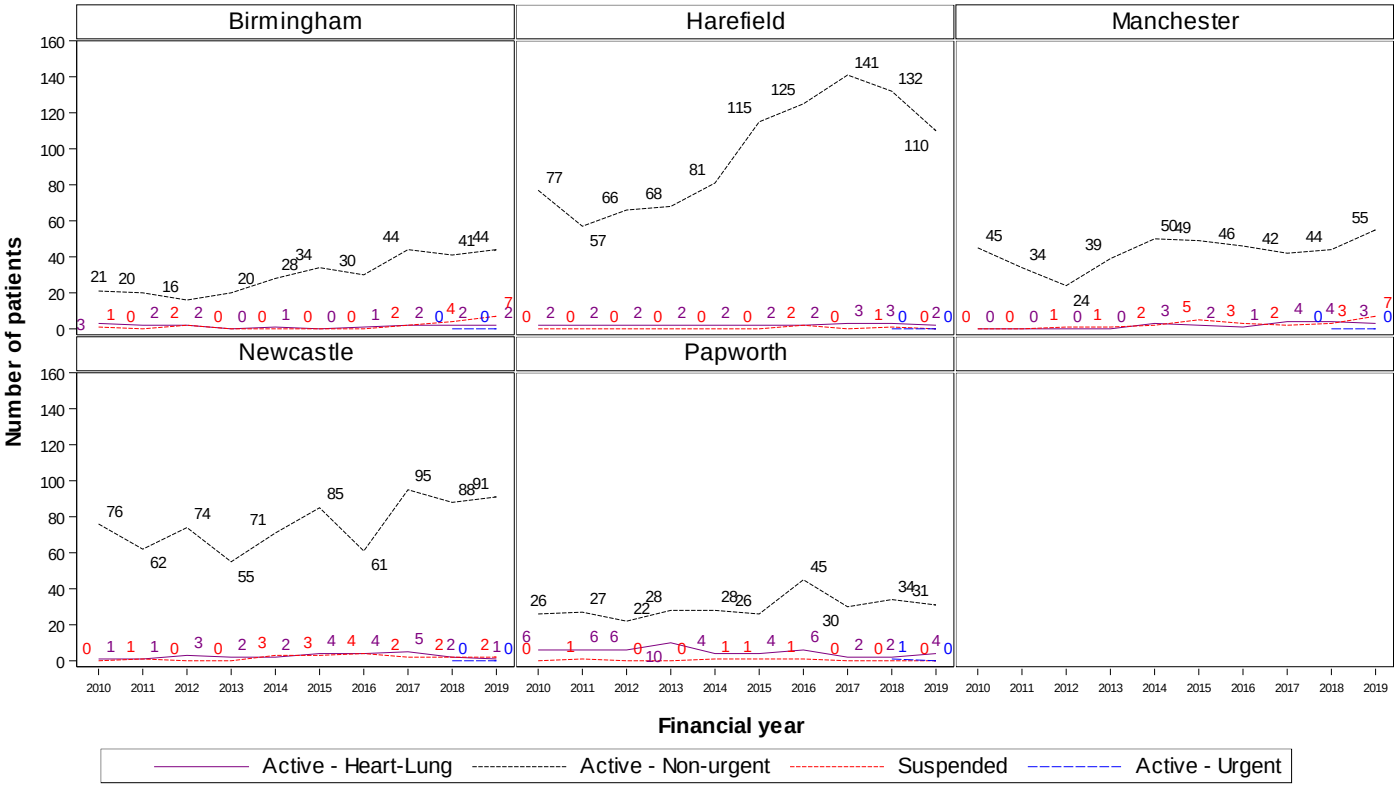


Figure 9.3 shows the trend over time in the number of adult patients on the lung transplant list at 31 March each year across centre. Harefield have experienced a marked increase in their lung list since 2011 compared with other centres, however in the last two years it has decreased slightly.

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 2018 – 31 March 2019

There were 271 adult patient registrations onto the lung or heart-lung transplant lists between 1 April 2018 and 31 March 2019. 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 54 years. Note that there were 18 urgent lung registrations and 4 super-urgent lung registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

Table 9.1 Demographic characteristics of adult patients registered onto the lung transplant list between 1 April 2018 and 31 March 2019, by centre

		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL** N (%)
Number of registrations		42 (100)	84 (100)	44 (100)	53(100)	48 (100)	**271 (100)**
Highest urgency on the lung list during registration	Non-urgent	38 (90)	80 (95)	43 (98)	47 (89)	41 (85)	**249 (92)**
	Urgent	4 (10)	0 (0)	1 (2)	6 (11)	7 (15)	**18 (7)**
	Super-urgent	0 (0)	4 (5)	0 (0)	0 (0)	0 (0)	**4 (2)**
Recipient sex	Male	21 (50)	45 (54)	22 (50)	33 (62)	29 (60)	**150 (55)**
	Female	21 (50)	39 (46)	22 (50)	19 (36)	19 (40)	**120 (44)**
	Missing	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)	**1 (0)**
Recipient ethnicity	White	38 (90)	78 (93)	41 (93)	49 (92)	41 (85)	**247 (91)**
	Non-white	4 (10)	6 (7)	3 (7)	4 (8)	7 (15)	**24 (9)**
Recipient age (years)	Median (IQR)	55 (49, 59)	46 (33, 57)	52 (46, 59)	57 (50, 61)	57 (46, 63)	**54 (41, 60)**
	Missing	0	0	0	0	0	**0**
Primary Disease	Cystic fibrosis and bronchiectasis	6 (14)	33 (39)	11 (25)	7 (13)	7 (15)	**64 (24)**
	Fibrosing lung disease	15 (36)	24 (29)	14 (32)	27 (51)	24 (50)	**104 (38)**
	COPD and emphysema	16 (38)	21 (25)	15 (34)	9 (17)	7 (15)	**68 (25)**
	Primary pulmonary hypertension	1 (2)	0 (0)	2 (5)	2 (4)	3 (6)	**8 (3)**
	Other	4 (10)	6 (7)	2 (5)	8 (15)	7 (15)	**27 (10)**
Smoker	No	42 (100)	84 (100)	44 (100)	53 (100)	47 (98)	**270 (100)**
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	**1 (0)**
Lung function - FEV1 (litres)	Median (IQR)	0.97 (0.66, 1.49)	0.92 (0.68, 1.68)	0.92 (0.66, 1.45)	1.50 (0.90, 2.13)	1.18 (0.77, 2.02)	**1.06 (0.72, 1.81)**
	Missing	1	3	0	3	0	**7**
Lung function – FVC (litres)	Median (IQR)	2.01 (1.70, 2.64)	2.08 (1.61, 2.48)	2.27 (1.88, 3.07)	2.03 (1.62, 2.77)	2.21 (1.36, 2.83)	**2.10 (1.61, 2.75)**
	Missing	1	3	0	5	0	**9**

9.3 Post-registration outcomes, 1 April 2015 – 31 March 2016

The registration outcomes of adult patients listed for a lung transplant between 1 April 2015 and 31 March 2016 are summarised nationally in **Figure 9.4** and by centre in **Figure 9.5**. The possible outcomes for patients on the list include receiving a transplant, removal from the list, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be “transplanted”.

Nationally, within six months of registration, 33% of lung patients had been transplanted and 7% had died. Three years after listing, 60% have been transplanted and 20% had died. Note that the urgent and super-urgent lung allocation schemes were introduced in May 2017 and a small number of patients in this cohort were moved to these new lists after this date. By centre, within 1 year of registration, the proportion transplanted ranged from 30% at Harefield to 63% at Papworth. Removals from the list were predominantly due to deteriorating condition.

Figure 9.4 Post-registration outcome for 259 lung only registrations made in the UK, 1 April 2015 to 31 March 2016

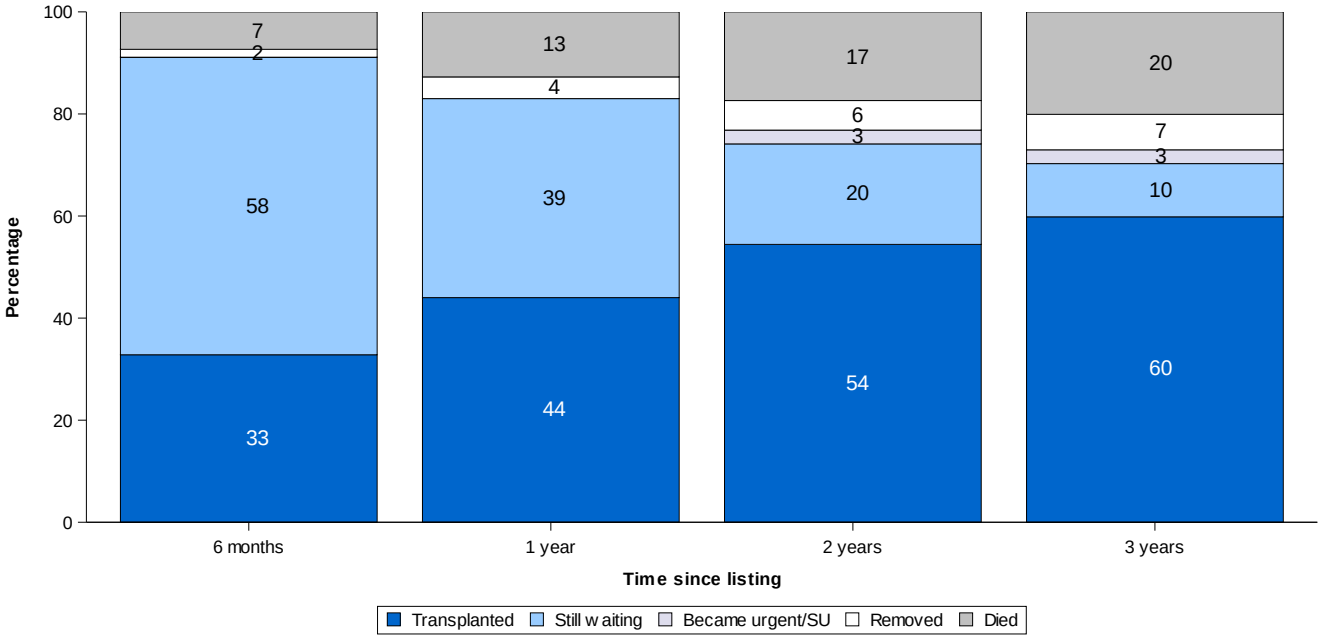
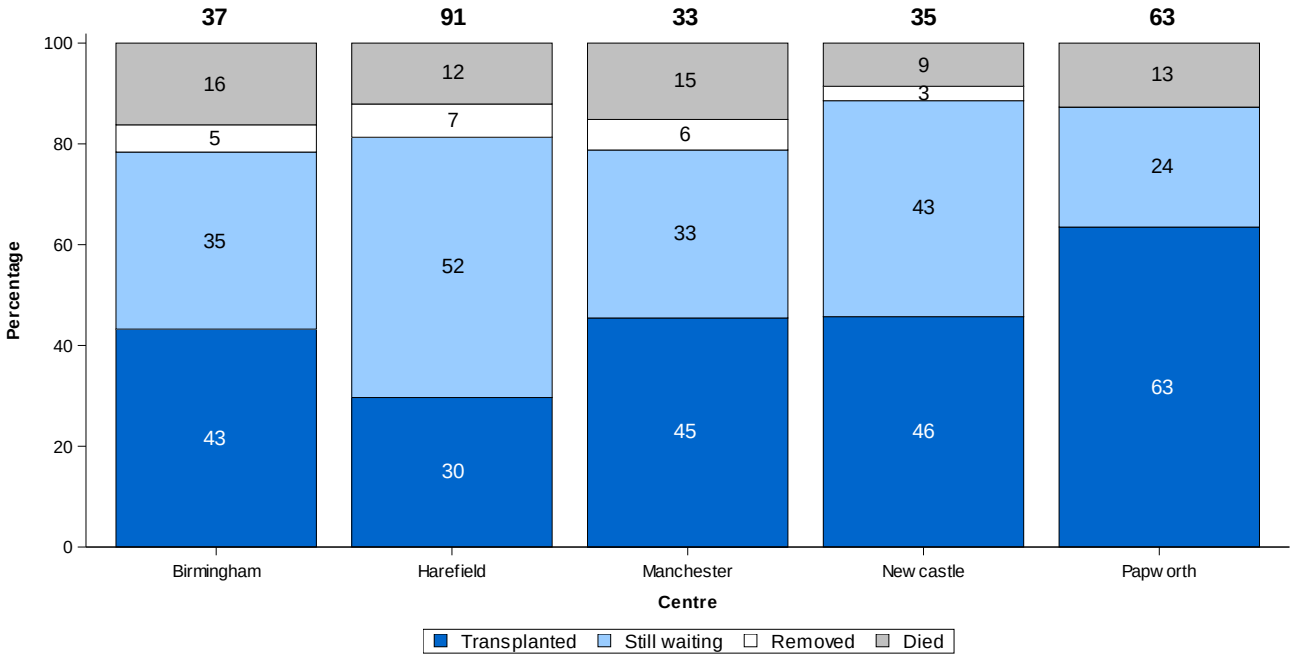


Figure 9.5 1 year registration outcomes by centre, for lung only registrations made in the UK, 1 April 2015 to 31 March 2016



9.4 Median waiting time to transplant, 1 April 2013 - 31 March 2016

The median waiting time to lung transplant from registration for adult patients is shown in **Figure 9.6** and **Table 9.2**. This is estimated for patients registered on the lung only transplant list between 1 April 2013 and 31 March 2016 using the Kaplan Meier method (before the introduction of the super-urgent and urgent lung allocation schemes in May 2017 but for patients that were moved to these lists after May 2017 this waiting time is included). The national median waiting time was 326 days and ranged from 212 days at Papworth to 449 days at Manchester (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 2013 and 31 March 2016, by centre

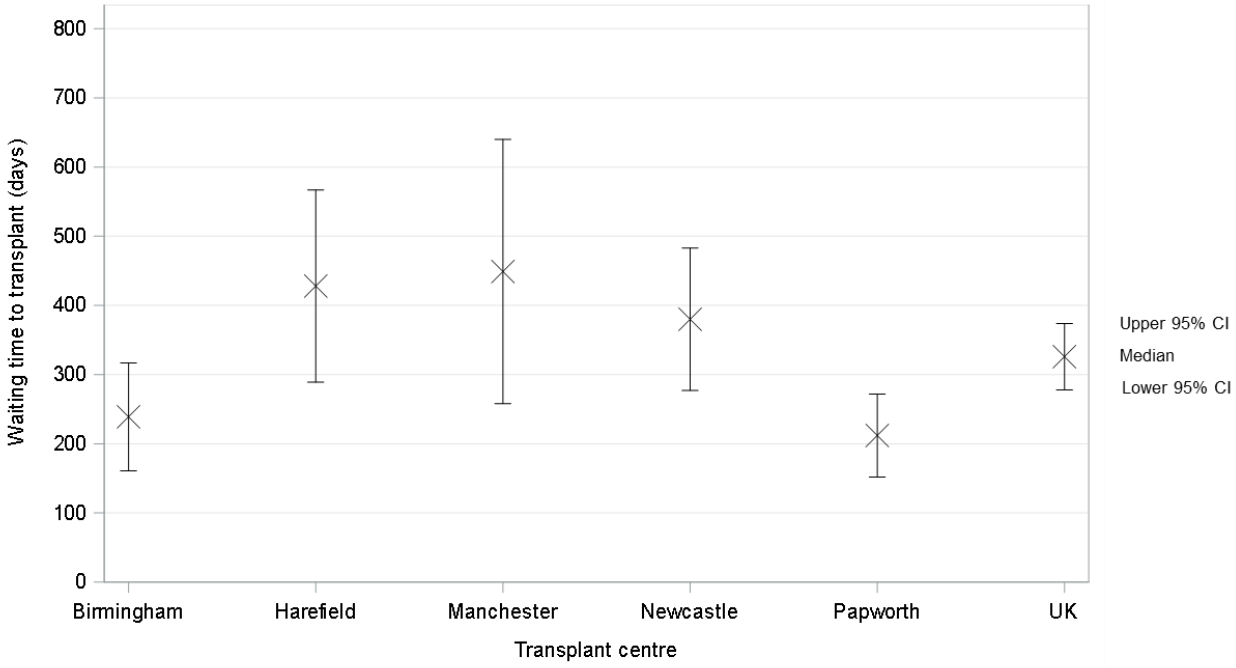


Table 9.2 Median active waiting time to lung transplant for adult patients registered on the transplant list, by centre, 1 April 2013 to 31 March 2016

Transplant centre	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Birmingham	114	239	161 - 317
Harefield	267	428	289 - 567
Manchester	125	449	258 - 640
Newcastle	191	380	277 - 483
Papworth	165	212	152 - 272
UK	**862**	**326**	**278 - 374**

The median waiting time to lung transplant for adult patients is also considered by blood group. This is shown in **Figure 9.7** and **Table 9.3**. Blood group O patients have the longest average wait (478 days) compared with the other blood groups (log-rank p<0.0001).

Figure 9.7 Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2013 and 31 March 2016, by blood group

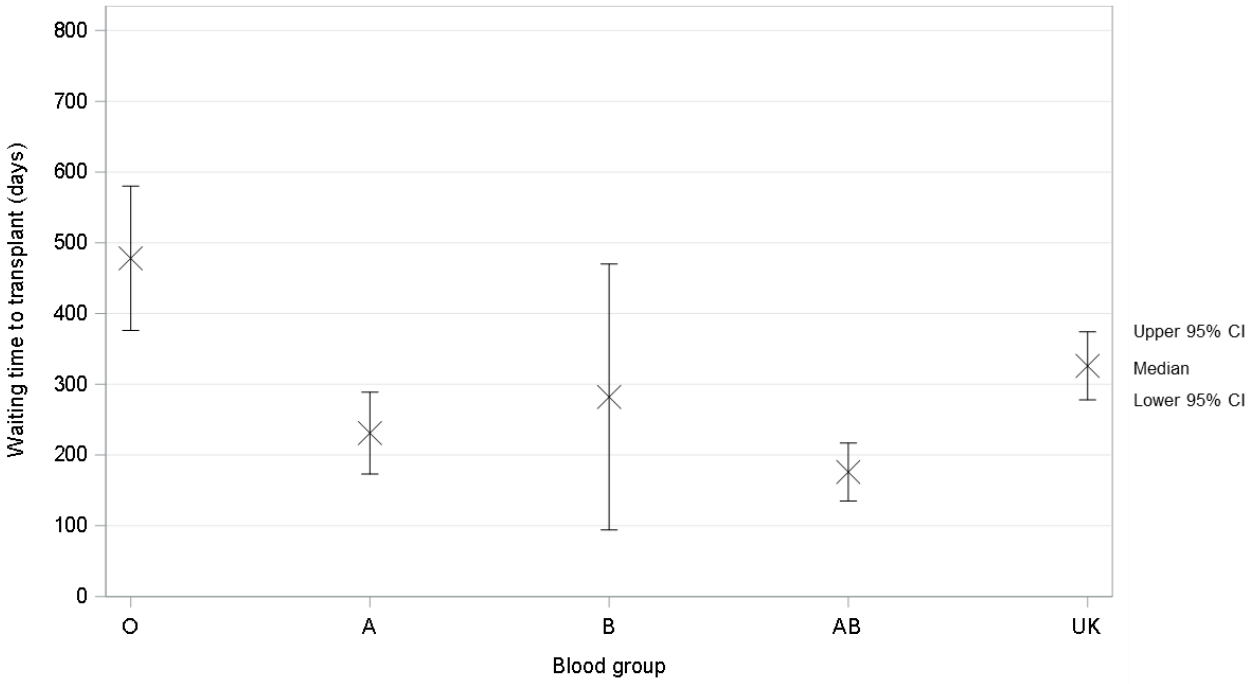


Table 9.3 Median active waiting time to lung transplant for adult patients registered on the transplant list, by blood group, 1 April 2013 to 31 March 2016

Blood group	Number of patients registered	Waiting time (days) Median	95% Confidence interval
A	381	231	173 - 289
AB	22	176	135 - 217
B	79	282	94 - 470
O	380	478	376 - 580
UK	**862**	**326**	**278 - 374**

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 2016 and 31 March 2019 that were eventually transplanted and excludes all fast track offers. A bilateral lung offer is counted as accepted if either both the lungs were accepted or just a single lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lung(s) is/are declined as well as cases where both the heart and lung(s) are declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

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

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

Figure 10.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2016 to 31 March 2019

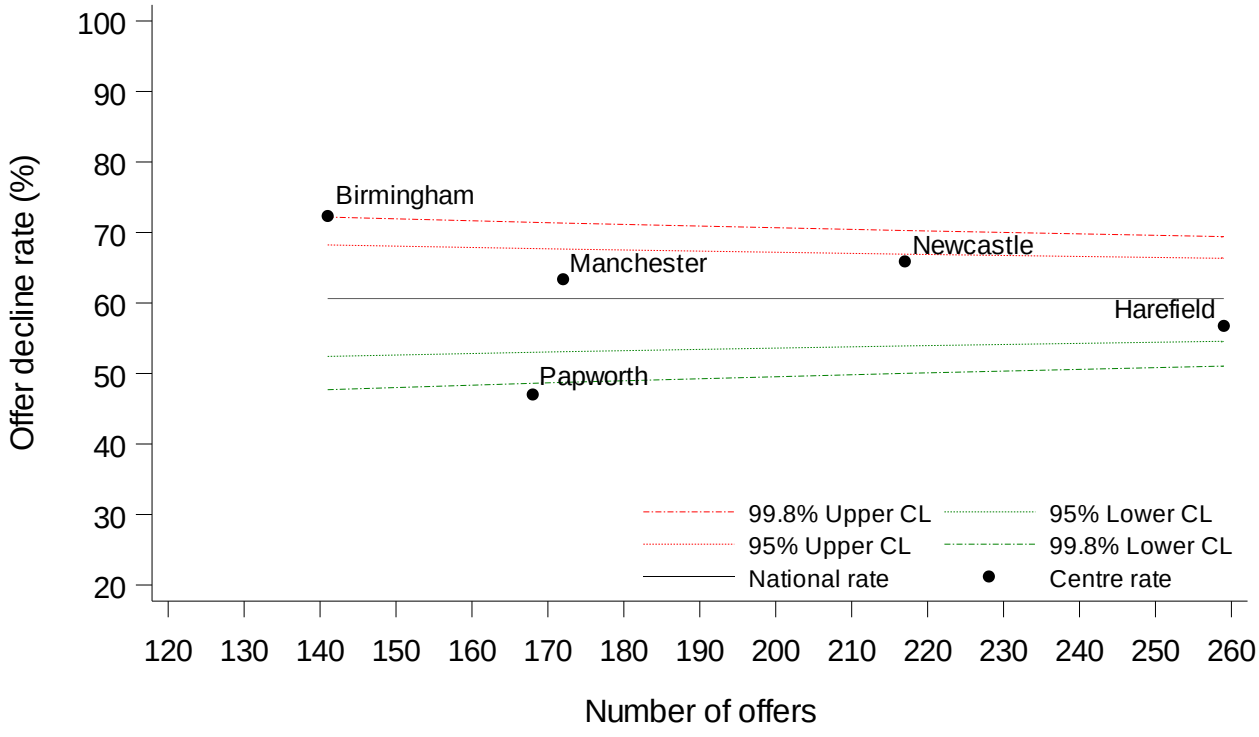


Table 10.1 shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the number of offers (for lungs that were eventually transplanted) increased in 2017/2018 but reduced back down in 2018/2019. There have been several changes in donor lung offering during this period which will affect these numbers; the introduction of patient-specific offers for urgent and super-urgent patients in May 2017, an increase in transplant activity in 2017/2018 (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 2016 and 31 March 2019

Centre	2016/17		2017/18		2018/19		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	42	(76.2)	59	(69.5)	40	(72.5)	141	(72.3)
Harefield	74	(54.1)	117	(61.5)	68	(51.5)	259	(56.8)
Manchester	53	(54.7)	79	(70.9)	40	(60.0)	172	(63.4)
Newcastle	54	(51.9)	100	(70.0)	63	(71.4)	217	(65.9)
Papworth	45	(31.1)	77	(59.7)	46	(41.3)	168	(47.0)
UK	**268**	**(53.4)**	**432**	**(66.0)**	**257**	**(59.1)**	**957**	**(60.6)**

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 LUNG TRANSPLANTATION

Transplants

11.1 Adult lung and heart-lung transplants, 1 April 2009 – 31 March 2019

Figure 11.1 and **11.2** show the number of adult lung transplants performed per year over the last ten years, by donor type, nationally and by centre, respectively. The number of transplants increased over the first half of the period, reaching a peak of 210 in 2013/2014. The number has since fallen (except in 2017/2018 which was another peak year), with only 158 transplants last year. **Figure 11.2** shows that all centres performed fewer transplants in 2018/2019 compared with the previous year, most notably Newcastle. In the last year DCD lung transplantation represented approximately 24% 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 2009 to 31 March 2019

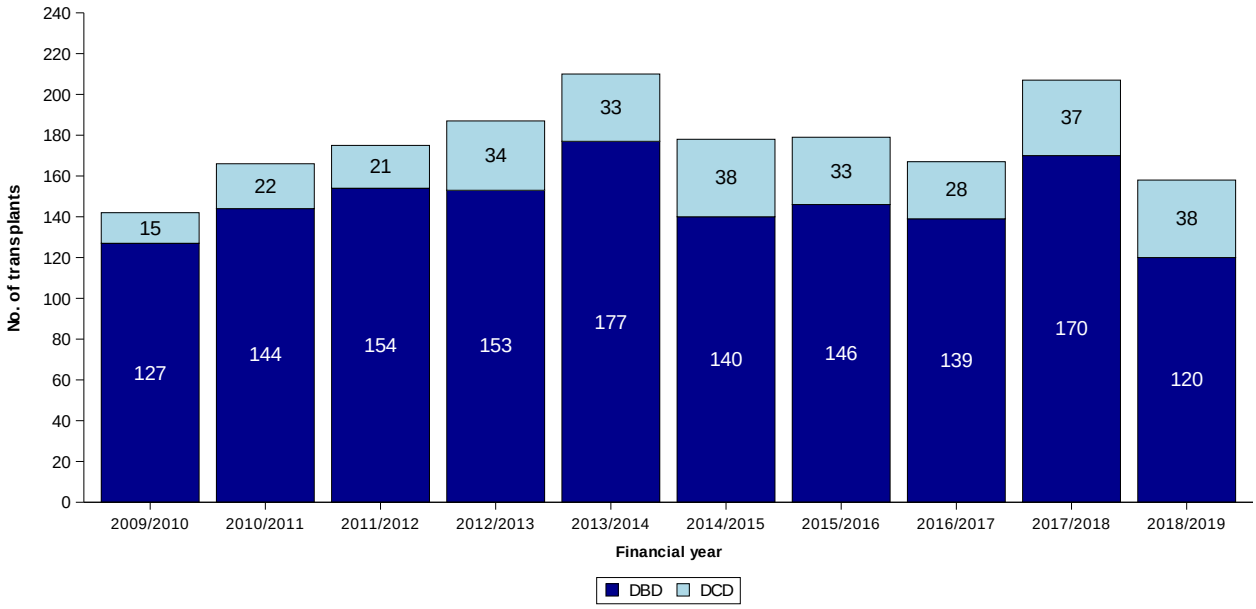


Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2009 to 31 March 2019

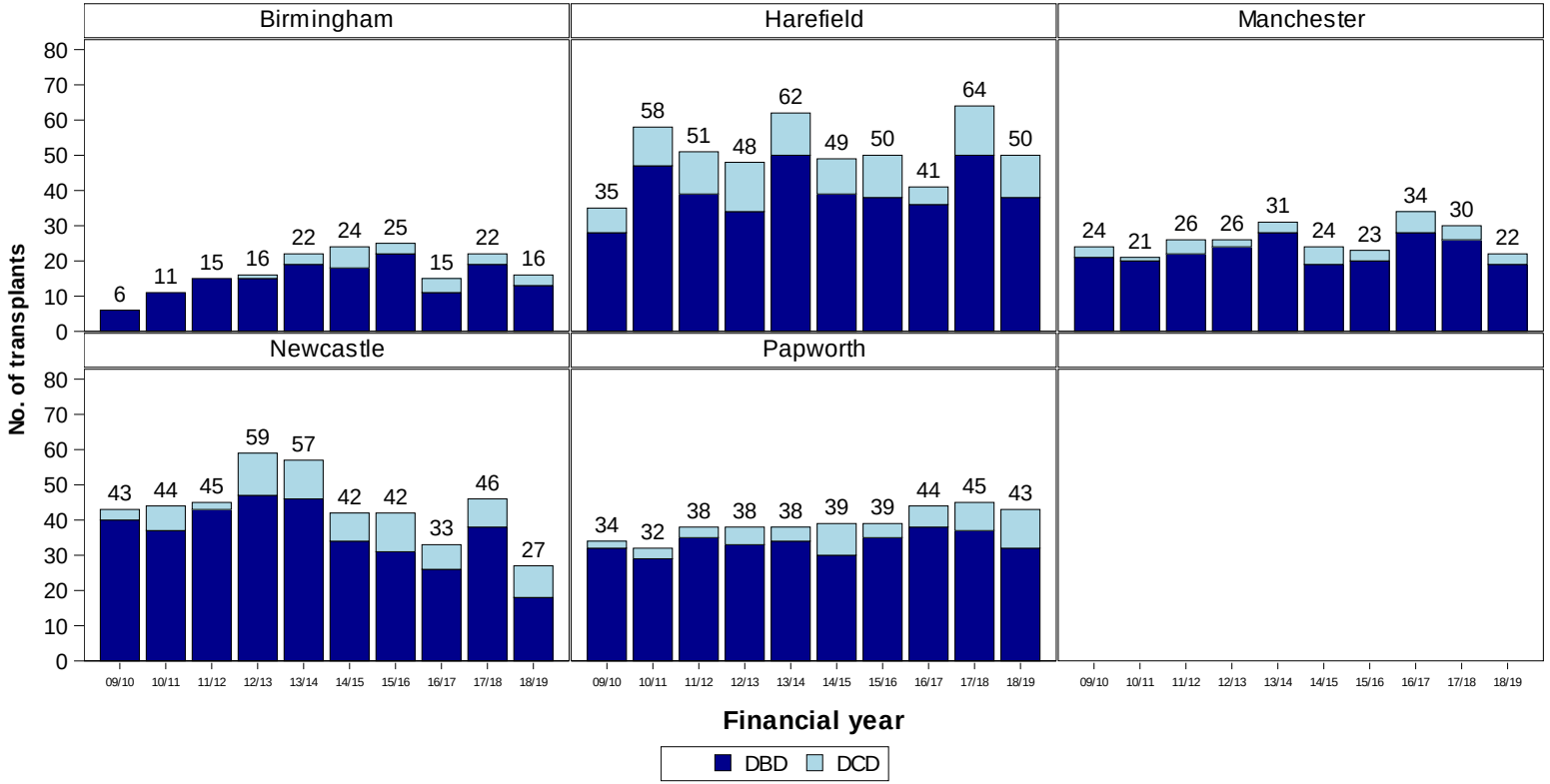


Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2018 to 31 March 2019

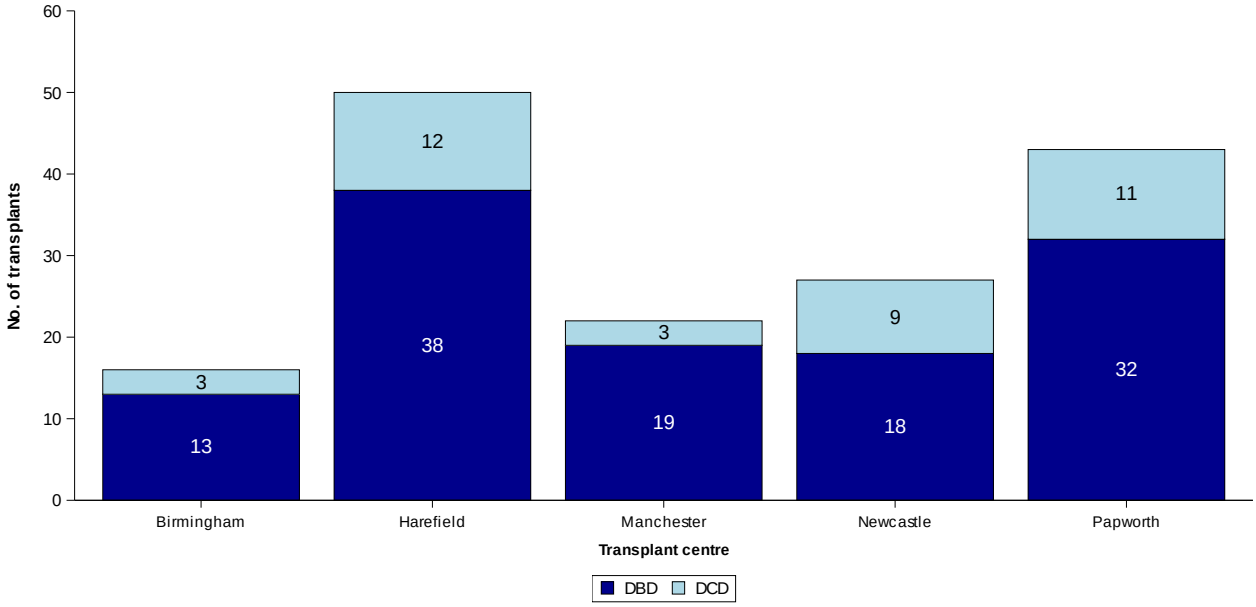


Figure 11.4 and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. The number of transplants by transplant type in the latest financial year (2018/2019) is shown by centre in **Figure 11.6**. There was a total of 46 heart-lung block transplants, and no partial lung transplants, over the decade. The overall proportion of single lung transplants has decreased from 25% in 2009/2010 to 10% in 2018/2019. When broken down by centre, it can be seen that Newcastle and Birmingham have reduced their use of single lungs. In the last financial year Papworth was the highest user of single lungs and Manchester and Newcastle were the only centres to have performed heart-lung block transplants (**Figure 11.6**).

Figure 11.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2009 to 31 March 2019

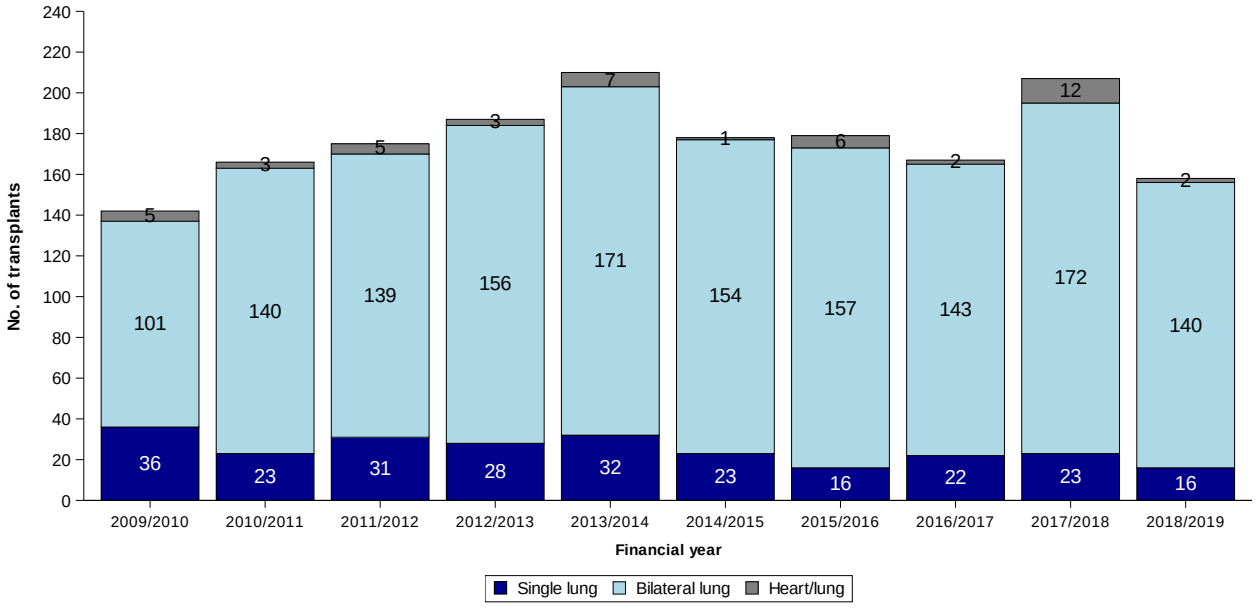


Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2009 to 31 March 2019

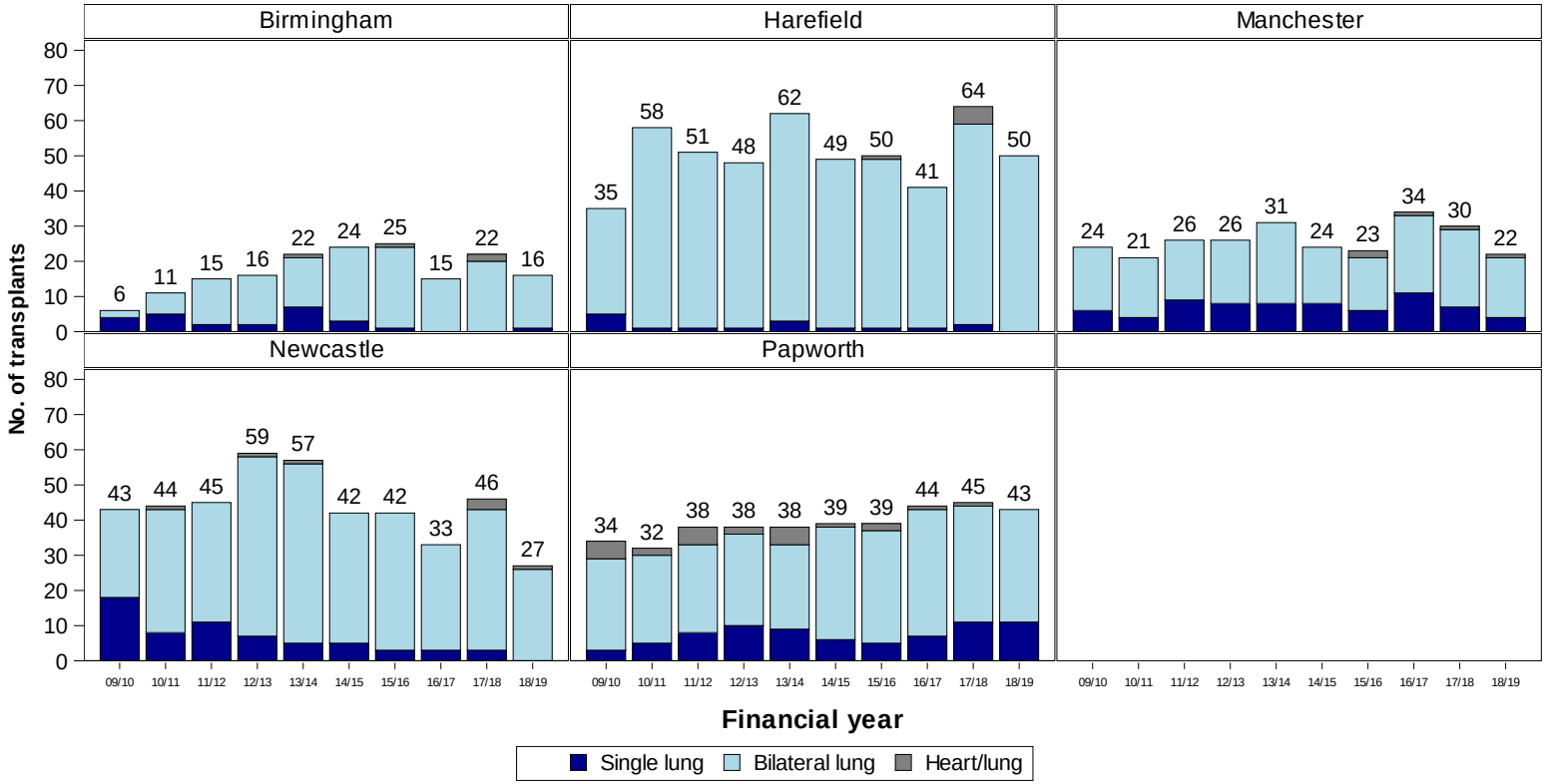
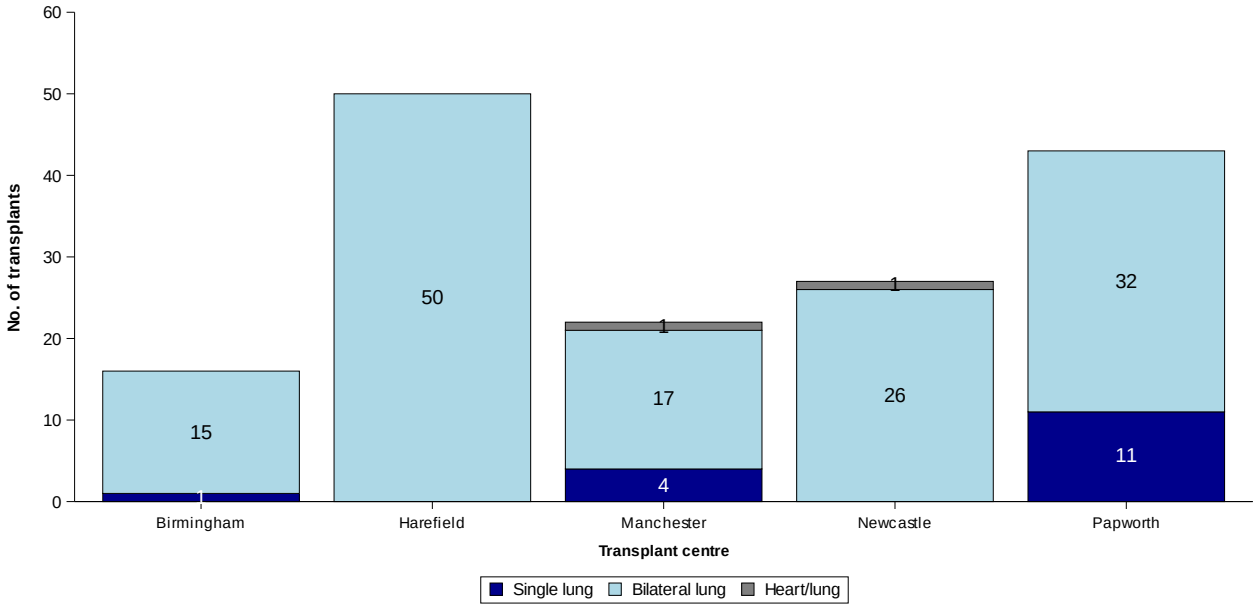


Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2018 to 31 March 2019



On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. The number of lung only transplants per year by urgency status is shown in **Figure 11.7**; the proportion of urgent or super-urgent lung transplants decreased in 2018/2019 compared with 2017/2018. **Figure 11.8** shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 24 urgent lung only transplants (ranging from 2 at Manchester to 8 at Papworth) and 7 super-urgent lung only transplants (6 performed by Harefield and 1 by Papworth). Heart-lung patients have access to urgent transplantation through the heart allocation scheme. Of the 2 adult heart-lung transplants in 2018/2019, 1 was non-urgent and 1 was urgent (Figure not shown).

Figure 11.7 Number of adult lung only transplants in the UK, by financial year and urgency status, 1 April 2009 to 31 March 2019

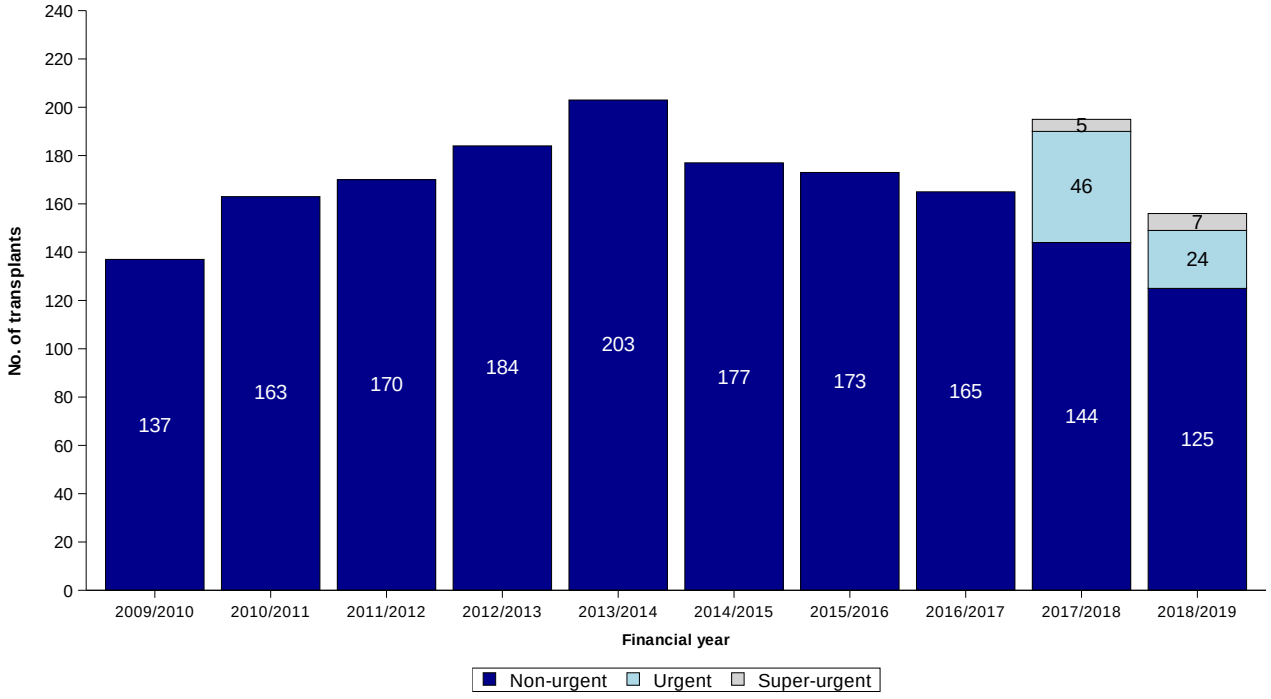
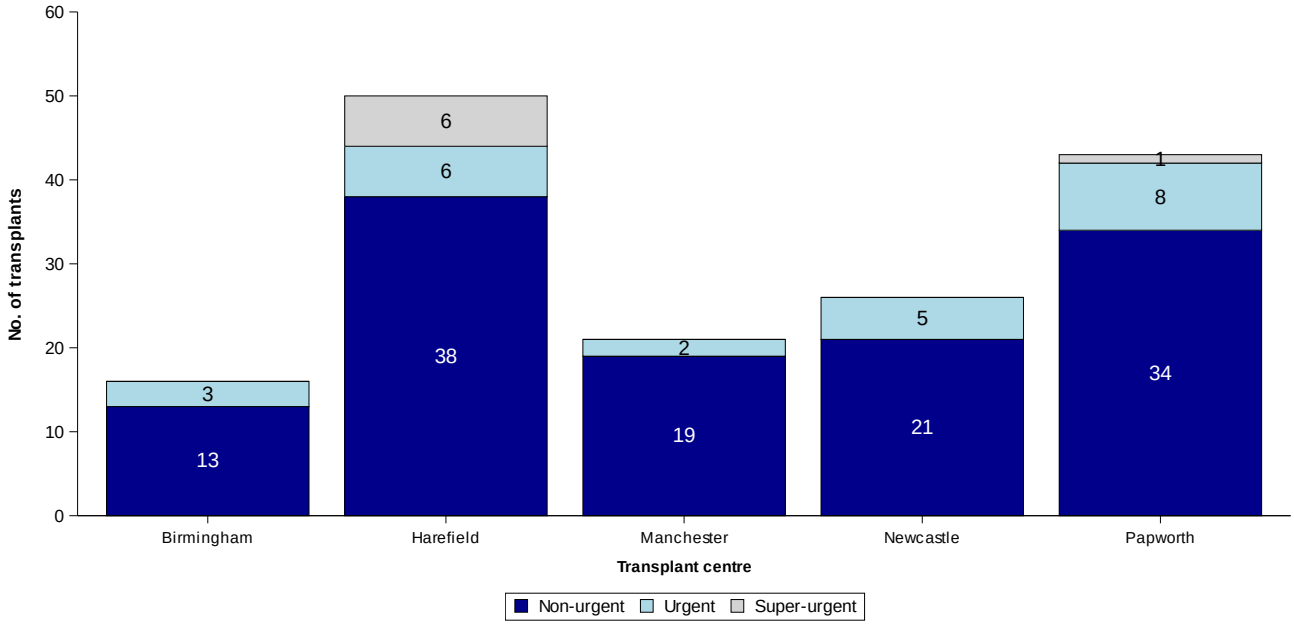


Figure 11.8 Number of adult lung only transplants in the UK, by centre and urgency status, 1 April 2018 to 31 March 2019



11.2 Demographic characteristics of transplants, 1 April 2018 – 31 March 2019

The demographic characteristics of the 158 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 54% of lung recipients were male and the median age was 51 years while the median age of donors was 46 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 2018 to 31 March 2019, by centre

		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL** N (%)
Number of transplants		16 (100)	50 (100)	22 (100)	27 (100)	43 (100)	**158 (100)**
Urgency status at transplant	Non-urgent	13 (81)	38 (76)	20 (91)	21 (78)	34 (79)	**126 (80)**
	Urgent	3 (19)	6 (12)	2 (9)	6 (22)	8 (19)	**25 (16)**
	Super-urgent	0 (0)	6 (12)	0 (0)	0 (0)	1 (2)	**7 (4)**
Transplant type	Single lung	1 (6)	0 (0)	4 (18)	0 (0)	11 (26)	**16 (10)**
	Bilateral lung	15 (94)	50 (100)	17 (77)	26 (96)	32 (74)	**140 (89)**
	Heart-lung	0 (0)	0 (0)	1 (5)	1 (4)	0 (0)	**2 (1)**
Recipient sex	Male	11 (69)	25 (50)	13 (59)	14 (52)	22 (51)	**85 (54)**
	Female	5 (31)	25 (50)	9 (41)	13 (48)	21 (49)	**73 (46)**
Recipient ethnicity	White	15 (94)	49 (98)	22 (100)	25 (93)	40 (93)	**151 (96)**
	Non-white	1 (6)	1 (2)	0 (0)	2 (7)	3 (7)	**7 (4)**
Recipient age (years)	Median (IQR)	54 (43, 60)	45 (33, 53)	54 (48, 61)	52 (37, 61)	56 (36, 62)	**51 (36, 59)**
	Missing	0	0	0	0	0	**0**
Recipient weight (kg)	Median (IQR)	65 (60, 78)	60 (53, 71)	69 (56, 84)	76 (59, 87)	69 (58, 85)	**67 (57, 77)**
	Missing	0	0	0	0	0	**0**
Recipient primary disease	Cystic fibrosis and bronchiectasis	4 (25)	31 (62)	4 (18)	6 (22)	9 (21)	**54 (34)**
	Fibrosing lung disease	4 (25)	6 (12)	5 (23)	8 (30)	23 (53)	**46 (29)**
	COPD and emphysema	5 (31)	12 (24)	10 (45)	6 (22)	7 (16)	**40 (25)**
	Primary pulmonary hypertension	1 (6)	0 (0)	0 (0)	3 (11)	2 (5)	**6 (4)**
	Other	2 (13)	1 (2)	3 (14)	4 (15)	2 (5)	**12 (8)**
NYHA class	I	4 (25)	0 (0)	0 (0)	0 (0)	0 (0)	**4 (3)**
	II	0 (0)	15 (30)	0 (0)	0 (0)	0 (0)	**15 (10)**
	III	2 (13)	25 (50)	22 (100)	10 (37)	22 (51)	**81 (51)**
	IV	0 (0)	9 (18)	0 (0)	3 (11)	21 (49)	**33 (21)**
	Missing	10 (63)	1 (2)	0 (0)	14 (52)	0 (0)	**25 (16)**

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2018 to 31 March 2019, by centre

		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL** N (%)
Recipient in hospital pre-transplant	No	11 (69)	31 (62)	20 (91)	23 (85)	34 (79)	**119 (75)**
	Yes	5 (31)	18 (36)	2 (9)	4 (15)	9 (21)	**38 (24)**
	Missing	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	**1 (1)**
If in hospital, recipient on ventilator	No	5 (100)	17 (94)	2 (100)	4 (100)	8 (89)	**36 (95)**
	Yes	0 (0)	1 (6)	0 (0)	0 (0)	0 (0)	**1 (3)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (11)	**1 (3)**
If in hospital, recipient on inotropes	No	3 (60)	16 (89)	2 (100)	4 (100)	5 (56)	**30 (79)**
	Yes	2 (40)	2 (11)	0 (0)	0 (0)	3 (33)	**7 (18)**
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (11)	**1 (3)**
If in hospital, recipient on ECMO	No	4 (80)	12 (67)	2 (100)	4 (100)	8 (89)	**30 (79)**
	Yes	0 (0)	6 (33)	0 (0)	0 (0)	0 (0)	**6 (16)**
	Missing	1 (20)	0 (0)	0 (0)	0 (0)	1 (11)	**2 (5)**
Recipient CMV status	No	11 (69)	29 (58)	14 (64)	12 (44)	22 (51)	**88 (56)**
	Yes	5 (31)	18 (36)	8 (36)	15 (56)	20 (47)	**66 (42)**
	Missing	0 (0)	3 (6)	0 (0)	0 (0)	1 (2)	**4 (3)**
Recipient HCV status	No	16 (100)	48 (96)	22 (100)	27 (100)	43 (100)	**156 (99)**
	Missing	0 (0)	2 (4)	0 (0)	0 (0)	0 (0)	**2 (1)**
Recipient HBV status	No	16 (100)	48 (96)	22 (100)	27 (100)	43 (100)	**156 (99)**
	Missing	0 (0)	2 (4)	0 (0)	0 (0)	0 (0)	**2 (1)**
Recipient HIV status	No	16 (100)	48 (96)	22 (100)	27 (100)	43 (100)	**156 (99)**
	Missing	0 (0)	2 (4)	0 (0)	0 (0)	0 (0)	**2 (1)**
Recipient serum creatinine (umol/l)	Median (IQR)	71 (60, 89)	57 (45, 67)	70 (56, 86)	82 (56, 100)	63 (52, 75)	**63 (52, 81)**
	Missing	0	0	0	0	1	**1**
Donor sex	Male	7 (44)	23 (46)	8 (36)	10 (37)	13 (30)	**61 (39)**
	Female	9 (56)	27 (54)	14 (64)	17 (63)	30 (70)	**97 (61)**
Donor ethnicity	White	13 (81)	46 (92)	19 (86)	25 (93)	37 (86)	**140 (89)**
	Non-white	3 (19)	2 (4)	3 (14)	2 (7)	4 (9)	**14 (9)**
	Missing	0 (0)	2 (4)	0 (0)	0 (0)	2 (5)	**4 (3)**

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2018 to 31 March 2019, by centre

		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	**TOTAL** N (%)
Donor age (years)	Median (IQR)	48 (31, 55)	53 (42, 58)	37 (24, 53)	46 (29, 51)	41 (26, 53)	**46 (29, 55)**
	Missing	0	0	0	0	0	**0**
Donor BMI (kg/m^2)	Median (IQR)	25 (22, 27)	28 (23, 32)	24 (22, 27)	25 (23, 28)	25 (23, 27)	**25 (23, 29)**
	Missing	0	0	0	0	0	**0**
Donor cause of death	CVA	14 (88)	39 (78)	22 (100)	23 (85)	35 (81)	**133 (84)**
	Trauma	2 (13)	2 (4)	0 (0)	2 (7)	4 (9)	**10 (6)**
	Others	0 (0)	9 (18)	0 (0)	2 (7)	4 (9)	**15 (10)**
Donor hypotension	No	12 (75)	41 (82)	18 (82)	17 (63)	30 (70)	**118 (75)**
	Yes	3 (19)	8 (16)	4 (18)	5 (19)	13 (30)	**33 (21)**
	Missing	1 (6)	1 (2)	0 (0)	5 (19)	0 (0)	**7 (4)**
Donor past cardiothoracic disease	No	16 (100)	47 (94)	21 (95)	26 (96)	41 (95)	**151 (96)**
	Yes	0 (0)	1 (2)	1 (5)	0 (0)	2 (5)	**4 (3)**
	Missing	0 (0)	2 (4)	0 (0)	1 (4)	0 (0)	**3 (2)**
Donor past hypertension	No	15 (94)	35 (70)	20 (91)	20 (74)	36 (84)	**126 (80)**
	Yes	1 (6)	15 (30)	2 (9)	7 (26)	7 (16)	**32 (20)**
Donor past tumour	No	15 (94)	50 (100)	21 (95)	25 (93)	40 (93)	**151 (96)**
	Yes	1 (6)	0 (0)	1 (5)	2 (7)	3 (7)	**7 (4)**
Donor past smoker	No	10 (63)	28 (56)	15 (68)	13 (48)	32 (74)	**98 (62)**
	Yes	5 (31)	22 (44)	7 (32)	14 (52)	11 (26)	**59 (37)**
	Missing	1 (6)	0 (0)	0 (0)	0 (0)	0 (0)	**1 (1)**
Total ischaemia time (hours)	Median (IQR)	5.5 (5.0, 6.6)	9.9 (8.6, 12.1)	5.0 (4.3, 5.8)	6.7 (5.5, 7.4)	6.5 (5.9, 7.2)	**6.9 (5.5, 8.8)**
	Missing	1	2	0	0	0	**3**

11.3 Total ischaemia time, 1 April 2009 – 31 March 2019

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 5.2 hours to 6.5 hours over the last decade.

Figure 11.9 Boxplots of total ischaemia time in adult DBD donor lung transplants, by financial year, 1 April 2009 to 31 March 2019

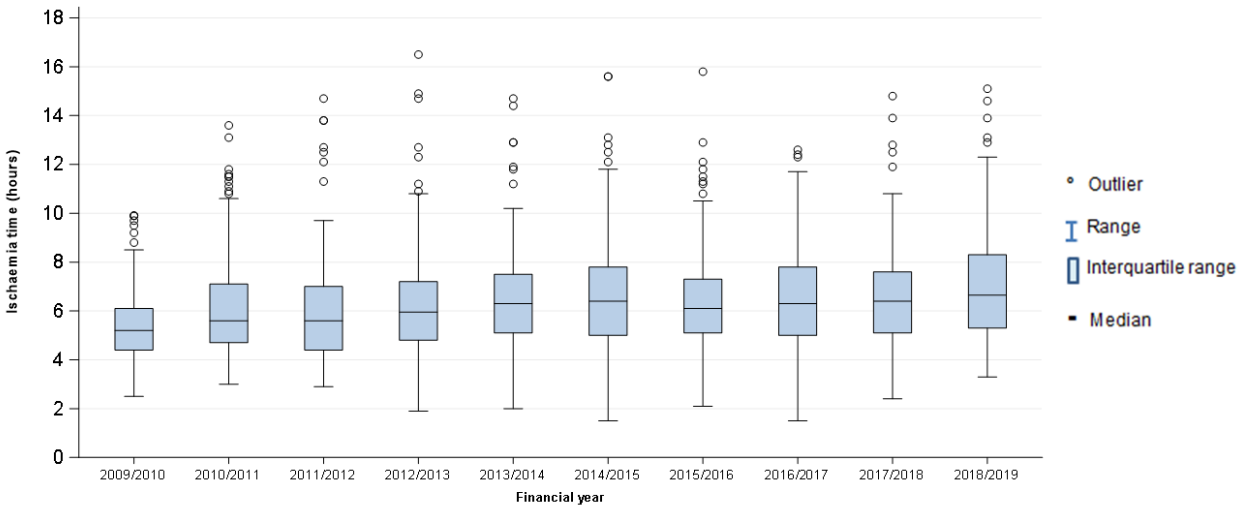


Figure 11.10 and **Figure 11.11** show boxplots of total ischaemia time by centre in the latest financial year (2018/2019) and over the last 10 years, respectively. Ischaemia times were longest in 2018/2019 for lungs transplanted by Harefield and shortest for Manchester. Harefield have seen the most noticeable increase in ischaemia times over the decade with other centres also seeing a general increase, except Manchester who have seen a decrease over the decade.

Figure 11.10 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2018 to 31 March 2019

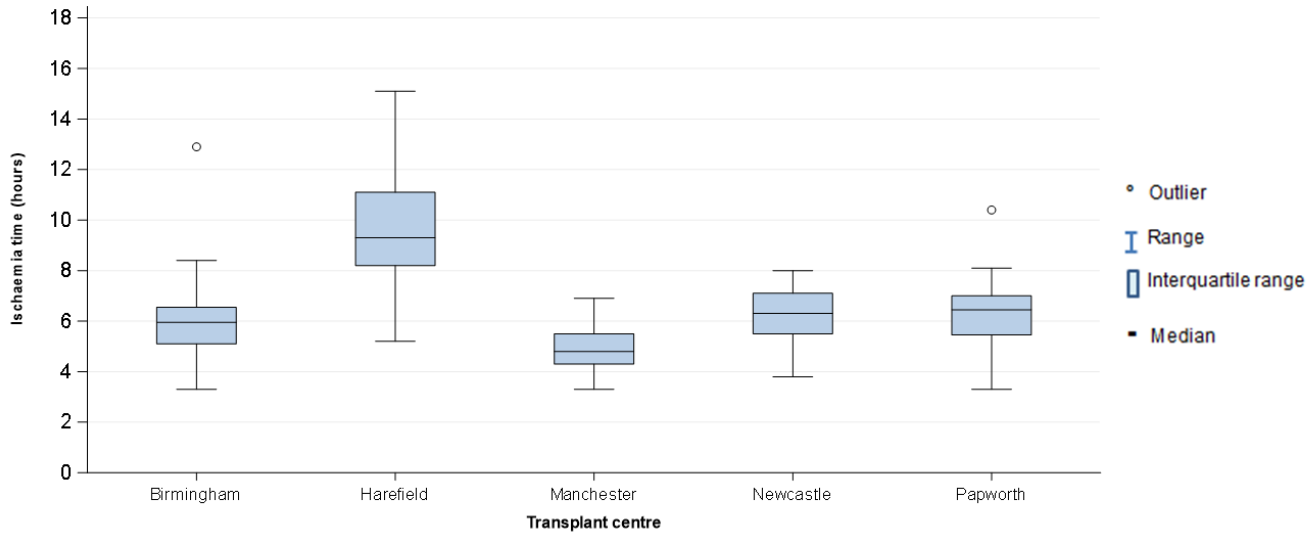
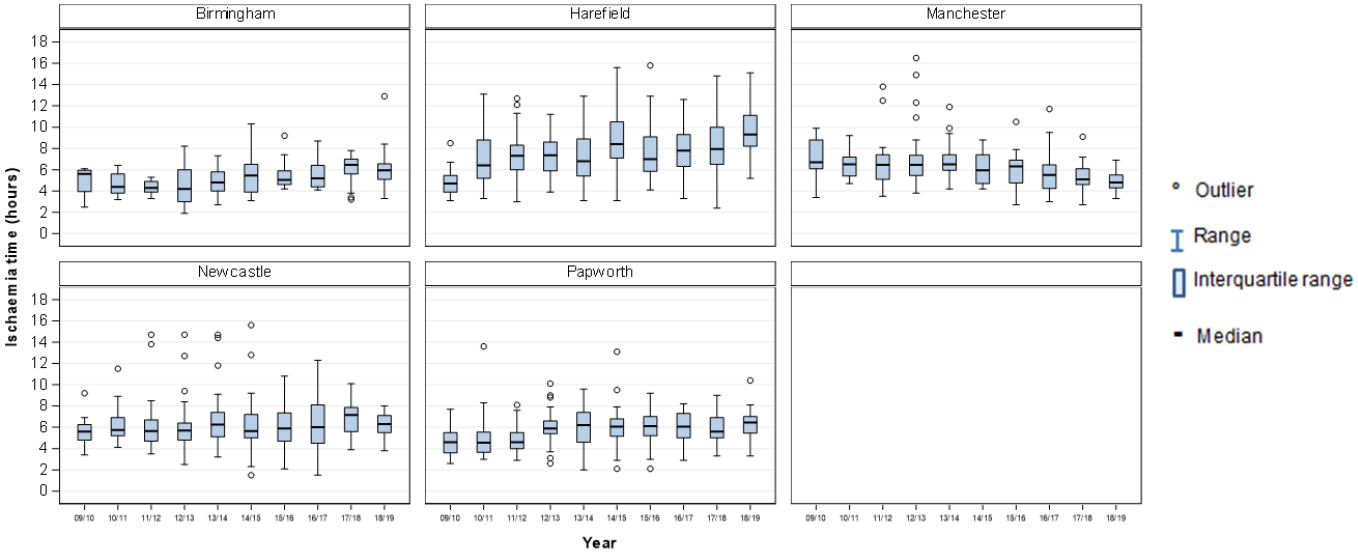


Figure 11.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2009 to 31 March 2019



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 2014 to 31 March 2018 while 5-year survival rates are based on transplants performed in the period 1 April 2010 to 31 March 2014. Both DBD and DCD lung transplants are included. Survival rates are presented by transplant centre in **Tables 12.1-12.3** and **Figures 12.1-12.3** as well as disease group in **Tables 12.4-12.5**. Heart-lung transplants are excluded but separate tables (**Table 12.6** and **12.7**) at the end of this section provide unadjusted survival rates for the small number of heart-lung transplant recipients between 1 April 2010 and 31 March 2018.

The survival data used for these analyses is reported to NHSBT via follow-up forms. It should be noted that one centre in particular (Birmingham) has a large number of follow-up forms outstanding which will affect the validity of some of these survival rates, especially the 5-year survival rates. Follow-up form return rates by centre, for forms issued during the 2018 calendar year, are presented in Section 14.

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 698 first adult lung only transplants in the period 1 April 2014 to 31 March 2018. Manchester's survival rate at 90 days falls above the 99.8% upper confidence limit, providing evidence that the survival rate is higher than the national average at this time period. All other centres were statistically consistent with the national rate of survival which was 88.8%.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of transplants	% 90 day survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	83	81.9	(71.8 - 88.7)	83.3	(72.3 - 89.9)
Harefield	189	90.5	(85.3 - 93.9)	88.8	(82.2 - 92.9)
Manchester	107	94.4	(87.9 - 97.4)	95.4	(89.7 - 97.9)
Newcastle	160	85.0	(78.5 - 89.7)	85.3	(78.1 - 90.2)
Papworth	159	90.6	(84.8 - 94.2)	90.2	(83.8 - 94.1)
UK	**698**	**88.8**	**(86.2 - 90.9)**		

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

Figure 12.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2014 to 31 March 2018

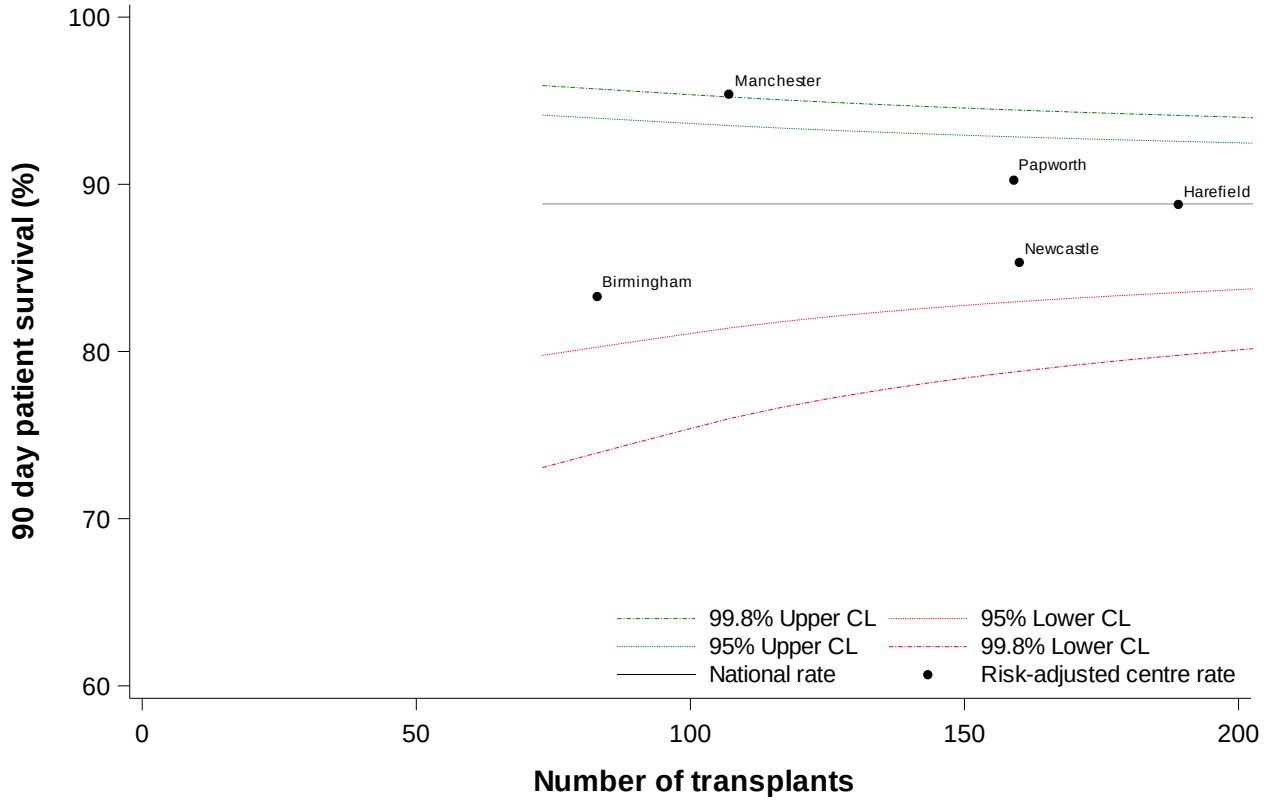


Table 12.2 and **Figure 12.2** show the 1-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 698 first adult lung only transplants in the period 1 April 2014 to 31 March 2018. The national rate of survival was 80.8%. The rates for all centres lie with the funnel, except Manchester whose risk-adjusted survival rate is between the upper 95% and 99.8% confidence limits, providing some evidence of higher than average survival at one year.

Table 12.2 1 year patient survival rates after first adult lung transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of transplants	% 1 year survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	83	72.7	(61.5 - 81.1)	71.6	(56.9 - 81.3)
Harefield	189	84.0	(77.9 - 88.5)	83.3	(76.1 - 88.3)
Manchester	107	85.6	(77.2 - 91.1)	87.4	(79.1 - 92.4)
Newcastle	160	79.1	(71.9 - 84.7)	78.6	(69.9 - 84.8)
Papworth	159	79.8	(72.6 - 85.3)	79.9	(71.6 - 85.8)
UK	**698**	**80.8**	**(77.7 - 83.6)**		

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

Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2014 to 31 March 2018

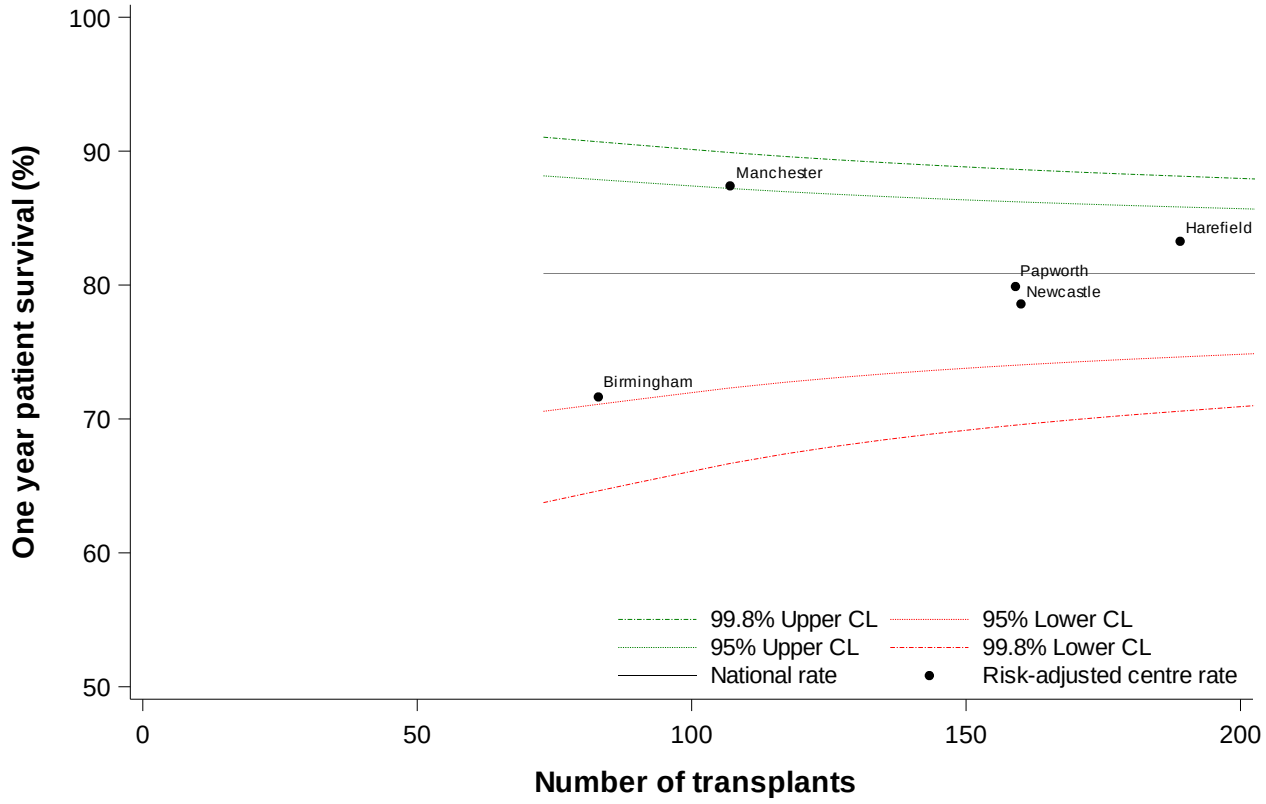


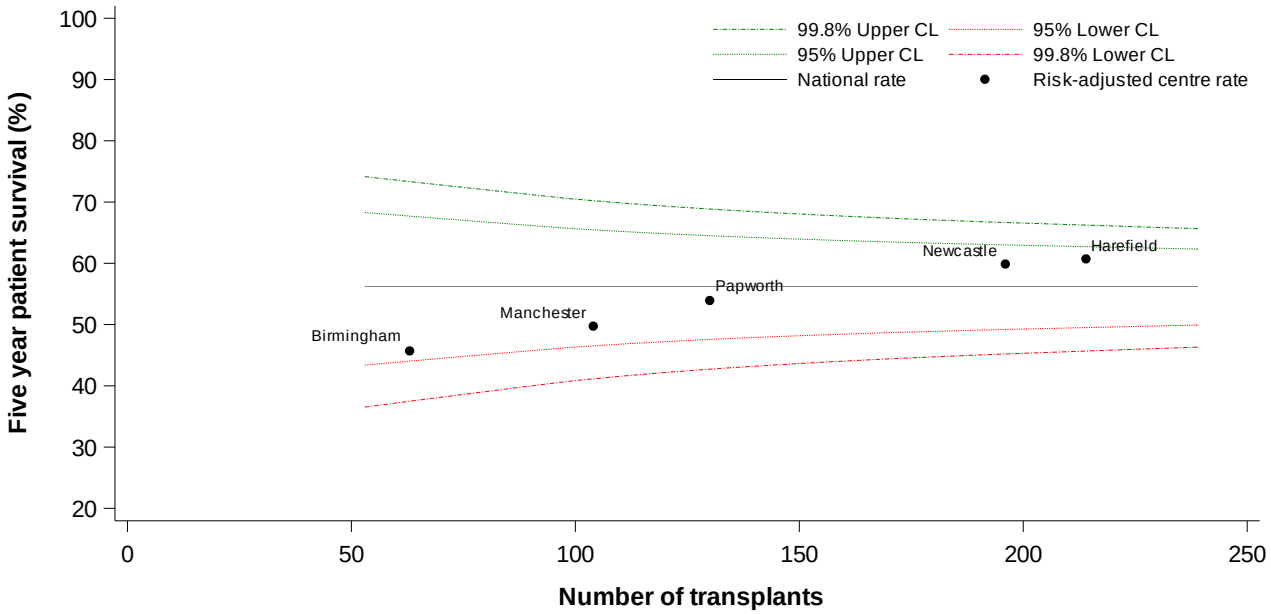
Table 12.3 and **Figure 12.3** show the 5-year post-transplant unadjusted and risk-adjusted patient survival rates for each centre and nationally for the 707 first adult lung only transplants in the period 1 April 2010 to 31 March 2014. All centres were statistically consistent with the national rate of survival which was 56.2%.

Table 12.3 5 year patient survival rates after first adult lung transplant, by centre, 1 April 2010 to 31 March 2014

Centre	Number of transplants	% 5 year survival (95% CI) Unadjusted		Risk-adjusted	
Birmingham	63	48.7	(35.2 - 60.8)	45.7	(22.8 - 61.8)
Harefield	214	62.1	(55.2 - 68.2)	60.7	(51.2 - 68.4)
Manchester	104	47.1	(37.3 - 56.3)	49.7	(34.5 - 61.4)
Newcastle	196	59.9	(52.5 - 66.6)	59.9	(49.7 - 68.0)
Papworth	130	52.7	(43.8 - 60.9)	53.9	(40.8 - 64.2)
UK	**707**	**56.2**	**(52.4 - 59.8)**		

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

Figure 12.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2010 to 31 March 2014



12.2 Survival by disease group

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

Table 12.4 1 year patient survival rates after first adult lung transplant, by disease group, 1 April 2014 to 31 March 2018

Disease group	Number of transplants	% 1 year survival (95% CI) Unadjusted		Risk-adjusted	
Cystic fibrosis and bronchiectasis	209	80.6	(74.5 - 85.4)	78.2	(70.3 - 84.0)
COPD and emphysema	185	83.5	(77.3 - 88.2)	83.1	(75.8 - 88.2)
Fibrosing lung disease	155	80.5	(73.3 - 85.9)	81.0	(72.8 - 86.7)
Other	149	78.3	(70.7 - 84.1)	81.2	(73.5 - 86.7)
UK	**698**	**80.8**	**(77.7 - 83.6)**		

Table 12.5 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2010 to 31 March 2014

Disease group	Number of transplants	% 5 year survival (95% CI) Unadjusted		Risk-adjusted	
Cystic fibrosis and bronchiectasis	208	63.5	(56.4 - 69.8)	60.1	(49.8 - 68.3)
COPD and emphysema	252	58.2	(51.8 - 64.1)	57.0	(47.9 - 64.5)
Fibrosing lung disease	145	48.5	(40.0 - 56.4)	56.8	(45.7 - 65.7)
Other	102	47.8	(37.8 - 57.1)	46.1	(29.4 - 58.8)
UK	**707**	**56.2**	**(52.4 - 59.8)**		

12.3 Survival post heart-lung transplant

Table 12.6 and **Table 12.7** present short-term patient survival rates following combined heart-lung transplant, by centre and nationally. During the time period 1 April 2010 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 81.6% at 90 days and 70.7% at one year.

Table 12.6 90 day patient survival after first adult heart-lung transplant, by centre, 1 April 2010 and 31 March 2018

Centre	Number of transplants	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Birmingham[1]	4	0	-	-
Harefield[1]	6	3	-	-
Manchester[1]	4	0	-	-
Newcastle[1]	6	2	-	-
Papworth	18	2	88.9	(62.4 - 97.1)
UK	**38**	**7**	**81.6**	**(65.2 - 90.8)**

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

Table 12.7 1 year patient survival after first adult heart-lung transplant, by centre, 1 April 2010 and 31 March 2018

Centre	Number of transplants	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Birmingham[1]	4	0	-	-
Harefield[1]	6	5	-	-
Manchester[1]	4	1	-	-
Newcastle[1]	6	3	-	-
Papworth	18	2	88.9	(62.4 - 97.1)
UK	**38**	**11**	**70.7**	**(53.3 - 82.6)**

[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 2007 and 31 December 2018. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The risk factors used to produce the risk-adjusted survival rates are listed in **Appendix A2.1**.

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

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

Table 13.1 **Risk-adjusted 1 and 5 year patient survival from listing for first lung only transplants in patients registered between 1 January 2007 to 31 December 2018**

Centre	Number at risk[1] at day 0	One year Survival rate (%)	One year (95% CI)	One year Number at risk[1]	Five year Survival rate (%)	Five year (95% CI)	Five year Number at risk[1]
Birmingham	326	69.1	(62.3 - 74.8)	200	32.1	(20.5 - 42.0)	32
Harefield	831	81.4	(78.1 - 84.2)	621	53.7	(48.2 - 58.6)	198
Manchester	448	83.3	(79.1 - 86.6)	325	50.7	(43.2 - 57.3)	90
Newcastle	742	74.4	(70.5 - 77.9)	509	47.2	(41.2 - 52.6)	162
Papworth	514	77.1	(72.6 - 80.9)	348	47.9	(40.5 - 54.4)	116
UK	2861	77.7	(76.1 - 79.2)	2003	48.3	(46.1 - 50.5)	598

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

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

Figure 13.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2007 – 31 December 2018

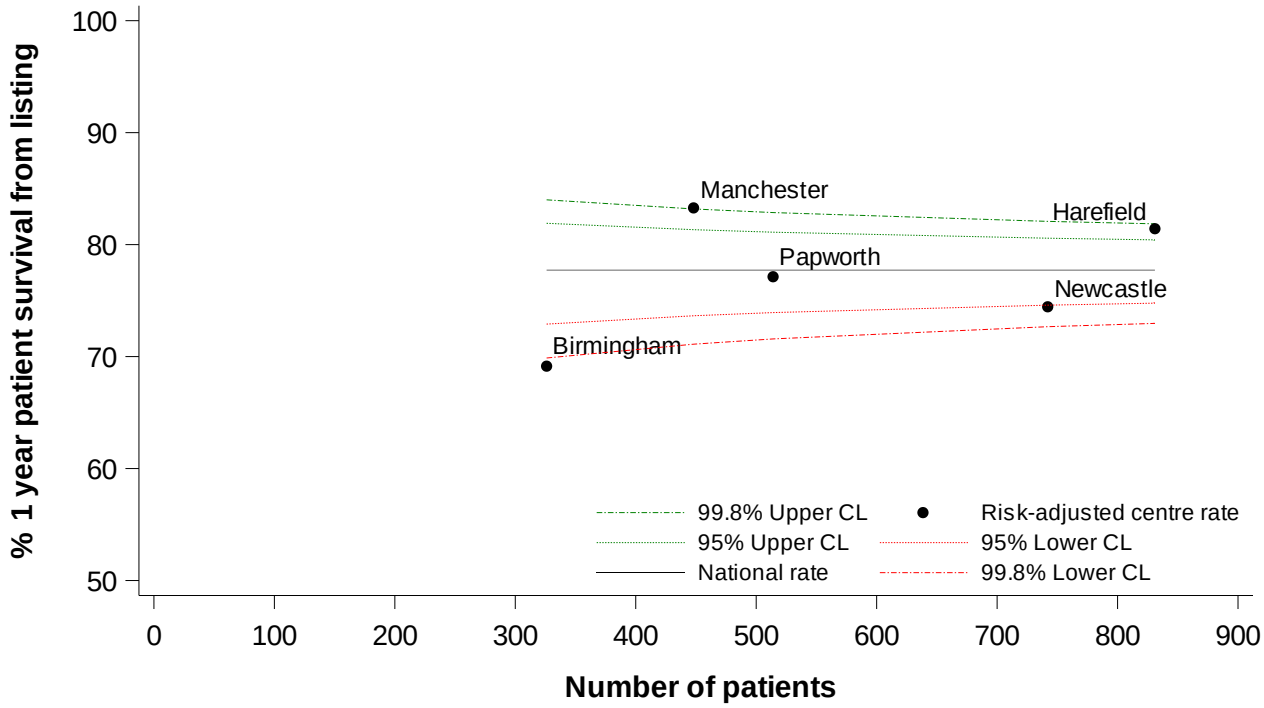
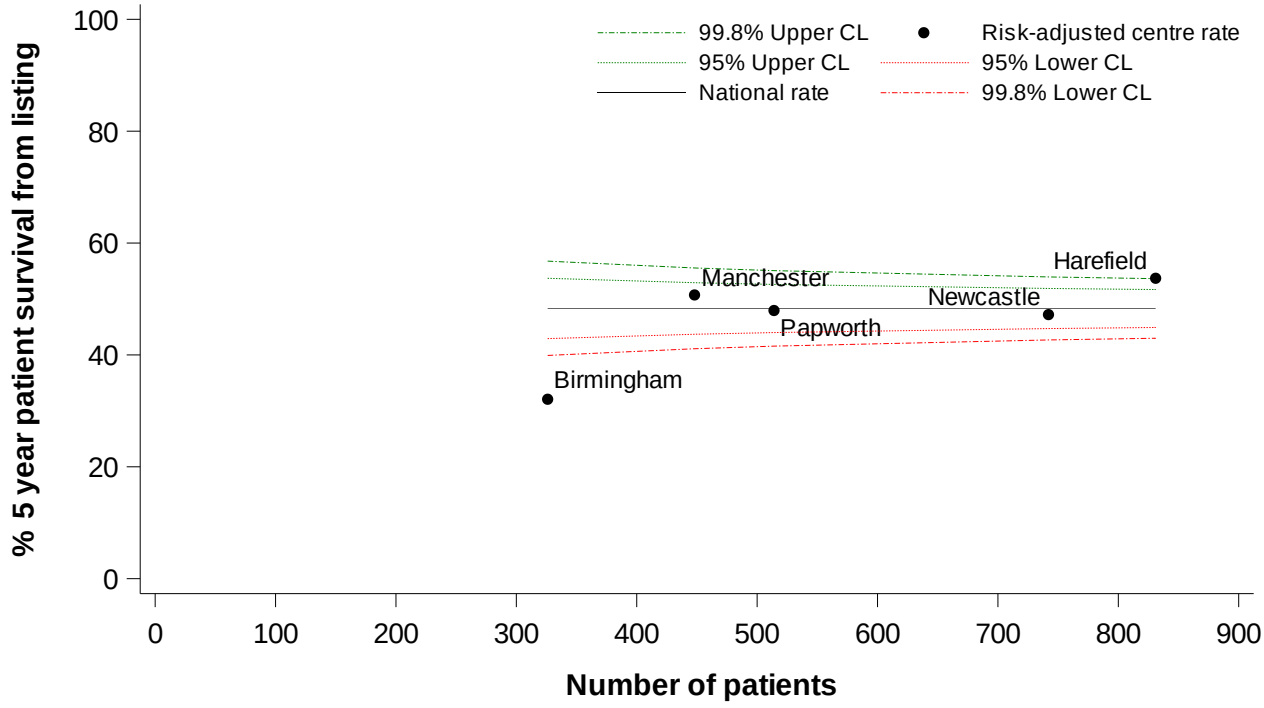


Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2007 – 31 December 2018



ADULT LUNG TRANSPLANTATION

Form Return Rates

14. Adult lung form return rates, 1 January – 31 December 2018

Form return rates are reported in **Table 14.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult lung and heart-lung transplants between 1 January and 31 December 2018 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 follow-up forms outstanding for this period, however most notably Birmingham who have only returned 28% of lifetime follow-up forms.

Table 14.1 Form return rates for adult lung transplants, 1 January 2018 to 31 December 2018

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	22	100	21	100	16	75	103	28
Harefield Hospital	54	100	51	100	53	100	397	96
Leeds St James's Hospital	-	-	-	-	-	-	1	0
Manchester Wythenshawe Hospital	26	100	27	100	31	100	164	99
Newcastle Freeman Hospital	34	100	35	97	41	90	324	94
Royal Papworth Hospital	49	100	38	100	34	100	288	98
Sheffield Northern General Hospital	-	-	-	-	-	-	3	100
Overall	**185**	**100**	**172**	**99**	**175**	**95**	**1280**	**91**

PAEDIATRIC HEART TRANSPLANTATION

Transplant List

15.1 Paediatric heart only transplant list as at 31 March, 2010 – 2019

Figure 15.1 shows the number of paediatric patients on the heart transplant list at 31 March each year between 2010 and 2019 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased significantly during the first half of the decade, then fell to 16 in 2018 but has since risen to 23 in 2019. The number of patients on the urgent transplant list has also increased in recent years with 11 paediatric patients waiting on 31 March 2019.

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

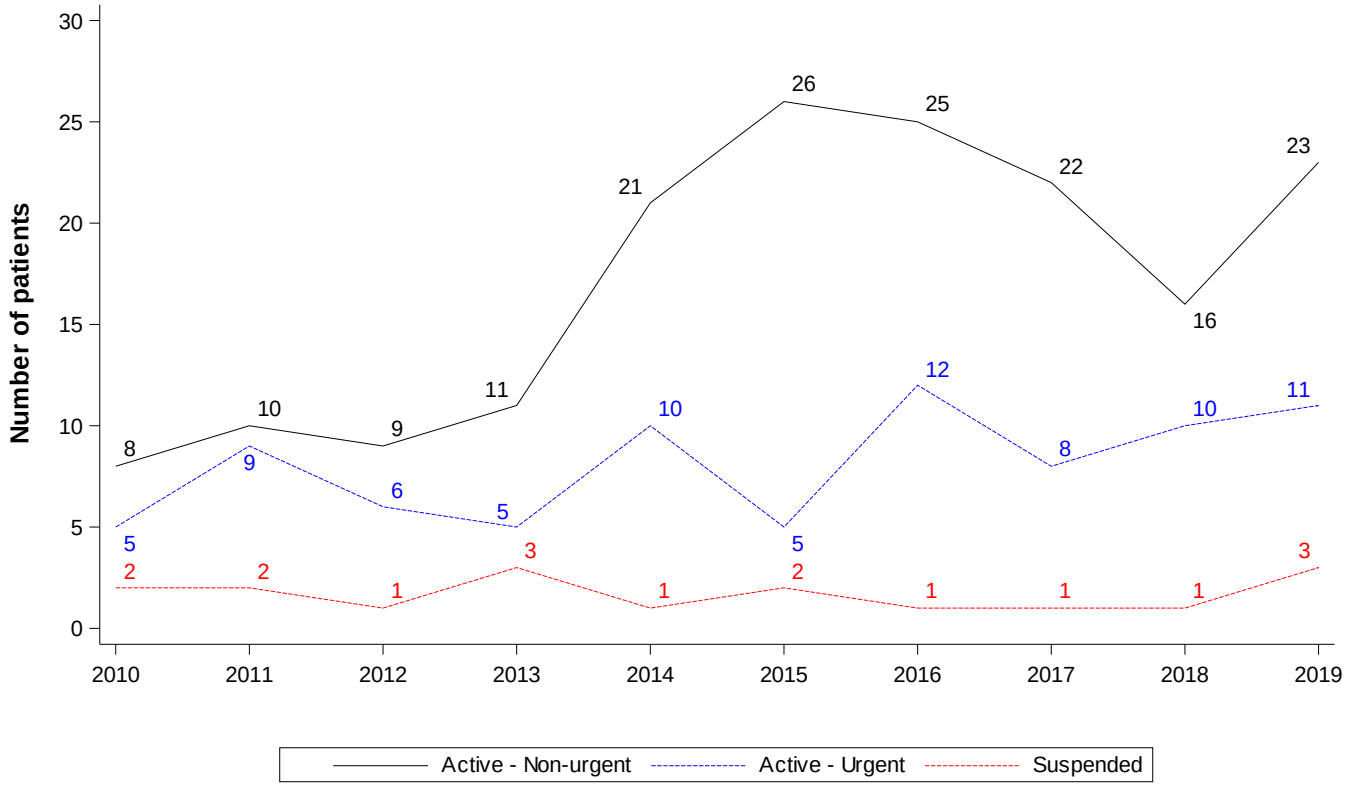


Figure 15.2 shows the number of paediatric patients on the active heart transplant list at 31 March 2019 by centre and urgency. In total, there were 34 paediatric patients waiting. Great Ormond Street Hospital had the largest overall number of paediatric patients on the transplant list, with more non-urgent than urgent. **Figure 15.3** shows the number of patients split by centre and mechanical circulatory support (MCS) status where MCS includes ventricular assist devices and extracorporeal membrane oxygenation. A total of 6 (18%) of the paediatric heart list were on MCS at 31 March 2019.

Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2019, by centre and urgency

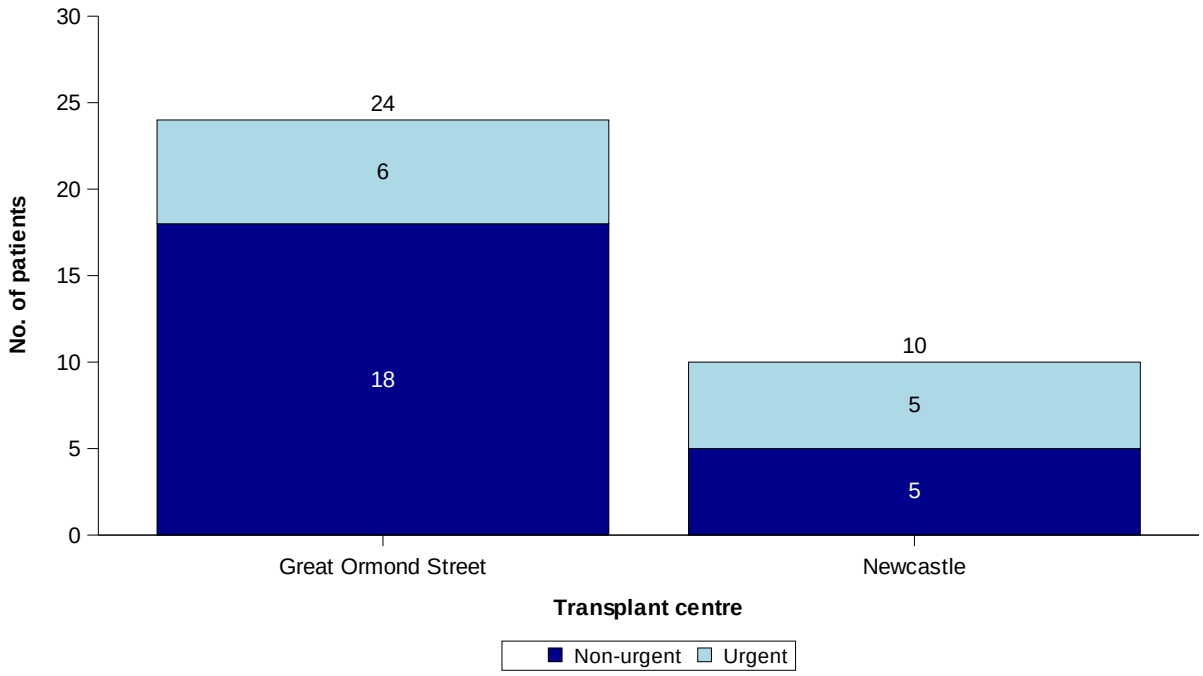


Figure 15.3 Number of paediatric patients on the active heart transplant list at 31 March 2019, by centre and mechanical circulatory support status

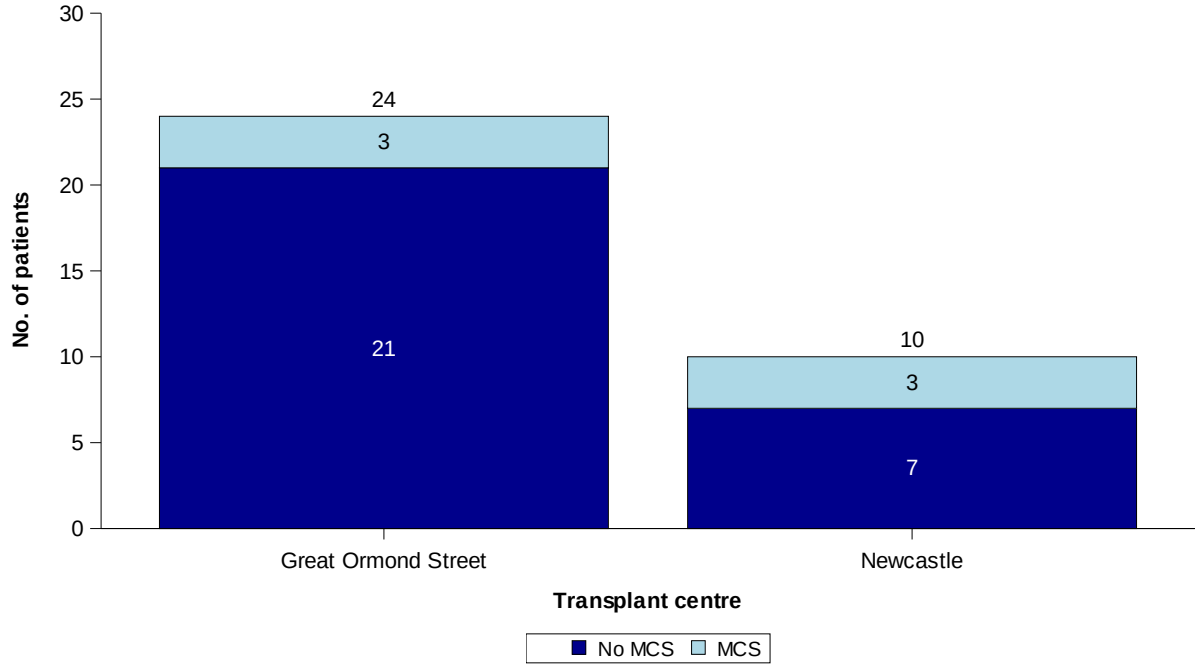
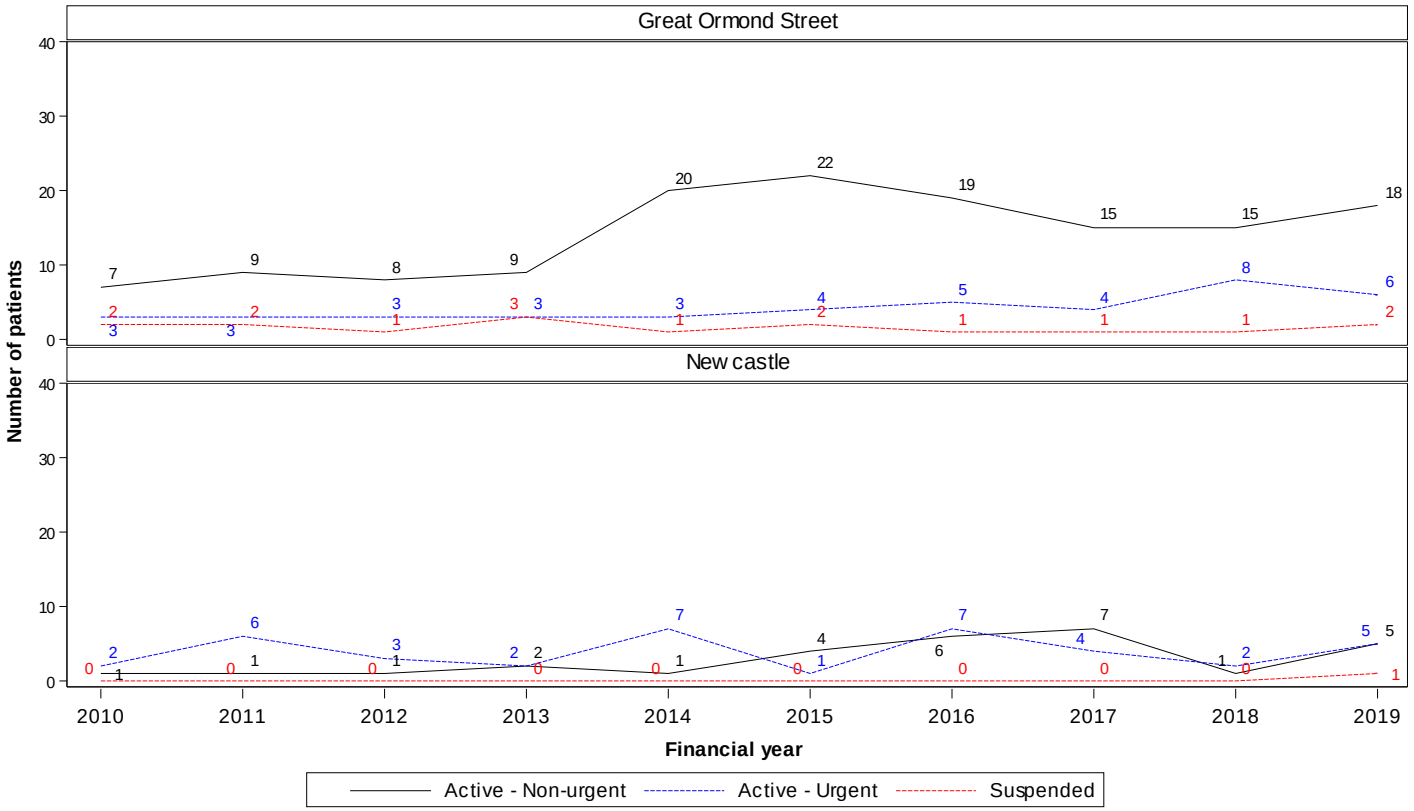


Figure 15.4 shows the trend over time in the number of paediatric patients on the heart transplant list at 31 March each year across each centre. Great Ormond Street Hospital experienced a substantial increase in their non-urgent list in 2014 and since then it has reduced slightly with 18 patients on the list at 31 March 2019. Their urgent list has seen an increase in recent years. Newcastle's non-urgent list decreased in 2017/18 to 1 but has since risen again this year to 5. There has been no clear upward or downward trend in their urgent list.

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



15.2 Demographic characteristics, 1 April 2018 – 31 March 2019

There were 56 paediatric patient registrations onto the heart transplant list between 1 April 2018 and 31 March 2019. Demographic characteristics of these patients are shown by centre and overall in **Table 15.1**. Nationally, 50% of the patients were male and the median age was 4 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 15.1 Demographic characteristics of paediatric patients registered onto the heart transplant list between 1 April 2018 and 31 March 2019, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL N (%)**
Number of registrations		28 (100)	28 (100)	**56 (100)**
Highest urgency during registration	Non-urgent	15 (54)	7 (25)	**22 (39)**
	Urgent	13 (46)	21 (75)	**34 (61)**
Recipient sex	Male	14 (50)	14 (50)	**28 (50)**
	Female	14 (50)	14 (50)	**28 (50)**
Recipient ethnicity	White	17 (61)	17 (61)	**34 (61)**
	Non-white	11 (39)	11 (39)	**22 (39)**
Recipient age (years)	Median (IQR)	7 (2, 13)	2 (1, 8)	**4 (1, 11)**
	Missing	0	0	**0**
Recipient height (cm)	Median (IQR)	126 (83, 142)	84 (73, 127)	**103 (75, 142)**
	Missing	0	0	**0**
Recipient weight (kg)	Median (IQR)	23 (12, 31)	11 (8, 24)	**15 (9, 30)**
	Missing	0	0	**0**
Primary Disease	Coronary heart disease	2 (7)	1 (4)	**3 (5)**
	Cardiomyopathy	19 (68)	21 (75)	**40 (71)**
	Congenital heart disease	6 (21)	6 (21)	**12 (21)**
	Others	1 (4)	0 (0)	**1 (2)**
Previous open heart surgery	None	11 (39)	11 (39)	**22 (39)**
	One	9 (32)	12 (43)	**21 (38)**
	More than one	4 (14)	5 (18)	**9 (16)**
	Missing	4 (14)	0 (0)	**4 (7)**
Previous thoracotomy	No	23 (82)	28 (100)	**51 (91)**
	Yes	1 (4)	0 (0)	**1 (2)**
	Missing	4 (14)	0 (0)	**4 (7)**
Serum Bilirubin (umol/l)	Median (IQR)	15 (9, 22)	9 (6, 14)	**10 (7, 19)**
	Missing	7	2	**9**
Serum Creatinine (umol/l)	Median (IQR)	50 (31, 58)	35 (20, 52)	**38 (26, 54)**
	Missing	5	1	**6**

15.3 Post-registration outcomes, 1 April 2015 – 31 March 2016

The registration outcomes of paediatric patients listed for a non-urgent heart transplant between 1 April 2015 and 31 March 2016 are summarised in **Figure 15.5**. The same information is presented in **Figure 15.6** for those listed for an urgent heart transplant between 1 April 2015 and 31 March 2016 (including those previously on the non-urgent list). The possible outcomes for patients on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists (e.g. from the non-urgent list to the urgent list), dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted".

Within the first 2 years of listing, it is shown that no non-urgent heart patients in this cohort had been transplanted and 17% had died, while after three years, 6% had been transplanted. However, 39% of non-urgent recipients were added to the urgent list within 6 months which increases to 56% within 3 years. As can be seen in **Figure 15.6**, recipients have a greater chance of transplant on the urgent heart list comparative to the non-urgent list. Removals from the non-urgent list were mainly due to improved condition while removals from the urgent list were for a mixture of improved and deteriorating condition.

Figure 15.5 Post-registration outcome for 18 new non-urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016

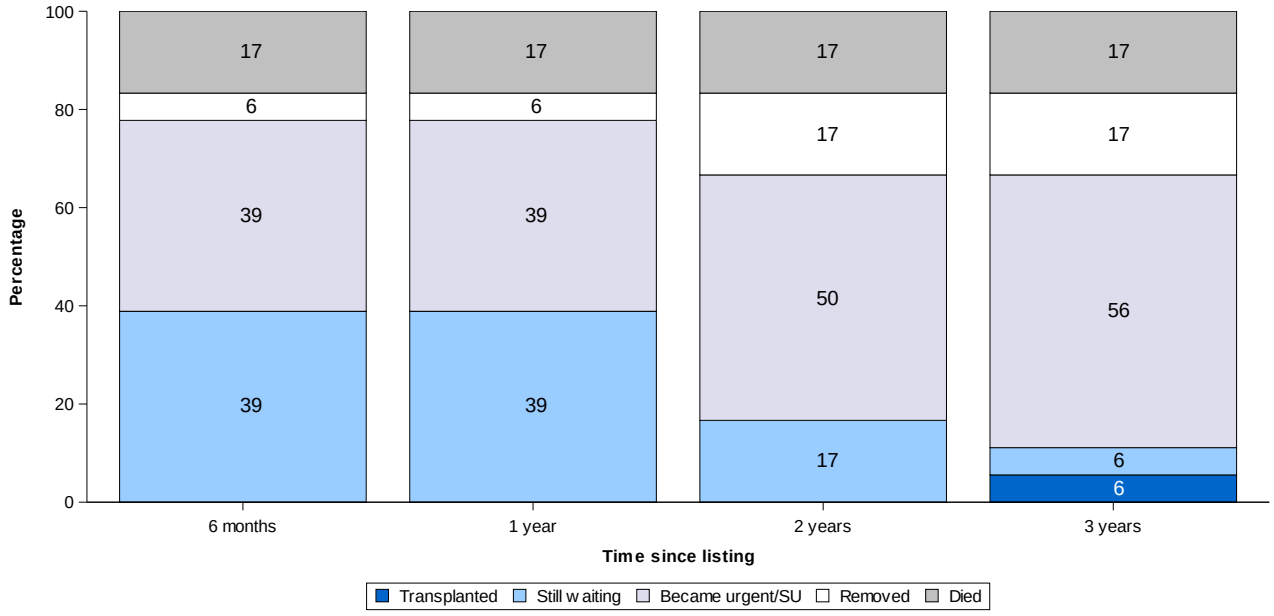
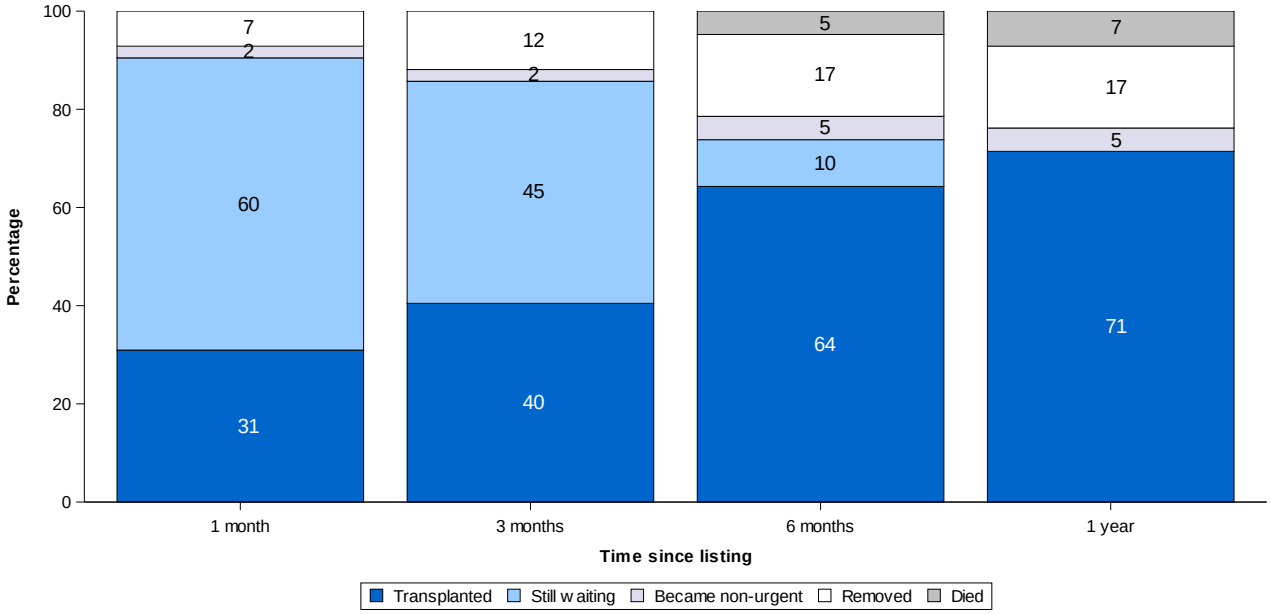


Figure 15.6 Post-registration outcome for 42 new urgent heart only registrations made in the UK, 1 April 2015 to 31 March 2016



15.4 Median waiting time to transplant, 1 April 2013 - 31 March 2016

Table 15.2 shows the median waiting time to heart transplant from listing for paediatric patients registered between 1 April 2013 and 31 March 2016. This is estimated using the Kaplan Meier method and is split by the urgency of the patient at initial registration; non-urgent or urgent. All waiting time from initial registration is considered for patients, regardless of any change in urgency. Any suspended time is discounted.

The national median waiting time to paediatric heart transplant was 414 days from non-urgent registration and 81 days from urgent registration. Waiting times were significantly longer at Great Ormond Street Hospital for non-urgent registrations (log-rank p=0.02) but for urgent registrations waiting times were comparable with Newcastle (log-rank p=0.7).The median waiting time to heart transplant for paediatric patients is also considered by blood group in **Table 15.3.**

Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency at registration and centre, 1 April 2013 to 31 March 2016

Transplant centre	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Overall			
Great Ormond Street Hospital	77	250	150 - 350
Newcastle	84	106	38 - 174
UK	**161**	**152**	**114 - 190**
Non-urgent at initial registration			
Great Ormond Street Hospital	40	491	144 - 838
Newcastle	16	160	96 - 224
UK	**56**	**414**	**239 - 589**
Urgent at initial registration			
Great Ormond Street Hospital	37	88	16 - 160
Newcastle	68	81	22 - 140
UK	**105**	**81**	**33 - 129**

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 2013 to 31 March 2016

Blood group	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Overall			
O	71	152	102 - 202
A	51	122	40 - 204
B	33	245	149 - 341
AB[1]	6	-	-
UK	**161**	**152**	**114 - 190**
Non-urgent at initial registration			
O	25	453	298 - 608
A	18	269	41 - 497
B	13	412	88 - 736
AB	0	-	-
UK	**56**	**414**	**239 - 589**
Urgent at initial registration			
O	46	88	29 - 147
A	33	42	0 - 139
B	20	154	23 - 285
AB[1]	6	-	-
UK	**105**	**81**	**33 - 129**

[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 2016 and 31 March 2019. This only considers offers of UK DBD donor hearts that were eventually transplanted and excludes fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

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

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

Table 16.1 UK paediatric DBD donor heart offer decline rates by transplant centre and year, 1 April 2016 to 31 March 2019

Centre	2016/17		2017/18		2018/19		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
GOSH	7	(57.1)	15	(73.3)	16	(50.0)	38	(60.5)
Newcastle	18	(55.6)	11	(27.3)	8	(25.0)	37	(40.5)
UK	**25**	**(56.0)**	**26**	**(53.8)**	**24**	**(41.7)**	**75**	**(50.7)**

PAEDIATRIC HEART TRANSPLANTATION

Transplants

17.1 Paediatric heart transplants, 1 April 2009 – 31 March 2019

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 in 2018/2019 decreased to 25. Last year's activity is shown by centre in **Figure 17.3**. The 25 transplants carried out in 2018/2019 comprised 10 at Newcastle and 15 at Great Ormond Street Hospital.

Figure 17.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2009 to 31 March 2019

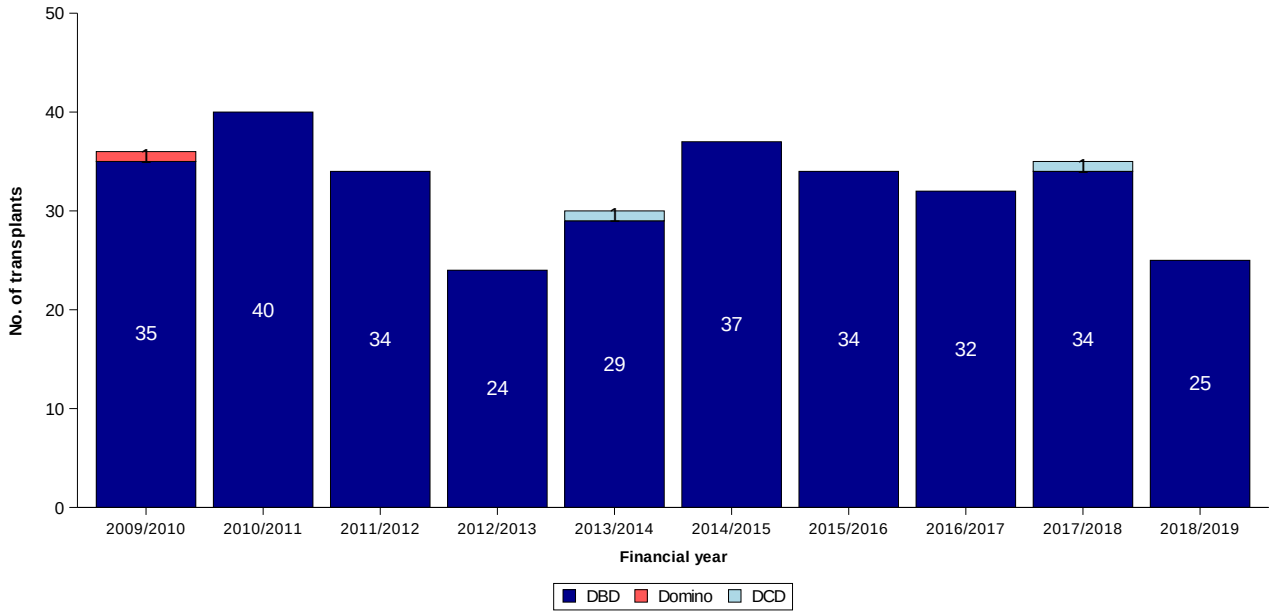


Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2009 to 31 March 2019

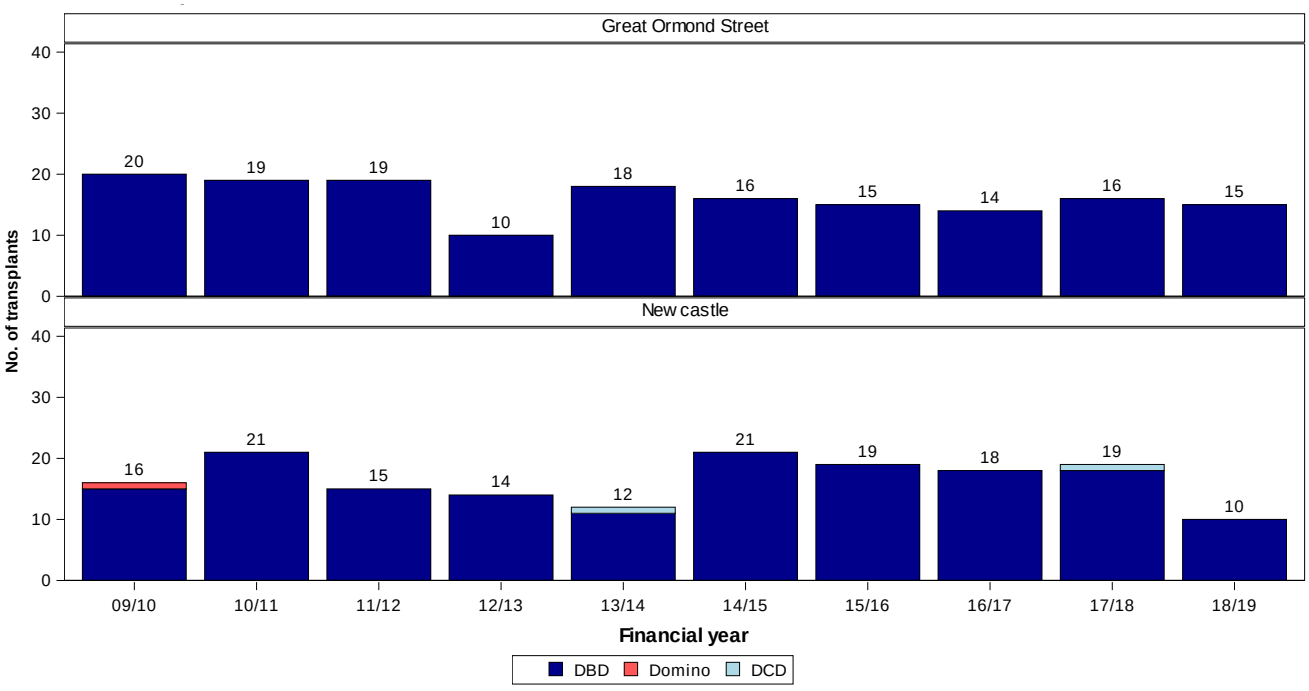


Figure 17.3 Number of paediatric heart transplants in the UK, by centre and donor type, 1 April 2018 to 31 March 2019

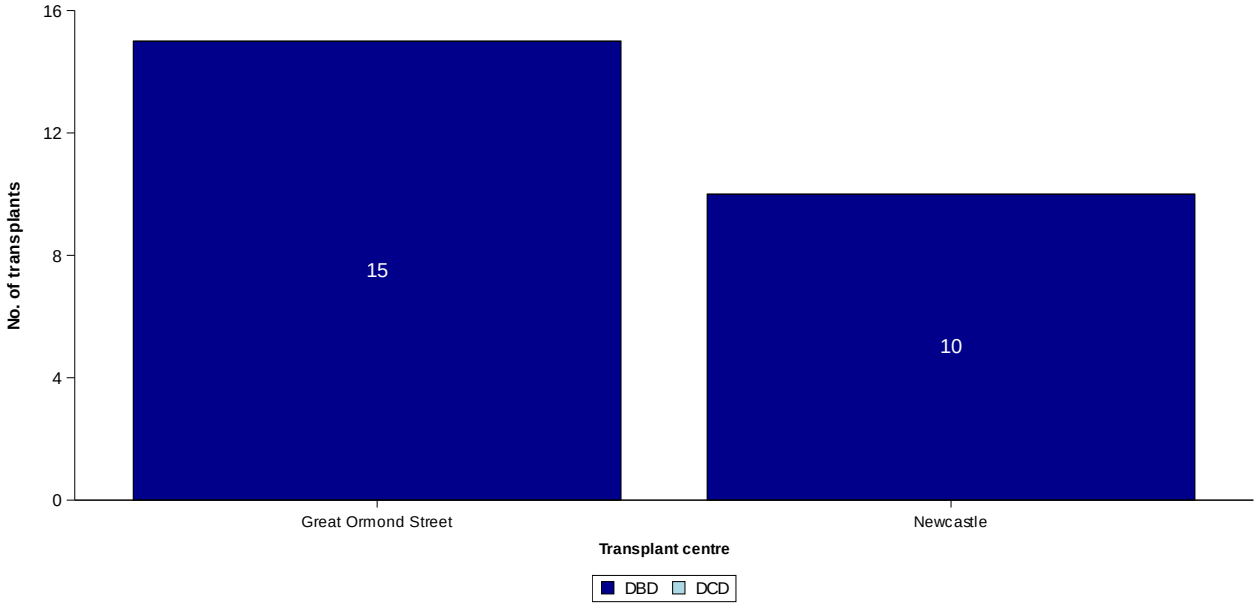


Figure 17.4 and **17.5** show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over the last two years the proportion of non-urgent transplants performed has been relatively high compared with the preceding five years, but overall the proportion of non-urgent transplants was 19%. 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 2009 to 31 March 2019

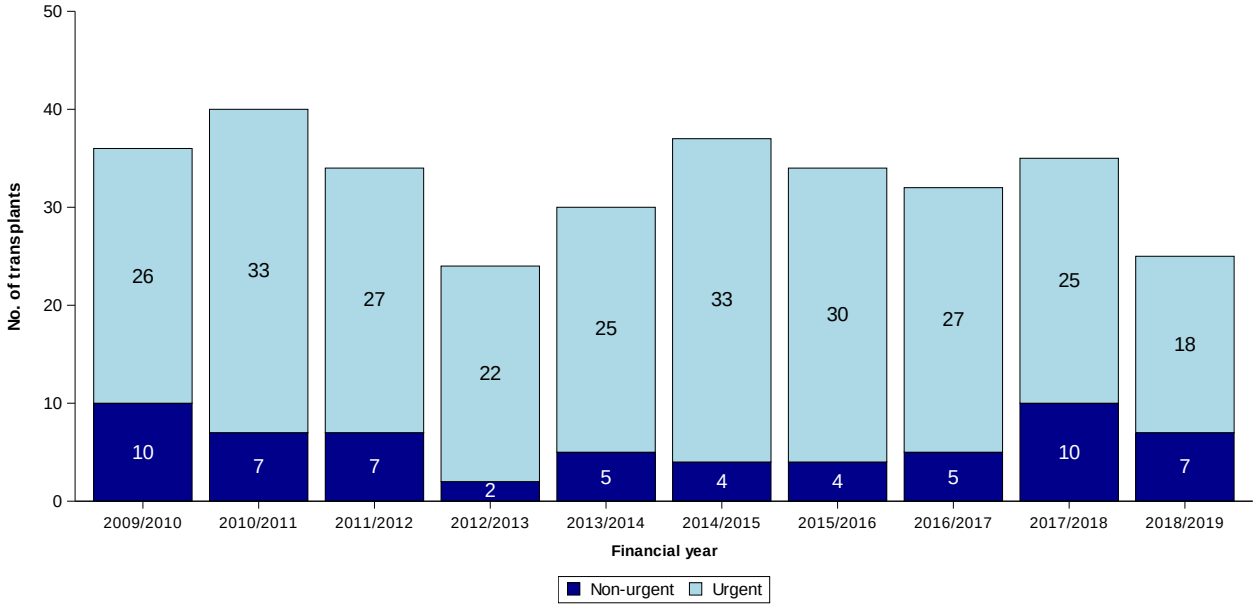


Figure 17.5 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2009 to 31 March 2019

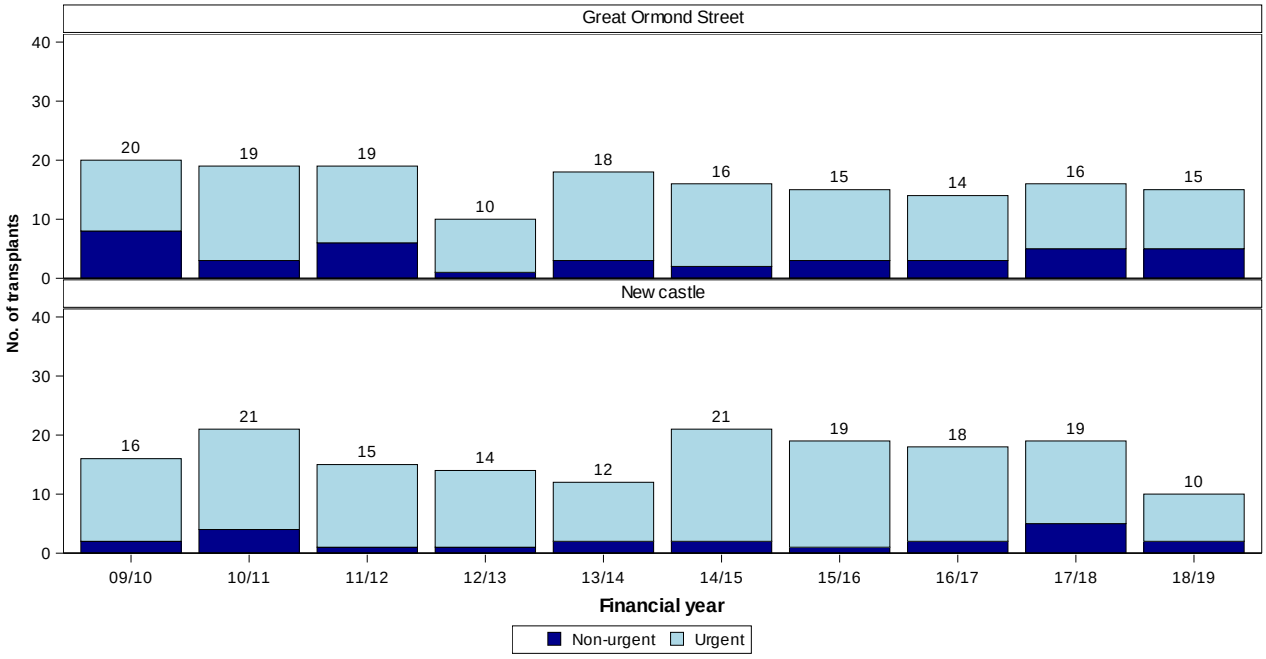
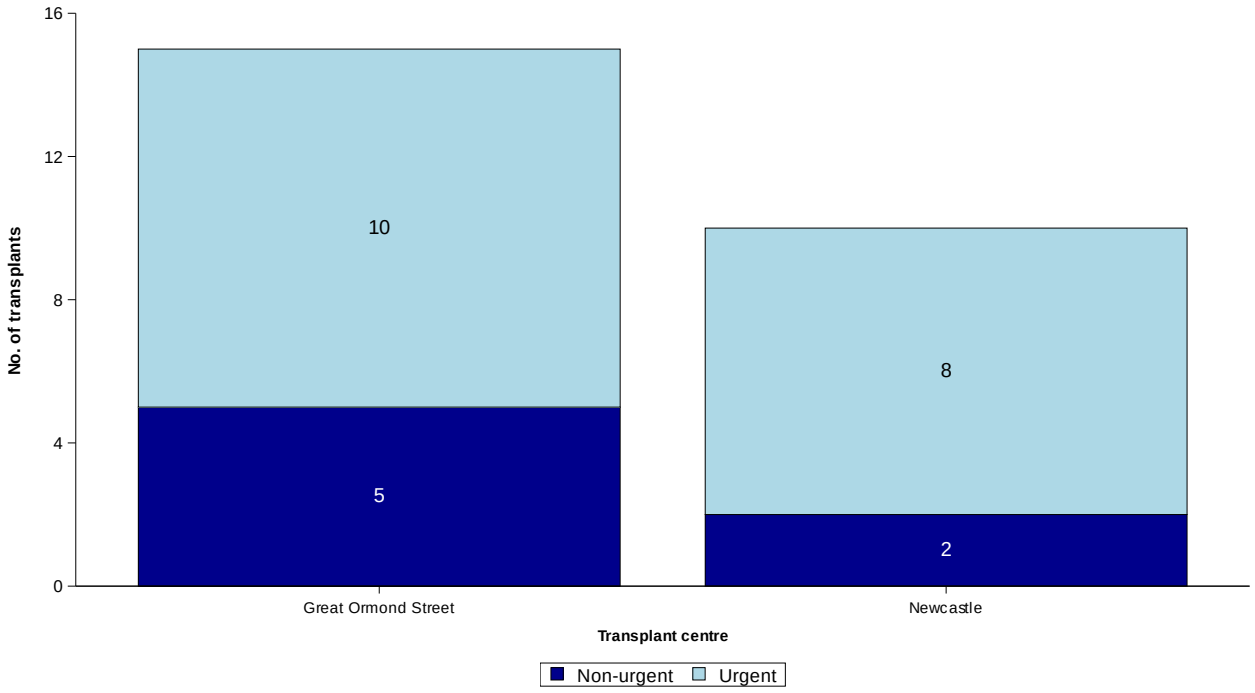


Figure 17.6 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2018 to 31 March 2019



17.2 Demographic characteristics of transplants, 1 April 2018 – 31 March 2019

The demographic characteristics of the 25 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 5 years, while the median age of donors was 11 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 2018 to 31 March 2019, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL N (%)**
Number of transplants		15 (100)	10 (100)	**25 (100)**
Urgency status at transplant	Non-urgent	5 (33)	2 (20)	**7 (28)**
	Urgent	10 (67)	8 (80)	**18 (72)**
Recipient sex	Male	10 (67)	5 (50)	**15 (60)**
	Female	5 (33)	5 (50)	**10 (40)**
Recipient ethnicity	White	12 (80)	7 (70)	**19 (76)**
	Non-white	3 (20)	3 (30)	**6 (24)**
Recipient age (years)	Median (IQR)	5 (3, 11)	8 (1, 12)	**5 (2, 11)**
	Missing	0	0	**0**
Recipient weight (kg)	Median (IQR)	17 (9, 27)	27 (7, 41)	**17 (9, 29)**
	Missing	0	0	**0**
Recipient primary disease	Coronary heart disease	0 (0)	1 (10)	**1 (4)**
	Cardiomyopathy	11 (73)	7 (70)	**18 (72)**
	Congenital heart disease	3 (20)	2 (20)	**5 (20)**
	Others	1 (7)	0 (0)	**1 (4)**
NYHA class	I	0 (0)	0 (0)	**0 (0)**
	II	0 (0)	0 (0)	**0 (0)**
	III	0 (0)	1 (10)	**1 (4)**
	IV	9 (60)	9 (90)	**18 (72)**
	Missing	6 (40)	0 (0)	**6 (24)**
Recipient in hospital pre-transplant	No	3 (20)	2 (20)	**5 (20)**
	Yes	6 (40)	8 (80)	**14 (56)**
	Missing	6 (40)	0 (0)	**6 (24)**
If in hospital, recipient on ventilator	No	5 (83)	6 (75)	**11 (79)**
	Yes	1 (17)	2 (25)	**3 (21)**
If in hospital, recipient on VAD	None	1 (17)	4 (50)	**5 (36)**
	Left	3 (50)	0 (0)	**3 (21)**
	Right	1 (17)	0 (0)	**1 (7)**
	Both	1 (17)	4 (50)	**5 (36)**
If in hospital, recipient on TAH	No	6 (100)	8 (100)	**14 (100)**
If in hospital, recipient on ECMO	No	5 (83)	7 (88)	**12 (86)**
	Missing	1 (17)	1 (13)	**2 (14)**
If in hospital, recipient on inotropes	No	3 (50)	1 (13)	**4 (29)**
	Yes	3 (50)	7 (88)	**10 (71)**
If in hospital, recipient on IABP	No	6 (100)	8 (100)	**14 (100)**

Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2018 to 31 March 2019, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL N (%)**
Recipient CMV status	No	4 (27)	6 (60)	**10 (40)**
	Yes	6 (40)	3 (30)	**9 (36)**
	Missing	5 (33)	1 (10)	**6 (24)**
Recipient HCV status	No	10 (67)	9 (90)	**19 (76)**
	Missing	5 (33)	1 (10)	**6 (24)**
Recipient HBV status	No	10 (67)	9 (90)	**19 (76)**
	Missing	5 (33)	1 (10)	**6 (24)**
Recipient HIV status	No	10 (67)	9 (90)	**19 (76)**
	Missing	5 (33)	1 (10)	**6 (24)**
Recipient serum creatinine (umol/l)	Median (IQR)	34 (33, 47)	46 (27, 53)	**43 (30, 52)**
	Missing	6	0	**6**
Donor sex	Male	5 (33)	4 (40)	**9 (36)**
	Female	10 (67)	6 (60)	**16 (64)**
Donor ethnicity	White	8 (53)	8 (80)	**16 (64)**
	Non-white	2 (13)	2 (20)	**4 (16)**
	Missing	5 (33)	0 (0)	**5 (20)**
Donor age (years)	Median (IQR)	11 (1, 16)	13 (1, 16)	**11 (1, 16)**
	Missing	0	0	**0**
Donor BMI (kg/m^2)	Median (IQR)	17 (15, 20)	18 (17, 21)	**18 (16, 20)**
	Missing	0	0	**0**
Donor cause of death	CVA	8 (53)	7 (70)	**15 (60)**
	Trauma	2 (13)	1 (10)	**3 (12)**
	Others	5 (33)	2 (20)	**7 (28)**
Donor hypotension	No	1 (7)	1 (10)	**2 (8)**
	Yes	5 (33)	6 (60)	**11 (44)**
	Missing	9 (60)	3 (30)	**12 (48)**
Donor past diabetes	No	14 (93)	10 (100)	**24 (96)**
	Missing	1 (7)	0 (0)	**1 (4)**
Donor past cardiothoracic disease	No	10 (67)	9 (90)	**19 (76)**
	Missing	5 (33)	1 (10)	**6 (24)**
Donor past hypertension	No	14 (93)	9 (90)	**23 (92)**
	Yes	0 (0)	1 (10)	**1 (4)**
	Missing	1 (7)	0 (0)	**1 (4)**
Donor past tumour	No	14 (93)	10 (100)	**24 (96)**
	Missing	1 (7)	0 (0)	**1 (4)**
Donor past smoker	No	13 (87)	9 (90)	**22 (88)**
	Yes	1 (7)	1 (10)	**2 (8)**
	Missing	1 (7)	0 (0)	**1 (4)**
Total ischaemia time (hours)	Median (IQR)	4.1 (2.0, 4.7)	3.7 (3.2, 3.9)	**3.8 (3.1, 4.2)**
	Missing	7	1	**8**

17.3 Total ischaemia time, 1 April 2009 – 31 March 2019

Figure 17.7 shows boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The national median total ischaemia time varied between 3 and 4 hours over the decade with no upward or downward trend.

Figure 17.7 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by financial year, 1 April 2009 to 31 March 2019

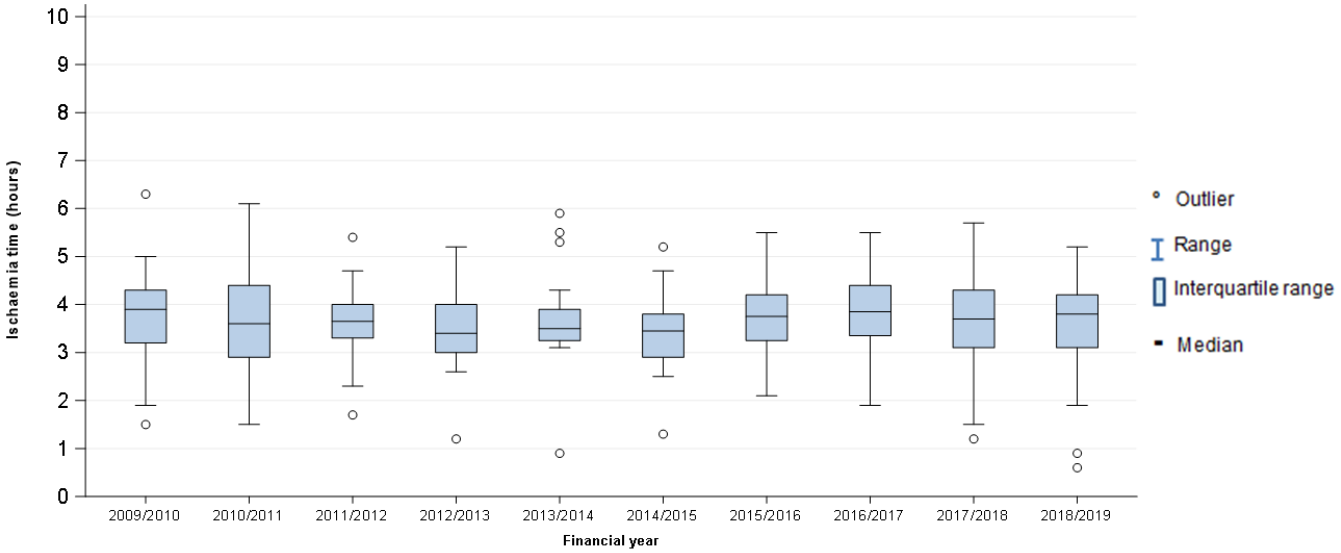


Figure 17.8 and **Figure 17.9** show boxplots of total ischaemia time by centre in the latest financial year (2018/2019) and over the last 10 years, respectively. Generally, the median ischaemia times for Newcastle were marginally shorter than the median ischaemia times for Great Ormond Street Hospital.

Figure 17.8 Boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients, by transplant centre, 1 April 2018 to 31 March 2019

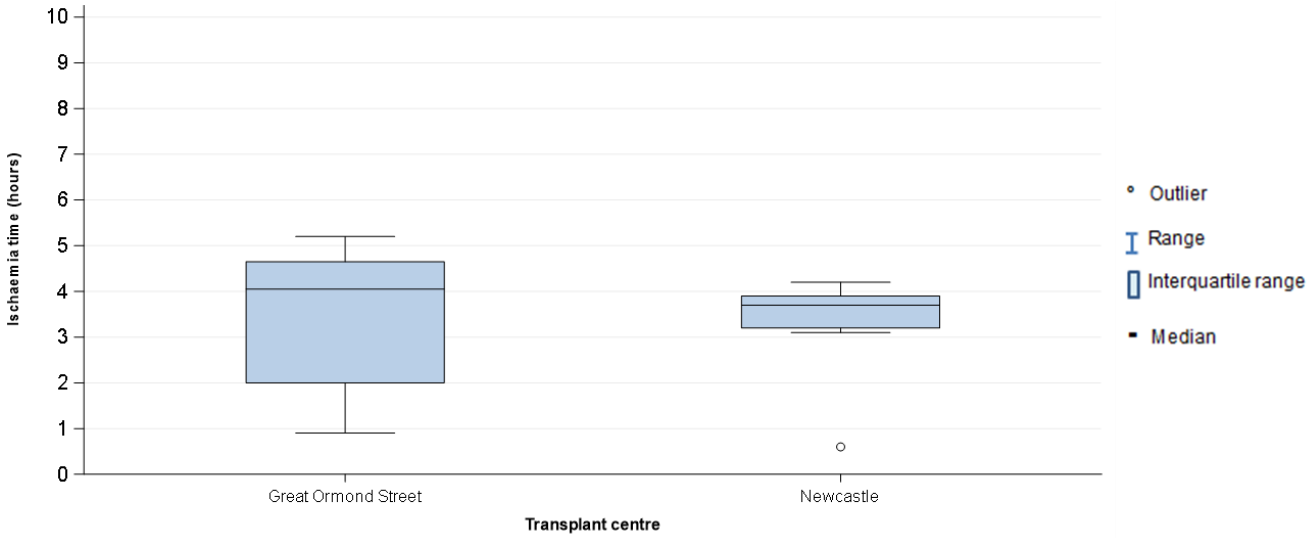
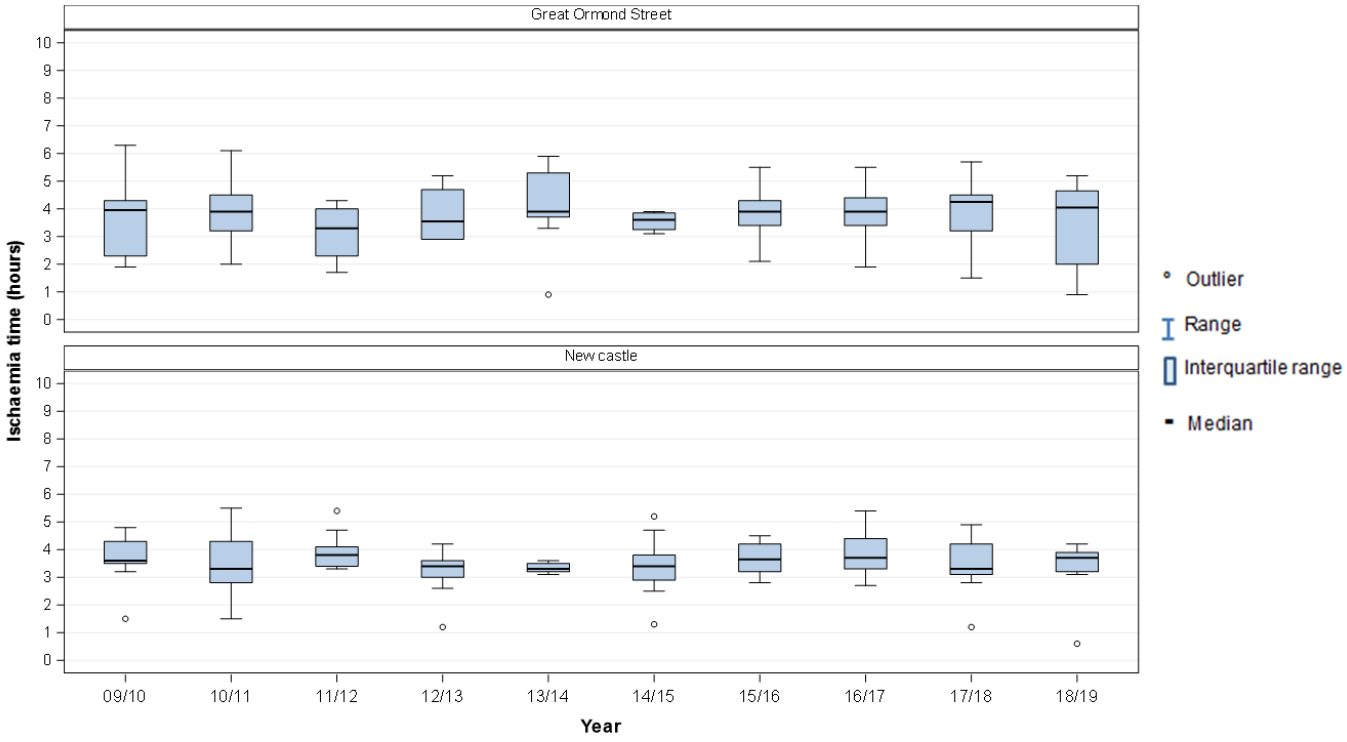


Figure 17.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2009 to 31 March 2019



PAEDIATRIC HEART TRANSPLANTATION

Post-Transplant Survival

18. Post-Transplant Survival

The survival analyses presented in this section exclude multi-organ transplants and include first time transplants only. Thirty-day, ninety-day and 1-year survival rates are based on transplants performed in the period 1 April 2014 to 31 March 2018 while 5-year survival rates are based on transplants performed in the period 1 April 2010 to 31 March 2014.

The 30-day post-transplant unadjusted patient survival rate for each centre and nationally are shown in **Table 18.1** for the 134 first paediatric heart only transplants in the period 1 April 2014 to 31 March 2018. 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 2014 to 31 March 2018

Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	60	1	98.3	(88.8 - 99.8)
Newcastle	74	5	93.2	(84.5 - 97.1)
UK	**134**	**6**	**95.5**	**(90.3 – 98.0)**

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

Table 18.2 90 day patient survival rates after first paediatric heart only transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	60	2	96.7	(87.3 - 99.2)
Newcastle	74	5	93.2	(84.5 - 97.1)
UK	**134**	**7**	**94.8**	**(89.4 - 97.5)**

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

Table 18.3 1 year day patient survival after first paediatric heart only transplant, by centre, 1 April 2014 to 31 March 2018

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	60	2	96.7	(87.3 - 99.2)
Newcastle	74	9	87.8	(77.9 - 93.5)
UK	**134**	**11**	**91.8**	**(85.7 - 95.4)**

Five year survival rates were estimated from the 126 first paediatric heart only transplants performed in the period 1 April 2010 to 31 March 2014. The unadjusted patient survival rates are shown in **Table 18.4**. There was no statistically significant difference between the two centres' rates.

Table 18.4 5 year patient survival after first paediatric heart only transplant, by centre, 1 April 2010 to 31 March 2014

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	66	11	82.8	(71.1 - 90.1)
Newcastle	60	10	83.1	(70.9 - 90.5)
UK	**126**	**21**	**83.0**	**(75.0 - 88.5)**

PAEDIATRIC HEART TRANSPLANTATION

Form Return Rates

19. Paediatric heart form return rates, 1 January – 31 December 2018

Form return rates are reported in **Table 19.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric heart transplants between 1 January and 31 December 2018 for the transplant record, and all follow up forms issued in this time period. A small number of forms from each centre are outstanding for this period.

Table 19.1 Form return rates for paediatric heart transplants, 1 January 2018 to 31 December 2018

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	16	100	16	100	15	100	120	96
Newcastle, Freeman Hospital	15	100	18	94	14	100	194	96
Overall	**31**	**100**	**34**	**97**	**29**	**100**	**314**	**96**

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List

20.1 Paediatric lung and heart/lung transplant list as at 31 March, 2010 – 2019

Figure 20.1 shows the number of paediatric patients on the lung transplant list at 31 March each year between 2010 and 2019 split by urgency status. The number of patients on the active lung transplant list was highest in 2013. It has since decreased to 5 as at 31 March 2019. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2019, there were no patients on the super-urgent list and one patient on the urgent list. There are usually 3 or fewer paediatric patients active for a heart-lung transplant, but none at the end of the last two financial years.

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

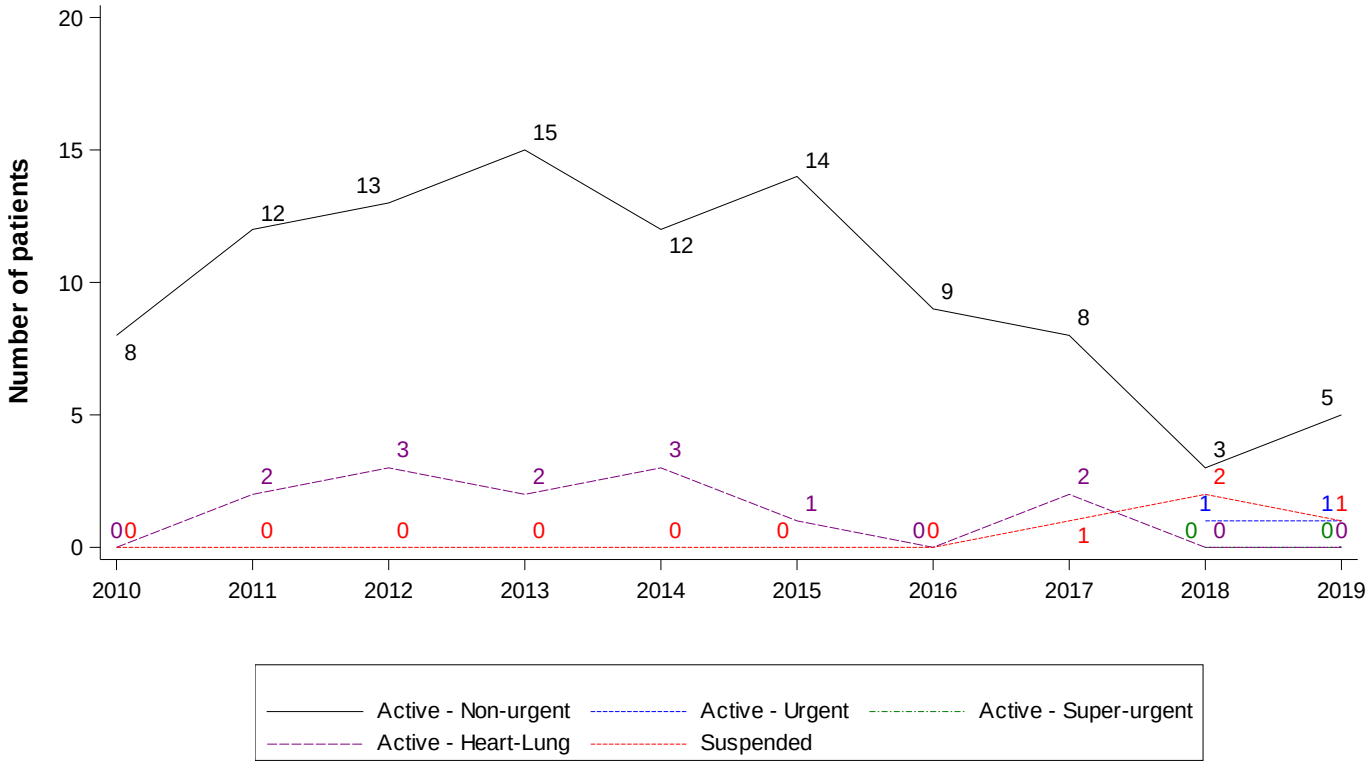


Figure 20.2 shows the number of paediatric patients on the active lung transplant list at 31 March 2019 by centre. In total, there were 6 paediatric patients waiting; 4 at Great Ormond Street Hospital and 2 at Newcastle. One patient at Great Ormond Street Hospital was on the urgent list and no patients were on the super-urgent list at either centre.

Figure 20.2 Number of paediatric patients on the active lung transplant list at 31 March 2019, by centre and urgency

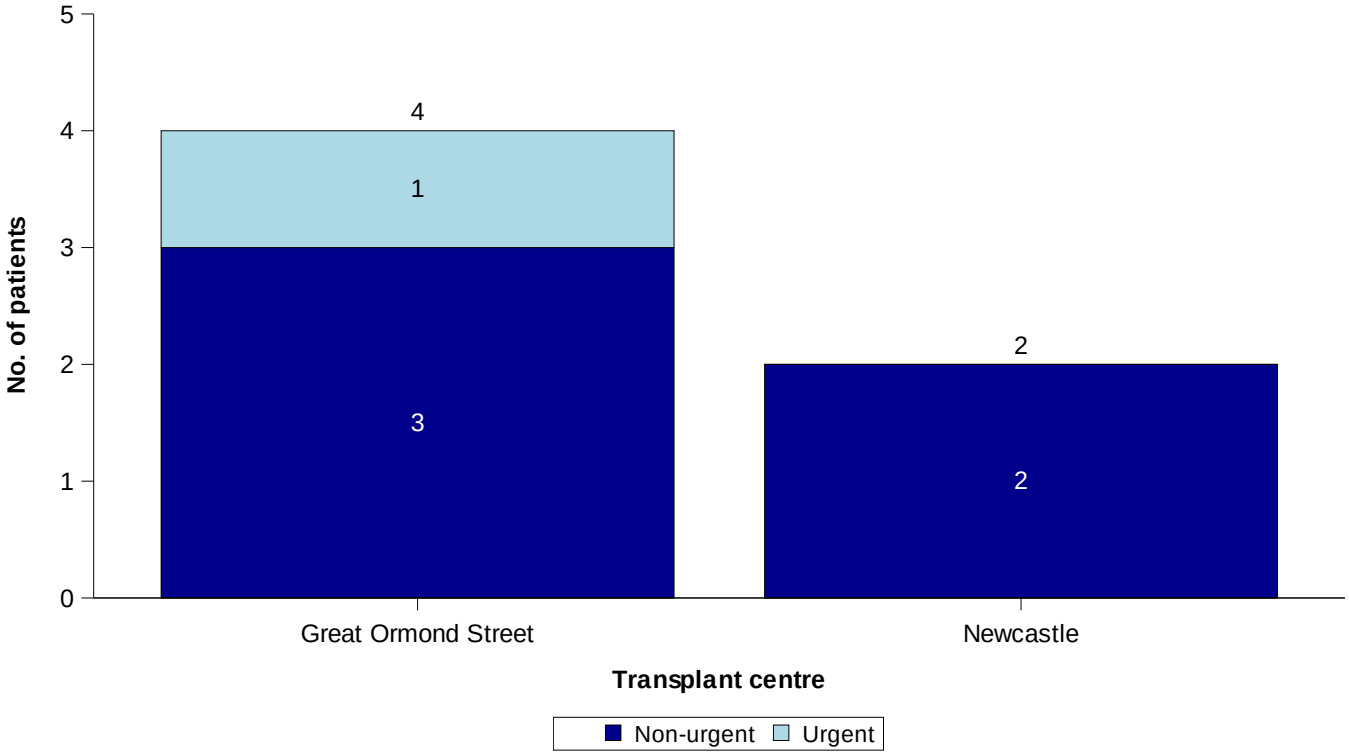


Figure 20.3 shows the trend over time in the number of paediatric patients on the lung transplant list at each centre at 31 March each year between 2010 and 2019. Great Ormond Street Hospital experienced an increase in their list between 2010 and 2013 but after remaining high for several years it has now decreased to just three patients on the non-urgent list on 31 March 2019. Newcastle had a peak of five patients on their list in 2017, but this has now 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 2017 – 31 March 2019

There were 13 paediatric registrations onto the lung transplant list between 1 April 2017 and 31 March 2019 (two years analysed due to small numbers). Newcastle registered no patients in 2017/2018 and only one patient in 2018/2019. Demographic characteristics of these patients are shown by centre and overall in **Table 20.1**. Nationally, 69% of the patients were female and the median age was 13 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 20.1 Demographic characteristics of paediatric patients registered onto the lung transplant list between 1 April 2017 and 31 March 2019, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL** N (%)
Number of registrations		12 (100)	1 (100)	**13(100)**
Year of registration	2017/2018	4 (33)	0 (0)	**4 (31)**
	2018/2019	8 (67)	1 (100)	**9 (69)**
Highest urgency during registration	Non-urgent	10 (83)	1 (100)	**11 (85)**
	Urgent	2 (17)	0 (0)	**2 (15)**
Recipient sex	Male	4 (33)	0 (0)	**4 (31)**
	Female	8 (67)	1 (100)	**9 (69)**
Recipient ethnicity	White	11 (92)	1 (100)	**12 (92)**
	Non-white	1 (8)	0 (0)	**1 (8)**
Recipient age (years)	Median (IQR) [1]	13 (10, 14)	-	**13 (8, 14)**
	Missing	0	0	**0**
Height (cm)	Median (IQR) [1]	146 (134, 162)	-	**146 (124, 154)**
	Missing	0	0	**0**
Weight (kg)	Median (IQR) [1]	38 (24, 58)	-	**35 (21, 52)**
	Missing	0	0	**0**
Primary Disease	Cystic fibrosis and bronchiectasis	3 (25)	0 (0)	**3 (23)**
	Fibrosing lung disease	2 (17)	0 (0)	**2 (15)**
	Primary pulmonary hypertension	4 (33)	0 (0)	**4 (31)**
	Other heart/lung disease	3 (25)	1 (100)	**4 (31)**
Lung function - FEV1 (litres)	Median (IQR)[1]	1.07 (0.81, 2.80)	-	**1.07 (0.81, 2.80)**
	Missing	3	1	**4**
Lung function – FVC (litres)	Median (IQR)[1]	1.35 (1.18, 3.87)	-	**1.35 (1.18, 3.87)**
	Missing	3	1	**4**

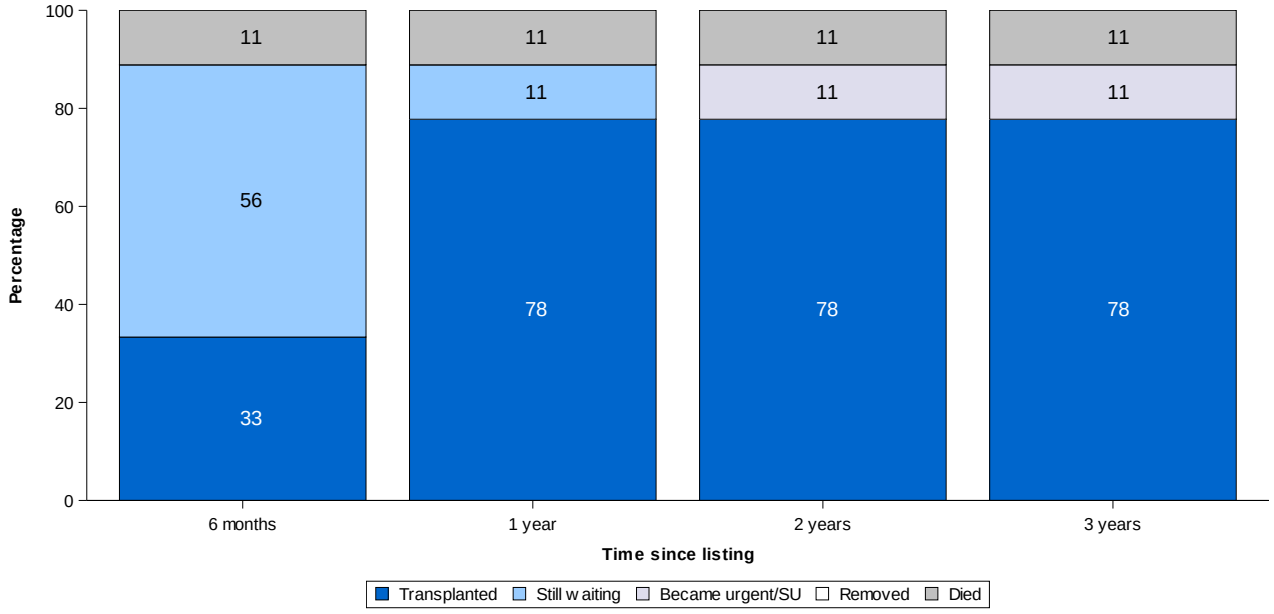
[1] Medians for groups with less than 5 registrations are not presented due to small numbers

20.3 Post-registration outcomes, 1 April 2015 – 31 March 2016

The registration outcomes of paediatric patients listed for a lung transplant between 1 April 2015 and 31 March 2016 are summarised in **Figure 20.4**. The possible outcomes for patients on the list include receiving a transplant, removal from the list, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted".

Within six months of listing, 33% of patients were transplanted and 11% had died, whilst after three years, the transplant rate had increased to 78%, with no change in the death rate. Please note this is only based on 9 patients. Note also that the urgent and super-urgent lung allocation schemes were introduced in May 2017 and one patient in this cohort was moved to the urgent list after this date.

Figure 20.4 Post-registration outcome for 9 new lung only registrations made in the UK, 1 April 2015 to 31 March 2016



20.4 Median waiting time to transplant, 1 April 2013 - 31 March 2016

The median waiting time to lung transplant from registration for paediatric patients registered between 1 April 2013 and 31 March 2016 is shown in **Table 20.2**. This is estimated using the Kaplan Meier method. Any suspended time is discounted, but any time on the urgent list which was introduced in May 2017 is included. The national median waiting time to paediatric lung transplant was 233 days.

Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the transplant list, by centre, 1 April 2013 to 31 March 2016

Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Great Ormond Street Hospital	21	202	115 - 289
Newcastle[1]	5	-	-
UK	**26**	**233**	**189 - 277**

[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 between 1 April 2016 and 31 March 2019. This only considers offers of UK DBD donor lungs that were eventually transplanted and excludes fast track offers. A bilateral lung offer is counted as accepted if both lungs or just one lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lung(s) is/are declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

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

The national decline rate was 82.8% and was very similar between centres.

Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2016 to 31 March 2019

Centre	Number of offers	Decline rate (%)
Great Ormond Street Hospital	13	(84.6)
Newcastle	16	(81.3)
UK	**29**	**(82.8)**

PAEDIATRIC LUNG TRANSPLANTATION

Transplants

22.1 Paediatric lung and heart-lung transplants, 1 April 2009 – 31 March 2019

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 2017/2018 decreased to six and in 2018/2019 only increased slightly to eight. 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 (2018/2019) is shown by centre and donor type 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 2009 to 31 March 2019

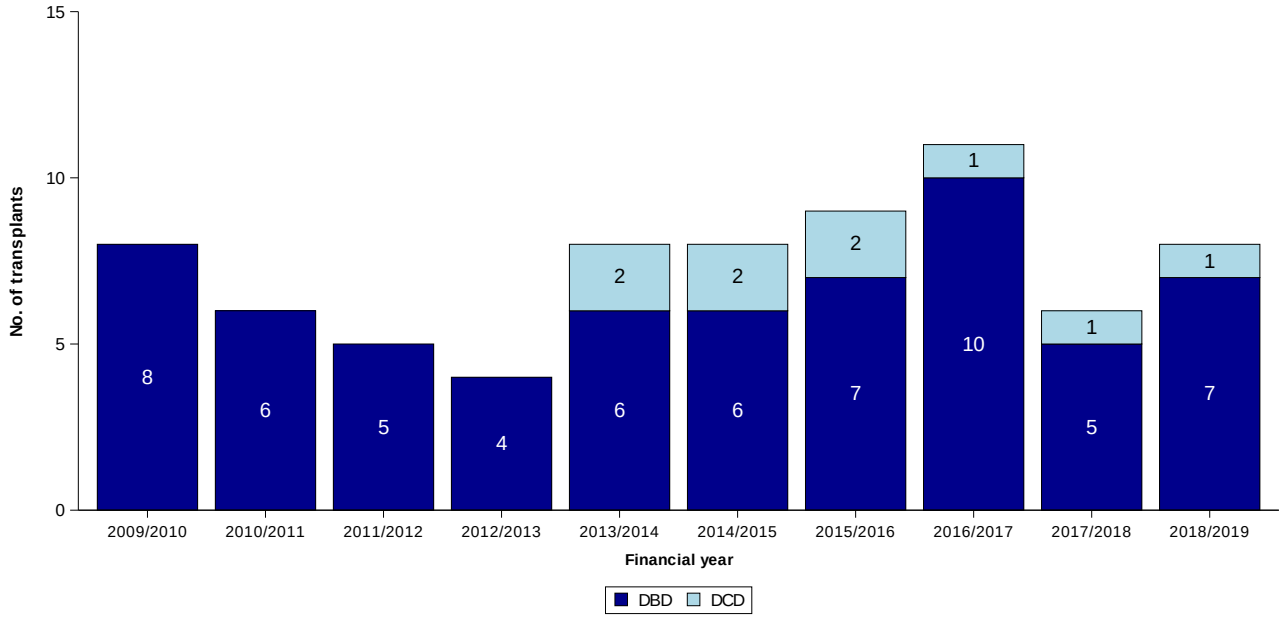


Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2009 to 31 March 2019

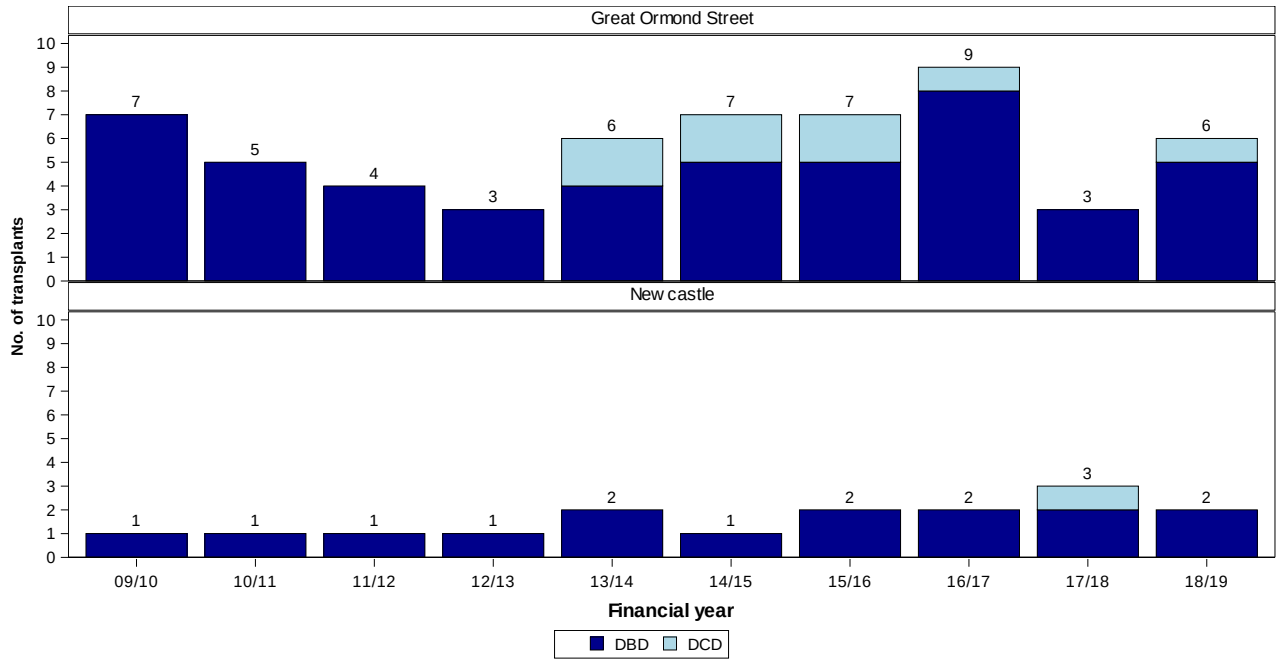


Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2018 to 31 March 2019

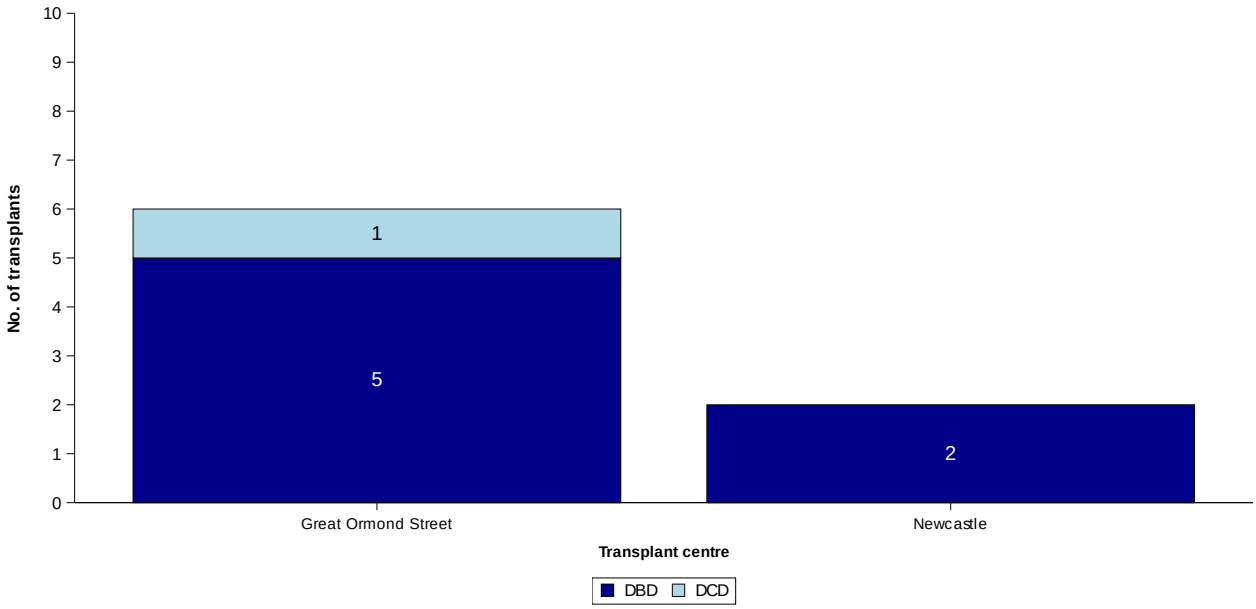


Figure 22.4 and **22.5** show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period there have been three paediatric heart-lung block transplants; two in the latest year. Newcastle performed one partial lung transplant in 2012/2013. The number of transplants in the latest financial year (2018/2019) is shown by centre and transplant type in **Figure 22.6**.

Figure 22.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2009 to 31 March 2019

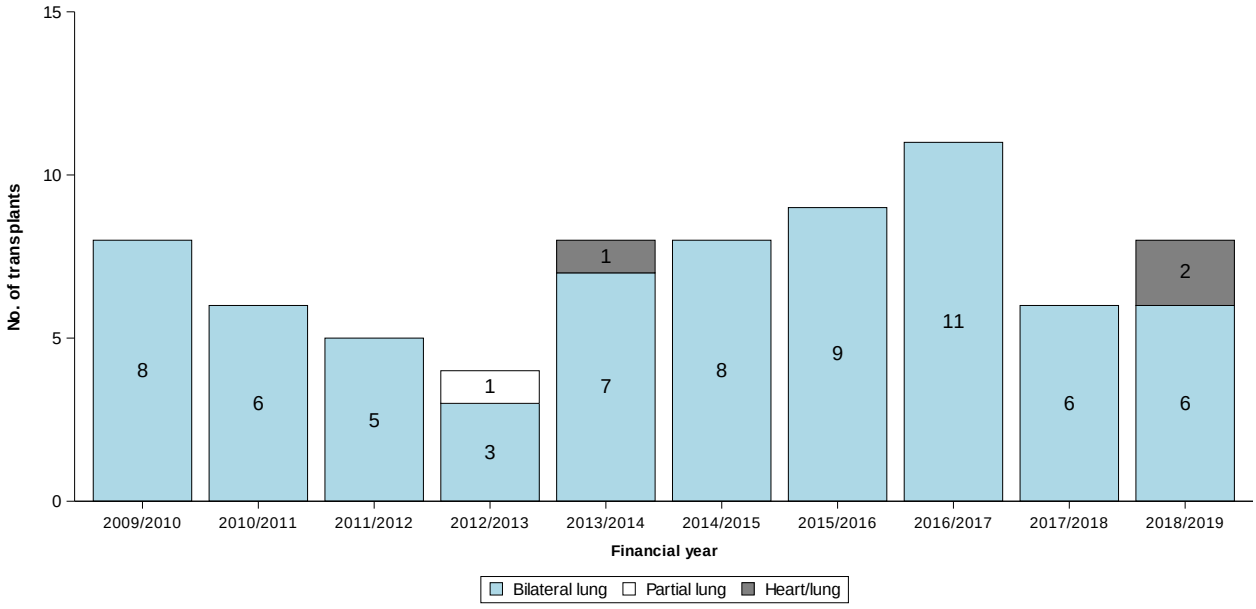


Figure 22.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2009 to 31 March 2019

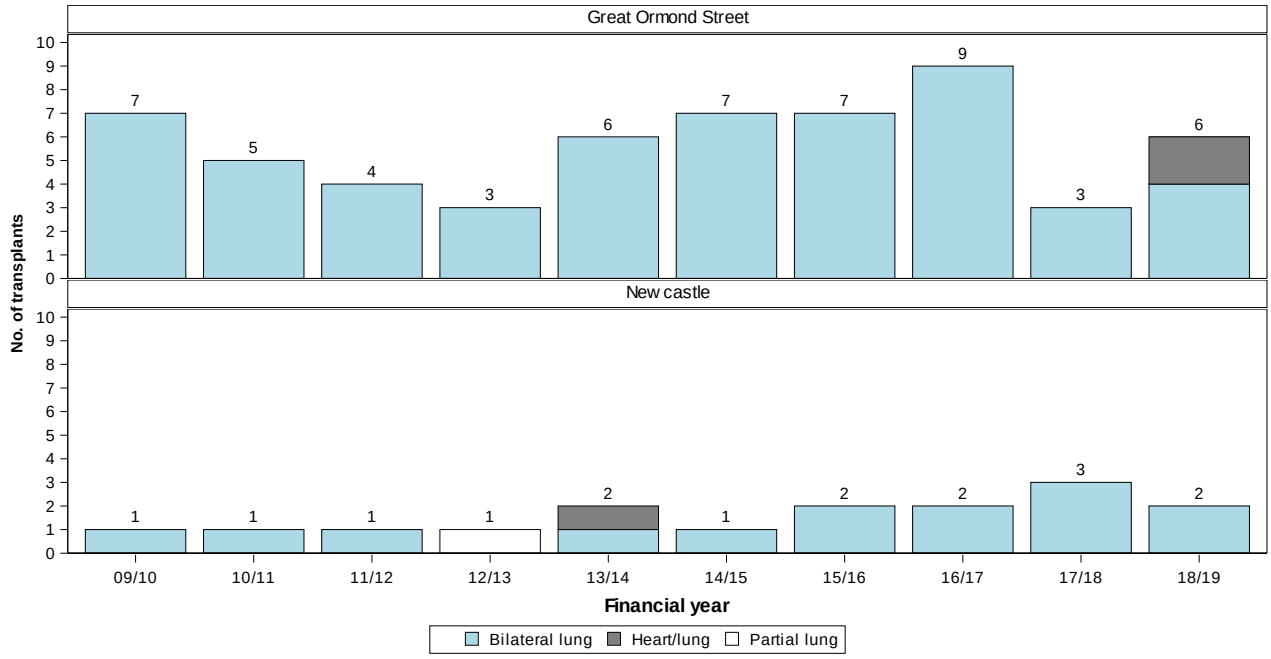
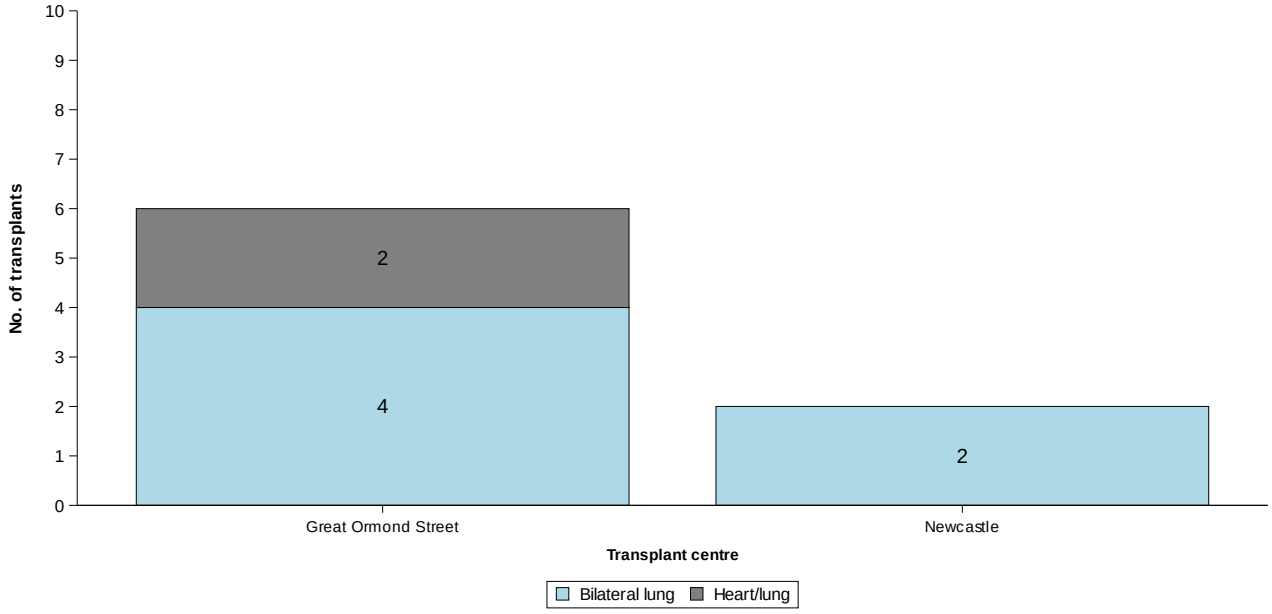


Figure 22.6 Number of paediatric lung transplants in the UK, by centre and transplant type, 1 April 2018 to 31 March 2019



On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. **Figure 22.7** displays the number of paediatric lung only transplants performed in the last 10 financial years by urgency. The number of lung only transplants by urgency status in the latest financial year (2018/2019) is shown by centre in **Figure 22.7**. There were two urgent lung only transplants last year and both were at Newcastle. Heart-lung patients have access to urgent transplants through the heart allocation scheme and of the two paediatric heart-lung transplants during 2018/2019, one was urgent which was performed by Great Ormond Street Hospital (Figure not shown).

Figure 22.7 Number of paediatric lung only transplants in the UK, by financial year, centre and urgency, 1 April 2009 to 31 March 2019

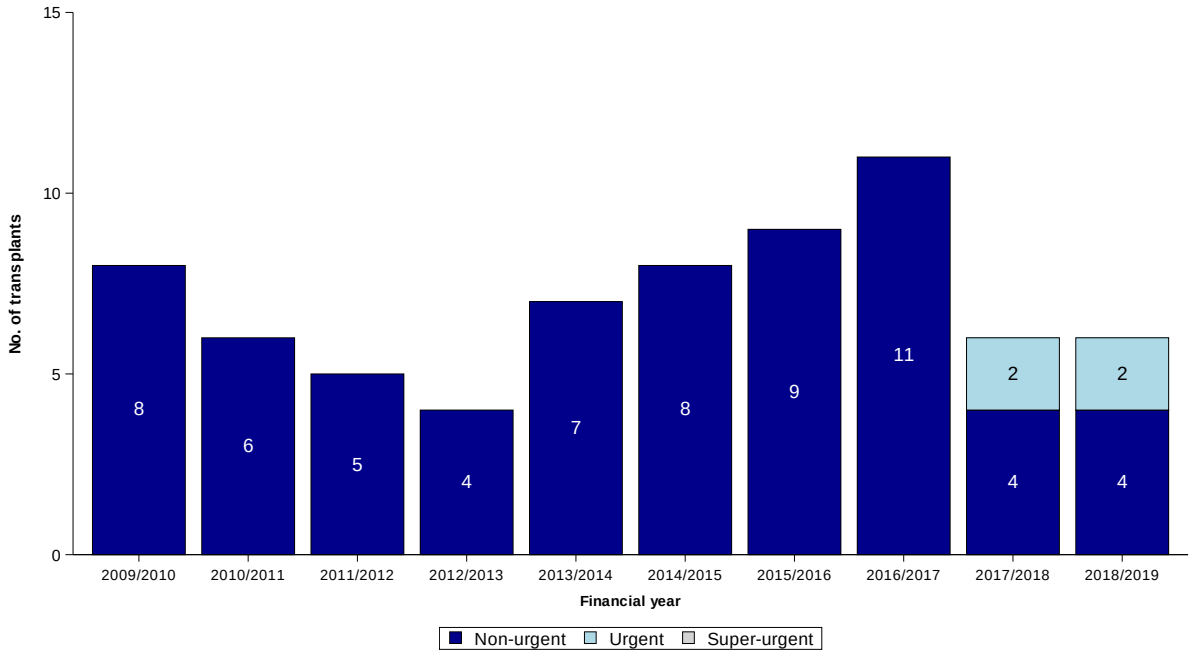
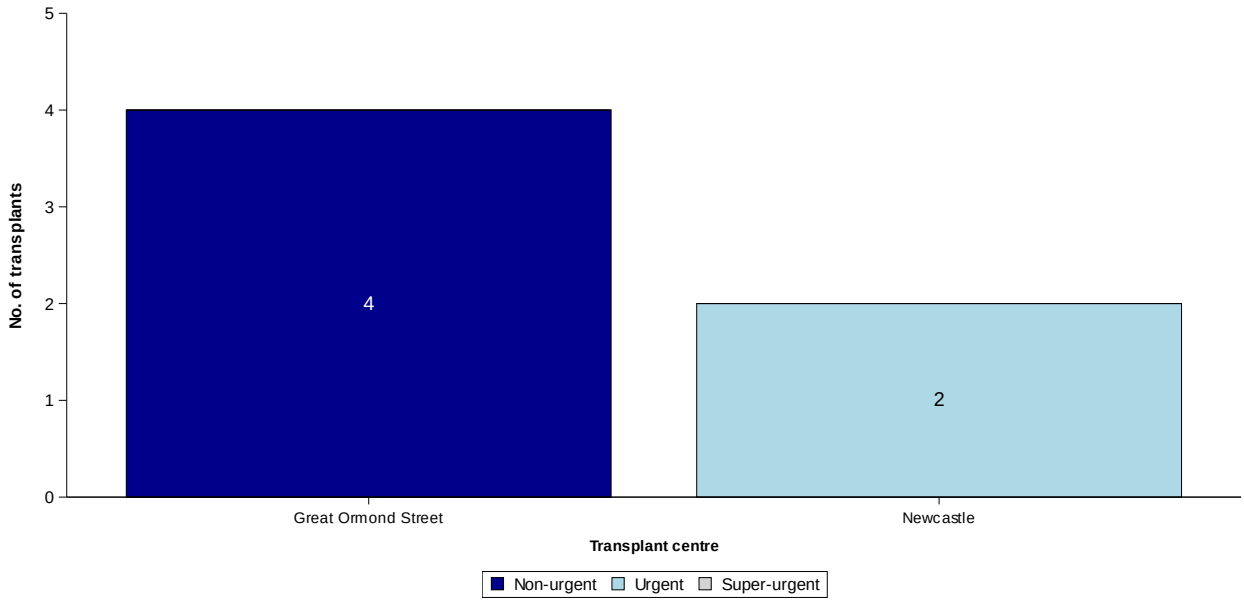


Figure 22.8 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2018 to 31 March 2019



22.2 Demographic characteristics of transplants, 1 April 2017 – 31 March 2019

The demographic characteristics of the 14 paediatric lung transplant recipients and donors in the last two years are shown by centre and overall in **Table 22.1**. Nationally, 57% of lung recipients were female and the median age was 14 years, while the median age of donors was 20 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 2017 to 31 March 2019, by centre

		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL** N (%)
Number of transplants		9 (100)	5 (100)	**14 (100)**
Year of transplant	2017/2018	3 (33)	3 (60)	**6 (43)**
	2018/2019	6 (67)	2 (40)	**8 (57)**
Urgency status at transplant	Non-urgent	7 (78)	2 (40)	**9 (64)**
	Urgent	2 (22)	3 (60)	**5 (36)**
Recipient sex	Male	4 (44)	2 (40)	**6 (43)**
	Female	5 (56)	3 (60)	**8 (57)**
Recipient ethnicity	White	8 (89)	5 (100)	**13 (93)**
	Non-white	1 (11)	0 (0)	**1 (7)**
Recipient age (years)	Median (IQR)	14 (12, 14)	15 (11, 15)	**14 (11, 15)**
	Missing	0	0	**0**
Recipient weight (kg)	Median (IQR)	42 (35, 63)	40 (38, 43)	**41 (35, 52)**
	Missing	0	0	**0**
Recipient primary disease	Cystic fibrosis and bronchiectasis	2 (22)	4 (80)	**6 (43)**
	Primary pulmonary hypertension	5 (56)	1 (20)	**6 (43)**
	Other heart/lung disease	2 (22)	0 (0)	**2 (14)**
NYHA class	I	0 (0)	0 (0)	**0 (0)**
	II	0 (0)	0 (0)	**0 (0)**
	III	1 (11)	1 (20)	**2 (14)**
	IV	4 (44)	1 (20)	**5 (36)**
	Missing	4 (44)	3 (60)	**7 (50)**
Recipient in hospital pre-transplant	No	5 (56)	2 (40)	**7 (50)**
	Yes	1 (11)	3 (60)	**4 (29)**
	Missing	3 (33)	0 (0)	**3 (21)**
If in hospital, recipient on ventilator	No	1 (100)	3 (100)	**4 (100)**
If in hospital, recipient on inotropes	No	1 (100)	3 (100)	**4 (100)**
Recipient CMV status	No	4 (44)	4 (80)	**8 (57)**
	Yes	5 (56)	1 (20)	**6 (43)**

Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2017 to 31 March 2019, by centre

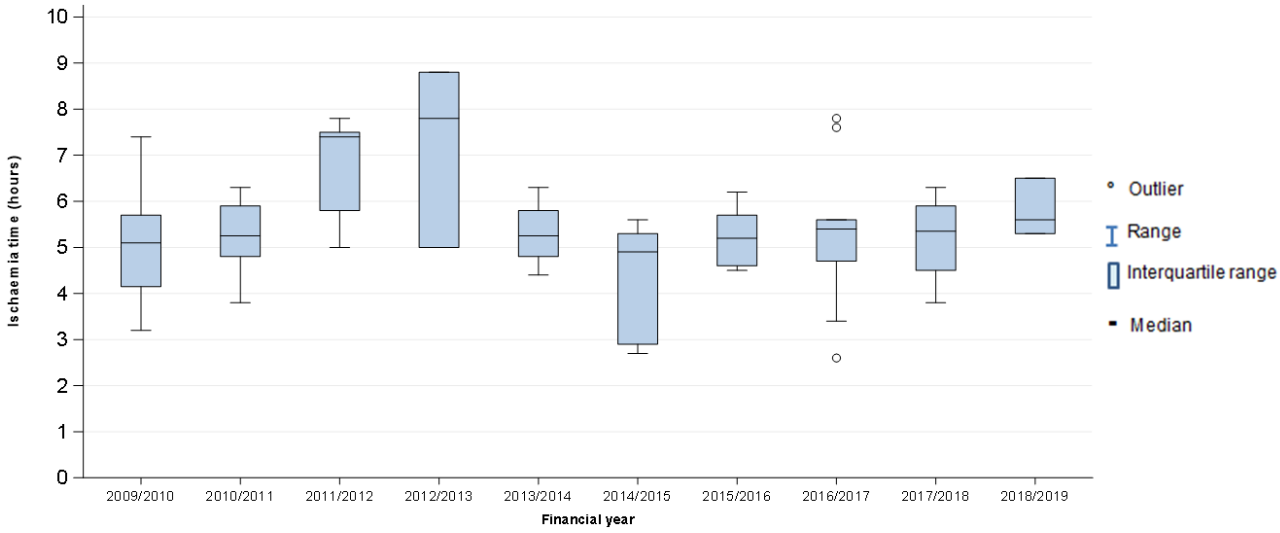
		Great Ormond Street Hospital N (%)	Newcastle N (%)	**TOTAL** N (%)
Recipient HCV status	No	9 (100)	5 (100)	**14 (100)**
Recipient HBV status	No	9 (100)	5 (100)	**14 (100)**
Recipient HIV status	No	9 (100)	5 (100)	**14 (100)**
Recipient serum creatinine (umol/l)	Median (IQR)[1]	-	-	**39 (29, 50)**
	Missing	6	1	**7**
Donor sex	Male	4 (44)	1 (20)	**5 (36)**
	Female	5 (56)	4 (80)	**9 (64)**
Donor ethnicity	White	8 (89)	5 (100)	**13 (93)**
	Non-white	1 (11)	0 (0)	**1 (7)**
Donor age (years)	Median (IQR)	39 (23, 47)	10 (9, 14)	**20 (14, 44)**
	Missing	0	0	**0**
Donor BMI (kg/m^2)	Median (IQR)	23 (21, 24)	19 (19, 21)	**22 (19, 24)**
	Missing	0	0	**0**
Donor cause of death	CVA	7 (78)	4 (80)	**11 (79)**
	Trauma	1 (11)	0 (0)	**1 (7)**
	Others	1 (11)	1 (20)	**2 (14)**
Donor hypotension	No	3 (33)	3 (60)	**6 (43)**
	Yes	3 (33)	2 (40)	**5 (36)**
	Missing	3 (33)	0 (0)	**3 (21)**
Donor past cardiothoracic disease	No	8 (89)	5 (100)	**13 (93)**
	Yes	1 (11)	0 (0)	**1 (7)**
Donor past hypertension	No	9 (100)	5 (100)	**14 (100)**
Donor past tumour	No	9 (100)	5 (100)	**14 (100)**
Donor past smoker	No	7 (78)	5 (100)	**12 (86)**
	Yes	2 (22)	0 (0)	**2 (14)**
Total ischaemia time (hours)	Median (IQR)[1]	-	5.5 (5.3, 5.6)	**5.6 (5.3, 6.2)**
	Missing	6	0	**6**

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

22.3 Total ischaemia time, 1 April 2009 – 31 March 2019

Figure 22.9 shows boxplots of total ischaemia time for DBD donor lungs transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The median total ischaemia time varied quite substantially over the decade, however these are based on a very small number of transplants per year (≤11). No further breakdown by centre is shown due to small numbers.

Figure 22.9 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2009 to 31 March 2019



PAEDIATRIC LUNG TRANSPLANTATION

Post-Transplant Survival

23. Post-Transplant Survival

The survival analyses presented in this section exclude heart-lung transplants and other multi-organ transplants and include first time transplants only. Partial lung transplants are also excluded. Both DBD and DCD lung transplants are included. Ninety-day and 1-year survival rates are based on transplants performed in the period 1 April 2014 to 31 March 2018 while 5-year survival rates are based on transplants performed in the period 1 April 2010 to 31 March 2014.

The 90-day post-transplant unadjusted patient survival rates are shown in **Table 23.1** for the 34 first paediatric lung only transplants in the period 1 April 2014 to 31 March 2018. Only 8 of these transplants were performed by Newcastle so it was not possible to generate a robust survival rate, however there were no reported deaths within 90 days for these patients. Nationally, the 90 day survival rate following first paediatric lung transplant was 91.2%.

Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre, 1 April 2014 to 31 March 2018

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	26	3	88.5	(68.4 - 96.1)
Newcastle[1]	8	0	-	-
UK	**34**	**3**	**91.2**	**(75.1 - 97.1)**

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

There were two additional deaths between 90 days and 1 year for the 34 paediatric lung only transplants performed in the period 1 April 2014 to 31 March 2018; one from each centre.

Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2014 to 31 March 2018

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	26	4	84.6	(64.0 - 93.9)
Newcastle[1]	8	1	-	-
UK	**34**	**5**	**84.9**	**(67.4 - 93.4)**

[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 20 first lung only transplants performed in the period 1 April 2010 to 31 March 2014. 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 2010 to 31 March 2014

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street Hospital	17	5	70.6	(43.1 - 86.6)
Newcastle[1]	3	0	-	-
UK	**20**	**5**	**73.9**	**(48.2 - 88.2)**

[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 2018

Form return rates are reported in **Table 24.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric lung and heart-lung transplants between 1 January and 31 December 2018 for the transplant record, and all follow up forms issued in this time period. Only a small number of forms are outstanding for this period for each centre.

Table 24.1 Form return rates for paediatric lung transplants, 1 January 2018 to 31 December 2018

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	2	100	5	100	18	94
Newcastle, Freeman Hospital	0	-	0	-	3	67	17	82
Overall	**4**	**100**	**2**	**100**	**8**	**88**	**35**	**89**

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 2009 – 31 March 2019	• Introduction	None	1364	1772
1 April 2009 – 31 March 2019	• Transplants	• Multi-organ transplants	1356	1769
1 April 2014 – 31 March 2018	Post-transplant survival – • 30/90-day • 1-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	566	698
1 April 2010 – 31 March 2014	Post-transplant survival – • 5-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	474	707

Table A1.2 Paediatric transplants analysed

Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2009 – 31 March 2019	• Introduction	None	327	73
1 April 2009 – 31 March 2019	• Transplants	• Multi-organ transplants	327	73
1 April 2014 – 31 March 2018	Post-transplant survival – • 30/90-day • 1-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	134	34
1 April 2010 – 31 March 2014	Post-transplant survival – • 5-year survival	• Multi-organ transplants (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	126	20

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 2018 and 31 March 2019 were extracted from the UK Transplant Registry on 14 June 2019 (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-2017 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 2018 and 31 March 2019 (numerator), divided by the mid-2017 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 2018 and 31 March 2019 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 on offer decline rate that is higher than the national rate, while centres positioned below the lower limits indicates on offer decline

Unadjusted post-transplant survival rates

Kaplan-Meier methods were used to estimate the unadjusted patient survival rates. Patients can be included in this method of analysis irrespective of the length of follow-up recorded. If a patient is alive at the end of the follow-up then information about the survival of the patient is censored.

Risk-adjusted post-transplant survival rates

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

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

Missing values were imputed using multiple imputation where missing values for heart transplants ranged from <1% for several variables to 8.5% for respiratory arrest, and for lung transplants ranged from <1% for several variables to 10.6% for recipient cholesterol at registration (the proportion missing for some centres was higher). Multiple imputation was implemented in SAS Enterprise Guide, using chained equations. The form of the imputation model used to estimate missing values consisted of a list of transplant related variables as well as the outcome variables (survival time and censoring indicator). Twenty imputations were run with 50 burn-in iterations before each imputation. Post-transplant survival models were fitted to the resulting 20 datasets and estimates were obtained for each parameter in the model by analysing the results of these 20 models collectively.

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

Systematic component of variation
For a given individual who is a resident in a given 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 2007 and 31 December 2018. 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 14 June 2019 if the patient was on the transplant list at time of analysis.

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

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

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

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

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

A3: Risk models

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

Table A3.2	Risk factors and categories used in the adult lung risk adjusted 90-day. 1- year and 5-year survival model
Donor CMV	Negative Positive
Donor history of smoking	No Yes
Recipient daily dose of prednisolone at registration	0 1-14 ≥ 15
Donor:recipient calculated TLC mismatch (recipient – donor)	(modelled as continuous variable)
Recipient FVC at registration	(modelled as continuous variable)
Recipient bilirubin at registration	(modelled as continuous variable)
Recipient cholesterol at registration	(modelled as continuous variable)
Recipient age at transplant	Non-linear spline with knots at 22, 45, 56, and 64.
Transplant type	Single lung Bilateral lung
Primary disease group	COPD and emphysema Cystic fibrosis and bronchiectasis Fibrosing lung disease Other

A4: Glossary of terms

Active transplant list
When a patient is registered for a transplant, they are registered on what is called the 'active' transplant list. This means that when a donor organ becomes available, the patient is included among those who are matched against the donor to determine whether or not the organ is suitable for them. It may sometimes be necessary to take a patient off the transplant list, either temporarily or permanently. This may be done, for example, if someone becomes too ill to receive a transplant. The patient is told about the decision to suspend them from the list and is informed whether the suspension is temporary or permanent. If a patient is suspended from the list, they are not included in the matching of any donor organs that become available.

Boxplots
The length of the box in this plot represents the inter-quartile range. The line inside the box indicates the median value. The vertical lines issuing from the box are called the whiskers and indicate the range of values that are outside of the inter-quartile range but are close enough not to be considered outliers. The circles that are outside the box indicate the outliers (any points that are a distance of more than 1.5*IQR from the box).

Case mix
The types of patients treated at a unit for a common condition. This can vary across units depending on the facilities available at the unit as well as the types of people in the catchment area of the unit. The definition of what type of patient a person is depends on the patient characteristics that influence the outcome of the treatment.

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

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

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

Donor after brain death (DBD)
Donation after brainstem death means donation which takes place following the diagnosis of death using neurological criteria.

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

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

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

Kaplan-Meier method
A method that allows patients with incomplete follow-up information to be included in estimating survival rates. For example, when estimating one year patient survival rates, a patient may be followed up for only nine months before they relocate. If we calculated a crude survival estimate using the number of patients who survived for at least a year, this patient would have to be excluded as it is not known whether or not the patient was still alive at one year after transplant. The Kaplan-Meier method allows information about such patients to be used for the length of time that they are followed-up, when this information would otherwise be discarded. Such instances of incomplete follow-up are not uncommon and the Kaplan-Meier method allows the computation of estimates that are more meaningful in these cases. The Kaplan-Meier method can be used for any time to event analysis, including time to transplant. If not enough events have occurred or if there are not enough patients in the cohort, an estimate of the median may not be possible.

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

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

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

Patient survival rate
The percentage of patients who are still alive (whether the graft is still functioning or not). This is usually specified for a given time period after transplant. For example, a five-year patient survival rate is the percentage of patients who are still alive five years after their first transplant.

***p* value**
In the context of comparing survival rates across centres, the *p* value is the probability that the differences observed in the rates across centres occurred by chance. As this is a probability, it takes values between 0 and 1. If the *p* value is small, say less than 0.05, this implies that the differences are unlikely to be due to chance and there may be some identifiable cause for these differences. If the *p* value is large, say greater than 0.1, then it is quite likely that any differences seen are due to chance.

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

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

Unadjusted survival rate
Unadjusted survival rates do not take account of risk factors and are based only on the number of transplants at a given centre and the number and timing of those that fail within the post-transplant period of interest. In this case, unlike for risk-adjusted rates, all transplants are assumed to be equally likely to fail at any given time. However, some centres may have lower unadjusted survival rates than others simply because they tend to undertake transplants that have increased risks of failure. Comparison of unadjusted survival rates across centres and to the national rate is therefore inappropriate.

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

Prepared by:

Statistics and Clinical Studies, NHS Blood and Transplant

Frederick Smith
Rachel Hogg
Sally Rushton

Cardiothoracic Advisory Group (CTAG) Clinical Audit Group