



**Blood and Transplant**

**ANNUAL REPORT ON CARDIOTHORACIC  
ORGAN TRANSPLANTATION**

**REPORT FOR 2016/2017  
(1 APRIL 2007 – 31 MARCH 2017)**

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# **EXECUTIVE SUMMARY**



## 1. Executive Summary

This report presents key figures about cardiothoracic organ transplantation in the UK. The period reported covers 10 years of heart and lung transplant data, from 1 April 2007 to 31 March 2017. The data include number of patients listed for a transplants, number of transplants performed and [survival rates](#) following heart and lung transplantation; both on a national and centre-specific basis.

### Key findings

- The number of heart transplants performed in 2016/2017 was 198. This was the highest number over the decade, joint with 2013/2014. The number of lung transplants was 178 which was a 5% drop compared with 2015/2016. These numbers, which are adult and paediatric combined, represent 3 heart transplants per million population and 2.7 lung transplants per million population of the UK.
- A super-urgent registration tier for adult heart transplantation was introduced on 26 October 2016 as a result of the growing number of patients registered urgently and by 31 March 2017 there had been 19 such registrations nationally.
- The national lung transplant list was especially high at the end of March 2017, at 378 patients. It is hoped that the introduction of super-urgent and urgent lung listing schemes in May 2017 will reduce the waiting list and the high waiting list mortality rate of 12% within 6 months for adults.
- The national 30 day rate of **survival following adult heart transplantation** was 89.9%, which ranged from 82.4% to 96.8% across centres ([risk-adjusted](#)) with Papworth having a significantly high rate. The national 1 year survival rate was 82.4%, ranging from 74.5% to 89.7% across centres ([risk-adjusted](#)) with Papworth having a borderline significantly high rate. The national 5 year survival rate was 70.5%, ranging from 49.9% to 79.0% across centres ([risk-adjusted](#)) with Glasgow and Harefield having borderline significantly low survival rates and Papworth having a borderline significantly high rate.
- The national 90 day rate of **survival following adult lung transplantation** was 90.0%, which ranged from 84.9% to 94.1% across centres ([risk-adjusted](#)) with Papworth having a borderline significantly high rate. The national 1 year survival rate was 79.8%, ranging from 69.3% to 84.5% across centres ([risk-adjusted](#)) with Birmingham having a borderline significantly low rate. The national 5 year survival rate was 58.3%, ranging from 37.8% to 63.5% across centres ([risk-adjusted](#)) with Birmingham having a significantly low survival rate.
- The national 30 day rate of **survival following paediatric heart transplantation** was 95.9%. This reduced to 92.5% after 1 year and 82.6% after 5 years. These rates were very similar between the two paediatric centres.
- The national 90 day rate of **survival following paediatric lung transplantation** was 92.0%. This reduced to 73.9% after 5 years.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Cardiothoracic Organ Transplantation 2016/17, 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 2007 and 31 March 2017, 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 report, 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, heart-lung block transplants and patients receiving their second (or subsequent) graft are excluded from the survival analysis calculations.

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

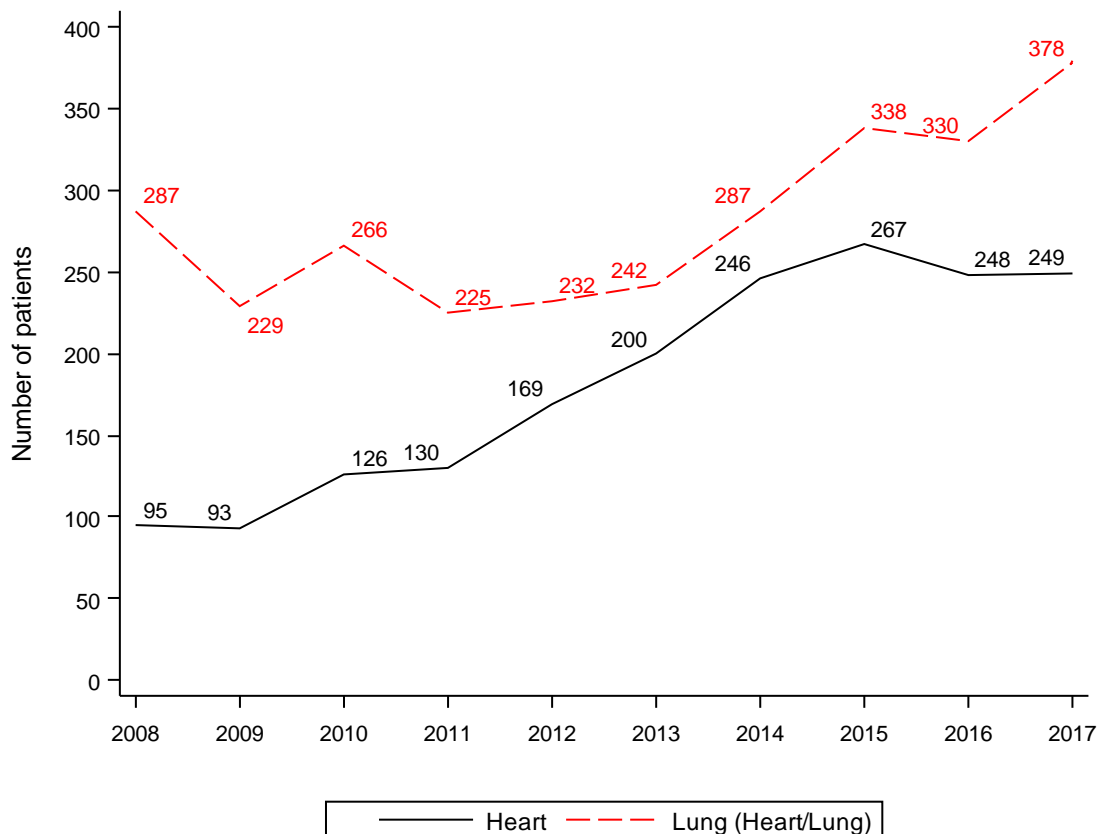
In the last year the UK has made changes in the listing and allocation policies for heart and lung transplantation. As of 26 October 2016, patients can be registered super-urgently on the heart transplant list. This additional tier is a result of the growing number of patients registered urgently and will help to prioritise those with a greatest need for a heart transplant. Urgent and super-urgent categories were introduced for patients requiring a lung transplant on 18 May 2017, outside of the time period analysed in this report.



## 2.1 Overview

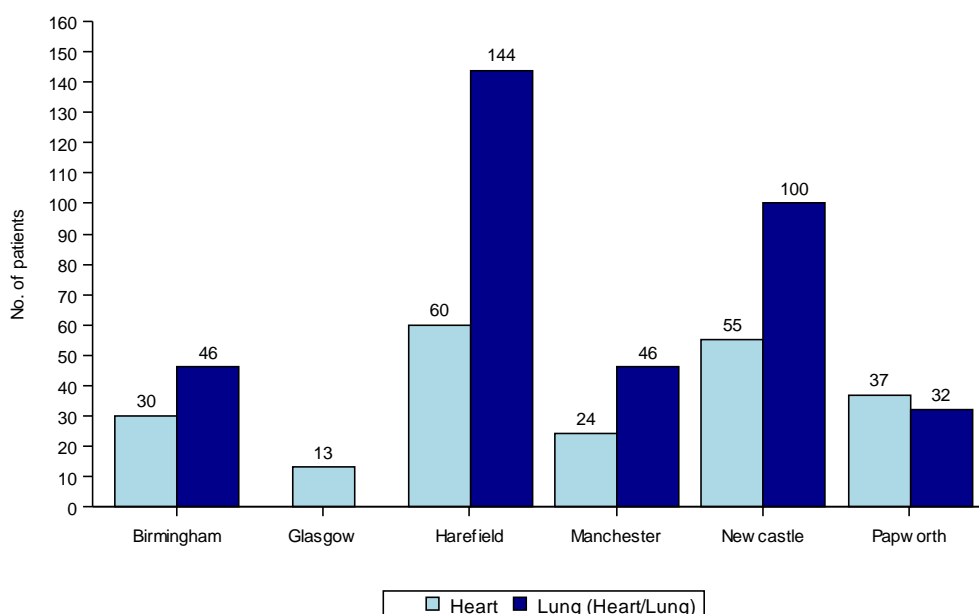
**Figure 2.1** shows the number of patients on the [active transplant list](#) at financial year end between 2008 and 2017. The number of patients waiting for a lung transplant varied at the start of the decade but since 2011 has generally increased year on year, reaching a peak of 378 in 2017, representing a 15% increase from the previous year. The number of patients waiting for a heart transplant increased substantially from 95 in 2008 to 267 in 2015, but in the last two years has reduced slightly, to 249 at the end of March 2017.

**Figure 2.1 Number of patients on the national active heart and lung transplant lists at 31 March each year, 2008 to 2017**

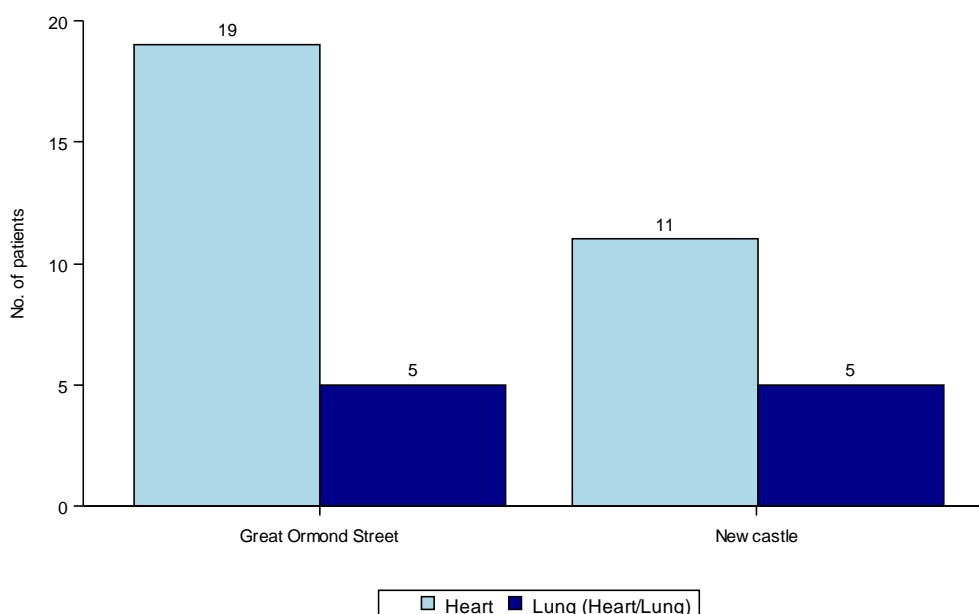


**Figure 2.2** and **Figure 2.3** show the number of adult and paediatric patients on the [active transplant list](#) at 31 March 2017 at each centre. In total, there were 587 adult and 40 paediatric patients. Harefield had the highest number of adult patients on both the heart and lung transplant lists. Note that Glasgow does not perform lung transplantation. Great Ormond Street Hospital had the highest number of paediatric patients on the heart transplant list, but both paediatric centres had the same number on the lung transplant list. These numbers include 3 patients waiting for a multi-organ transplant (2 heart and kidney, 1 heart and liver).

**Figure 2.2 Number of adult patients on the active heart and lung transplant lists at 31 March 2017, by centre**

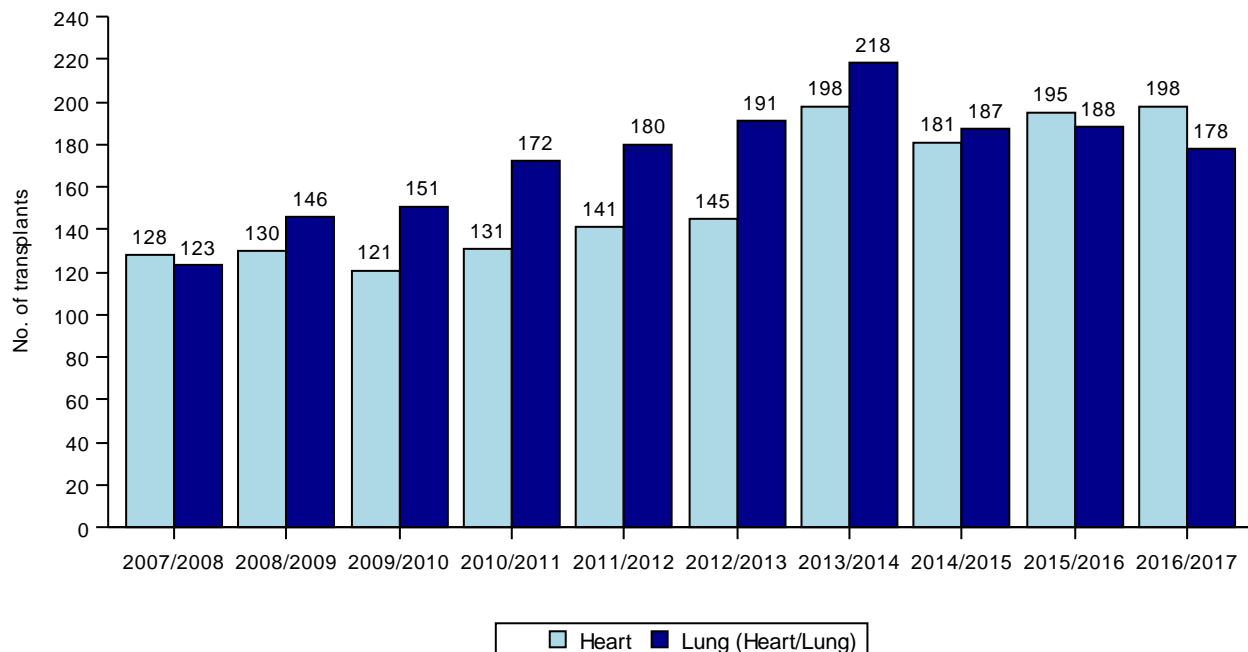


**Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists at 31 March 2017, by centre**



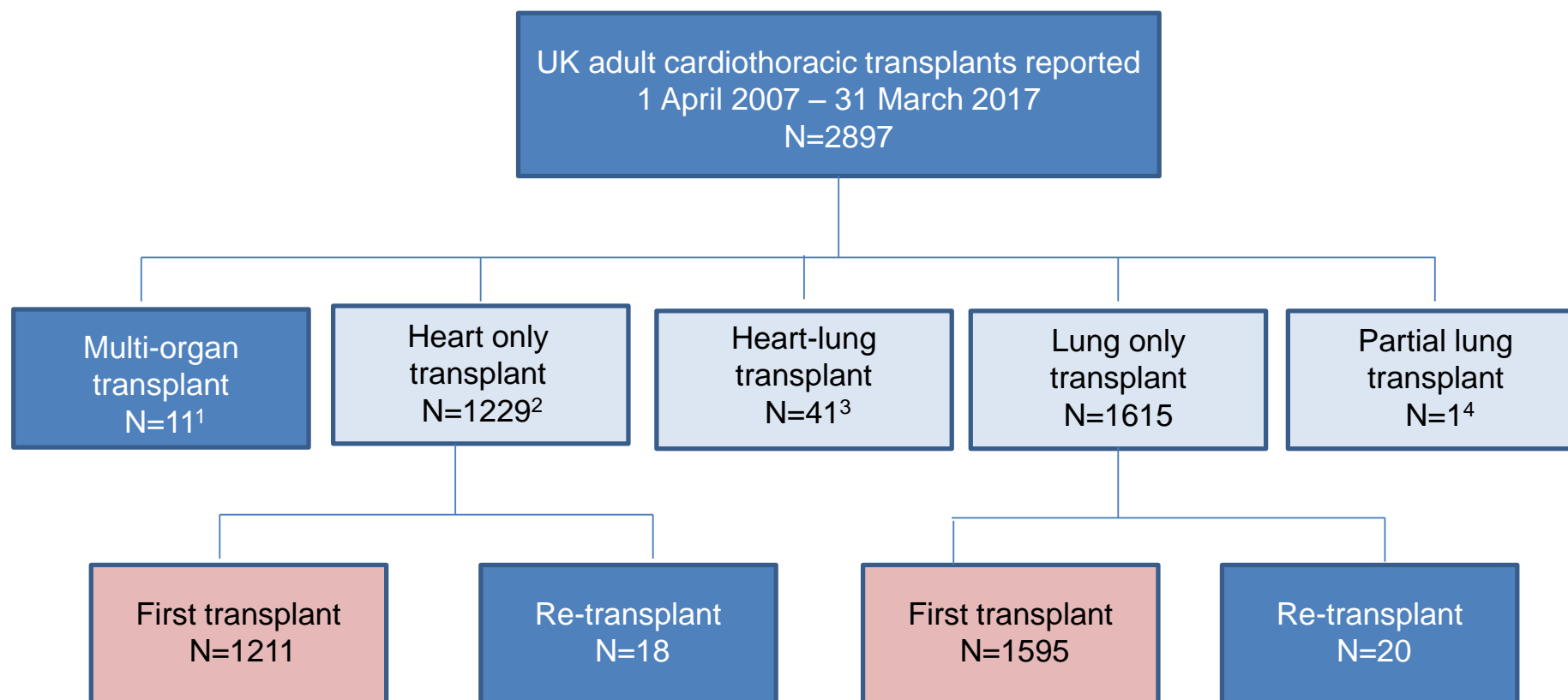
**Figure 2.4** shows the total number of transplants performed in the last ten years. The number of heart transplants last year was 198, matching the number in 2013/2014. The number of lung transplants per year increased steadily between 2007/2008 and 2013/2014, reaching a peak of 218, but has since dropped to 178 in the last year.

**Figure 2.4 Number of cardiothoracic organ transplants in the UK, by financial year, 1 April 2007 to 31 March 2017**



**Figure 2.5** breaks down the 2897 adult cardiothoracic organ transplants performed in the UK in the ten year period whilst **Figure 2.6** shows the same information for the 405 paediatric transplants performed during the same period. In the remainder of this report, [multi-organ transplants](#) are excluded, hence 2886 adult and 405 paediatric transplants are analysed further (those in the light blue boxes). In the survival sections, first transplants 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 2.5 Adult cardiothoracic organ transplants performed in the UK, 1 April 2007 to 31 March 2017**



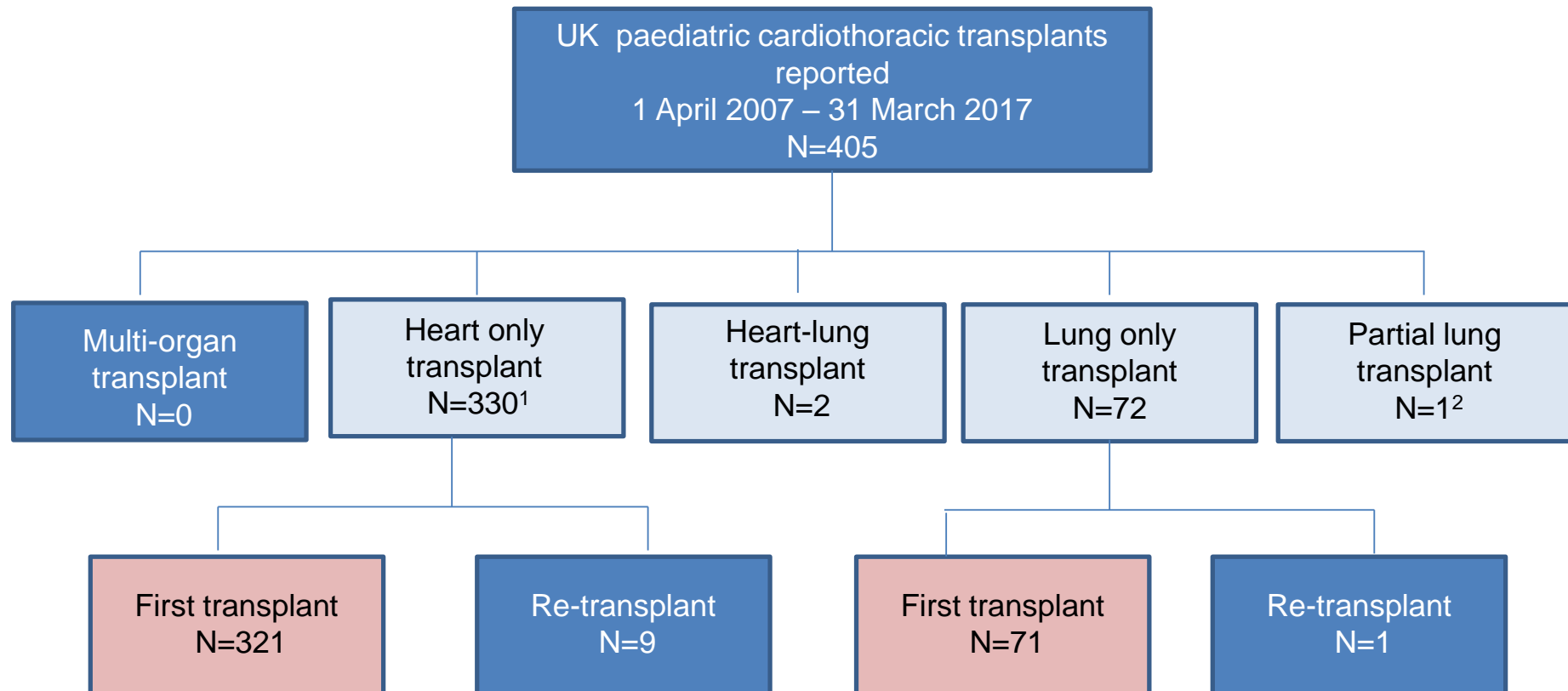
<sup>1</sup> Includes 8 heart and kidney transplants, 1 heart and liver, 1 lung and kidney and 1 lung and liver

<sup>2</sup> Includes 3 domino donor transplants and 33 DCD heart transplants

<sup>3</sup> Includes 1 re-transplant

<sup>4</sup> Living donor transplant

**Figure 2.6 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2007 to 31 March 2017**



<sup>1</sup> Includes 1 domino donor transplant and 1 DCD heart transplant

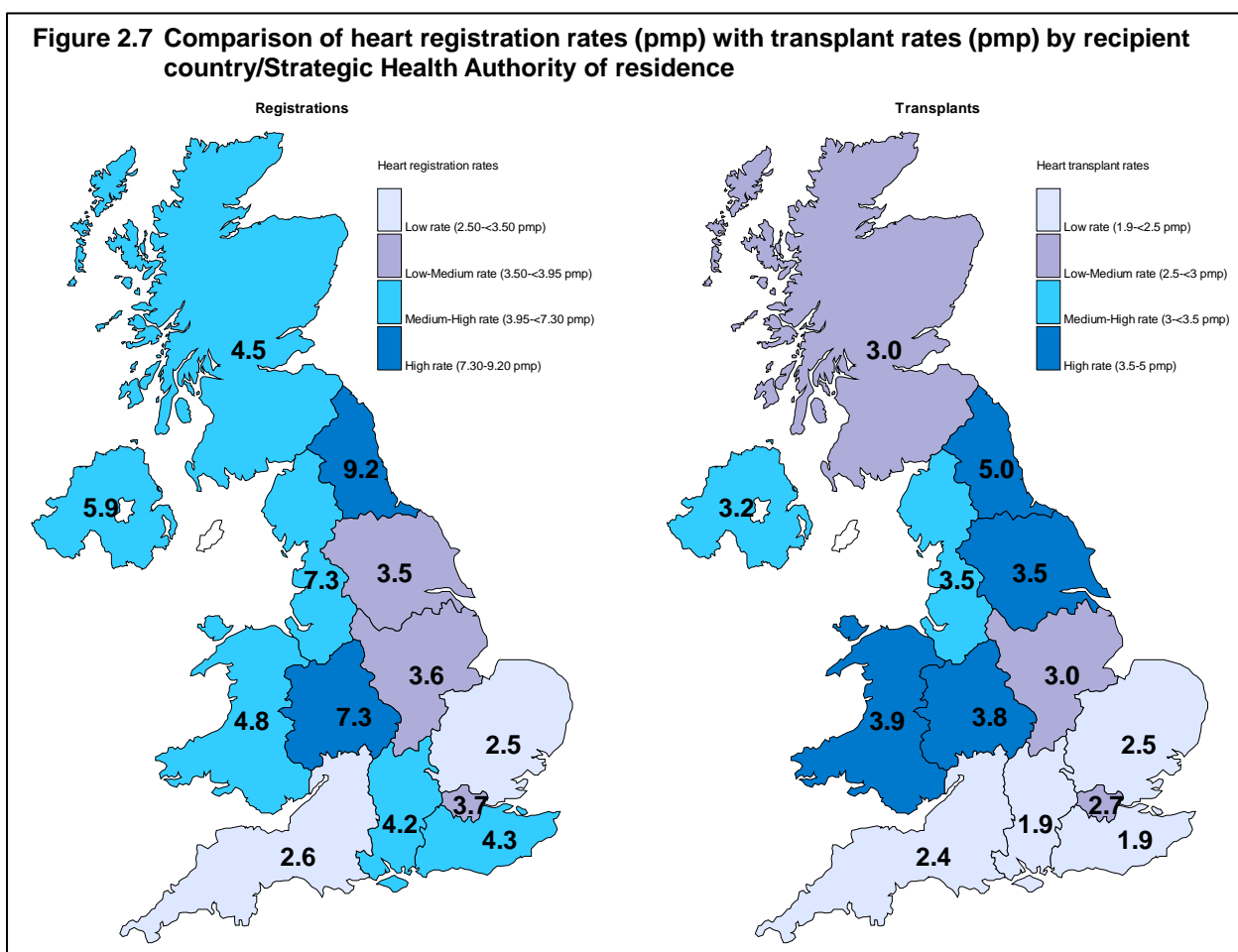
<sup>2</sup> Deceased donor transplant

## 2.2 Geographical variation in registration and transplant rates

**Figure 2.7** shows rates of registration to the heart transplant list per million population (pmp) between 1 April 2016 and 31 March 2017 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 4.7 pmp and 3.0 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 0.2 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 2.8** 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 5.4 pmp 2.7 pmp respectively. For lungs, both registration and transplant rates yielded a SCV of 0, and therefore no evidence of geographical variation beyond what would be expected at random.



**Table 2.1 Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2016 – 31 March 2017, by Country/Strategic Health Authority**

<b>Country/ Strategic Health Authority</b>	<b>Registrations (pmp)</b>		<b>Transplants (pmp)</b>	
North East	24	(9.2)	13	(5.0)
North West	52	(7.3)	25	(3.5)
Yorkshire and The Humber	19	(3.5)	19	(3.5)
<b>North of England</b>	<b>95</b>	<b>(6.3)</b>	<b>57</b>	<b>(3.8)</b>
East Midlands	17	(3.6)	14	(3.0)
West Midlands	42	(7.3)	22	(3.8)
East of England	15	(2.5)	15	(2.5)
<b>Midlands and East</b>	<b>74</b>	<b>(4.5)</b>	<b>51</b>	<b>(3.1)</b>
<b>London</b>	<b>32</b>	<b>(3.7)</b>	<b>23</b>	<b>(2.7)</b>
South East Coast	20	(4.3)	9	(1.9)
South Central	18	(4.2)	8	(1.9)
South West	14	(2.6)	13	(2.4)
<b>South of England</b>	<b>52</b>	<b>(3.6)</b>	<b>30</b>	<b>(2.1)</b>
<b>England</b>	<b>253</b>	<b>(4.6)</b>	<b>161</b>	<b>(2.9)</b>
<b>Isle of Man</b>	0	(0.0)	0	(0.0)
<b>Channel Islands</b>	0	(0.0)	0	(0.0)
<b>Wales</b>	<b>15</b>	<b>(4.8)</b>	<b>12</b>	<b>(3.9)</b>
<b>Scotland</b>	<b>24</b>	<b>(4.5)</b>	<b>16</b>	<b>(3.0)</b>
<b>Northern Ireland</b>	<b>11</b>	<b>(5.9)</b>	<b>6</b>	<b>(3.2)</b>
<b>TOTAL</b>	<b>310<sup>1</sup></b>	<b>(4.7)</b>	<b>197<sup>2</sup></b>	<b>(3.0)</b>

<sup>1</sup> Total includes 7 recipients whose postcode was unknown and excludes 3 recipients who reside in the Republic of Ireland

<sup>2</sup> Total includes 2 recipients whose postcode was unknown and excludes 1 recipient who reside in the Republic of Ireland

**Figure 2.8 Comparison of lung registration rates (pmp) with transplant rates (pmp) by recipient country/Strategic Health Authority of residence**

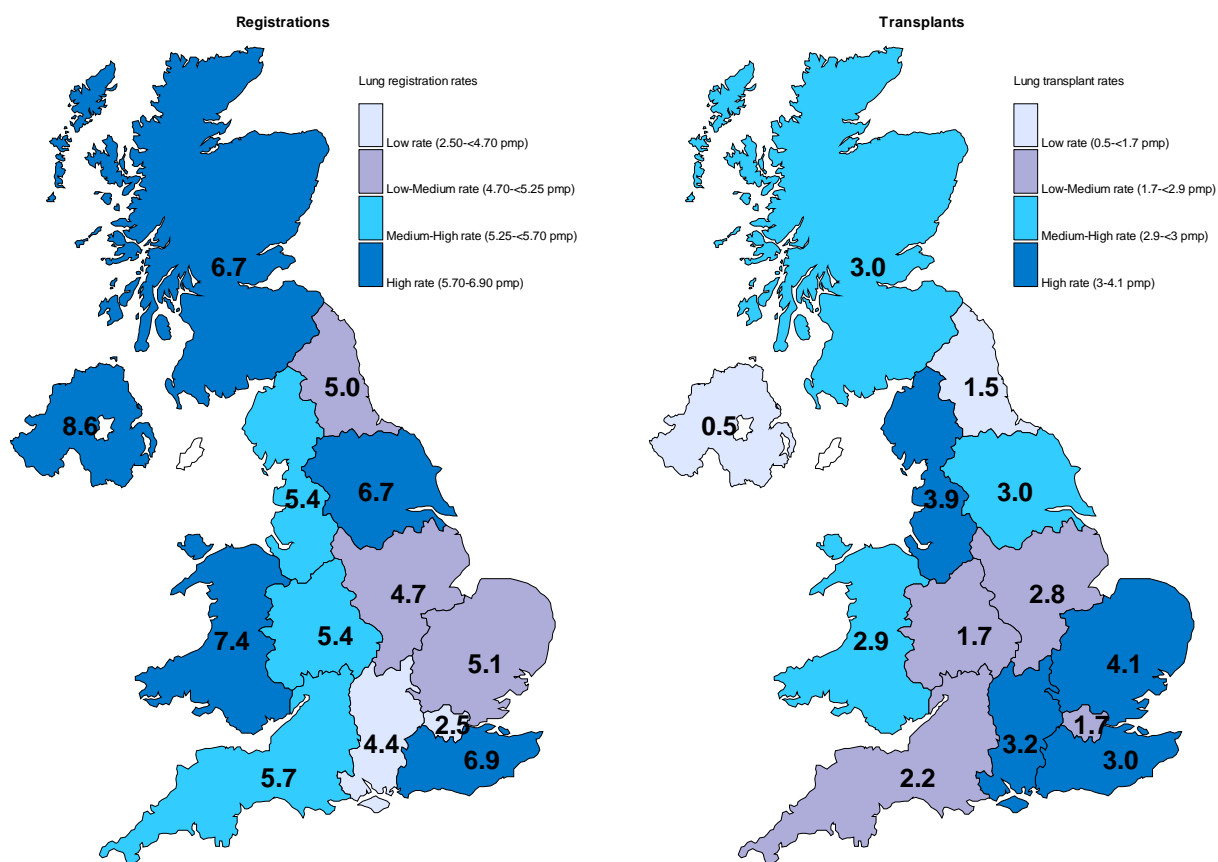




Table 2.2 Lung registration and transplant rates per million population (pmp) in the UK, 1 April 2016 – 31 March 2017, by Country/Strategic Health Authority				
Country/ Strategic Health Authority	Registrations (pmp)		Transplants (pmp)	
North East	13	(5.0)	4	(1.5)
North West	39	(5.4)	28	(3.9)
Yorkshire and The Humber	36	(6.7)	16	(3.0)
<b>North of England</b>	<b>88</b>	<b>(5.8)</b>	<b>48</b>	<b>(3.2)</b>
East Midlands	22	(4.7)	13	(2.8)
West Midlands	31	(5.4)	10	(1.7)
East of England	31	(5.1)	25	(4.1)
<b>Midlands and East</b>	<b>84</b>	<b>(5.1)</b>	<b>48</b>	<b>(2.9)</b>
<b>London</b>	<b>22</b>	<b>(2.5)</b>	<b>15</b>	<b>(1.7)</b>
South East Coast	32	(6.9)	14	(3.0)
South Central	19	(4.4)	14	(3.2)
South West	31	(5.7)	12	(2.2)
<b>South of England</b>	<b>82</b>	<b>(5.7)</b>	<b>40</b>	<b>(2.8)</b>
<b>England</b>	<b>276</b>	<b>(5.0)</b>	<b>151</b>	<b>(2.8)</b>
<b>Isle of Man</b>	0	(0.0)	0	(0.0)
<b>Channel Islands</b>	0	(0.0)	0	(0.0)
<b>Wales</b>	<b>23</b>	<b>(7.4)</b>	<b>9</b>	<b>(2.9)</b>
<b>Scotland</b>	<b>36</b>	<b>(6.7)</b>	<b>16</b>	<b>(3.0)</b>
<b>Northern Ireland</b>	<b>16</b>	<b>(8.6)</b>	<b>1</b>	<b>(0.5)</b>
<b>TOTAL</b>	<b>352<sup>1</sup></b>	<b>(5.4)</b>	<b>177<sup>2</sup></b>	<b>(2.7)</b>

<sup>1</sup> Registrations include 1 recipients whose postcode was unknown and excludes 2 recipients who reside in the Republic of Ireland

<sup>2</sup> Transplants excludes 1 recipients who reside in the Republic of Ireland

# **ADULT HEART TRANSPLANTATION**

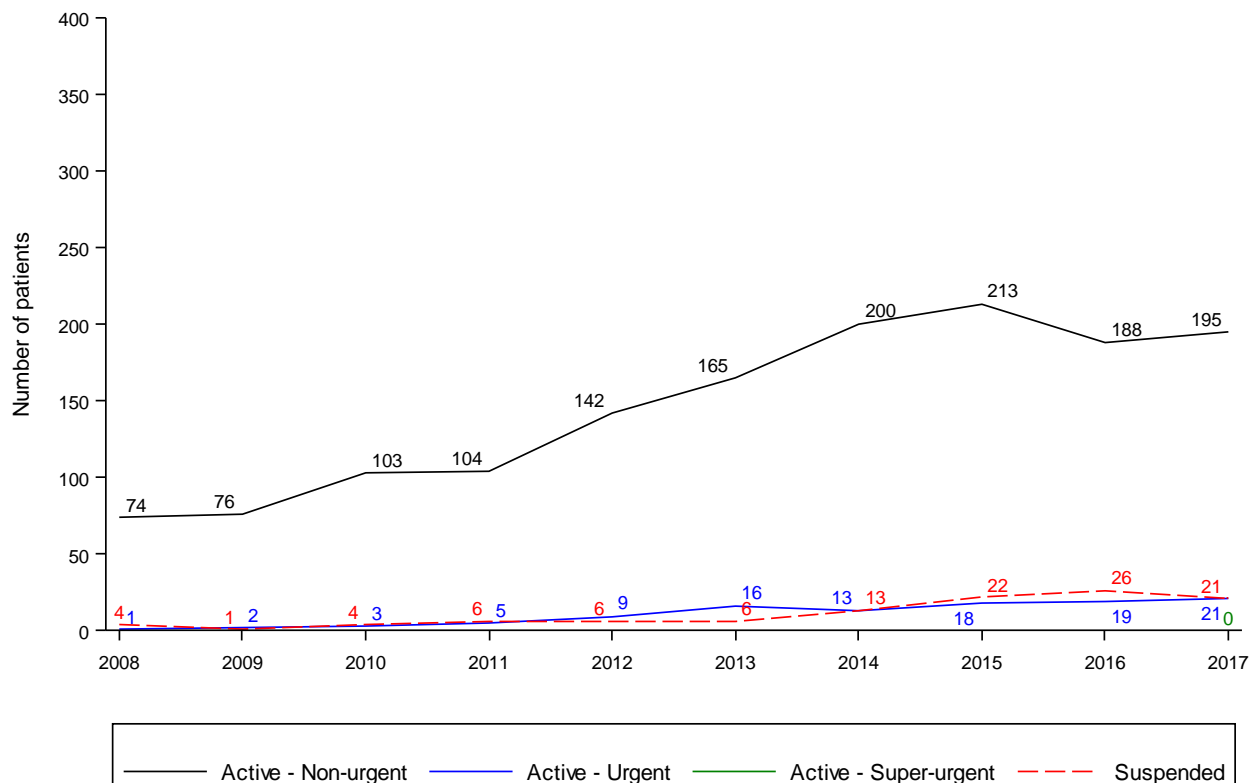
## **Transplant List**



### 3.1 Adult heart only transplant list as at 31 March, 2008 – 2017

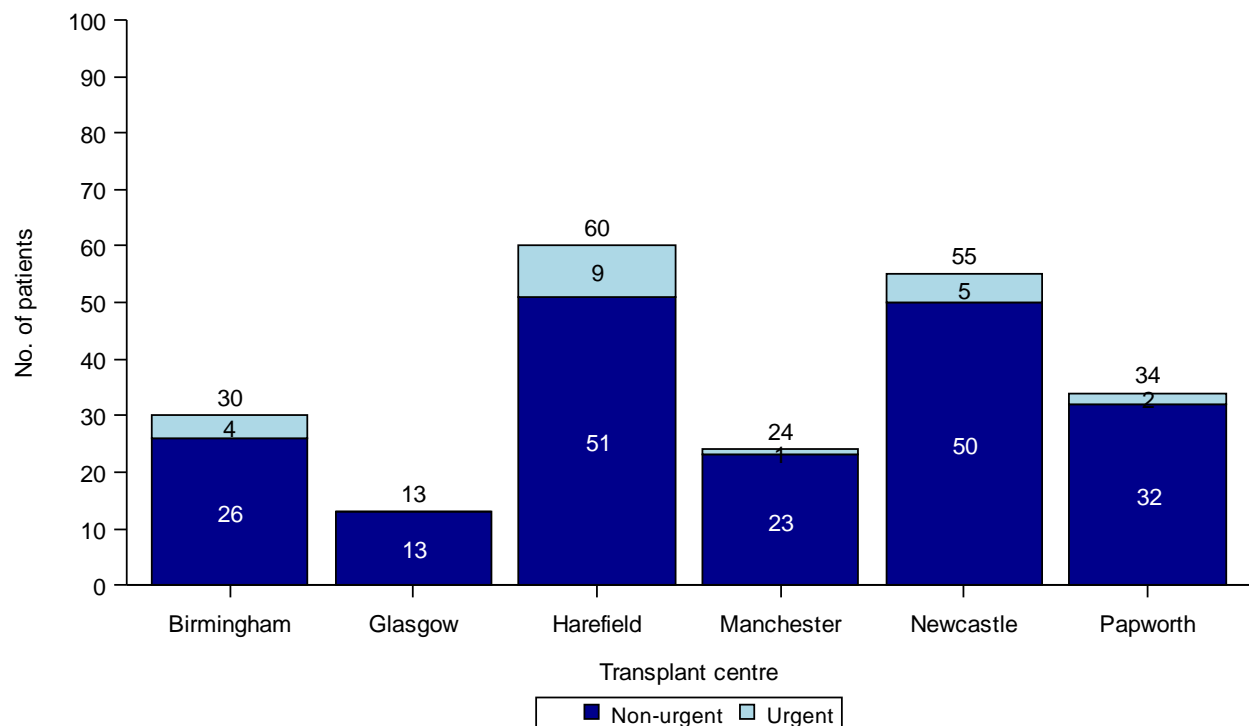
**Figure 3.1** shows the number of adult patients on the heart transplant list at 31 March each year between 2008 and 2017 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased each year from 74 in 2008 to 213 in 2015, and has since dropped to 195 on 31 March 2017. The number of patients on the urgent list has increased from 1 in 2008 to 21 in 2017. There were no super-urgent patients on the list on 31 March 2017.

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



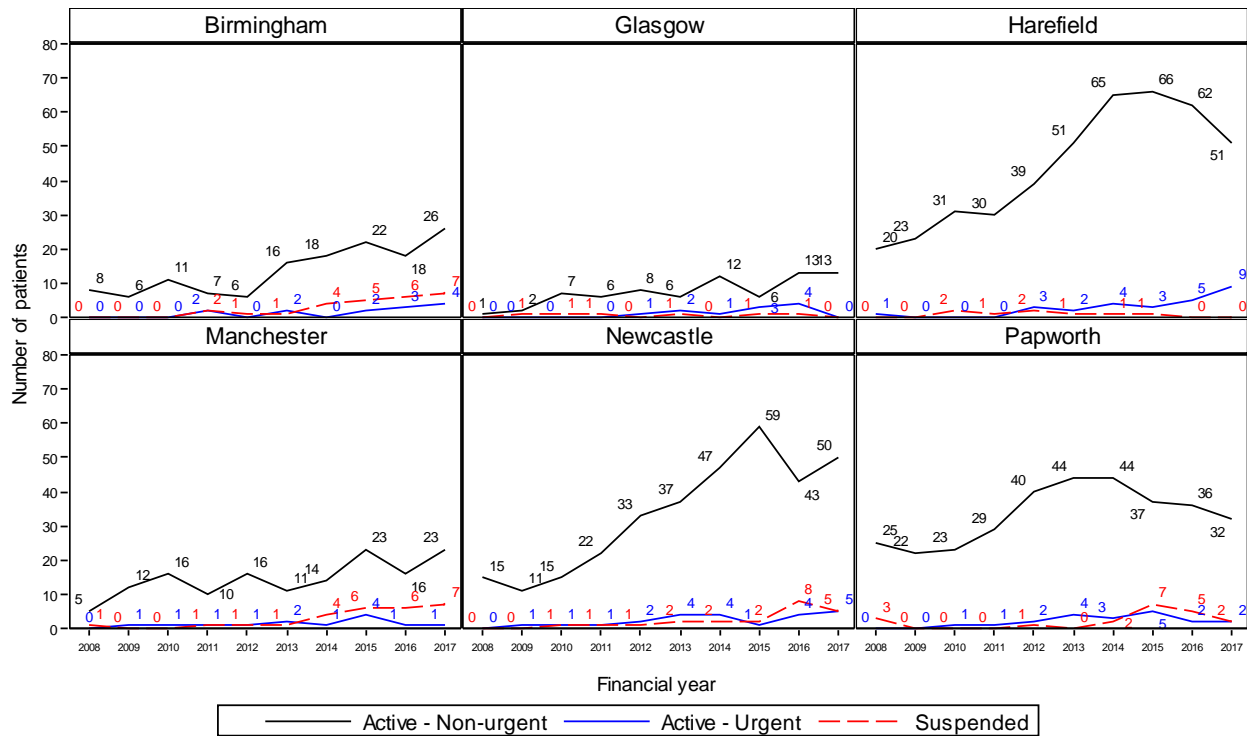
**Figure 3.2** shows the number of adult patients on the [active heart transplant list](#) at 31 March 2017 by centre. In total, there were 216 adult patients. Harefield had the largest number on the transplant list whilst Glasgow had the smallest. The number of patients on the urgent transplant list at 31 March 2017 ranged from none at Glasgow to nine at Harefield. There were no patients at any centre on the super-urgent list on this date.

**Figure 3.2 Number of adult patients on the active heart transplant list at 31 March 2017, by centre**



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

**Figure 3.3 Number of adult patients on the heart transplant list at 31 March each year for the last 10 years, by centre**



### 3.2 Demographic characteristics, 1 April 2016 – 31 March 2017

There were 265 adult patient registrations onto the heart transplant list between 1 April 2016 and 31 March 2017. Demographic characteristics of these patients are shown by centre and overall in **Table 3.1**. Nationally, 72% of patients were male and the [median](#) age was 49 years. Note that there were 19 super-urgent heart registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		50 (100)	17 (100)	43 (100)	42 (100)	62 (100)	51 (100)	<b>265 (100)</b>
Highest urgency during registration	Non-urgent	22 (44)	6 (35)	15 (35)	19 (45)	32 (52)	23 (45)	<b>117 (44)</b>
	Urgent	23 (46)	7 (41)	24 (56)	20 (48)	30 (48)	25 (49)	<b>129 (49)</b>
	Super-urgent	5 (10)	4 (24)	4 (9)	3 (7)	0 (0)	3 (6)	<b>19 (7)</b>
Recipient sex	Male	41 (82)	11 (65)	24 (56)	29 (69)	46 (74)	40 (78)	<b>191 (72)</b>
	Female	9 (18)	6 (35)	19 (44)	13 (31)	16 (26)	11 (22)	<b>74 (28)</b>
Recipient ethnicity	White	40 (80)	16 (94)	37 (86)	36 (86)	58 (94)	43 (84)	<b>230 (87)</b>
	Non-white	10 (20)	1 (6)	6 (14)	6 (14)	4 (6)	8 (16)	<b>35 (13)</b>
Recipient age (years)	Median ( <a href="#">IQR</a> )	54 (41, 63)	49 (45, 55)	39 (28, 54)	41 (36, 58)	47 (34, 59)	53 (40, 59)	<b>49 (36, 59)</b>
	Missing	0	0	0	0	0	0	<b>0</b>
Primary Disease	Coronary heart disease	2 (4)	6 (35)	2 (5)	2 (5)	7 (11)	10 (20)	<b>29 (11)</b>
	Cardiomyopathy	31 (62)	7 (41)	19 (44)	22 (52)	17 (27)	27 (53)	<b>123 (46)</b>
	Congenital heart disease	1 (2)	0 (0)	0 (0)	0 (0)	17 (27)	0 (0)	<b>18 (7)</b>
	Other heart disease	1 (2)	1 (6)	7 (16)	10 (24)	11 (18)	1 (2)	<b>31 (12)</b>
	Graft failure/Rejection	0 (0)	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	<b>1 (0)</b>
	Others	13 (26)	3 (18)	14 (33)	8 (19)	9 (15)	13 (25)	<b>60 (23)</b>
	Missing	2 (4)	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)	<b>3 (1)</b>
Previous open heart surgery	None	28 (56)	12 (71)	24 (56)	21 (50)	26 (42)	25 (49)	<b>136 (51)</b>
	One	17 (34)	4 (24)	16 (37)	14 (33)	27 (44)	23 (45)	<b>101 (38)</b>
	More than one	2 (4)	0 (0)	2 (5)	5 (12)	9 (15)	3 (6)	<b>21 (8)</b>
	Missing	3 (6)	1 (6)	1 (2)	2 (5)	0 (0)	0 (0)	<b>7 (3)</b>
Previous thoracotomy	No	48 (96)	15 (88)	38 (88)	37 (88)	61 (98)	51 (100)	<b>250 (94)</b>
	Yes	2 (4)	1 (6)	4 (9)	3 (7)	1 (2)	0 (0)	<b>11 (4)</b>
	Missing	0 (0)	1 (6)	1 (2)	2 (5)	0 (0)	0 (0)	<b>4 (2)</b>
Serum Bilirubin (umol/l)	Median ( <a href="#">IQR</a> )	14 (8, 28)	11 (9, 20)	17 (11, 27)	19 (12, 34)	17 (11, 30)	16 (10, 23)	<b>17 (10, 28)</b>
	Missing	0	4	1	3	1	4	<b>13</b>

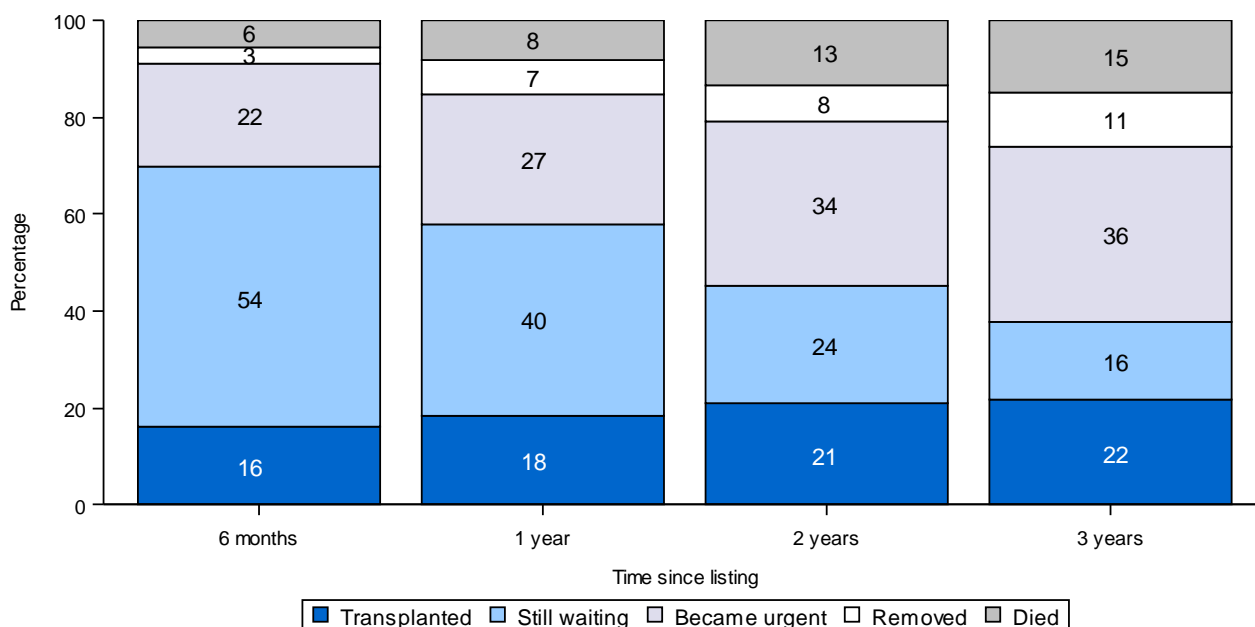
Table 3.1      Demographic characteristics of adult patients registered onto the heart transplant list between 1 April 2016 and 31 March 2017, by centre		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Serum Creatinine (umol/l)	Median ( <a href="#">IQR</a> ) Missing	96 (81, 128) 0	113 (96, 130) 4	87 (72, 102) 1	85 (71, 112) 2	101 (85, 128) 1	115 (89, 140) 3	<b>98 (80, 125) 11</b>

### 3.3 Post-registration outcomes, 1 April 2013 – 31 March 2014

The transplant list outcomes of adult patients listed for a non-urgent heart transplant between 1 April 2013 and 31 March 2014 are summarised in **Figure 3.4**. The same information is presented in **Figure 3.5** for those listed for an urgent heart transplant between 1 April 2013 and 31 March 2014 (including those previously on the non-urgent list). These charts show the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two year and three years after joining the list.

Within six months of listing 16% of non-urgent heart patients had been transplanted and 6% had died, while after three years 22% had been transplanted and 15% had died. Also, 22% had been moved to the urgent heart list within 6 months, reaching 36% by three years. About half of removals from the list were due to improved condition and the other half due to deteriorating condition.

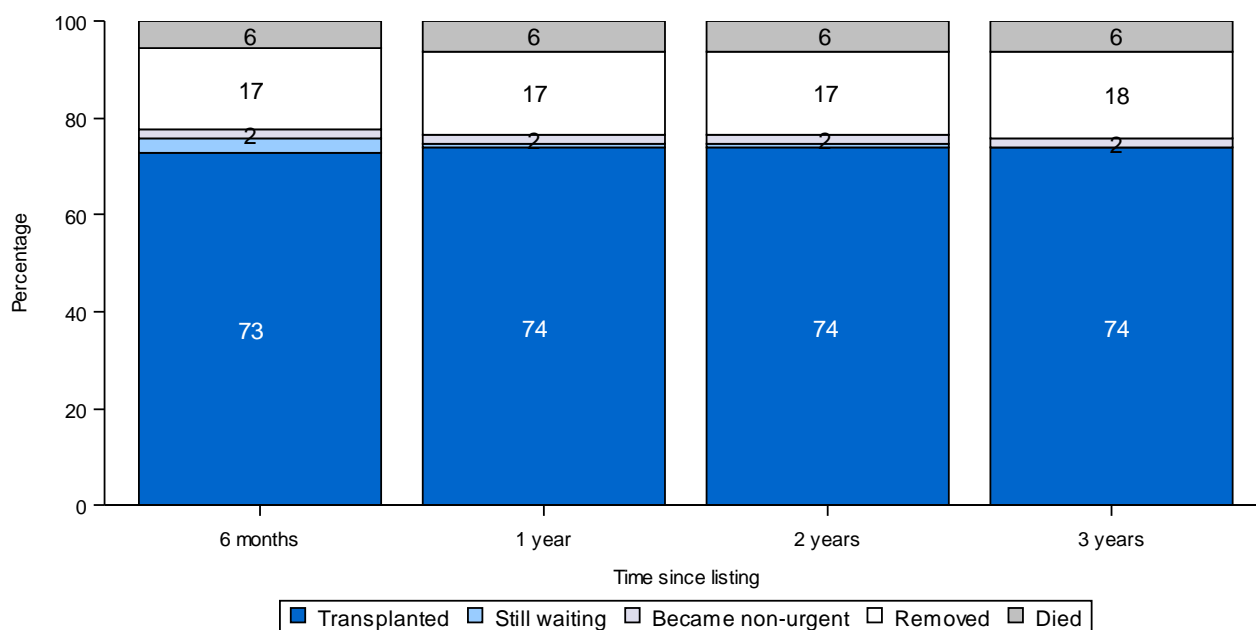
**Figure 3.4 Post-registration outcome for 181 non-urgent heart only registrations made in the UK, 1 April 2013 to 31 March 2014**





In comparison to **Figure 3.4**, **Figure 3.5** shows that within six months of listing, 73% of urgent heart patients were transplanted and 6% had died. In most cases patients reached an outcome within six months so there is little change over the remaining time intervals. Removals from the list were for a variety of reasons including improved condition, deteriorating condition and no longer meeting the necessary criteria for urgent listing.

**Figure 3.5 Post-registration outcome for 161 urgent heart only registrations made in the UK, 1 April 2013 to 31 March 2014**

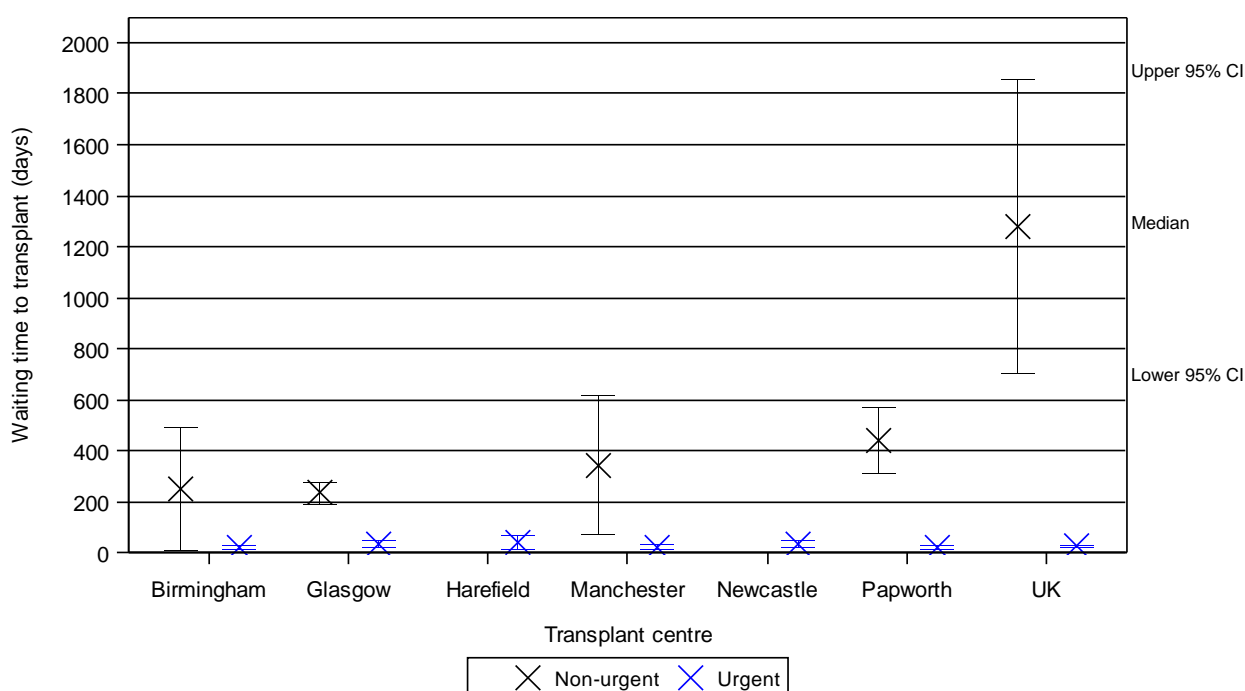


### 3.4 Median waiting time to transplant, 1 April 2011 - 31 March 2014

The [median](#) waiting time to heart transplant from listing for adult patients is shown in **Figure 3.6** and **Table 3.2**. This is estimated for patients registered on the heart only transplant list between 1 April 2011 and 31 March 2014 using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. This is split between never urgent patients and ever urgent patients, where only urgent waiting time is counted for any patients who changed between the urgent and non-urgent lists. Any suspended time is discounted.

The overall national non-urgent [median](#) waiting time is 1280 days (3.5 years) which is driven by the high number of prolonged waiters at Harefield and Newcastle for whom a median cannot be estimated. For urgent patients, the national [median](#) waiting time is 26 days, and ranges from 20 days at Birmingham and Papworth to 38 days at Harefield.

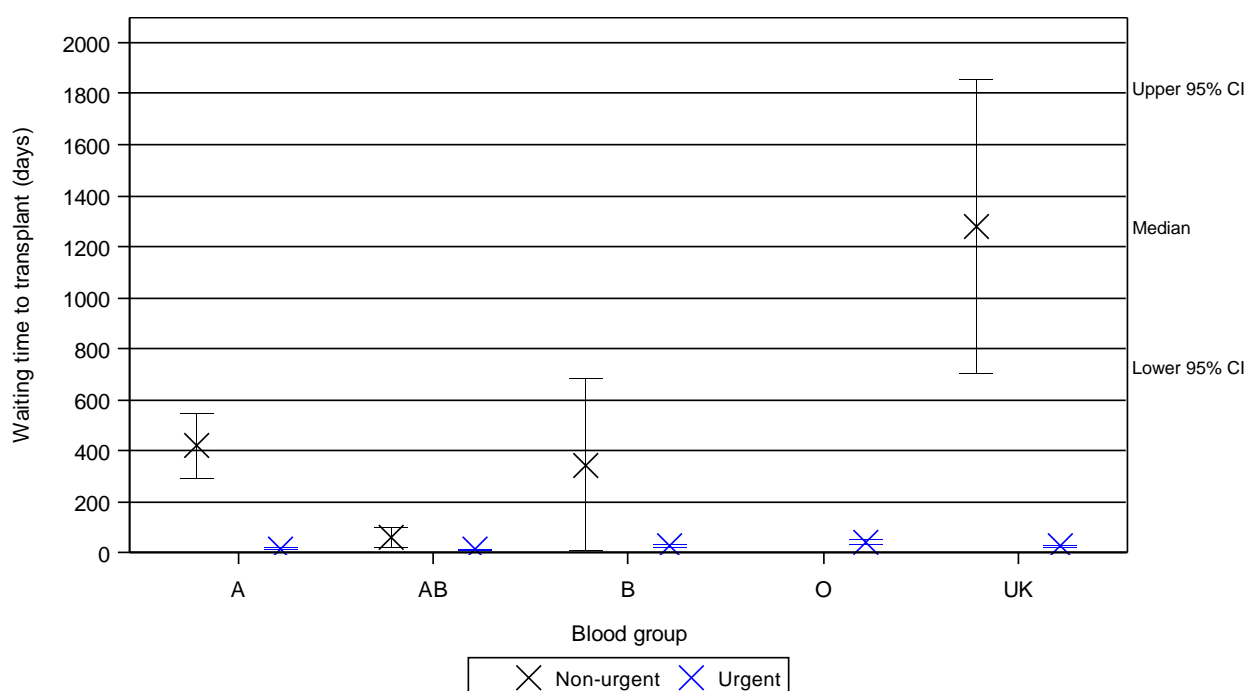
**Figure 3.6 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2011 and 31 March 2014, by centre and urgency status**



<b>Table 3.2      Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency and centre, 1 April 2011 to 31 March 2014</b>			
Transplant centre	Number of patients registered	Waiting time (days) <u>Median</u>	95% <u>Confidence interval</u>
<b>Never urgent patients</b>			
Birmingham	45	253	10 - 496
Glasgow	29	236	193 - 279
Harefield <sup>1</sup>	59	-	-
Manchester	32	344	73 - 615
Newcastle <sup>1</sup>	57	-	-
Papworth	65	441	311 - 571
<b>UK</b>	<b>287</b>	<b>1280</b>	<b>703 - 1857</b>
<b>Ever urgent patients (urgent time only)</b>			
Birmingham	52	20	13 - 27
Glasgow	38	33	18 - 48
Harefield	78	38	12 - 64
Manchester	69	23	14 - 32
Newcastle	74	36	23 - 49
Papworth	95	20	15 - 25
<b>UK</b>	<b>406</b>	<b>26</b>	<b>21 - 31</b>
<sup>1</sup> <u>Median</u> waiting time cannot be estimated as not enough patients had been transplanted by the time of analysis			

The median waiting time to heart transplant for adult patients is also considered by blood group. This is shown in **Figure 3.7** and **Table 3.3** by both blood group and urgency status. The high national median non-urgent waiting time is driven by the prolonged blood group O waiters for whom a median cannot be estimated. For ever-urgent patients, blood group O patients have the longest average wait (44 days) compared with the other groups.

**Figure 3.7 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2011 and 31 March 2014, by blood group and urgency status**



**Table 3.3 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency and blood group, 1 April 2011 to 31 March 2014**

Transplant centre	Number of patients registered	Waiting time (days)	
		<a href="#">Median</a>	95% <a href="#">Confidence interval</a>
Never urgent			
A	135	418	289 - 547
AB	15	58	19 - 97
B	23	344	7 - 681
O <sup>1</sup>	114	-	-
UK	287	1280	703 - 1857
Ever urgent patients (urgent time only)			
A	150	15	12 - 18
AB	16	13	10 - 16
B	57	30	23 - 37
O	183	44	35 - 53
UK	406	26	21 - 31

<sup>1</sup> [Median](#) waiting time cannot be estimated as not enough patients had been transplanted by the time of analysis

# **ADULT HEART TRANSPLANTATION**

## **Response to Offers**

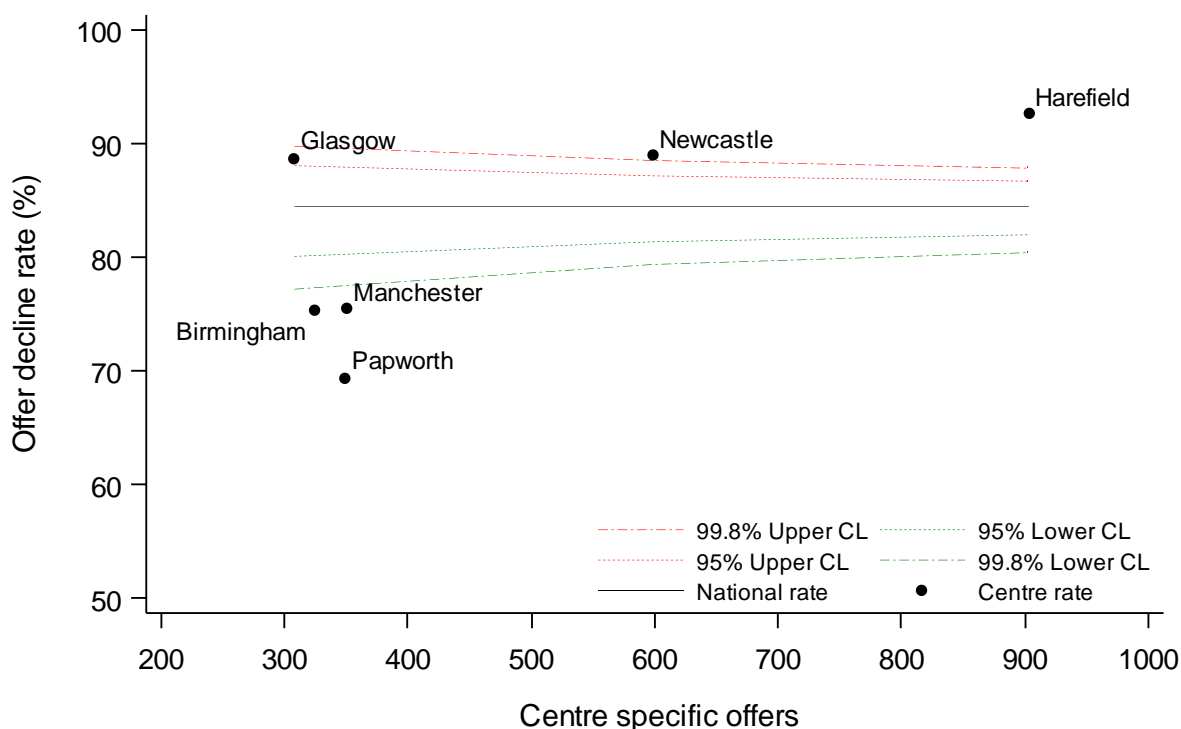


#### 4. Response to Offers

**Figure 4.1** compares individual centre adult donor heart offer decline rates with the national rate using a [funnel plot](#). This only considers offers of UK DBD donor hearts between 1 April 2014 and 31 March 2017 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a cardiac block offer are considered, as are all super-urgent, urgent and non-urgent patient offers. Offers to paediatric patients at Newcastle are excluded.

Offer decline rates for Harefield, Newcastle, Birmingham, Manchester and Papworth fell outside of the 99.8% [confidence limits](#). This indicates that Harefield and Newcastle had significantly high heart offer decline rates and Manchester, Papworth and Birmingham had significantly low heart offer decline rates compared with the national rate.

**Figure 4.1 UK adult DBD donor heart offer decline rates by centre, 1 April 2014 to 31 March 2017**



**Table 4.1** shows a breakdown of each centre's decline rate across the three years analysed. The heart offer decline rates for Harefield have been consistently higher than the upper 99.8% [confidence limit](#) over the last three financial years whilst Papworth has had consistently low rates. Nationally, the heart offer decline rate has decreased by 1.6% over the time period.

<b>Table 4.1 UK adult DBD donor heart offer decline rates by transplant centre and year, between 1 April 2014 and 31 March 2017</b>								
Centre	2014/15		2015/16		2016/17		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	111	(73.9)	98	(73.5)	116	(78.4)	325	(75.4)
Glasgow	97	(86.6)	118	(94.1)	93	(83.9)	308	(88.6)
Harefield	284	(91.2)	262	(92.0)	357	(94.4)	903	(92.7)
Manchester	142	(81.7)	116	(73.3)	93	(68.8)	351	(75.5)
Newcastle	207	(92.3)	213	(89.2)	178	(84.8)	598	(89.0)
Papworth	130	(73.8)	127	(70.1)	92	(62.0)	349	(69.3)
<b>UK</b>	<b>971</b>	<b>(85.3)</b>	<b>934</b>	<b>(84.4)</b>	<b>929</b>	<b>(83.7)</b>	<b>2834</b>	<b>(84.5)</b>
	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 98.8% confidence limit							

# **ADULT HEART TRANSPLANTATION**

## **Transplants**

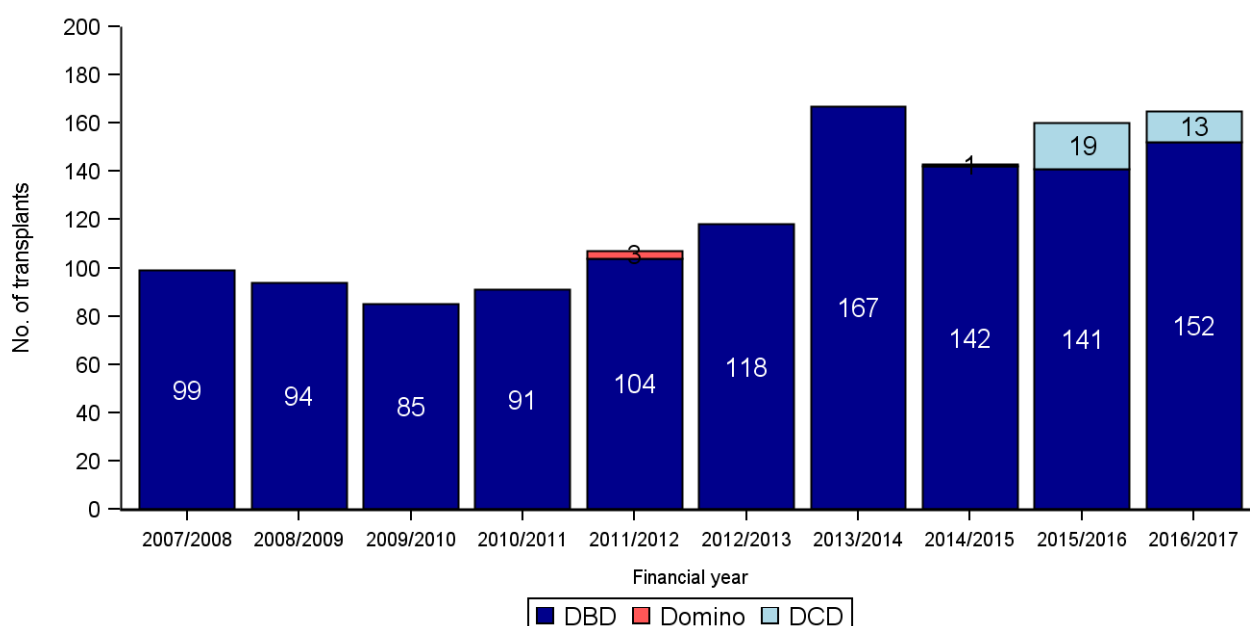




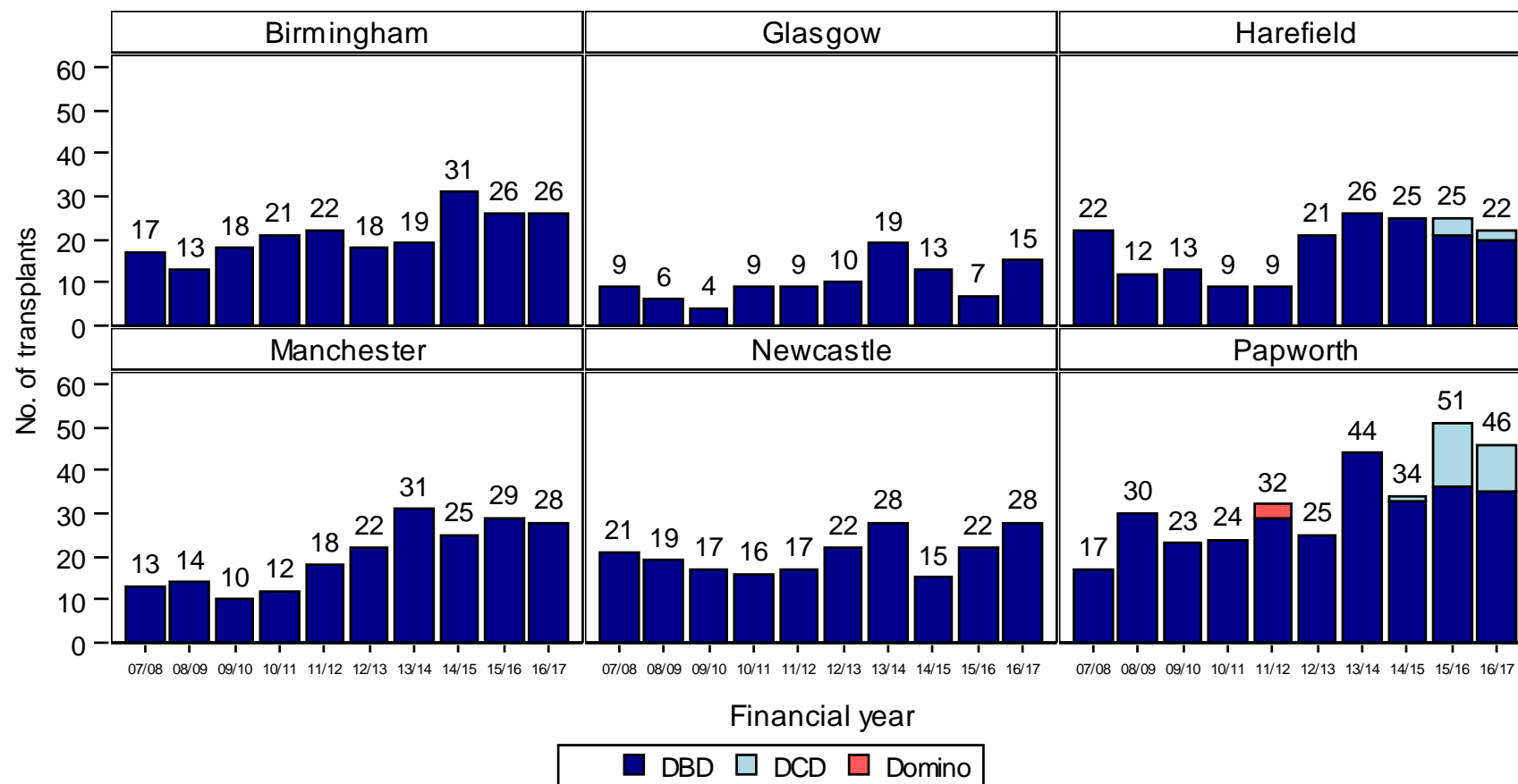
## 5.1 Adult heart transplants, 1 April 2007 – 31 March 2017

**Figure 5.1** and **5.2** show the number of adult heart transplants performed per year over the last ten years, by donor type, nationally and by centre, respectively. Last year there were 165 adult heart transplants; five higher than 2015/2016 and two lower than the most active year, which was 2013/2014. Compared with 2007/2008, activity has increased by 66%. Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants, performed by two centres in this time period, represented 8% of last year's adult heart transplants.

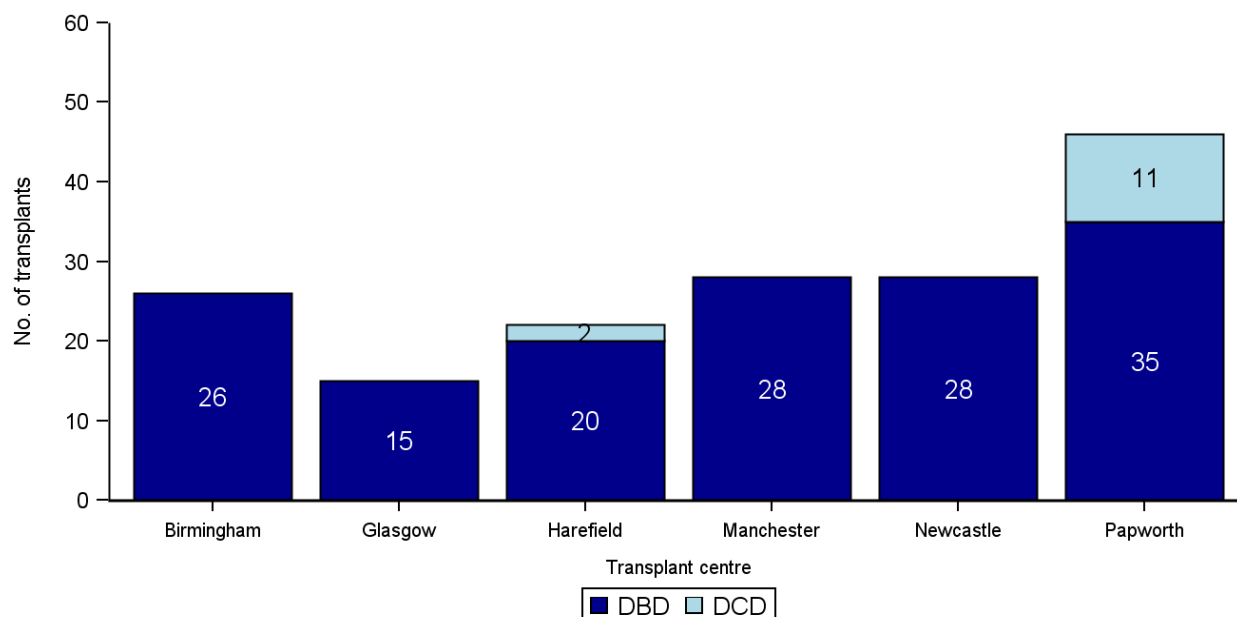
**Figure 5.1 Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2007 to 31 March 2017**



**Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2007 to 31 March 2017**

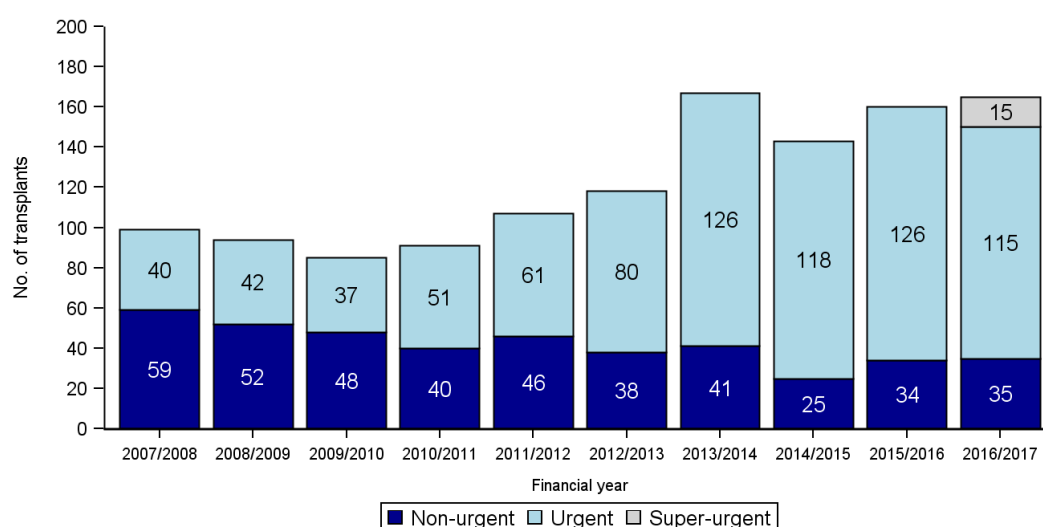


**Figure 5.3 Number of adult heart transplants in the UK, by centre and donor type, 1 April 2016 to 31 March 2017**

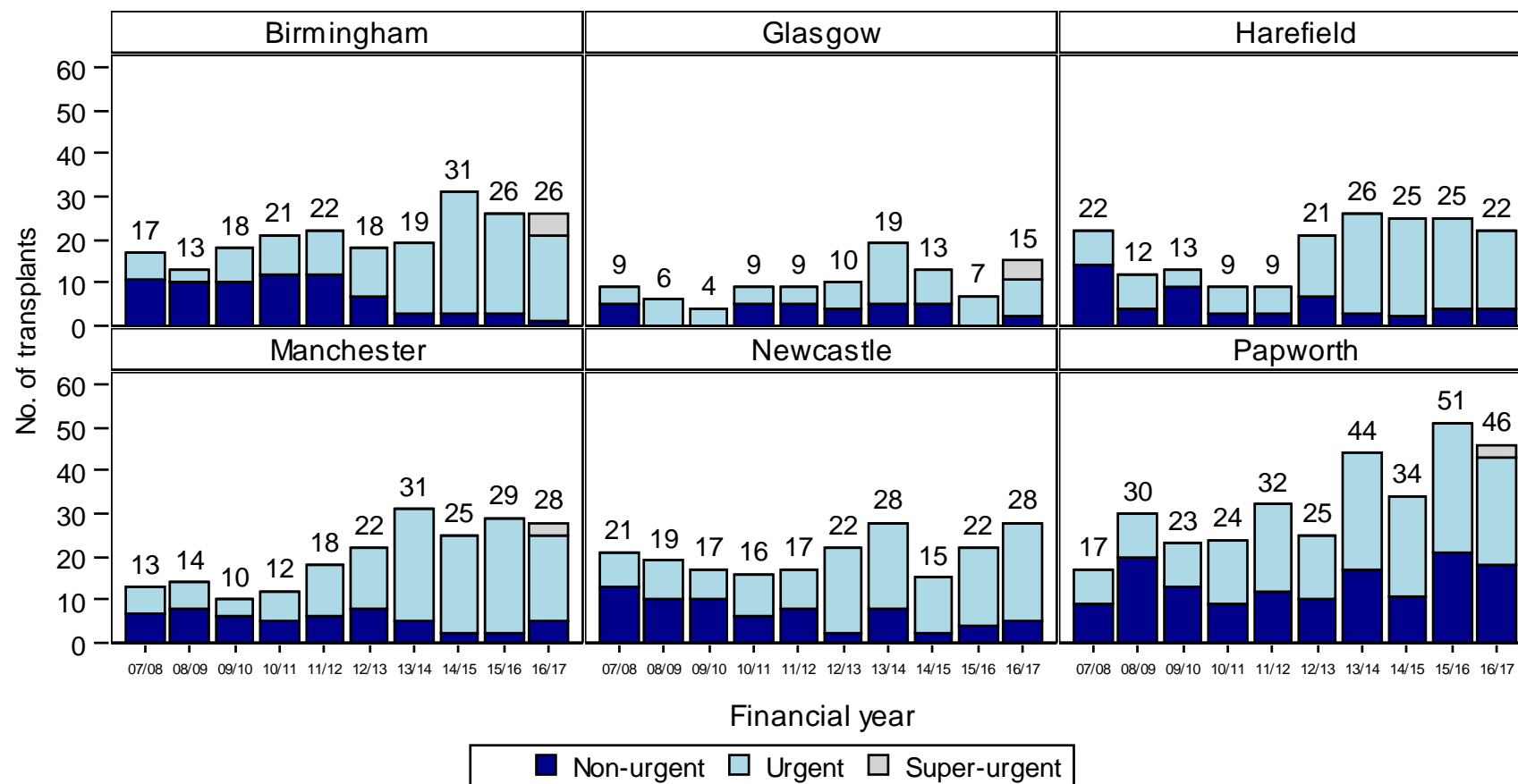


**Figure 5.4** and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time the proportion of urgent transplants has increased; from 40% in 2007/2008 to 79% in 2016/2017, including 15 super-urgent transplants. Last year's activity is shown by centre and urgency status in **Figure 5.6**. More than half of the non-urgent transplants performed in 2016/2017 were at Papworth.

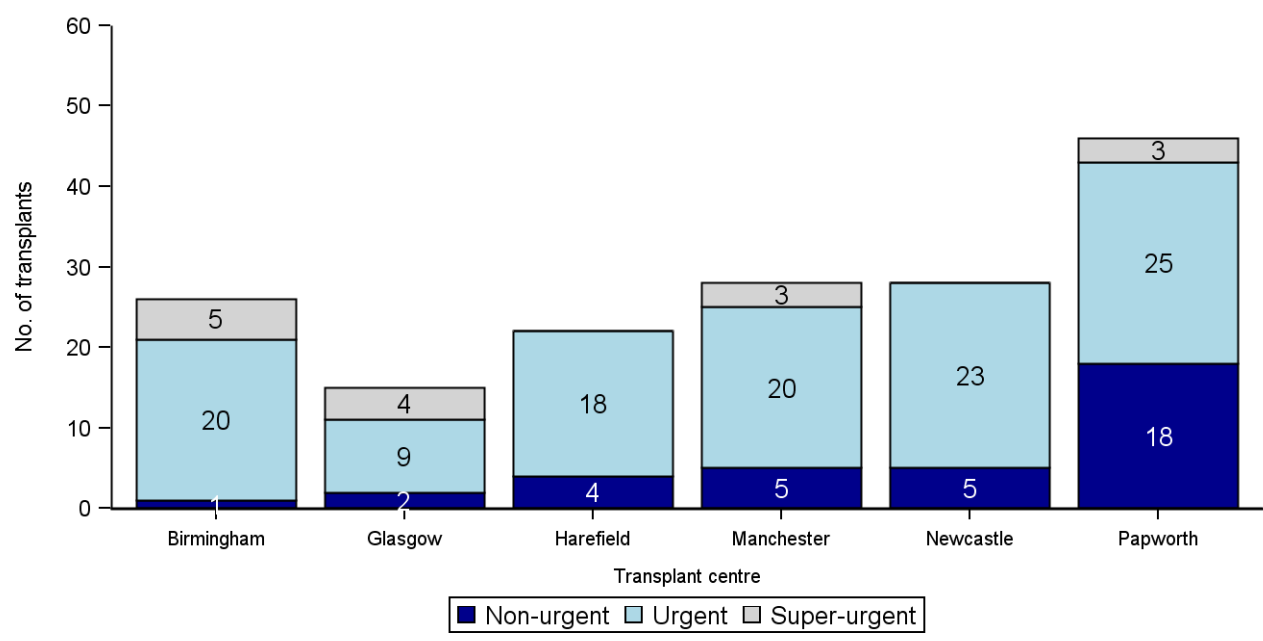
**Figure 5.4 Number of adult heart transplants in the UK, by financial year and urgency status, 1 April 2007 to 31 March 2017**



**Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2007 to 31 March 2017**



**Figure 5.6 Number of adult heart transplants in the UK, by centre and urgency status, 1 April 2016 to 31 March 2017**



## 5.2 Demographic characteristics of transplants, 1 April 2016 – 31 March 2017

The demographic characteristics of the 165 adult heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 71% of heart recipients were male and the [median](#) age was 49 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 2016 to 31 March 2017, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		26 (100)	15 (100)	22 (100)	28 (100)	28 (100)	46 (100)	165 (100)
Urgency status at transplant	Non-urgent	1 (4)	2 (13)	4 (18)	5 (18)	5 (18)	18 (39)	35 (21)
	Urgent	20 (77)	9 (60)	18 (82)	20 (71)	23 (82)	25 (54)	115 (70)
	Super-urgent	5 (19)	4 (27)	0 (0)	3 (11)	0 (0)	3 (7)	15 (9)
Recipient sex	Male	17 (65)	12 (80)	13 (59)	19 (68)	21 (75)	35 (76)	117 (71)
	Female	9 (35)	3 (20)	9 (41)	9 (32)	7 (25)	11 (24)	48 (29)
Recipient ethnicity	White	21 (81)	14 (93)	21 (95)	21 (75)	25 (89)	39 (85)	141 (86)
	Non-white	5 (19)	1 (7)	1 (5)	7 (25)	3 (11)	7 (15)	24 (15)
Recipient age (years)	Median ( <a href="#">IQR</a> )	42 (32, 55)	52 (40, 56)	40 (28, 54)	46 (34, 60)	45 (30, 55)	55 (38, 62)	49 (33, 57)
	Missing	0	0	0	0	0	0	0
Recipient weight (kg)	Median ( <a href="#">IQR</a> )	71 (64, 79)	71 (61, 88)	72 (60, 81)	77 (61, 85)	74 (57, 88)	80 (68, 85)	75 (64, 86)
	Missing	0	0	0	1	0	0	1
Recipient primary disease	Coronary heart disease	1 (4)	3 (20)	3 (14)	1 (4)	2 (7)	8 (17)	18 (11)
	Cardiomyopathy	13 (50)	8 (53)	10 (45)	17 (61)	14 (50)	27 (59)	89 (54)
	Congenital heart disease	0 (0)	0 (0)	2 (9)	0 (0)	7 (25)	1 (2)	10 (6)
	Other heart disease	1 (4)	0 (0)	4 (18)	4 (14)	1 (4)	4 (9)	14 (9)
	Others	10 (38)	4 (27)	3 (14)	6 (21)	4 (14)	6 (13)	33 (20)
	Missing	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
NYHA class	II	0 (0)	3 (20)	0 (0)	0 (0)	0 (0)	1 (2)	4 (2)
	III	1 (4)	3 (20)	8 (36)	15 (54)	5 (18)	21 (46)	53 (32)
	IV	7 (27)	7 (47)	14 (64)	13 (46)	22 (79)	23 (50)	86 (52)
	Missing	18 (69)	2 (13)	0 (0)	0 (0)	1 (4)	1 (2)	22 (13)
Recipient in hospital pre-transplant	No	2 (8)	1 (7)	3 (14)	5 (18)	24 (86)	18 (39)	53 (32)
	Yes	24 (92)	13 (87)	19 (86)	23 (82)	4 (14)	28 (61)	111 (67)
	Missing	0 (0)	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2016 to 31 March 2017, by centre		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
If in hospital, recipient on ventilator	No	19 (79)	13 (100)	18 (95)	23 (100)	4 (100)	28 (100)	105 (95)
	Yes	5 (21)	0 (0)	1 (5)	0 (0)	0 (0)	0 (0)	6 (5)
If in hospital, recipient on VAD	None	4 (17)	11 (85)	15 (79)	16 (70)	3 (75)	23 (82)	72 (65)
	Left	0 (0)	2 (15)	4 (21)	1 (4)	1 (25)	0 (0)	8 (7)
	Right	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	1 (1)
	Both	4 (17)	0 (0)	0 (0)	6 (26)	0 (0)	3 (11)	13 (12)
	Missing	16 (67)	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	17 (15)
If in hospital, recipient on TAH	No	8 (33)	13 (100)	17 (89)	23 (100)	4 (100)	28 (100)	93 (84)
	Yes	0 (0)	0 (0)	2 (11)	0 (0)	0 (0)	0 (0)	2 (2)
	Missing	16 (67)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	16 (14)
If in hospital, recipient on ECMO	No	6 (25)	13 (100)	19 (100)	23 (100)	4 (100)	27 (96)	92 (83)
	Yes	2 (8)	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	3 (3)
	Missing	16 (67)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	16 (14)
If in hospital, recipient on inotropes	No	0 (0)	5 (38)	6 (32)	9 (39)	2 (50)	9 (32)	31 (28)
	Yes	8 (33)	7 (54)	13 (68)	14 (61)	2 (50)	19 (68)	63 (57)
	Missing	16 (67)	1 (8)	0 (0)	0 (0)	0 (0)	0 (0)	17 (15)
If in hospital, recipient on IABP	No	7 (29)	6 (46)	19 (100)	22 (96)	4 (100)	27 (96)	85 (77)
	Yes	1 (4)	7 (54)	0 (0)	1 (4)	0 (0)	1 (4)	10 (9)
	Missing	16 (67)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	16 (14)
Recipient CMV status	No	16 (62)	10 (67)	7 (32)	12 (43)	16 (57)	25 (54)	86 (52)
	Yes	10 (38)	5 (33)	14 (64)	16 (57)	12 (43)	20 (43)	77 (47)
	Missing	0 (0)	0 (0)	1 (5)	0 (0)	0 (0)	1 (2)	2 (1)
Recipient HCV status	No	26 (100)	15 (100)	21 (95)	28 (100)	28 (100)	45 (98)	163 (99)
	Missing	0 (0)	0 (0)	1 (5)	0 (0)	0 (0)	1 (2)	2 (1)
Recipient HBV status	No	26 (100)	14 (93)	21 (95)	28 (100)	28 (100)	45 (98)	162 (98)
	Missing	0 (0)	1 (7)	1 (5)	0 (0)	0 (0)	1 (2)	3 (2)
Recipient HIV status	No	26 (100)	15 (100)	21 (95)	28 (100)	28 (100)	45 (98)	163 (99)
	Missing	0 (0)	0 (0)	1 (5)	0 (0)	0 (0)	1 (2)	2 (1)
Recipient serum creatinine (umol/l)	Median ( <a href="#">IQR</a> )	95 (65, 118)	82 (70, 82)	93 (70, 108)	90 (71, 115)	122 (80, 143)	102 (78, 119)	94 (75, 119)
	Missing	0	4	1	0	1	1	7
Donor sex	Male	20 (77)	9 (60)	17 (77)	18 (64)	22 (79)	33 (72)	119 (72)
	Female	6 (23)	6 (40)	5 (23)	10 (36)	6 (21)	13 (28)	46 (28)

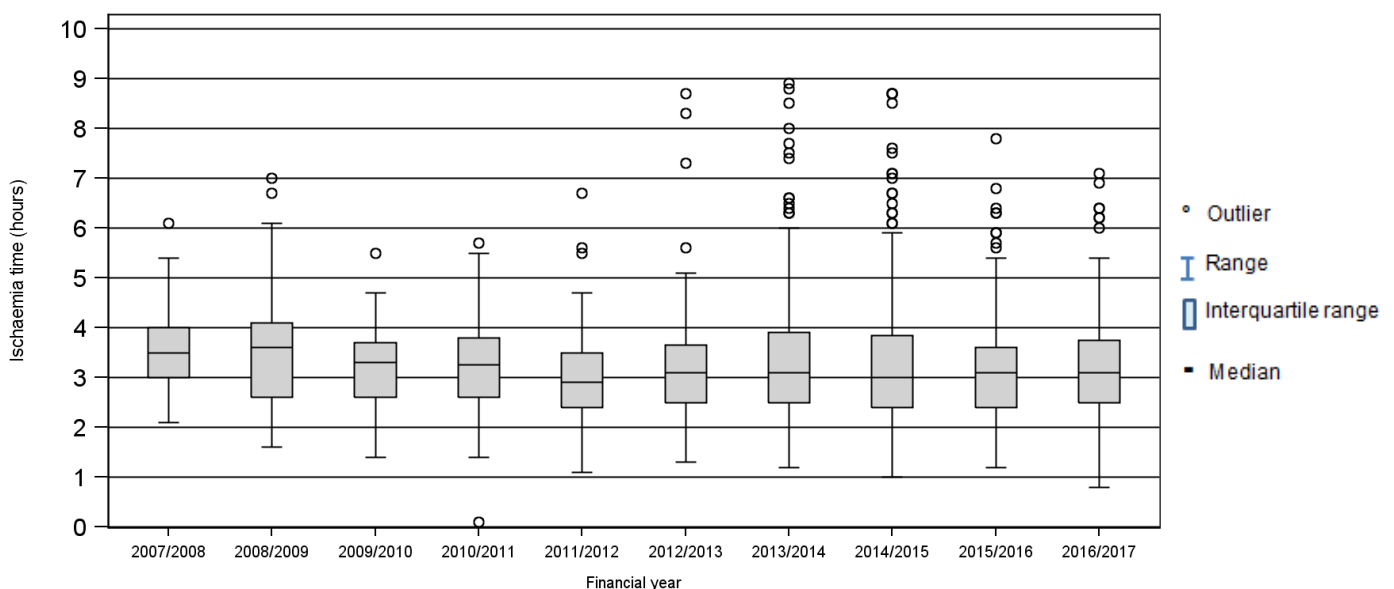
Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2016 to 31 March 2017, by centre		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Donor ethnicity	White	23 (88)	15 (100)	22 (100)	25 (89)	27 (96)	42 (91)	154 (93)
	Non-white	1 (4)	0 (0)	0 (0)	2 (7)	1 (4)	3 (7)	7 (4)
	Missing	2 (8)	0 (0)	0 (0)	1 (4)	0 (0)	1 (2)	4 (2)
Donor age (years)	Median ( <a href="#">IQR</a> )	40 (28, 51)	35 (29, 49)	41 (31, 51)	42 (32, 49)	38 (27, 49)	36 (27, 48)	37 (28, 49)
	Missing	0	0	0	0	0	0	0
Donor BMI (kg/m <sup>2</sup> )	Median ( <a href="#">IQR</a> )	25 (23, 29)	26 (23, 32)	27 (23, 29)	24 (22, 27)	25 (23, 29)	25 (23, 27)	25 (23, 28)
	Missing	0	0	0	0	0	0	0
Donor cause of death	CVA	24 (92)	12 (80)	16 (73)	19 (68)	24 (86)	38 (83)	133 (81)
	Trauma	1 (4)	3 (20)	2 (9)	4 (14)	2 (7)	1 (2)	13 (8)
	Others	1 (4)	0 (0)	4 (18)	5 (18)	2 (7)	7 (15)	19 (12)
Donor hypotension	No	8 (31)	10 (67)	16 (73)	24 (86)	17 (61)	40 (87)	115 (70)
	Yes	1 (4)	4 (27)	5 (23)	4 (14)	10 (36)	5 (11)	29 (18)
	Missing	17 (65)	1 (7)	1 (5)	0 (0)	1 (4)	1 (2)	21 (13)
Donor past diabetes	No	26 (100)	15 (100)	21 (95)	27 (96)	27 (96)	43 (93)	159 (96)
	Yes	0 (0)	0 (0)	1 (5)	1 (4)	1 (4)	3 (7)	6 (4)
Donor past cardiothoracic disease	No	26 (100)	15 (100)	20 (91)	27 (96)	27 (96)	45 (98)	160 (97)
	Yes	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)	1 (1)
	Missing	0 (0)	0 (0)	2 (9)	0 (0)	1 (4)	1 (2)	4 (2)
Donor past hypertension	No	24 (92)	14 (93)	20 (91)	26 (93)	24 (86)	45 (98)	153 (93)
	Yes	2 (8)	1 (7)	2 (9)	2 (7)	4 (14)	1 (2)	12 (7)
Donor past tumour	No	26 (100)	14 (93)	21 (95)	26 (93)	28 (100)	44 (96)	159 (96)
	Yes	0 (0)	1 (7)	1 (5)	2 (7)	0 (0)	1 (2)	5 (3)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (1)
Donor past smoker	No	6 (23)	5 (33)	9 (41)	12 (43)	9 (32)	13 (28)	54 (33)
	Yes	19 (73)	10 (67)	13 (59)	16 (57)	19 (68)	33 (72)	110 (67)
	Missing	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Total ischaemia time (hours)	Median ( <a href="#">IQR</a> )	2.9 (2.0, 3.3)	3.2 (2.6, 3.4)	5.0 (4.1, 6.1)	3.1 (2.5, 3.5)	3.1 (2.2, 3.3)	3.1 (2.5, 3.9)	3.2 (2.5, 3.9)
	Missing	1	2	2	1	6	0	12



### 5.3 Total ischaemia time, 1 April 2007 – 31 March 2017

**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 (9%) not all of this time duration is ischaemic, and no adjustment has been made for this. The national [median](#) total ischaemia time has reduced from 3.5 hours to 3.1 hours over the last decade.

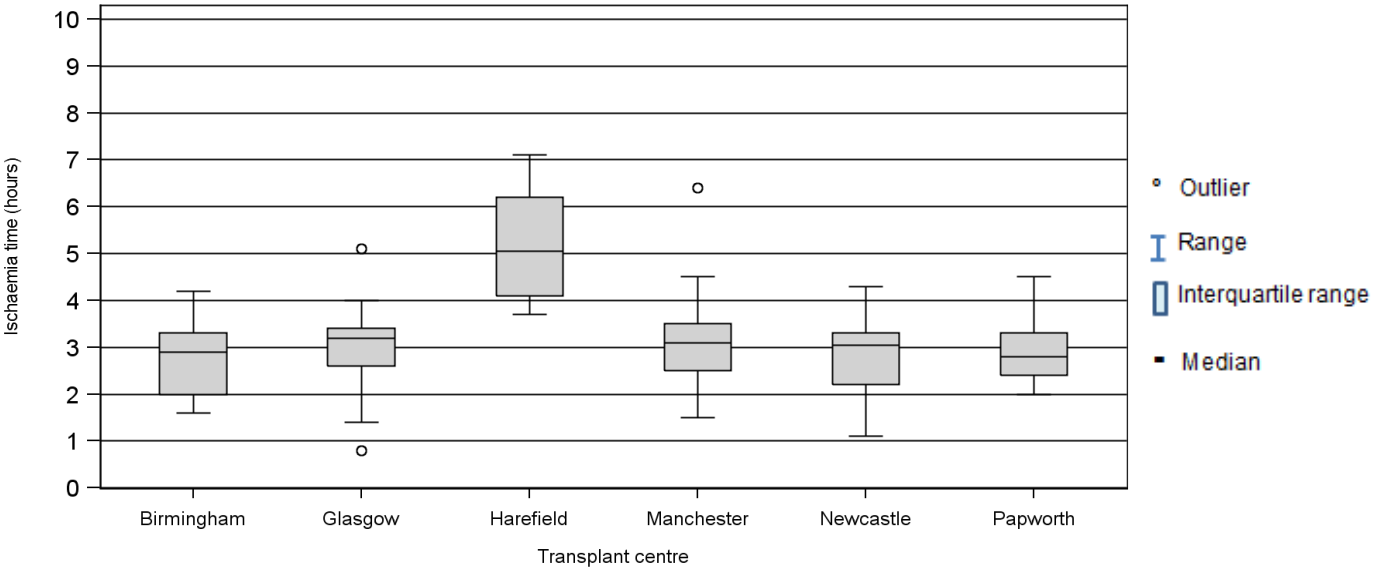
**Figure 5.7 Boxplots of total ischaemia time for DBD donor hearts transplanted into adult recipients, by financial year, 1 April 2007 to 31 March 2017**



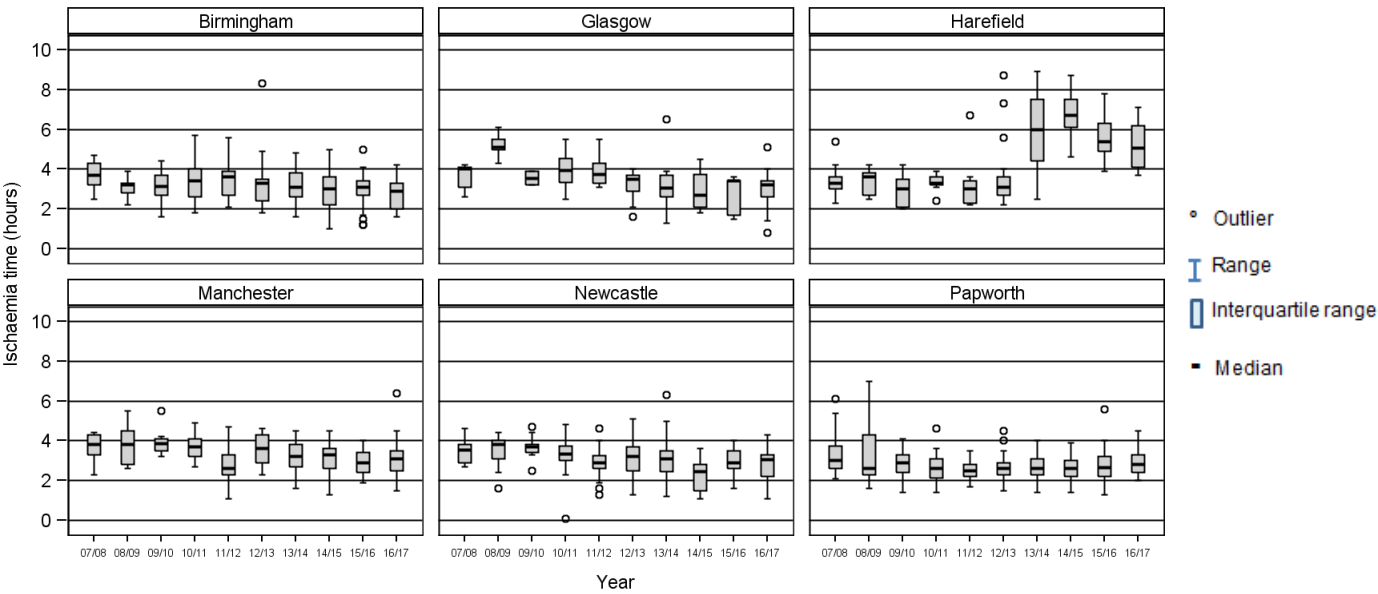
Does not take into account use of donor organ maintenance systems which have been in use since 2013/2014

**Figure 5.8** and **Figure 5.9** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2016/2017) and over the last 10 years, respectively. Harefield experienced a substantial increase in [median](#) total ischaemia time in 2013/2014 to 6 hours, but since then it has reduced to 5 hours, however this is still considerably higher than other centres which have a median of around 3 hours in 2016/2017. However, 100% of hearts transplanted by Harefield in 2016/2017 used organ maintenance systems, compared with 0%-11% for other centres.

**Figure 5.8** Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre, 1 April 2016 to 31 March 2017



**Figure 5.9** Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre and financial year, 1 April 2007 to 31 March 2017



# **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 and so provide a fairer comparison across centres. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in **Appendix A3.1**.

The survival analyses exclude [multi-organ transplants](#) and include first time transplants only. Thirty-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2012 to 31 March 2016 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2008 to 31 March 2012. [Survival rates](#) are presented by transplant centre in **Tables 6.1-6.3** and **Figures 6.1-6.3** as well as disease group in **Tables 6.4-6.6**. DCD heart transplants are excluded but separate tables (**Table 6.7** and **6.8**) at the end of this section provide [unadjusted survival rates](#) for the small number of DCD heart transplant recipients between 1 April 2012 and 31 March 2016.

## 6.1 Survival by centre

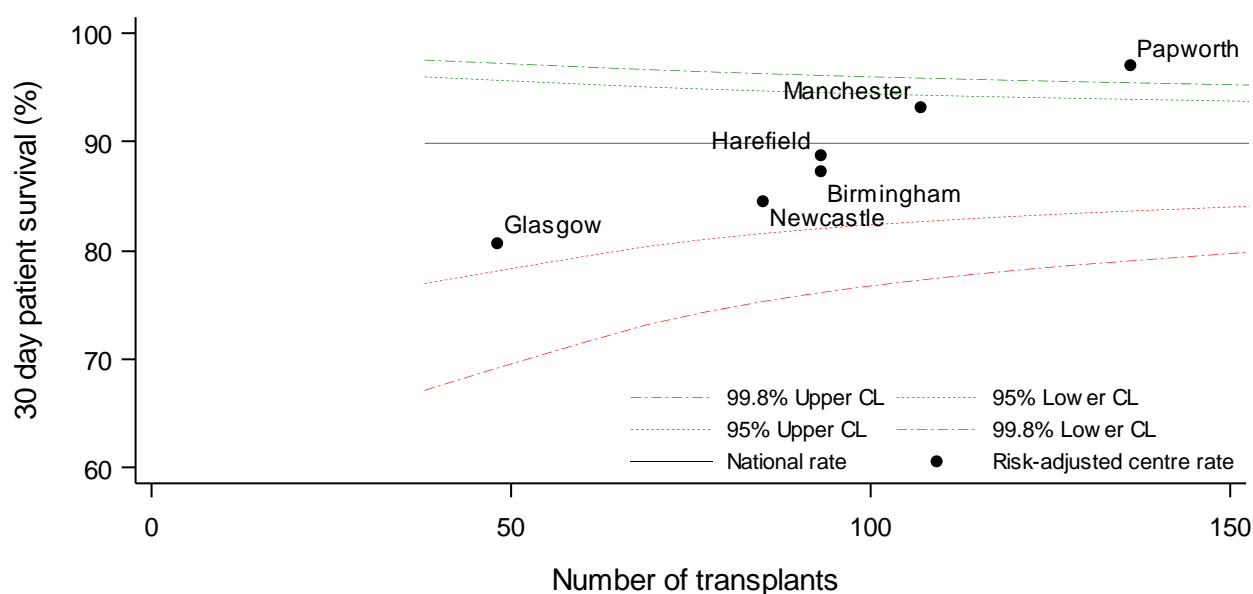
**Table 6.1** and **Figure 6.1** show the 30-day post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 562 first adult heart only transplants in the period 1 April 2012 to 31 March 2016. All of the centres, apart from Papworth, were statistically consistent with the national rate of survival which was 89.9%. The 30-day survival rate for Papworth exceeded the upper 99.8% [confidence limit](#) indicating that their [risk-adjusted](#) post-transplant survival rate was significantly higher than the national rate.

<b>Table 6.1 30 day patient survival rates after first adult heart transplant, by centre, 1 April 2012 to 31 March 2016</b>					
Centre	Number of transplants	% 30 day survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	93	88.2	(79.7 - 93.3)	87.3	(77.0 - 93.0)
Glasgow	48	83.3	(69.4 - 91.3)	80.7	(61.4 - 90.3)
Harefield	93	86.0	(77.1 - 91.6)	88.7	(80.5 - 93.4)
Manchester	107	94.4	(87.9 - 97.4)	93.2	(84.9 - 97.0)
Newcastle	85	82.4	(72.4 - 89.0)	84.6	(74.5 - 90.7)
Papworth	136	97.1	(92.4 - 98.9)	97.0	(92.0 - 98.9)
<b>UK</b>	<b>562</b>	<b>89.9</b>	<b>(87.1 - 92.1)</b>		

	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 98.8% confidence limit

**Figure 6.1 Risk-adjusted 30 day patient survival rates for adult heart transplants, by centre , 1 April 2012 to 31 March 2016**



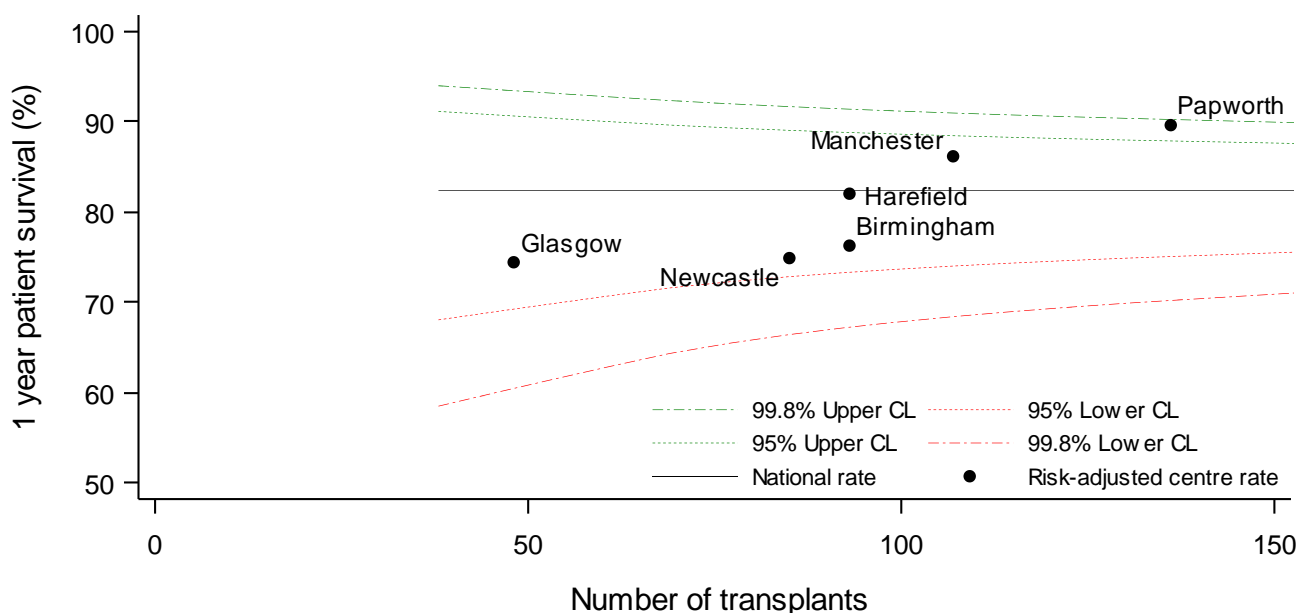
**Table 6.2** and **Figure 6.2** show the 1-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 562 first adult heart only transplants in the period 1 April 2012 to 31 March 2016. The national rate of survival was 82.4%. None of the centres were statistically significantly different to the national rate, as their rates lie with the funnel, except Papworth whose rate lies between the upper 95% and 99.8% [confidence limits](#) providing some evidence of a significantly high 1-year survival rate.

Table 6.2 1 year patient survival rates after first adult heart transplant, by centre, 1 April 2012 to 31 March 2016					
Centre	Number of transplants	% 1 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	93	78.5	(68.7 - 85.6)	76.2	(63.2 - 84.7)
Glasgow	48	76.9	(62.1 - 86.5)	74.5	(53.9 - 85.9)
Harefield	93	79.6	(69.9 - 86.4)	82.0	(71.7 - 88.5)
Manchester	107	87.9	(80.0 - 92.8)	86.1	(76.1 - 91.9)
Newcastle	85	76.5	(65.9 - 84.1)	74.9	(61.1 - 83.8)
Papworth	136	88.2	(81.5 - 92.6)	89.7	(83.2 - 93.7)
<b>UK</b>	<b>562</b>	<b>82.4</b>	<b>(79.0 - 85.3)</b>		

	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 98.8% confidence limit

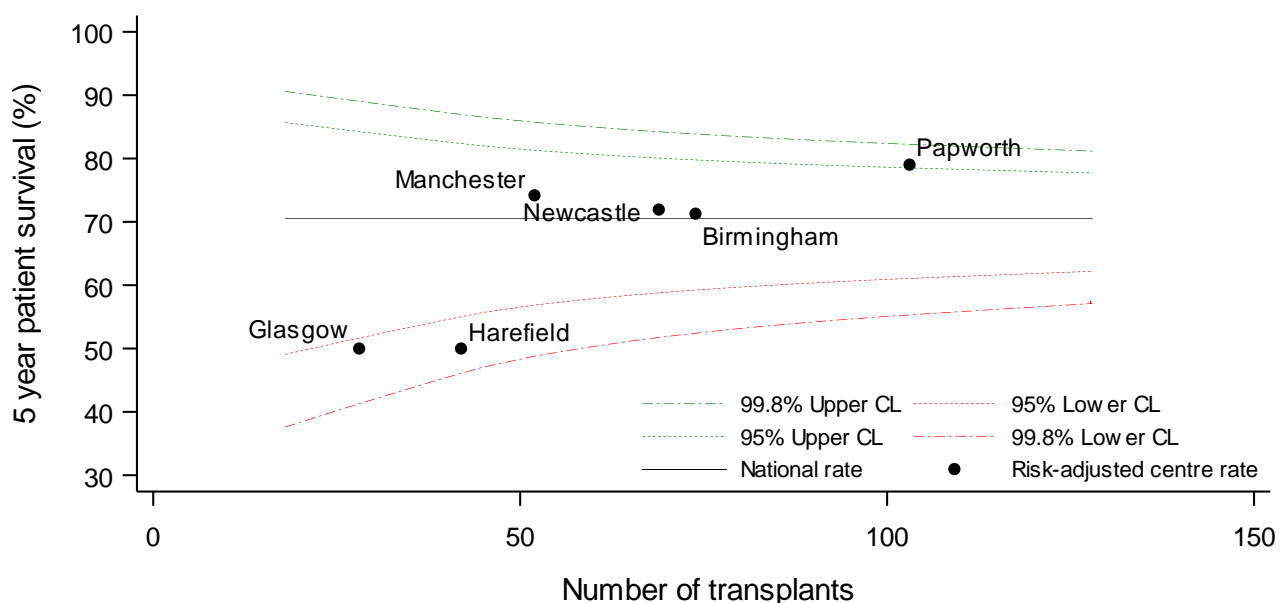
**Figure 6.2 Risk-adjusted one-year patient survival rates for adult heart transplants, by centre, 1 April 2012 to 31 March 2016**



**Table 6.3** and **Figure 6.3** show the 5-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 368 first adult heart only transplants in the period 1 April 2008 to 31 March 2012. The national rate of survival was 70.5%. The rates for Glasgow and Harefield lie between the lower 95% and 99.8% [confidence limits](#), indicating that they may be significantly lower than the national rate. The rate for Papworth lies between the upper 95% and 99.8% [confidence limits](#), indicating that their rate may be significantly higher than the national rate.

Table 6.3 5 year patient survival rates after first adult heart transplant, by centre, 1 April 2008 to 31 March 2012					
Centre	Number of transplants	% 5 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	74	67.5	(55.5 - 76.9)	71.2	(57.0 - 80.7)
Glasgow	28	60.1	(39.5 - 75.6)	50.2	(10.0 - 72.4)
Harefield	42	57.1	(40.9 - 70.4)	49.9	(20.5 - 68.4)
Manchester	52	73.0	(58.7 - 83.0)	74.1	(56.2 - 84.6)
Newcastle	69	71.0	(58.7 - 80.2)	72.0	(56.7 - 82.0)
Papworth	103	79.6	(70.5 - 86.2)	79.0	(67.8 - 86.3)
<b>UK</b>	<b>368</b>	<b>70.5</b>	<b>(65.6 - 74.9)</b>		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div>           Centre has reached the lower 99.8% confidence limit         </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div>           Centre has reached the lower 95% confidence limit         </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div>           Centre has reached the upper 95% confidence limit         </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div>           Centre has reached the upper 99.8% confidence limit         </div>					

**Figure 6.3 Risk-adjusted five year patient survival rates for adult heart transplants, by centre, 1 April 2008 to 31 March 2012**



## 6.2 Survival by disease group

Tables 6.4, 6.5 and 6.6 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 30 days, 1 year and 5 years post-transplant, respectively. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in **Appendix A3.1**, except centre was used in place of disease group. There were no statistically significant differences in [survival rates](#) across disease groups; however, coronary heart disease had the highest 30-day and 1-year survival rate while congenital heart disease had the highest 5-year survival rate.

**Table 6.4 30 day patient survival rates after first adult heart transplant, by disease group, 1 April 2012 and 31 March 2016**

Disease group	Number of transplants	% 30 day survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Congenital heart disease	40	82.5	(66.8 - 91.2)	89.4	(77.7 - 94.9)
Coronary heart disease	85	92.9	(85.0 - 96.8)	93.2	(84.9 - 97.0)
Dilated cardiomyopathy	333	89.5	(85.7 - 92.3)	89.1	(84.8 - 92.2)
Other	104	91.3	(84.0 - 95.4)	89.6	(80.0 - 94.6)
<b>UK</b>	<b>562</b>	<b>89.9</b>	<b>(87.1 - 92.1)</b>		

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 98.8% confidence limit

**Table 6.5 1 year patient survival rates after first adult heart transplant, by disease group, 1 April 2012 and 31 March 2016**

Disease group	Number of transplants	% 30 day survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Congenital heart disease	40	77.5	(61.2 - 87.6)	82.4	(66.1 - 90.8)
Coronary heart disease	85	82.3	(72.4 - 88.9)	83.8	(73.2 - 90.3)
Dilated cardiomyopathy	333	83.8	(79.4 - 87.3)	83.0	(77.8 - 87.0)
Other	104	79.8	(70.7 - 86.3)	78.9	(67.6 - 86.2)
<b>UK</b>	<b>562</b>	<b>82.4</b>	<b>(79.0 - 85.3)</b>		

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 98.8% confidence limit



**Table 6.6 5 year patient survival rates after first adult heart transplant, by disease group, 1 April 2008 and 31 March 2012**

Disease group	Number of transplants	% 30 day survival (95% CI)			
			<u>Unadjusted</u>		<u>Risk-adjusted</u>
Congenital heart disease	27	77.4	(56.5 - 89.2)	72.9	(39.6 - 87.8)
Coronary heart disease	67	68.6	(56.0 - 78.2)	70.5	(54.8 - 80.8)
Dilated cardiomyopathy	201	71.5	(64.7 - 77.3)	72.8	(64.7 - 79.0)
Other	73	67.1	(55.0 - 76.6)	62.4	(43.8 - 74.8)
<b>UK</b>	<b>368</b>	<b>70.5</b>	<b>(65.6 - 74.9)</b>		
		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 98.8% confidence limit			

### 6.3 Survival post DCD heart transplant

**Table 6.7** and **Table 6.8** present short-term patient [survival rates](#) following DCD heart only transplant, by centre and nationally. During the time period 1 April 2012 to 31 March 2016 a small number of transplant were performed, by two centres only, and there was only one death within 1 year.

**Table 6.7 30 day patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2012 and 31 March 2016**

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) ( <a href="#">unadjusted</a> )	
Harefield <sup>1</sup>	3	0	-	-
Papworth	16	0	100.0	-
<b>UK</b>	<b>19</b>	<b>0</b>	<b>100.0</b>	<b>-</b>

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

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

**Table 6.8 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2012 and 31 March 2016**

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) ( <a href="#">unadjusted</a> )	
Harefield <sup>1</sup>	3	0	-	-
Papworth	16	1	93.8	(63.2 - 99.1)
<b>UK</b>	<b>19</b>	<b>1</b>	<b>94.7</b>	<b>(68.1 - 99.2)</b>

<sup>1</sup> 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**



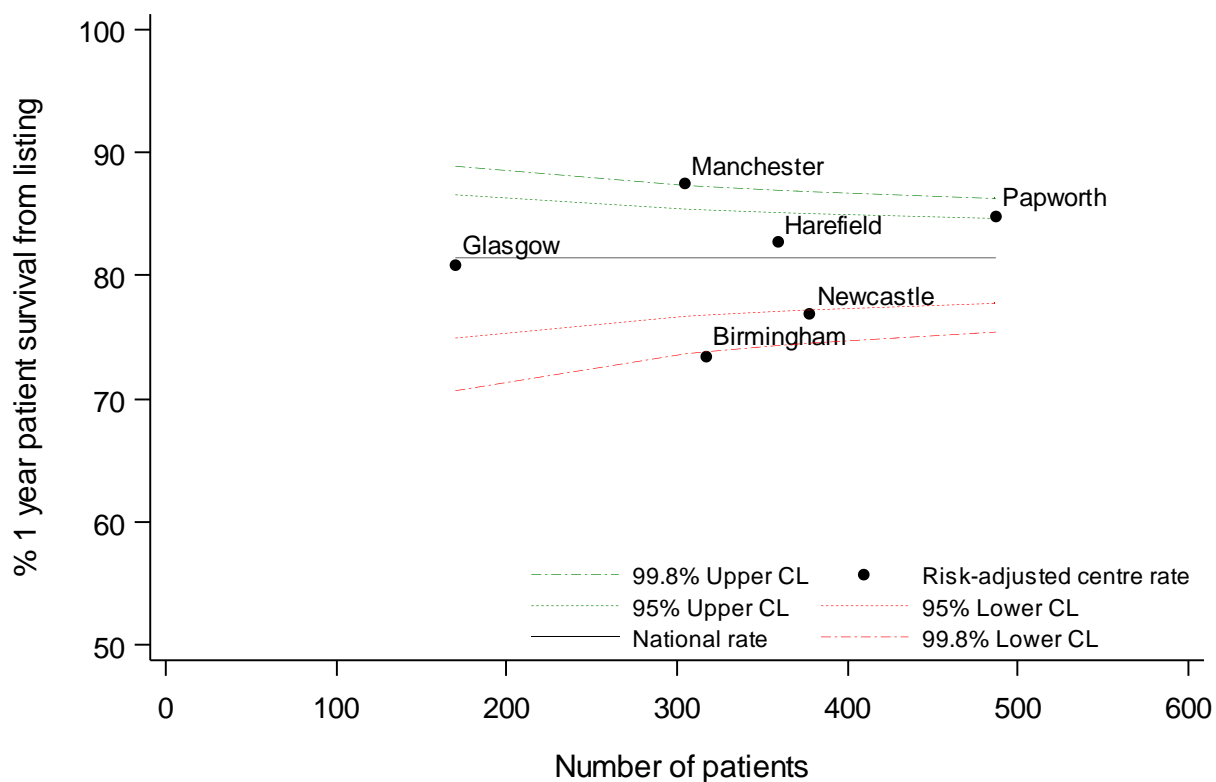
## 7. Survival from Listing

Survival from listing was analysed for patients 18 years or older registered for the first time for a heart transplant between 1 January 2005 and 31 December 2016. 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.

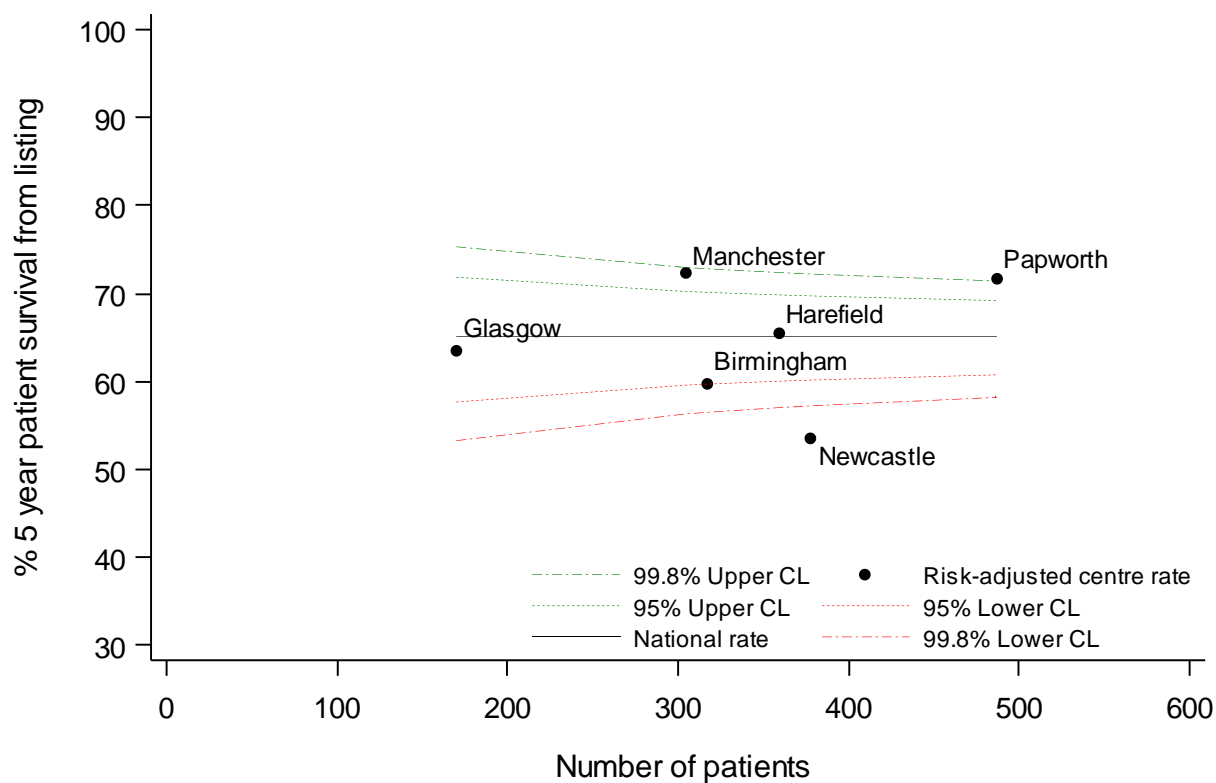
One, five and ten year [risk-adjusted survival rates](#) from the point of heart transplant listing are shown as [funnel plots](#) in **Figures 7.1, 7.2 and 7.3** respectively. These rates are also shown in **Table 7.1**. With respect to the one year [survival rates](#), two centres fell above the upper 95% [confidence limit](#) and two fell below the lower 95% confidence limit, indicating that these rates may be significantly different from the national rate. The one year survival rate from listing for Birmingham was below the 99.8% [confidence limit](#) indicating a significantly worse rate than the national rate. The five and ten year [survival rates](#) from listing fell below the 99.8% [confidence limit](#) for Newcastle and above the 99.8% [confidence limit](#) for Papworth.

<b>Table 7.1 Risk-adjusted 1, 5 and 10 year patient survival rates from listing for first heart transplant in patients registered between 1 January 2005 and 31 December 2016</b>						
Centre	One year		Five year		Ten year	
	No. patients	Survival rate (%)	No. patients	Survival rate (%)	No. patients	Survival rate (%)
Birmingham	317	(73.4)	317	(59.8)	317	(47.9)
Glasgow	170	(80.9)	170	(63.6)	170	(52.8)
Harefield	359	(82.8)	359	(65.6)	359	(54.5)
Manchester	305	(87.5)	305	(72.3)	305	(59.2)
Newcastle	378	(76.9)	378	(53.6)	378	(41.8)
Papworth	487	(84.8)	487	(71.6)	487	(62.3)
<b>UK</b>	<b>2016</b>	<b>(81.5)</b>	<b>2016</b>	<b>(65.1)</b>	<b>2016</b>	<b>(54.0)</b>
	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 98.8% confidence limit					

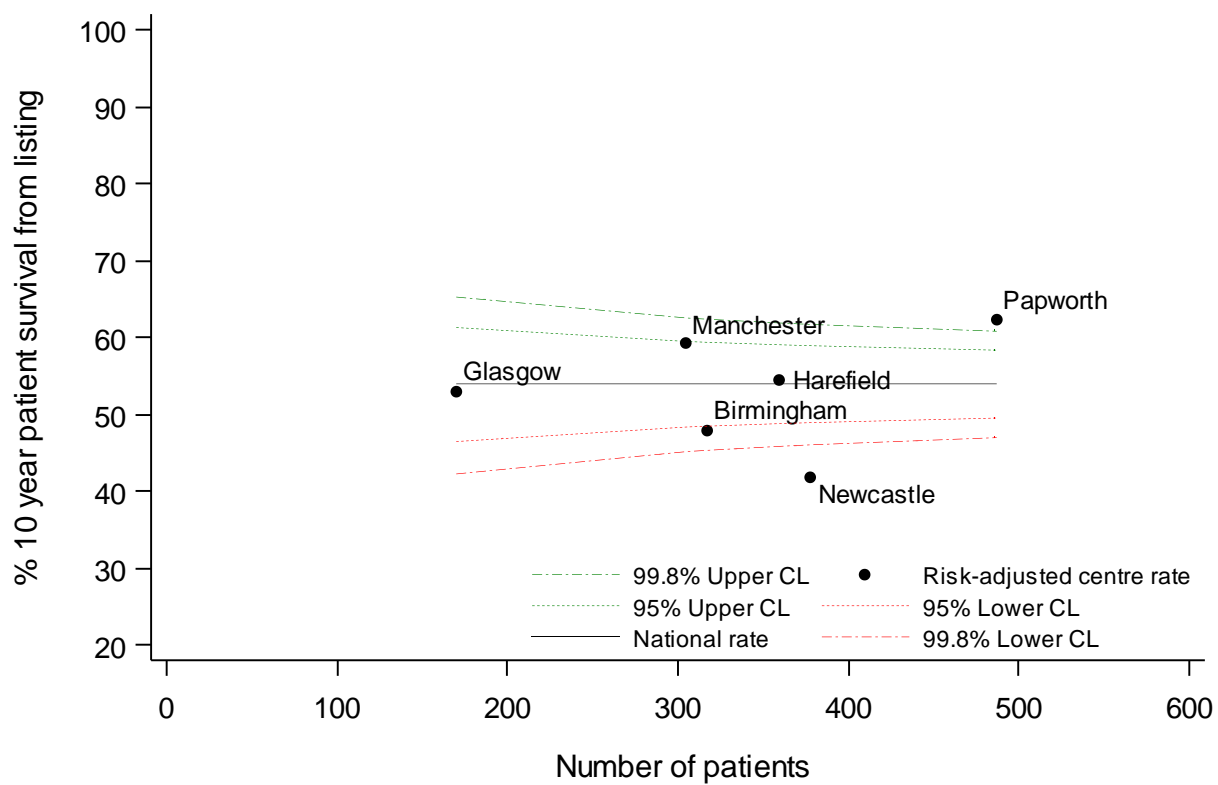
**Figure 7.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2005 – 31 December 2016**



**Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2005 – 31 December 2016**



**Figure 7.3 Risk-adjusted ten year patient survival rates from listing by centre,  
1 January 2005 – 31 December 2016**



# **ADULT HEART TRANSPLANTATION**

## **Form Return Rates**



## 8. Adult heart form return rates, 1 January – 31 December 2016

Form return rates are reported in **Table 8.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (more than 2 years). These include all adult heart transplants between 1 January and 31 December 2016 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. Overall, form return rates are in excess of 95% but some centres have a number of forms outstanding for this period.

**Table 8.1 Form return rates for adult heart transplants, 1 January 2016 to 31 December 2016**

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	26	100	23	100	20	100	215	100
Glasgow, Golden Jubilee National Hospital	13	100	12	100	5	80	146	86
Harefield, Harefield Hospital	22	100	21	95	19	100	540	98
Manchester, Wythenshawe Hospital	29	100	26	100	25	100	238	97
Newcastle, Freeman Hospital	29	100	23	100	19	100	290	99
Papworth, Papworth Hospital	52	100	54	100	43	100	537	100
Sheffield, Northern General Hospital	-	-	-	-	-	-	57	100
<b>Overall</b>	<b>171</b>	<b>100</b>	<b>159</b>	<b>99</b>	<b>131</b>	<b>99</b>	<b>2024</b>	<b>98</b>



# **ADULT LUNG TRANSPLANTATION**

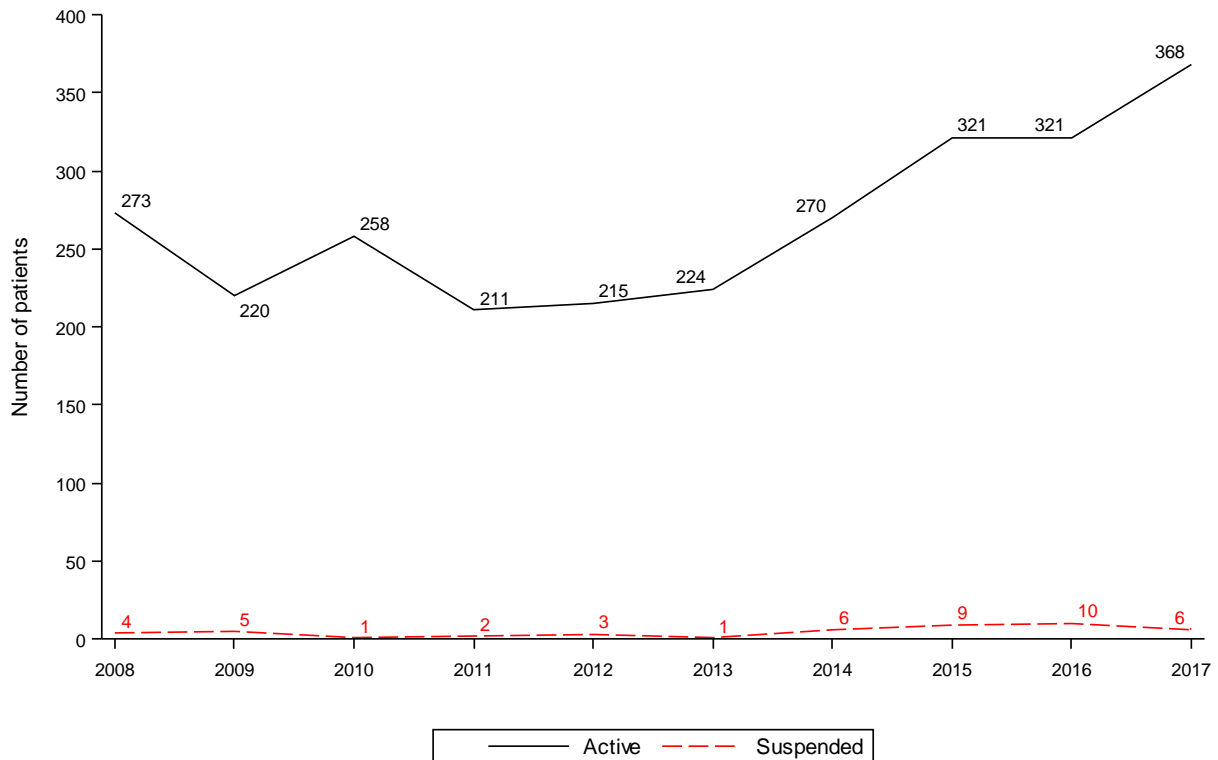
## **Transplant List**



## 9.1 Adult lung and heart-lung transplant list as at 31 March, 2008 – 2017

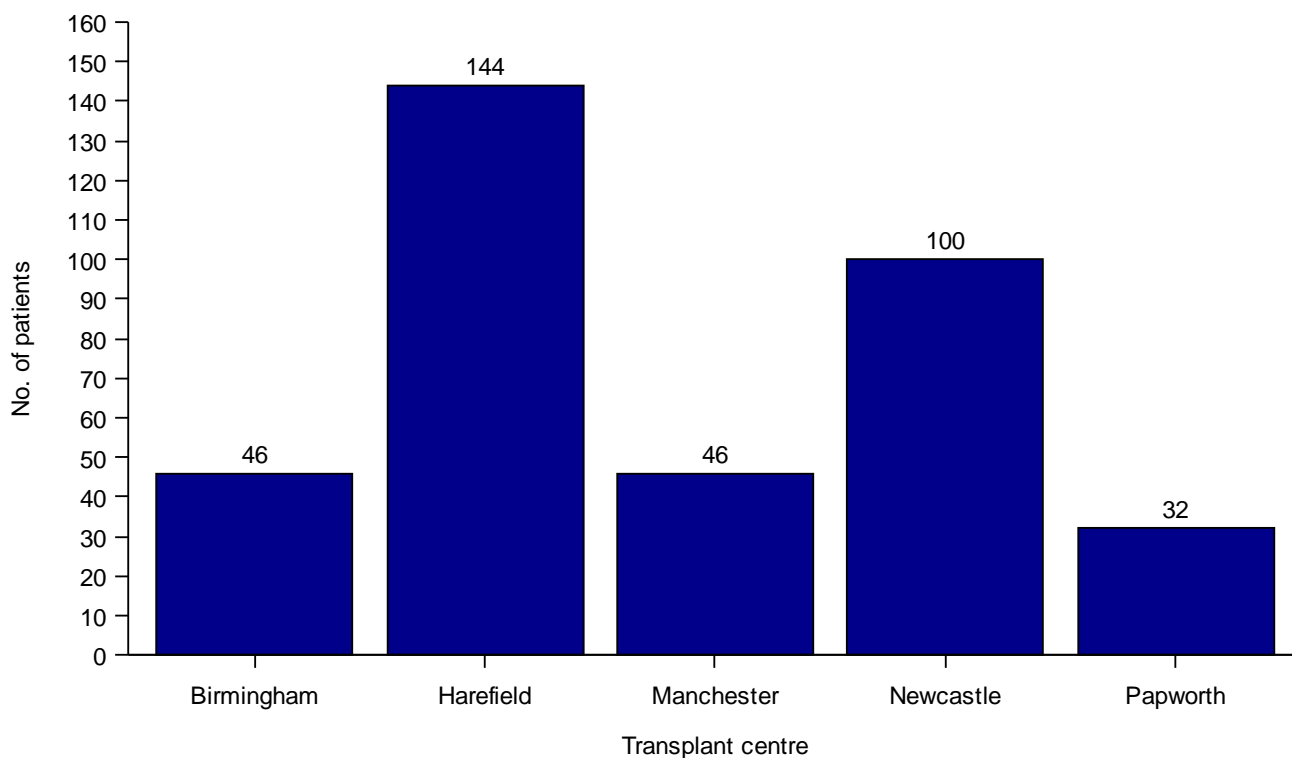
**Figure 9.1** shows the number of adult patients on the lung and heart-lung transplant lists at 31 March each year between 2008 and 2017 split by active/suspended status. The number of patients on the active lung transplant list has increased steadily since 2011, reaching 368 on 31 March 2017.

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



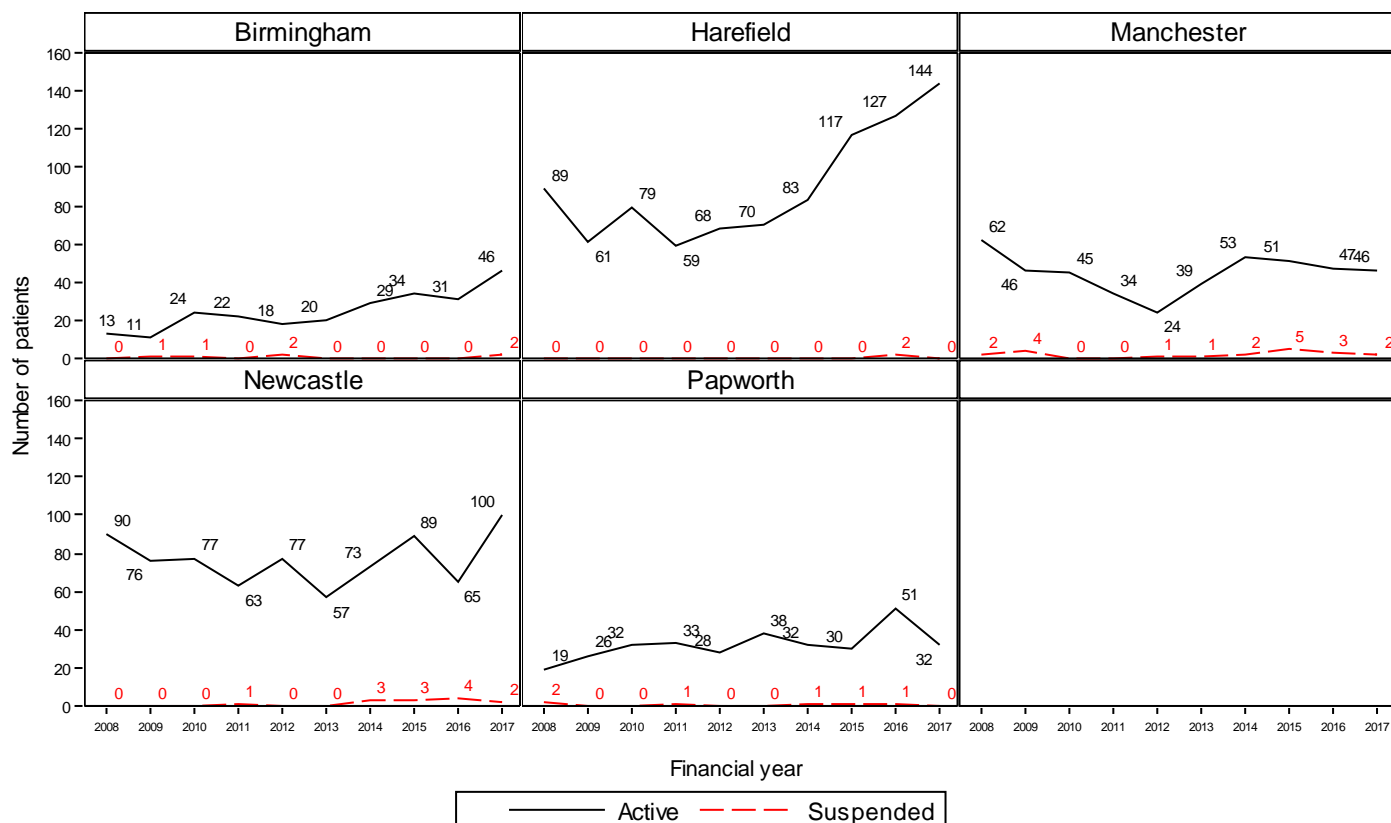
**Figure 9.2** shows the number of adult patients on the [active lung transplant list](#) on 31 March 2017 by centre. In total, there were 368 adult patients. Harefield had the highest number of patients on the transplant list while Papworth had the lowest.

**Figure 9.2 Number of adult patients on the active lung transplant list at 31 March 2017, by centre**



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

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



## 9.2 Demographic characteristics, 1 April 2016 – 31 March 2017

There were 341 adult patient registrations onto the lung transplant list between 1 April 2016 and 31 March 2017. Demographic characteristics of these patients are shown by centre and overall in **Table 9.1**. Nationally, 56% of patients were male and the [median](#) age was 52 years. For some characteristics, due to rounding, percentages may not add up to 100.

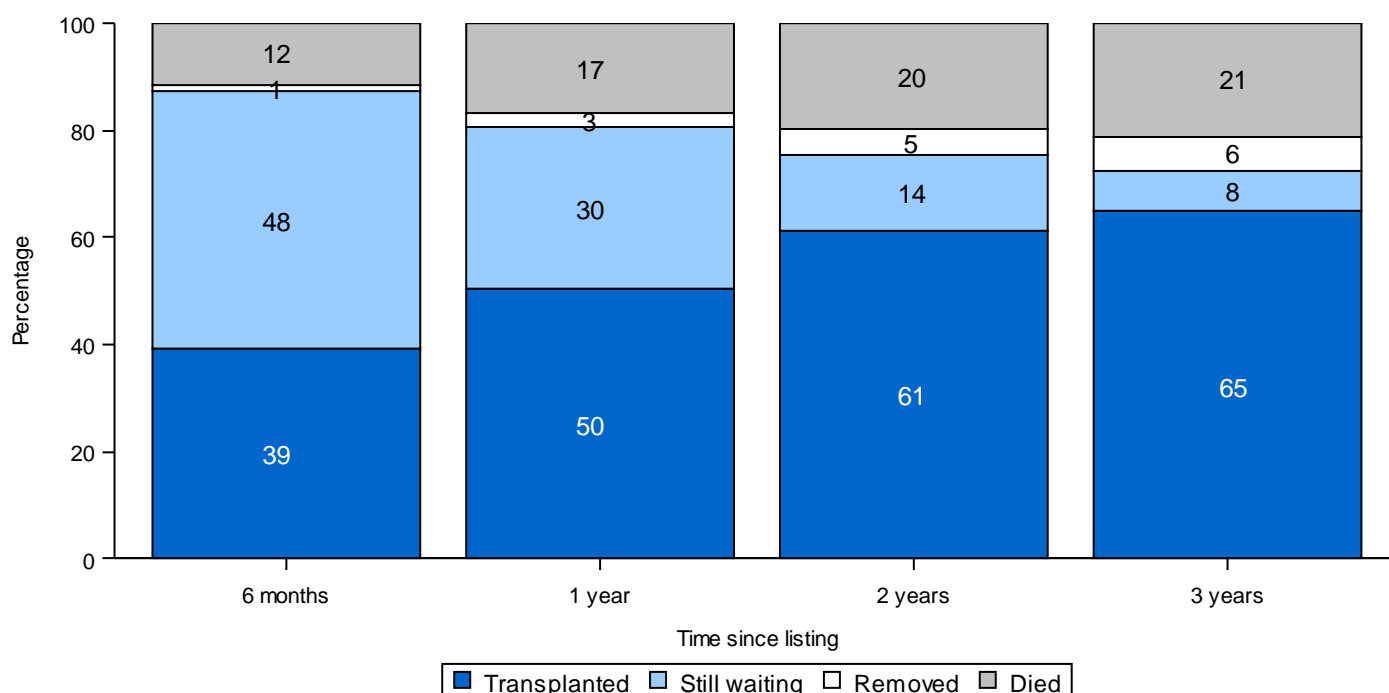
Table 9.1 Demographic characteristics of adult patients registered onto the lung transplant list between 1 April 2016 and 31 March 2017, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		45 (100)	105 (100)	47 (100)	96 (100)	48 (100)	341 (100)
Recipient sex	Male	25 (56)	56 (53)	25 (53)	59 (61)	25 (52)	190 (56)
	Female	20 (44)	49 (47)	22 (47)	37 (39)	23 (48)	151 (44)
Recipient ethnicity	White	40 (89)	99 (94)	43 (91)	93 (97)	46 (96)	321 (94)
	Non-white	5 (11)	6 (6)	3 (6)	3 (3)	2 (4)	19 (6)
	Missing	0 (0)	0 (0)	1 (2)	0 (0)	0 (0)	1 (0)
Recipient age (years)	Median ( <a href="#">IQR</a> )	54 (41, 60)	47 (36, 58)	55 (47, 62)	53 (43, 60)	52 (33, 60)	52 (38, 60)
	Missing	0	0	0	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	9 (20)	41 (39)	9 (19)	25 (26)	10 (21)	94 (28)
	Fibrosing lung disease	11 (24)	18 (17)	15 (32)	37 (39)	9 (19)	90 (26)
	COPD and emphysema	13 (29)	35 (33)	13 (28)	24 (25)	4 (8)	89 (26)
	Primary pulmonary hypertension	0 (0)	2 (2)	4 (9)	3 (3)	1 (2)	10 (3)
	Other	11 (24)	9 (9)	6 (13)	7 (7)	24 (50)	57 (17)
	Missing	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0)
Smoker	No	45 (100)	103 (98)	45 (96)	96 (100)	48 (100)	337 (99)
	Yes	0 (0)	1 (1)	0 (0)	0 (0)	0 (0)	1 (0)
	Missing	0 (0)	1 (1)	2 (4)	0 (0)	0 (0)	3 (1)
Lung function - FEV1 (litres)	Median ( <a href="#">IQR</a> )	0.87 (0.73, 1.48)	0.86 (0.66, 1.25)	1.08 (0.69, 2.14)	1.04 (0.68, 1.87)	1.05 (0.70, 1.51)	0.95 (0.70, 1.55)
	Missing	1	6	3	4	1	15
Lung function – FVC (litres)	Median ( <a href="#">IQR</a> )	1.93 (1.63, 2.43)	2.12 (1.62, 2.66)	2.07 (1.64, 3.10)	2.13 (1.57, 2.62)	1.88 (1.50, 2.56)	2.03 (1.57, 2.62)
	Missing	1	6	3	4	1	15

### 9.3 Post-registration outcomes, 1 April 2013 – 31 March 2014

The transplant list outcomes of adult patients listed for a lung transplant between 1 April 2013 and 31 March 2014 are summarised in **Figure 9.4**. This shows the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two year and three years after joining the list.

Within six month of listing 39% of lung patients had been transplanted and 12% had died. Three years after listing 65% have been transplanted and 21% had died. Removals from the list were mainly due to deteriorating condition.

**Figure 9.4 Post-registration outcome for 313 lung only registrations made in the UK, 1 April 2013 to 31 March 2014**



## 9.4 Median waiting time to transplant, 1 April 2011 - 31 March 2014

The [median](#) waiting time to lung transplant from listing for adult patients is shown in **Figure 9.5** and **Table 9.2**. This is estimated for patients registered on the lung only transplant list between 1 April 2011 and 31 March 2014 using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. The national [median](#) waiting time was 255 days and ranged from 203 days at Papworth to 291 days at Manchester. The variation between centres was not more than what would be expected by random variation (log rank  $p=0.2$ ).

**Figure 9.5** Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2011 and 31 March 2014, by centre

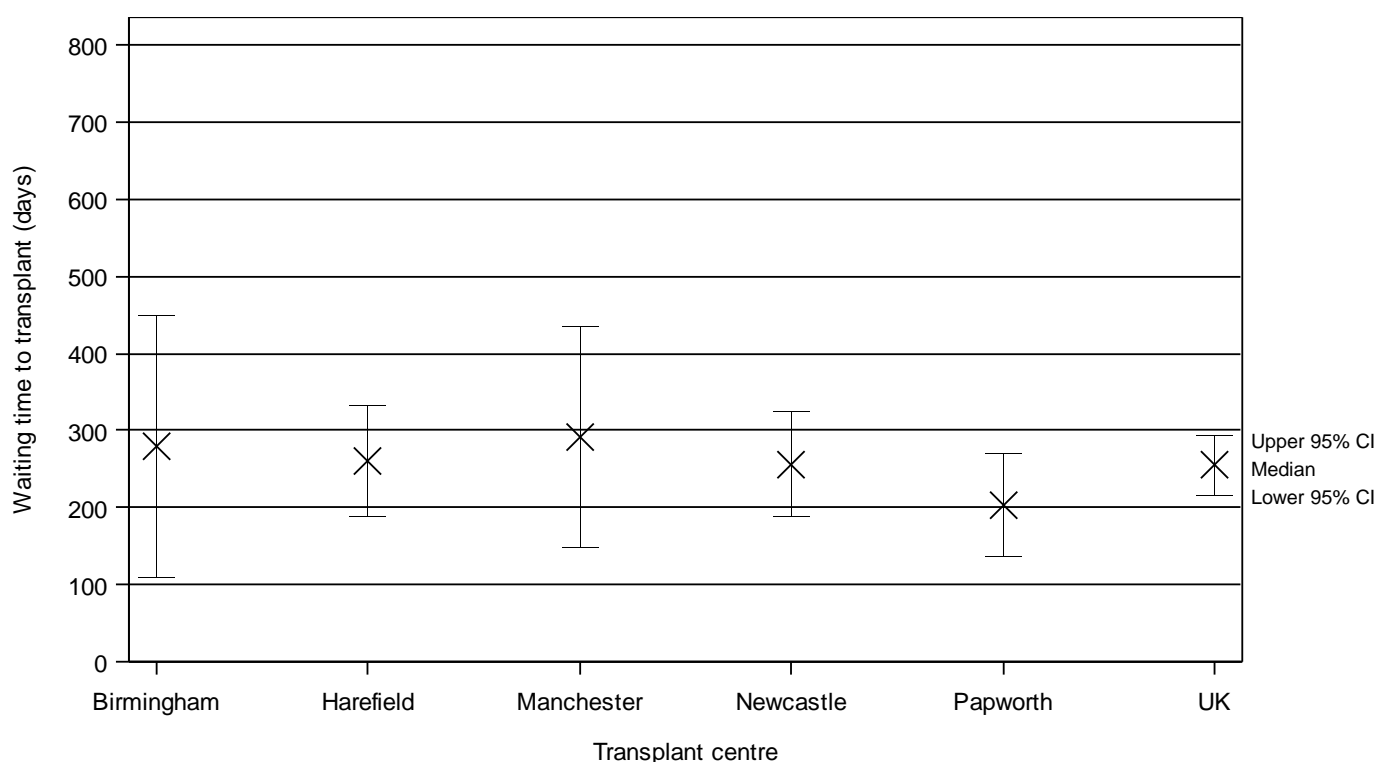


Table 9.2 Median active waiting time to lung transplant for adult patients registered on the transplant list, by centre, 1 April 2011 to 31 March 2014			
Transplant centre	Number of patients registered	Waiting time (days)	
		<a href="#">Median</a>	95% <a href="#">Confidence interval</a>
Birmingham	85	280	110 - 450
Harefield	221	261	190 - 332
Manchester	135	291	148 - 434
Newcastle	209	256	188 - 324
Papworth	143	203	136 - 270
<b>UK</b>	<b>793</b>	<b>255</b>	<b>216 - 294</b>

The [median](#) waiting time to lung transplant for adult patients is also considered by blood group. This is shown in **Figure 9.6** and **Table 9.3**. Blood group O patients have the longest average wait (406 days) compared with the other blood groups (log-rank  $p < 0.0001$ ).

**Figure 9.6** Median waiting time to lung transplant for adult patients registered on the transplant list between 1 April 2011 and 31 March 2014, by blood group

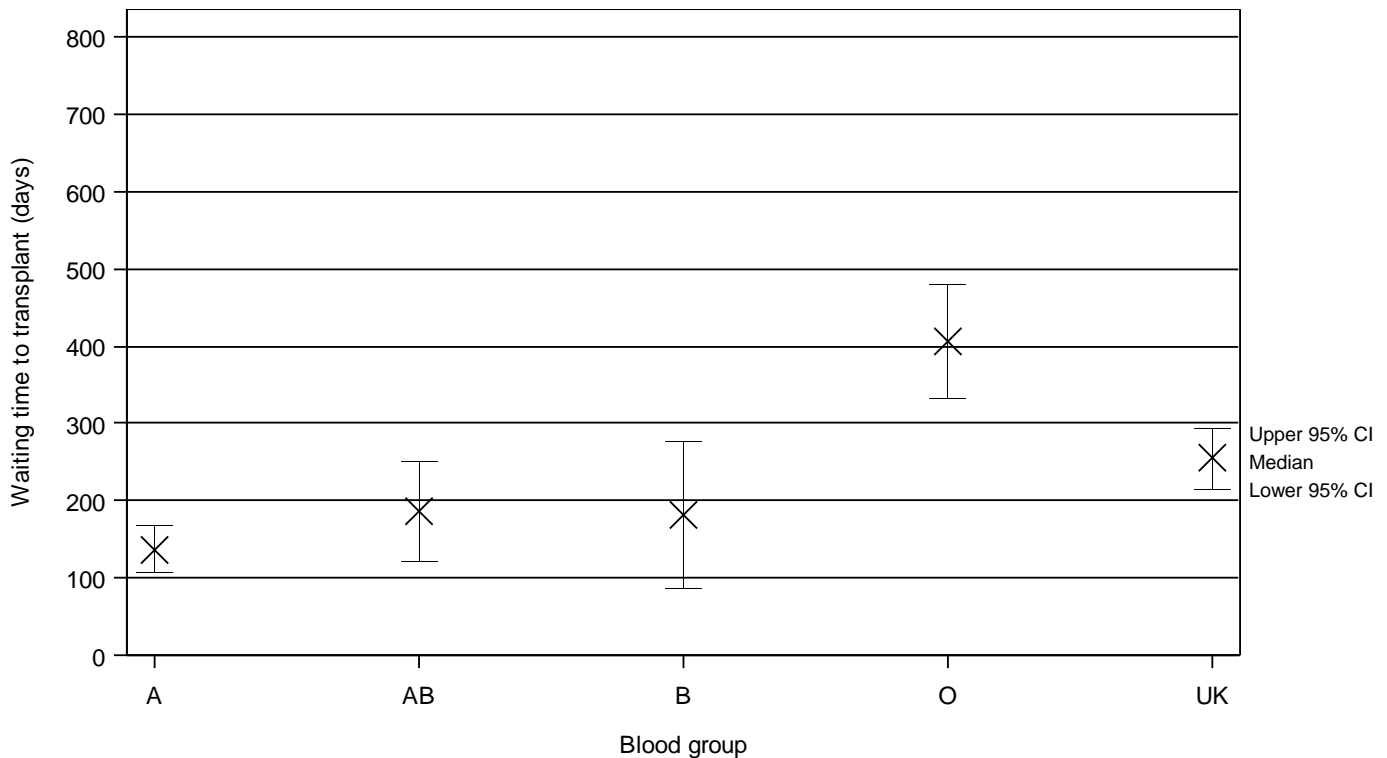


Table 9.3 Median active waiting time to lung transplant for adult patients registered on the transplant list, by blood group, 1 April 2011 to 31 March 2014			
Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
A	315	137	107 - 167
AB	18	186	121 - 251
B	83	182	87 - 277
O	377	406	332 - 480
<b>UK</b>	<b>793</b>	<b>255</b>	<b>216 - 294</b>



# **ADULT LUNG TRANSPLANTATION**

## **Response to Offers**



## 10. Response to Offers

**Figures 10.1** and **10.2** compare individual centre adult lung offer decline rates with the national rate using [funnel plots](#). The analysis is performed separately for bilateral lung offers and single lung offers, respectively. A bilateral lung offer is counted as accepted if either both the lungs were accepted or just a single lung was accepted. This only considers offers of UK DBD donor lungs between 1 April 2014 and 31 March 2017 that were eventually transplanted and excludes all fast track offers. Lungs offered as part of a cardiac block offer are included and offers to paediatric patients at Newcastle are excluded.

The bilateral lung offer decline rates for Papworth and Birmingham fell outside of the 99.8% [confidence limits](#). This indicates that Birmingham had a significantly high decline rate and Papworth had a significantly low decline rate compared with the national average. The number of single lung offers are comparatively small and no significant divergence from the national rate was detected.

**Table 10.1** shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the bilateral lung decline rate has increased by 10% over the three years. In **Table 10.2** there is no breakdown by year due to small numbers of single lung offers but it can be seen that the overall national decline rate is much higher than for bilateral lung offers, at 95.4%.

**Figure 10.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2014 to 31 March 2017**

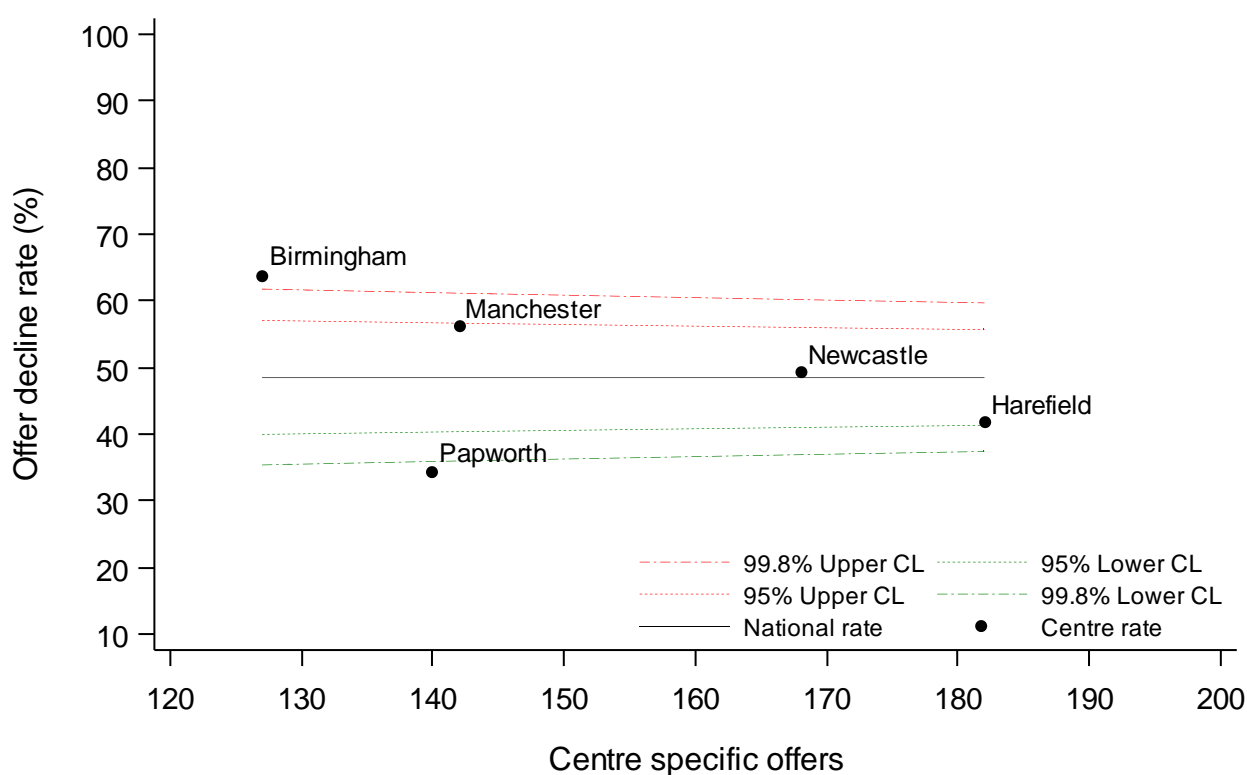
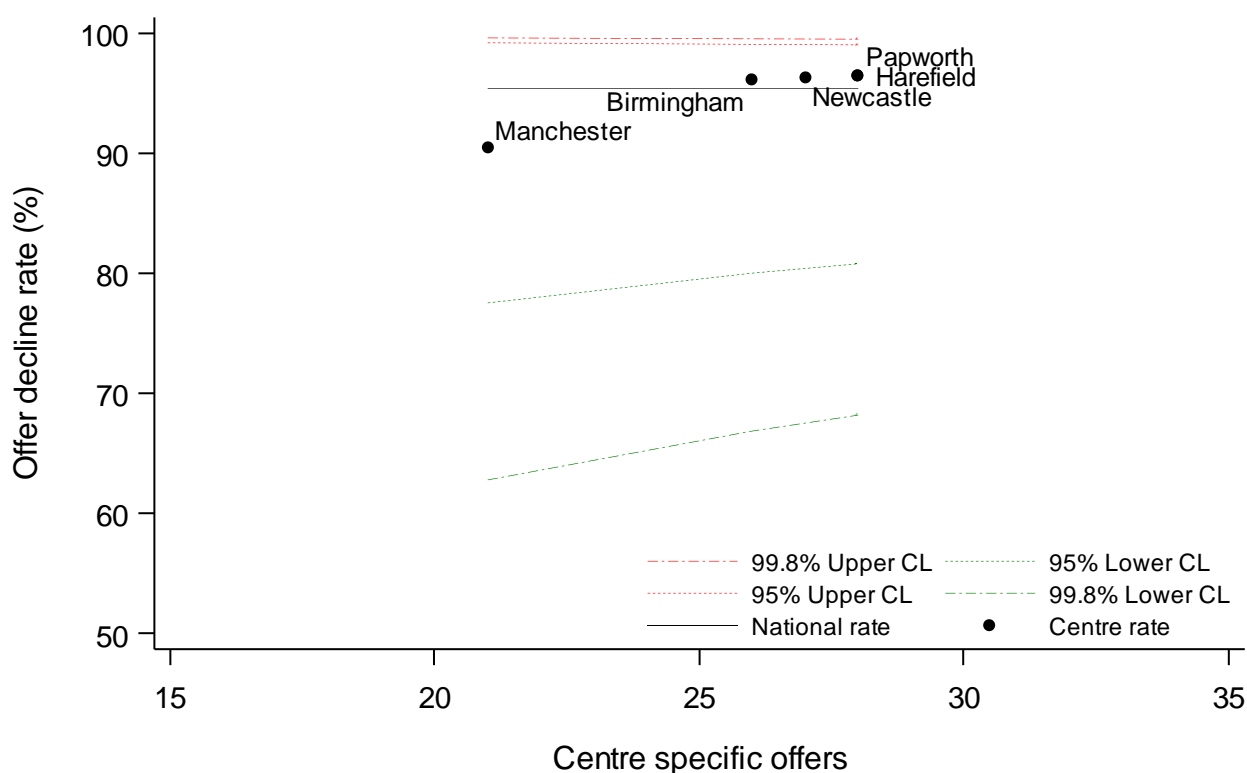


Table 10.1 UK adult DBD donor bilateral lung offer decline rates by transplant centre and year, between 1 April 2014 and 31 March 2017								
Centre	2014/15		2015/16		2016/17		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Birmingham	41	(58.5)	44	(56.8)	42	(76.2)	127	(63.8)
Harefield	55	(30.9)	54	(37.0)	73	(53.4)	182	(41.8)
Manchester	39	(56.4)	49	(57.1)	54	(55.6)	142	(56.3)
Newcastle	50	(36.0)	64	(57.8)	54	(51.9)	168	(49.4)
Papworth	48	(39.6)	49	(34.7)	43	(27.9)	140	(34.3)
<b>UK</b>	<b>233</b>	<b>(42.9)</b>	<b>260</b>	<b>(48.8)</b>	<b>266</b>	<b>(53.0)</b>	<b>759</b>	<b>(48.5)</b>
<div> <div></div>Centre has reached the upper 99.8% confidence limit </div> <div> <div></div>Centre has reached the upper 95% confidence limit </div> <div> <div></div>Centre has reached the lower 95% confidence limit </div> <div> <div></div>Centre has reached the lower 98.8% confidence limit </div>								

**Figure 10.2 UK adult DBD donor single lung offer decline rates by centre, 1 April 2014 to 31 March 2017**



**Table 10.2 UK adult DBD donor single lung offer decline rates by transplant centre, between 1 April 2014 and 31 March 2017**

Centre	Overall	
	No. offers	Decline rate (%)
Birmingham	26	(96.2)
Harefield	28	(96.4)
Manchester	21	(90.5)
Newcastle	27	(96.3)
Papworth	28	(96.4)
<b>UK</b>	<b>130</b>	<b>(95.4)</b>

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 98.8% confidence limit

# **ADULT LUNG TRANSPLANTATION**

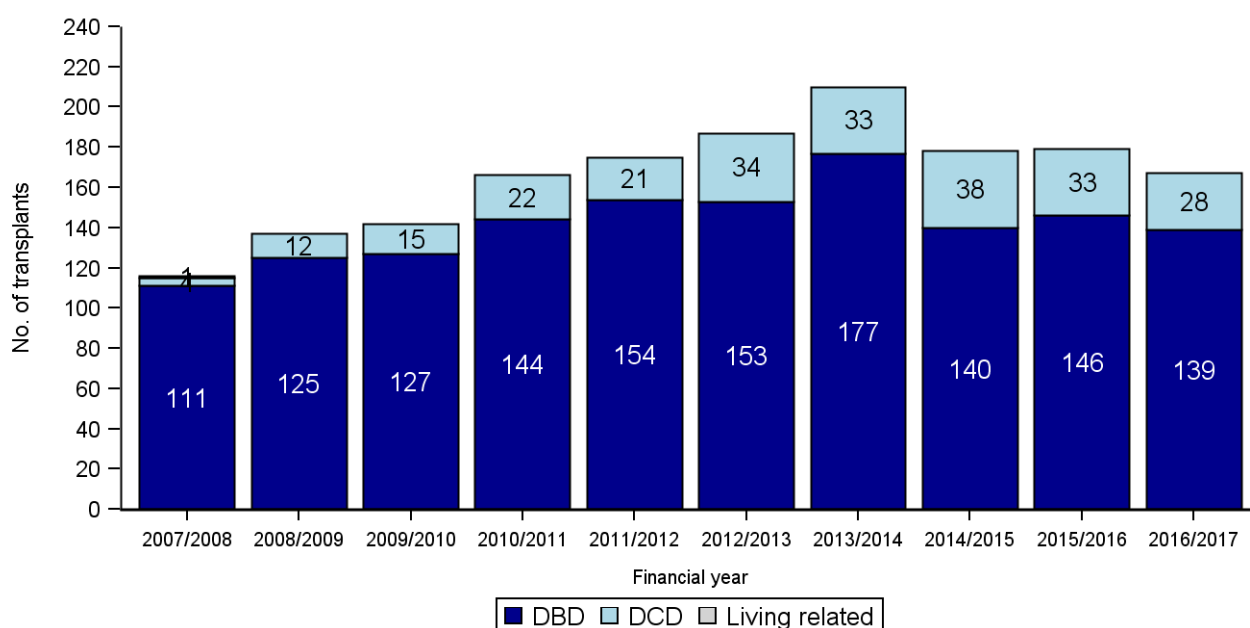
## **Transplants**



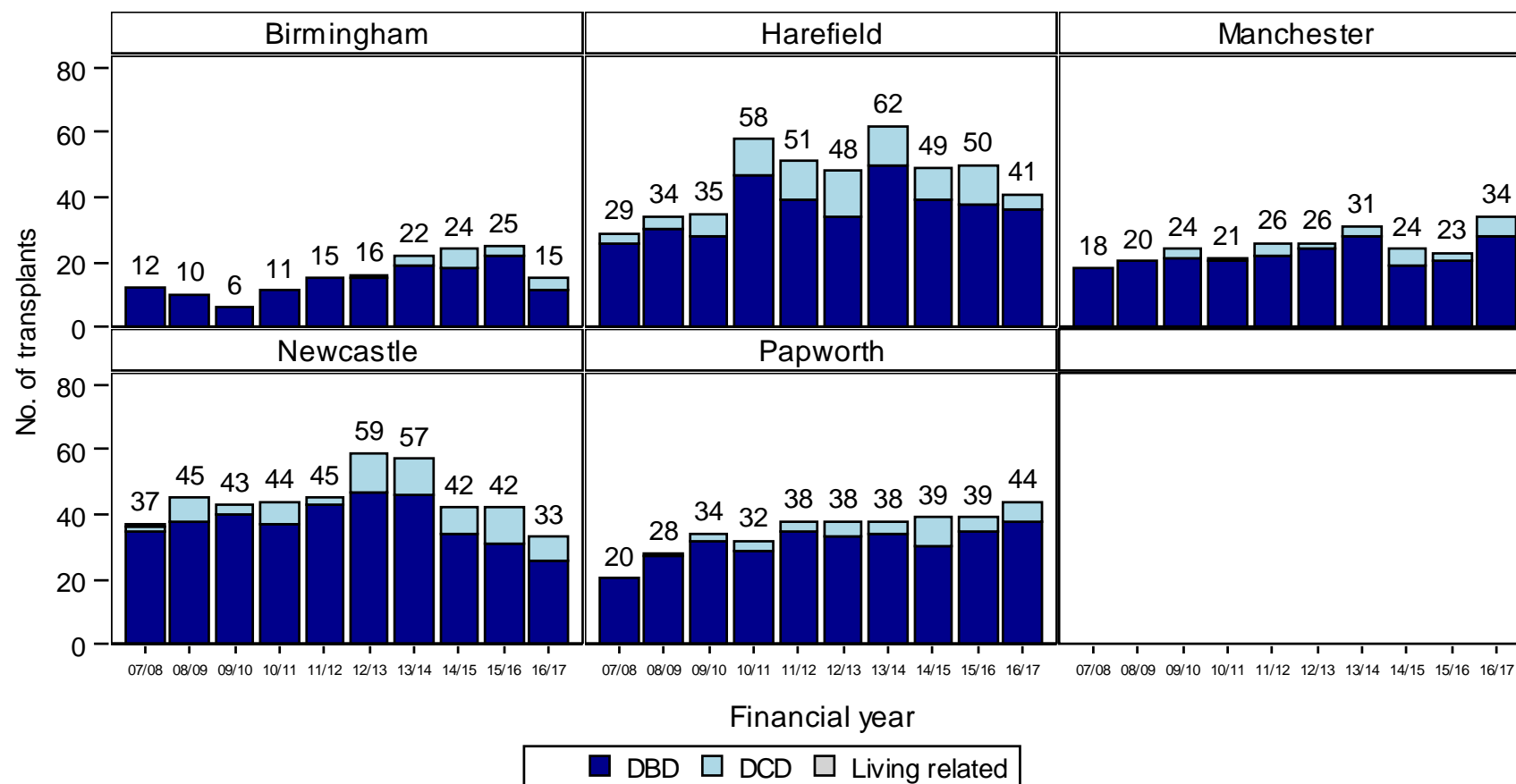
### 11.1 Adult lung and heart-lung transplants, 1 April 2007 – 31 March 2017

**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 between 2007/2008 and 2013/2014, reaching a peak of 210 in 2013/2014. The number then fell by 15% in 2014/2015 and has fallen by a further 6% in the latest year, 2016/2017. In recent years DCD lung transplantation has represented approximately 20% of the total activity. Last year's activity is shown by centre and donor type in **Figure 11.3**.

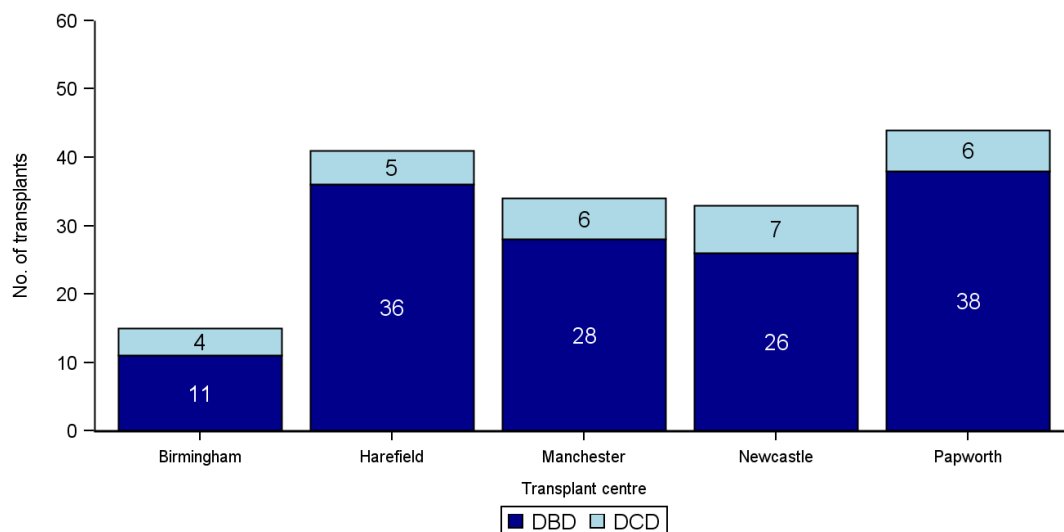
**Figure 11.1 Number of adult lung transplants in the UK, by financial year and donor type, 1 April 2007 to 31 March 2017**



**Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2007 to 31 March 2017**

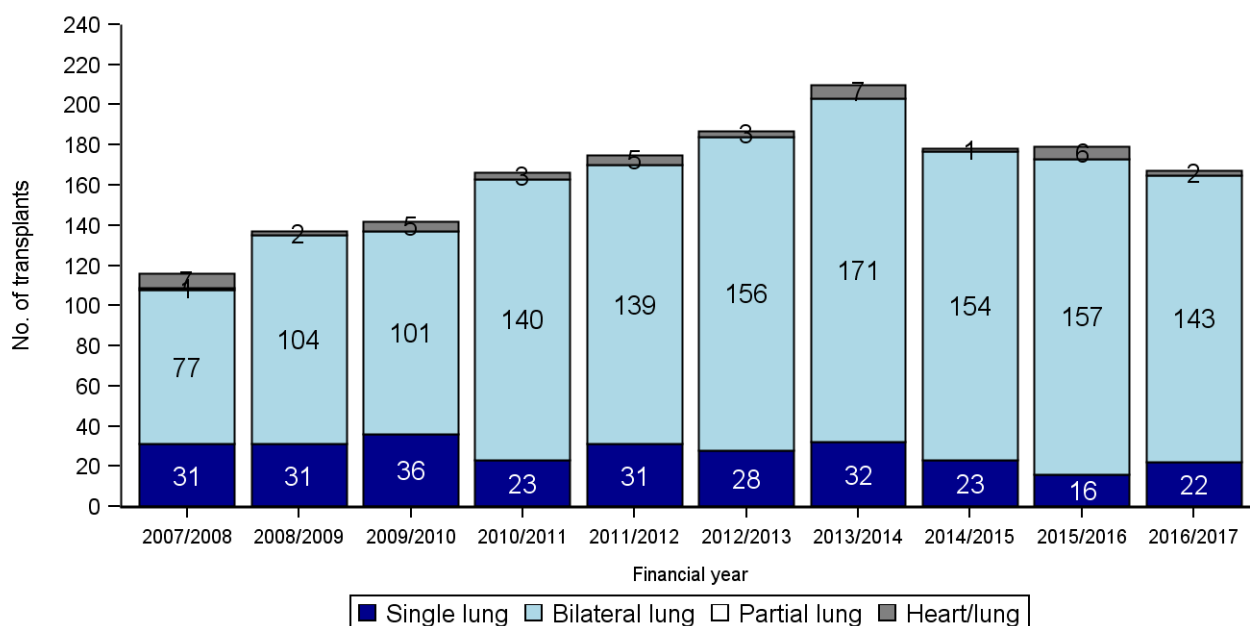


**Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2016 to 31 March 2017**



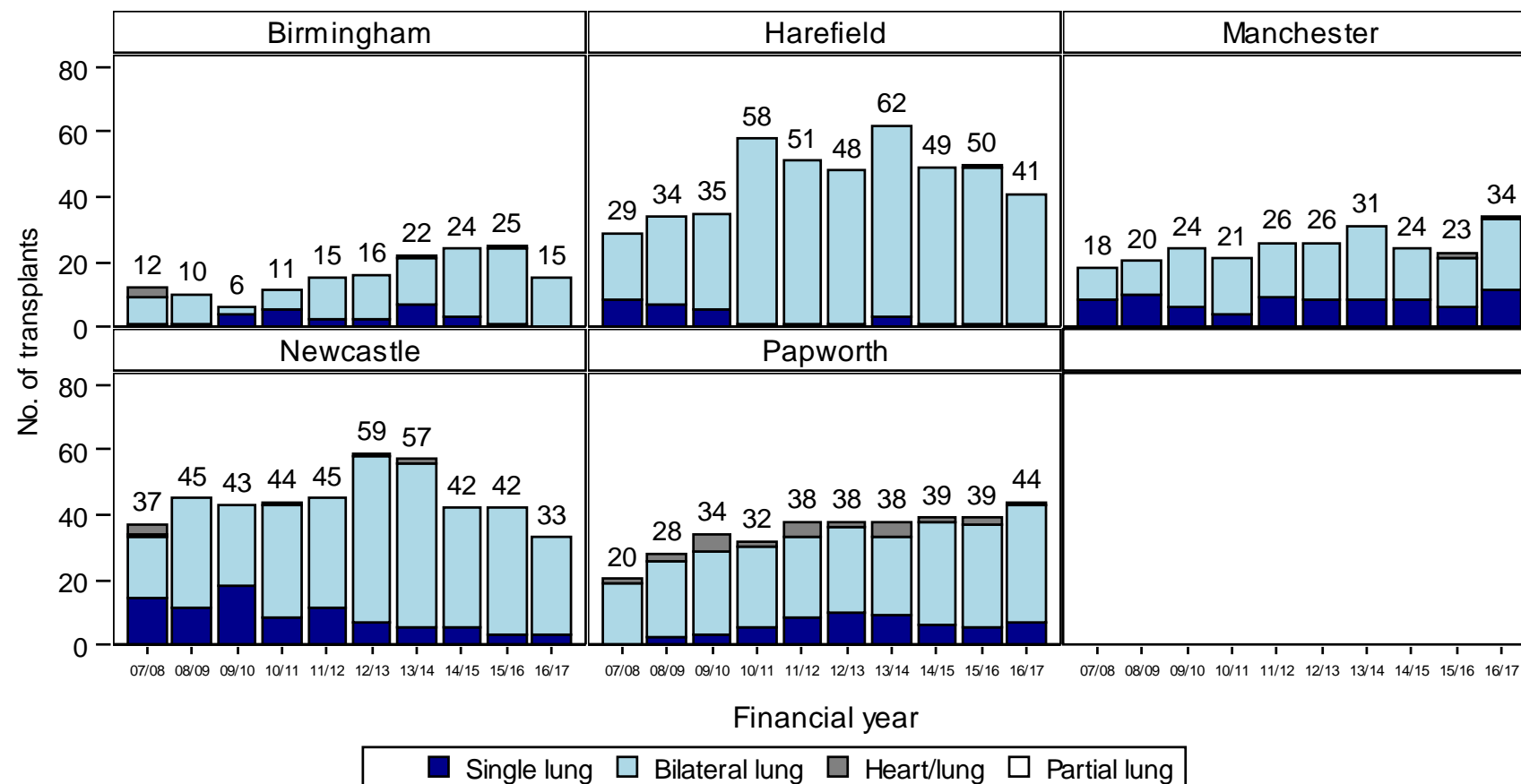
**Figure 11.4** and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. The number of transplants by transplant type in the latest financial year (2016/2017) is shown by centre in **Figure 11.6**. There was a total of 41 heart-lung block transplants, and only one partial lung transplant, over the decade. The overall proportion of single lung transplants has decreased from 27% in 2007/2008 to 13% in 2016/2017. This is mainly due to a reduction in the use of single lungs by Harefield and Newcastle as shown in **Figure 11.5**. In the last financial year Manchester was the highest user of single lungs for transplantation (**Figure 11.6**).

**Figure 11.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2007 to 31 March 2017**

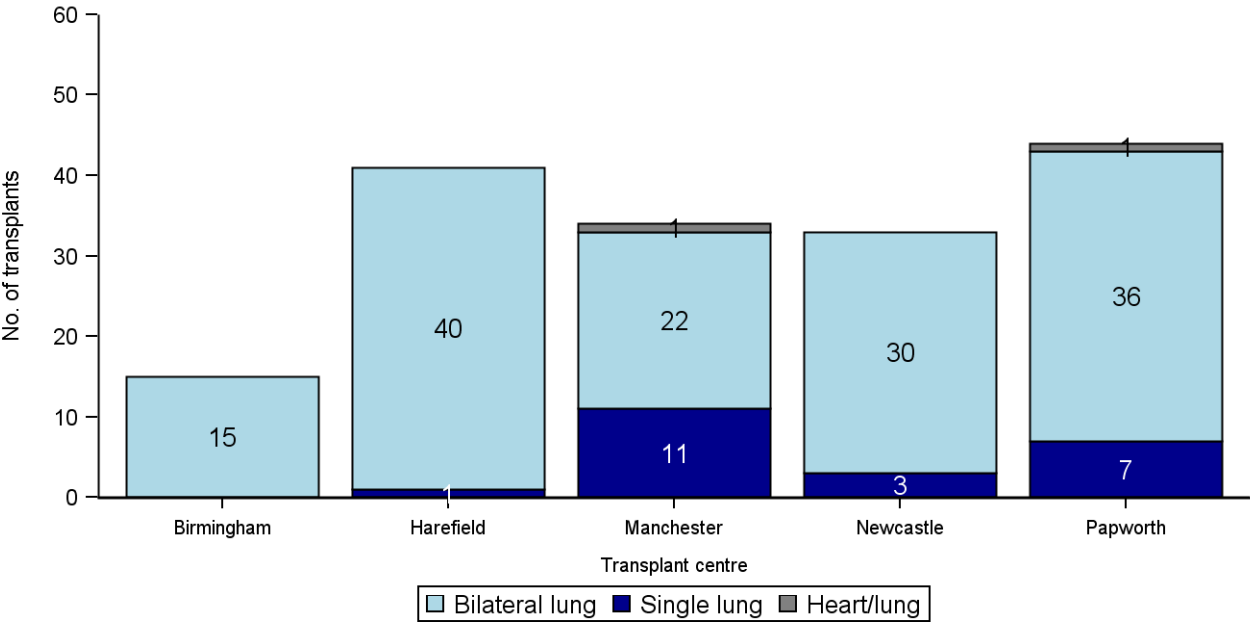




**Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2007 to 31 March 2017**



**Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2016 to 31 March 2017**



## 11.2 Demographic characteristics of transplants, 1 April 2016 – 31 March 2017

The demographic characteristics of the 167 adult lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 62% of lung recipients were male and the [median](#) age was 53 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 2016 to 31 March 2017, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		15 (100)	41 (100)	34 (100)	33 (100)	44 (100)	167 (100)
Transplant type	Single lung	0 (0)	1 (2)	11 (32)	3 (9)	7 (16)	22 (13)
	Bilateral lung	15 (100)	40 (98)	22 (65)	30 (91)	36 (82)	143 (86)
	Partial lung	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
	Heart/lung	0 (0)	0 (0)	1 (3)	0 (0)	1 (2)	2 (1)
Recipient sex	Male	7 (47)	28 (68)	19 (56)	23 (70)	27 (61)	104 (62)
	Female	8 (53)	13 (32)	15 (44)	10 (30)	17 (39)	63 (38)
Recipient ethnicity	White	15 (100)	41 (100)	33 (97)	33 (100)	43 (98)	165 (99)
	Non-white	0 (0)	0 (0)	1 (3)	0 (0)	1 (2)	2 (1)
Recipient age (years)	Median ( <a href="#">IQR</a> )	53 (34, 56)	47 (36, 55)	56 (49, 62)	53 (38, 59)	53 (40, 61)	53 (38, 60)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median ( <a href="#">IQR</a> )	65 (57, 75)	63 (53, 75)	75 (63, 88)	70 (62, 83)	68 (59, 79)	69 (57, 80)
	Missing	0	0	0	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	6 (40)	16 (39)	5 (15)	8 (24)	14 (32)	49 (29)
	Fibrosing lung disease	2 (13)	3 (7)	15 (44)	14 (42)	9 (20)	43 (26)
	COPD and emphysema	3 (20)	19 (46)	7 (21)	8 (24)	5 (11)	42 (25)
	Primary pulmonary hypertension	0 (0)	1 (2)	3 (9)	1 (3)	0 (0)	5 (3)
	Other	3 (20)	2 (5)	4 (12)	2 (6)	16 (36)	27 (16)
	Missing	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
NYHA class	I	4 (27)	0 (0)	0 (0)	0 (0)	0 (0)	4 (2)
	II	0 (0)	9 (22)	0 (0)	0 (0)	2 (5)	11 (7)
	III	0 (0)	19 (46)	32 (94)	1 (3)	28 (64)	80 (48)
	IV	1 (7)	13 (32)	2 (6)	0 (0)	14 (32)	30 (18)
	Missing	10 (67)	0 (0)	0 (0)	32 (97)	0 (0)	42 (25)

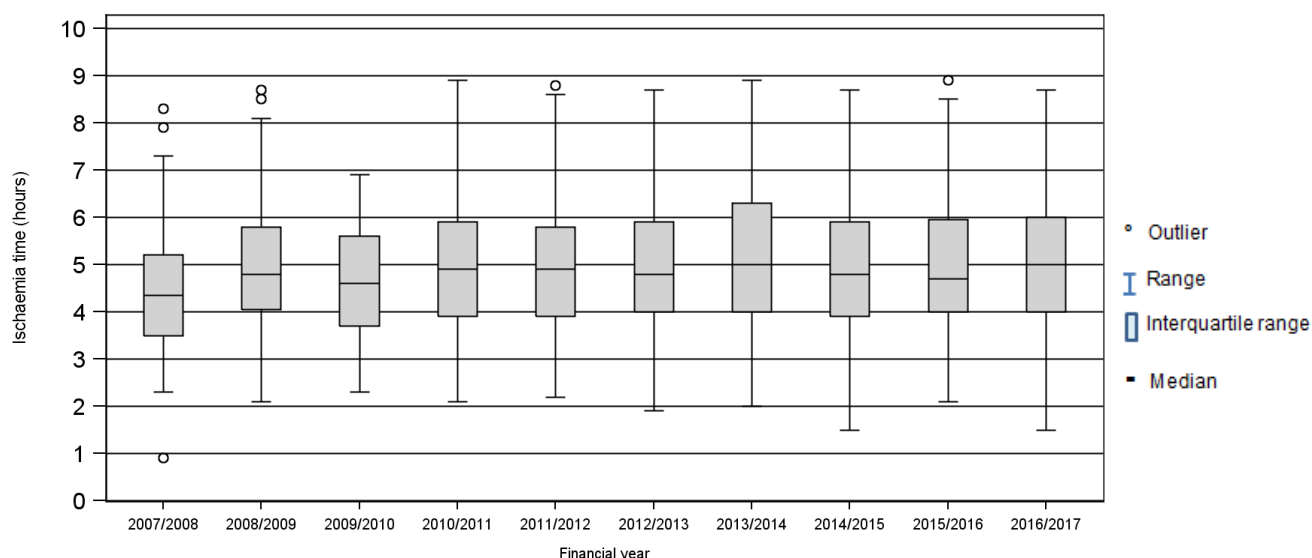
<b>Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2016 to 31 March 2017, by centre</b>							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	<b>TOTAL N (%)</b>
Recipient in hospital pre-transplant	No	11 (73)	28 (68)	31 (91)	33 (100)	39 (89)	<b>142 (85)</b>
	Yes	4 (27)	13 (32)	3 (9)	0 (0)	5 (11)	<b>25 (15)</b>
If in hospital, recipient on ventilator	No	3 (75)	6 (46)	2 (67)	0	5 (100)	<b>16 (64)</b>
	Yes	0 (0)	7 (54)	1 (33)	0	0 (0)	<b>8 (32)</b>
If in hospital, recipient on inotropes	No	1 (25)	9 (69)	3 (100)	0	5 (100)	<b>18 (72)</b>
	Yes	0 (0)	4 (31)	0 (0)	0	0 (0)	<b>4 (16)</b>
	Missing	3 (75)	0 (0)	0 (0)	0	0 (0)	<b>3 (12)</b>
If in hospital, recipient on ECMO	No	1 (25)	6 (46)	3 (100)	0	4 (80)	<b>14 (56)</b>
	Yes	0 (0)	7 (54)	0 (0)	0	1 (20)	<b>8 (32)</b>
	Missing	3 (75)	0 (0)	0 (0)	0	0 (0)	<b>3 (12)</b>
Recipient CMV status	No	9 (60)	25 (61)	16 (47)	18 (55)	22 (50)	<b>90 (54)</b>
	Yes	6 (40)	16 (39)	17 (50)	15 (45)	20 (45)	<b>74 (44)</b>
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	2 (5)	<b>3 (2)</b>
Recipient HCV status	No	15 (100)	41 (100)	34 (100)	33 (100)	43 (98)	<b>166 (99)</b>
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	<b>1 (1)</b>
Recipient HBV status	No	15 (100)	41 (100)	34 (100)	33 (100)	43 (98)	<b>166 (99)</b>
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	<b>1 (1)</b>
Recipient HIV status	No	15 (100)	41 (100)	34 (100)	33 (100)	42 (95)	<b>165 (99)</b>
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (5)	<b>2 (1)</b>
Recipient serum creatinine (umol/l)	Median ( <a href="#">IQR</a> )	66 (55, 79)	61 (48, 71)	68 (60, 73)	75 (60, 104)	64 (50, 74)	<b>66 (54, 77)</b>
	Missing	0	1	0	2	0	<b>3</b>
Donor sex	Male	6 (40)	21 (51)	16 (47)	20 (61)	21 (48)	<b>84 (50)</b>
	Female	9 (60)	20 (49)	18 (53)	13 (39)	23 (52)	<b>83 (50)</b>
Donor ethnicity	White	14 (93)	39 (95)	30 (88)	30 (91)	36 (82)	<b>149 (89)</b>
	Non-white	1 (7)	2 (5)	3 (9)	2 (6)	6 (14)	<b>14 (8)</b>
	Missing	0 (0)	0 (0)	1 (3)	1 (3)	2 (5)	<b>4 (2)</b>
Donor age (years)	Median ( <a href="#">IQR</a> )	46 (25, 54)	46 (31, 53)	46 (33, 55)	50 (30, 54)	47 (31, 56)	<b>46 (31, 54)</b>
	Missing	0	0	0	0	0	<b>0</b>
Donor BMI (kg/m <sup>2</sup> )	Median ( <a href="#">IQR</a> )	23 (21, 30)	25 (23, 27)	25 (23, 27)	25 (23, 28)	25 (23, 27)	<b>25 (23, 27)</b>
	Missing	0	0	0	0	0	<b>0</b>

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2016 to 31 March 2017, by centre							
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor cause of death	CVA	12 (80)	33 (80)	30 (88)	28 (85)	40 (91)	143 (86)
	Trauma	1 (7)	3 (7)	1 (3)	1 (3)	0 (0)	6 (4)
	Others	2 (13)	5 (12)	3 (9)	4 (12)	4 (9)	18 (11)
Donor hypotension	No	5 (33)	30 (73)	29 (85)	18 (55)	40 (91)	122 (73)
	Yes	1 (7)	7 (17)	5 (15)	15 (45)	4 (9)	32 (19)
	Missing	9 (60)	4 (10)	0 (0)	0 (0)	0 (0)	13 (8)
Donor past cardiothoracic disease	No	15 (100)	36 (88)	34 (100)	31 (94)	41 (93)	157 (94)
	Yes	0 (0)	2 (5)	0 (0)	1 (3)	2 (5)	5 (3)
	Missing	0 (0)	3 (7)	0 (0)	1 (3)	1 (2)	5 (3)
Donor past hypertension	No	12 (80)	31 (76)	31 (91)	28 (85)	35 (80)	137 (82)
	Yes	2 (13)	10 (24)	3 (9)	5 (15)	9 (20)	29 (17)
	Missing	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Donor past tumour	No	15 (100)	39 (95)	33 (97)	32 (97)	42 (95)	161 (96)
	Yes	0 (0)	2 (5)	1 (3)	1 (3)	2 (5)	6 (4)
Donor past smoker	No	7 (47)	24 (59)	18 (53)	15 (45)	25 (57)	89 (53)
	Yes	8 (53)	17 (41)	16 (47)	18 (55)	19 (43)	78 (47)
Total ischaemia time (hours)	Median (IQR)	5.4 (4.4, 6.4)	5.8 (5.0, 6.7)	4.3 (3.4, 4.8)	6.0 (5.0, 6.7)	4.9 (3.9, 5.5)	5.1 (4.2, 6.0)
	Missing	0	3	0	4	0	7

### 11.3 Total ischaemia time, 1 April 2007 – 31 March 2017

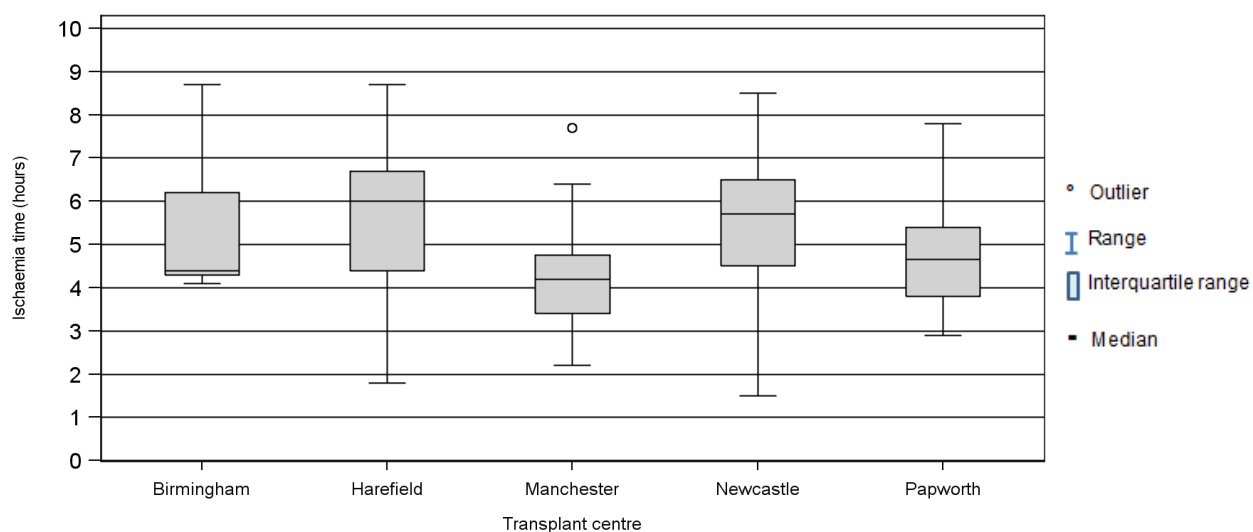
**Figure 11.7** shows [boxplots](#) of the total ischaemia time for [DBD](#) donor lungs transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. In cases where 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 4.4 hours to 5.0 hours over the last decade.

**Figure 11.7 Boxplots of total ischaemia time in adult DBD donor lung transplants, by financial year, 1 April 2007 to 31 March 2017**

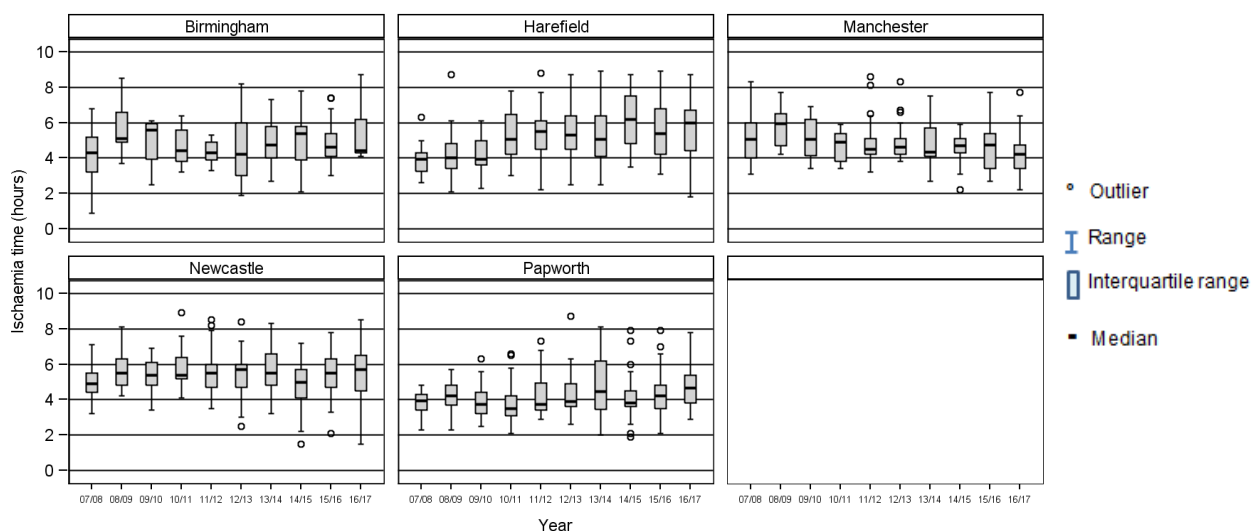


**Figure 11.8** and **Figure 11.9** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2016/2017) and over the last 10 years, respectively. Ischaemia times were longest in 2016/2017 for lungs transplanted by Harefield and Newcastle and shortest for Manchester. This may be due to the geographical positions of Harefield and Newcastle as the most northern and southern lung transplant centres, respectively. Harefield and Newcastle have also seen the most noticeable increases in ischaemia times over the decade, whilst other centres have seen a general decrease (Manchester) or no clear upward or downward trend (Papworth and Birmingham).

**Figure 11.8 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2016 to 31 March 2017**



**Figure 11.9 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2007 to 31 March 2017**



# **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 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 2012 to 31 March 2016 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2008 to 31 March 2012. DCD lung transplants are included. [Survival rates](#) are presented by transplant centre in **Tables 12.1-12.3** and **Figures 12.1-12.3** as well as disease group in **Tables 12.4-12.6**.

## 12.1 Survival by centre

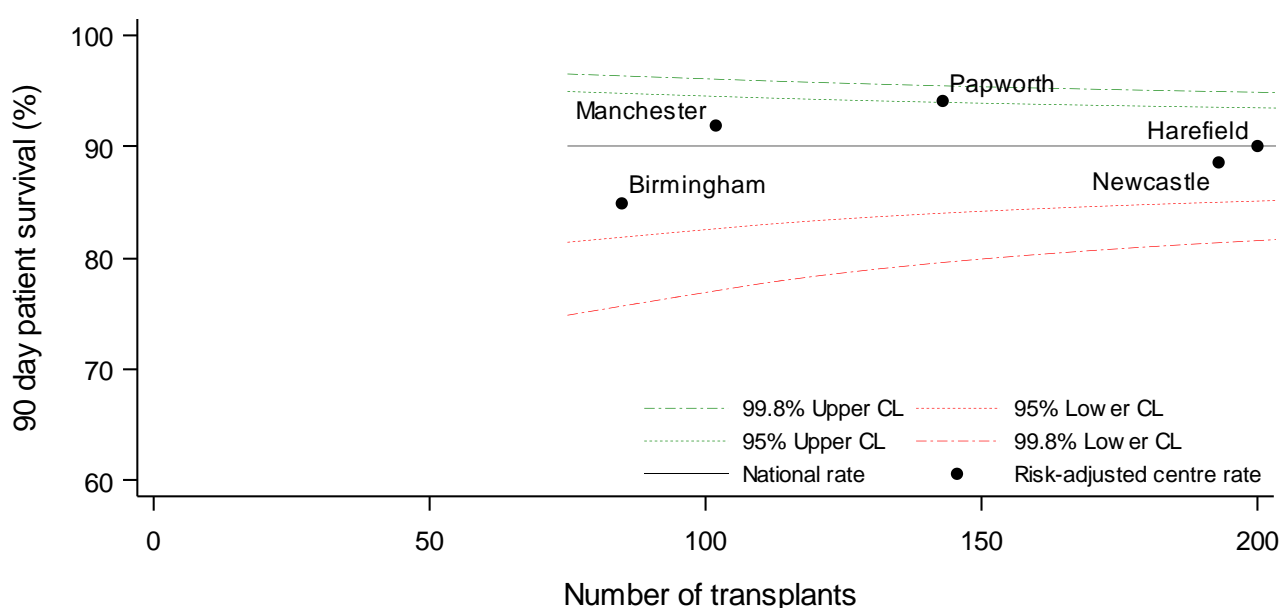
**Table 12.1** and **Figure 12.1** show the 90-day post-transplant [unadjusted](#) and [risk-adjusted](#) patient survival rate for each centre and nationally for the 723 first adult lung only transplants in the period 1 April 2012 to 31 March 2016. All of the centres, apart from Papworth, were statistically consistent with the national rate of survival which was 90.0%. The 90-day survival rate for Papworth lies between the 95% and 99.8% [confidence limits](#) indicating that their [risk-adjusted](#) post-transplant survival rate may be significantly higher than the national rate.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre, 1 April 2012 to 31 March 2016					
Centre	Number of transplants	% 90 day survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	85	82.4	(72.4 – 89.0)	84.9	(74.9 - 90.9)
Harefield	200	92.0	(87.3 – 95.0)	90.0	(83.6 - 93.9)
Manchester	102	91.2	(83.7 - 95.3)	91.9	(84.4 - 95.8)
Newcastle	193	88.1	(82.6 - 91.9)	88.6	(82.8 - 92.4)
Papworth	143	93.7	(88.3 - 96.7)	94.1	(88.6 - 96.9)
<b>UK</b>	<b>723</b>	<b>90.0</b>	<b>(87.6 – 92.0)</b>		

	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 98.8% confidence limit

**Figure 12.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2012 to 31 March 2016**



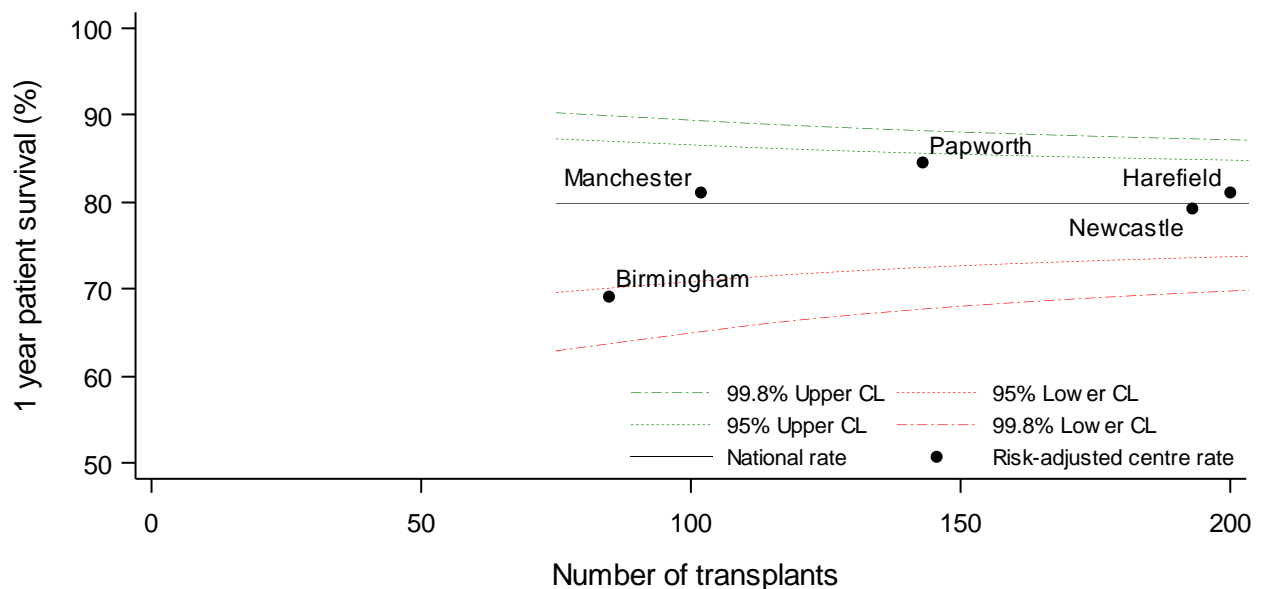
**Table 12.2** and **Figure 12.2** show the 1-year post-transplant [unadjusted](#) and [risk-adjusted](#) patient [survival rates](#) for each centre and nationally for the 723 first adult lung only transplants in the period 1 April 2012 to 31 March 2016. The national rate of survival was 79.8%. None of the centres were statistically significantly different to the national rate, as their rates lie with the funnel, except Birmingham whose rate lies between the lower 95% and 99.8% [confidence limits](#) providing some evidence of a significantly low 1-year survival rate.

Table 12.2 1 year patient survival rates after first adult lung transplant, by centre, 1 April 2012 to 31 March 2016					
Centre	Number of transplants	% 1 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	85	67.1	(56.0 - 75.9)	69.3	(55.5 - 78.8)
Harefield	200	83.5	(77.6 - 88.0)	81.1	(73.5 - 86.6)
Manchester	102	80.3	(71.2 - 86.8)	81.1	(70.8 - 87.8)
Newcastle	193	79.2	(72.7 - 84.3)	79.2	(71.7 - 84.7)
Papworth	143	83.2	(76.0 - 88.4)	84.5	(76.9 - 89.6)
<b>UK</b>	<b>723</b>	<b>79.8</b>	<b>(76.7 - 82.6)</b>		

	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 98.8% confidence limit

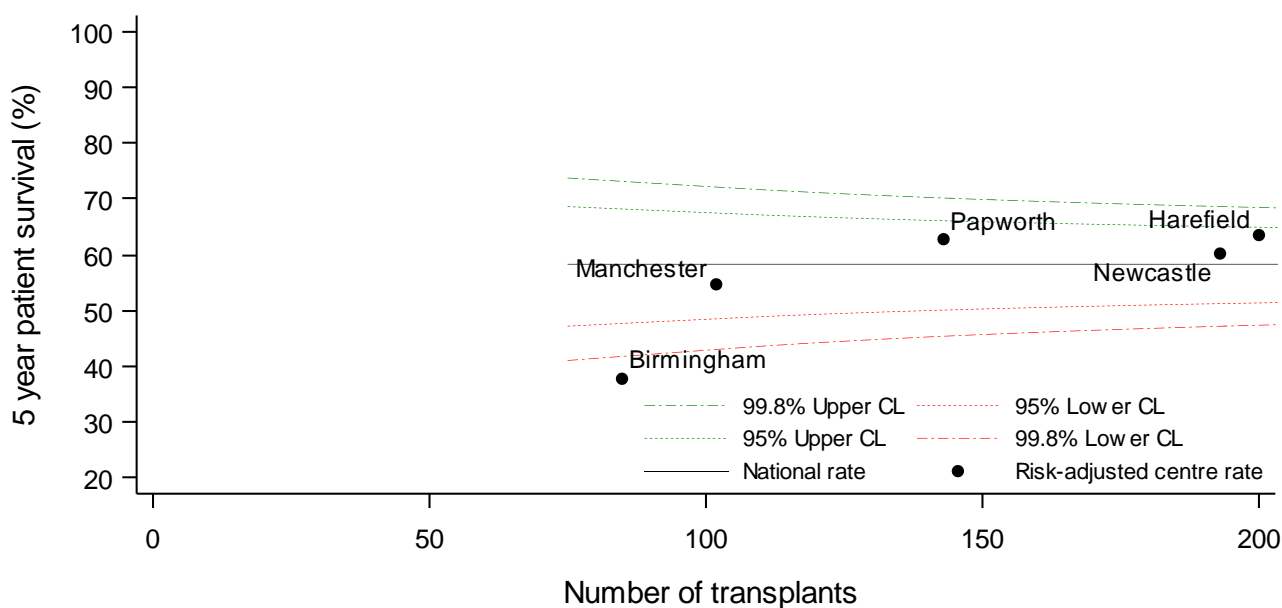
**Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2012 to 31 March 2016**



**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 597 first adult lung only transplants in the period 1 April 2008 to 31 March 2012. The national rate of survival was 58.3%. The rates for all centres except Birmingham lie with the funnel. The [risk-adjusted](#) 5-year survival rate for Birmingham was significantly low compared to the national rate.

Table 12.3 5 year patient survival rates after first adult lung transplant, by centre, 1 April 2008 to 31 March 2012					
Centre	Number of transplants	% 5 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Birmingham	42	51.5	(35.3 - 65.5)	37.8	(14.9 - 54.6)
Harefield	175	61.5	(53.8 - 68.3)	63.5	(52.6 - 71.9)
Manchester	91	48.3	(37.7 - 58.1)	54.5	(38.0 - 66.7)
Newcastle	173	63.1	(55.1 - 70)	60.1	(48.1 - 69.3)
Papworth	116	57.8	(48.2 - 66.1)	62.7	(50.5 - 71.9)
<b>UK</b>	<b>597</b>	<b>58.3</b>	<b>(54.2 - 62.2)</b>		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> <div>Centre has reached the lower 99.8% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> <div>Centre has reached the lower 95% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> <div>Centre has reached the upper 95% confidence limit</div> </div> <div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> <div>Centre has reached the upper 99.8% confidence limit</div> </div>					

**Figure 12.3** Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2008 to 31 March 2012



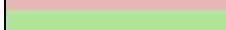



## 12.2 Survival by disease group

Tables 12.4, 12.5 and 12.6 present [unadjusted](#) and [risk-adjusted survival rates](#) by primary disease group, at 30 days, 1 year and 5 years post-transplant, respectively. The [risk factors](#) used to produce the [risk-adjusted survival rates](#) are listed in **Appendix A3.2**, except centre was used in place of disease group. There was some evidence that the 5-year [risk-adjusted](#) survival rate for the “other” disease group was significantly lower than the national rate of survival.



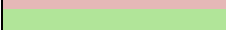

**Table 12.4 90 day patient survival rates after first adult lung transplant, by disease group, 1 April 2012 to 31 March 2016**

Centre	Number of transplants	% 1 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Cystic fibrosis and bronchiectasis	213	92.5	(88.0 - 95.3)	91.7	(86.5 - 94.9)
COPD and emphysema	224	92.9	(88.6 - 95.6)	91.2	(85.6 - 94.6)
Fibrosing lung disease	158	87.3	(81.1 - 91.6)	90.7	(85.6 - 94.0)
Other	128	84.4	(76.8 - 89.6)	84.9	(76.6 - 90.3)
<b>UK</b>	<b>723</b>	<b>90.0</b>	<b>(87.6 - 92.0)</b>		

 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 98.8% confidence limit

**Table 12.5 1 year patient survival rates after first adult lung transplant, by disease group, 1 April 2012 to 31 March 2016**

Centre	Number of transplants	% 1 year survival (95% CI)			
		<a href="#">Unadjusted</a>		<a href="#">Risk-adjusted</a>	
Cystic fibrosis and bronchiectasis	213	81.1	(75.2 - 85.8)	80.5	(73.4 - 85.7)
COPD and emphysema	224	85.2	(79.8 - 89.2)	82.7	(75.7 - 87.7)
Fibrosing lung disease	158	75.2	(67.7 - 81.2)	79.7	(72.2 - 85.2)
Other	128	74.2	(65.7 - 80.9)	74.9	(64.8 - 82.2)
<b>UK</b>	<b>723</b>	<b>79.8</b>	<b>(76.7 - 82.6)</b>		

 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 98.8% confidence limit

**Table 12.6 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2008 to 31 March 2012**

Centre	Number of transplants	% 1 year survival (95% CI)			
			<u>Unadjusted</u>	<u>Risk-adjusted</u>	
Cystic fibrosis and bronchiectasis	177	64.1	(56.2 - 70.8)	62.7	(52.1 - 71.0)
COPD and emphysema	212	60.4	(53.5 - 66.7)	57.1	(45.9 - 65.9)
Fibrosing lung disease	104	47.5	(37.6 - 56.7)	61.8	(50.4 - 70.6)
Other	104	55.8	(45.7 - 64.7)	47.3	(30.5 - 60.1)
<b>UK</b>	<b>597</b>	<b>58.3</b>	<b>(54.2 - 62.2)</b>		
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: red; margin-right: 5px;"></div> <div>Centre has reached the lower 99.8% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #f08080; margin-right: 5px;"></div> <div>Centre has reached the lower 95% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: #90ee90; margin-right: 5px;"></div> <div>Centre has reached the upper 95% confidence limit</div> </div>					
<div style="display: flex; align-items: center;"> <div style="width: 20px; height: 10px; background-color: green; margin-right: 5px;"></div> <div>Centre has reached the upper 98.8% confidence limit</div> </div>					

# **ADULT LUNG TRANSPLANTATION**

## **Survival from Listing**



### 13. Survival from Listing

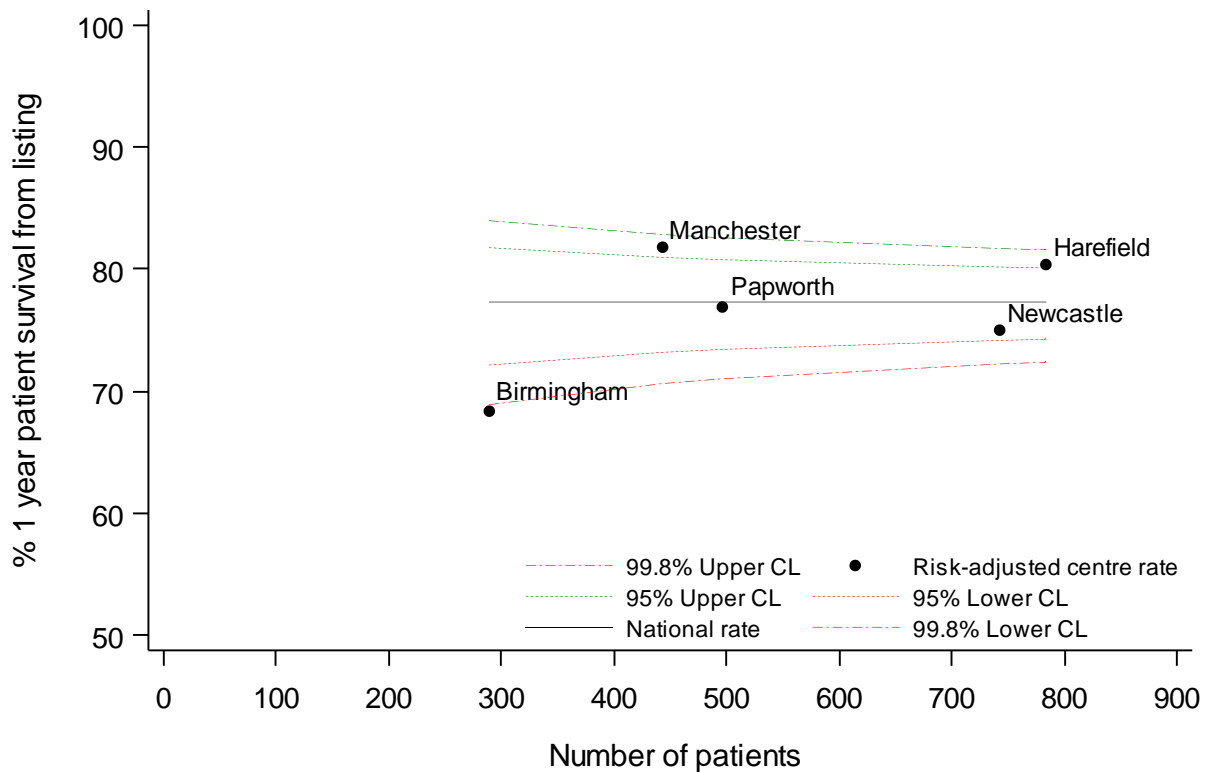
Survival from listing was analysed for patients 18 years or older registered for the first time for a lung transplant between 1 January 2005 and 31 December 2016. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, 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.

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

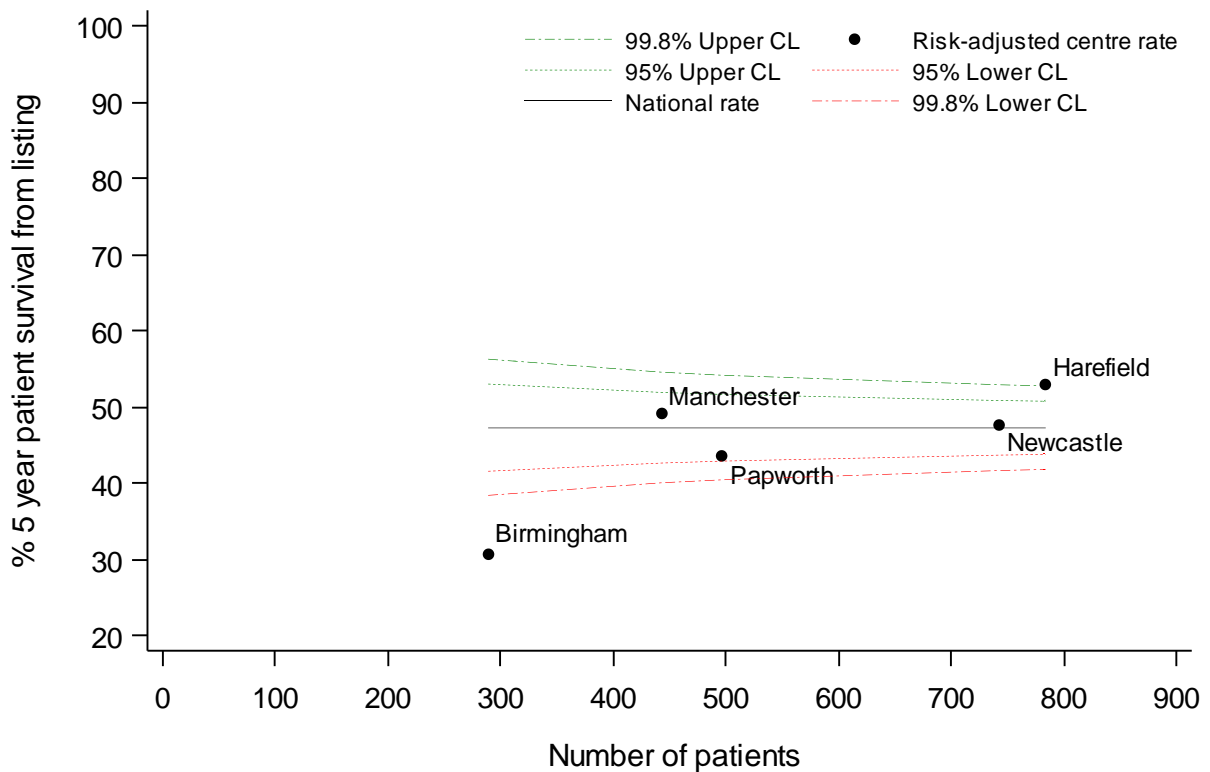
<b>Table 13.1 Risk-adjusted 1, 5 and 10 year patient survival rates from listing for first lung only transplant in patients registered between 1 January 2005 and 31 December 2016</b>						
Centre	One year		Five year		Ten year	
	No. patients	Survival rate (%)	No. patients	Survival rate (%)	No. patients	Survival rate (%)
Birmingham	289	(68.4)	289	(30.8)	289	(9.5)
Harefield	784	(80.3)	784	(53.0)	784	(37.8)
Manchester	443	(81.8)	443	(49.3)	443	(32.9)
Newcastle	743	(75.0)	743	(47.7)	743	(33.1)
Papworth	497	(77.0)	497	(43.7)	497	(26.0)
<b>UK</b>	<b>2756</b>	<b>(77.3)</b>	<b>2756</b>	<b>(47.2)</b>	<b>2756</b>	<b>(31.1)</b>
<div> <div></div> Centre has reached the lower 99.8% confidence limit         </div> <div> <div></div> Centre has reached the lower 95% confidence limit         </div> <div> <div></div> Centre has reached the upper 95% confidence limit         </div> <div> <div></div> Centre has reached the upper 98.8% confidence limit         </div>						



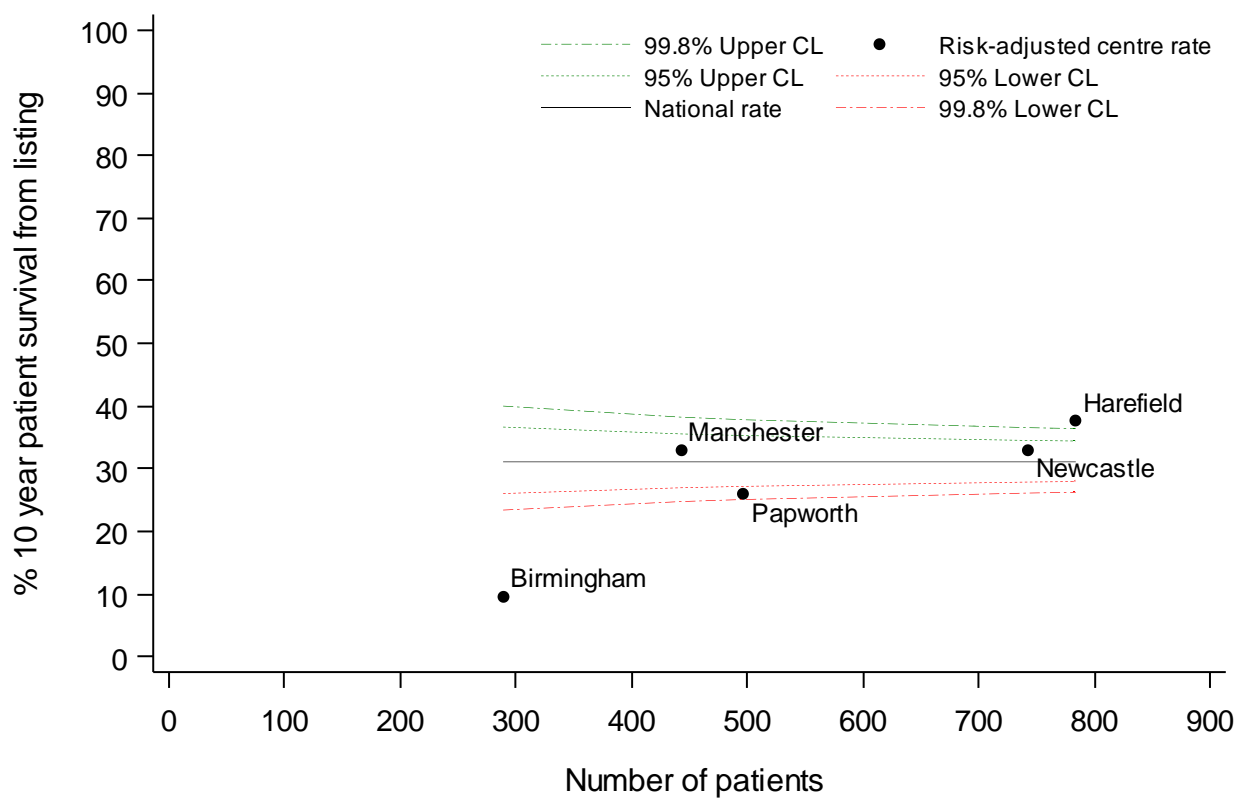
**Figure 13.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2005 – 31 December 2016**



**Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2005 – 31 December 2016**



**Figure 13.3 Risk-adjusted ten year patient survival rates from listing by centre,  
1 January 2005 – 31 December 2016**



# **ADULT LUNG TRANSPLANTATION**

## **Form Return Rates**



#### 14. Adult lung form return rates, 1 January – 31 December 2016

Form return rates are reported in **Table 14.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (more than 2 years). These include all adult lung and heart-lung transplants between 1 January and 31 December 2016 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. All form return rates are in excess of 97% for this period.

**Table 14.1 Form return rates for adult lung transplants, 1 January 2016 to 31 December 2016**

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	19	100	20	100	18	100	90	100
Harefield, Harefield Hospital	40	100	37	100	48	100	382	97
Manchester, Wythenshawe Hospital	30	100	26	100	21	100	153	99
Newcastle, Freeman Hospital	32	100	34	100	40	100	332	100
Papworth, Papworth Hospital	39	100	36	100	37	100	271	100
Sheffield, Northern General Hospital	-	-	-	-	-	-	5	100
<b>Overall</b>	<b>160</b>	<b>100</b>	<b>153</b>	<b>100</b>	<b>164</b>	<b>100</b>	<b>1233</b>	<b>99</b>

# **PAEDIATRIC HEART TRANSPLANTATION**

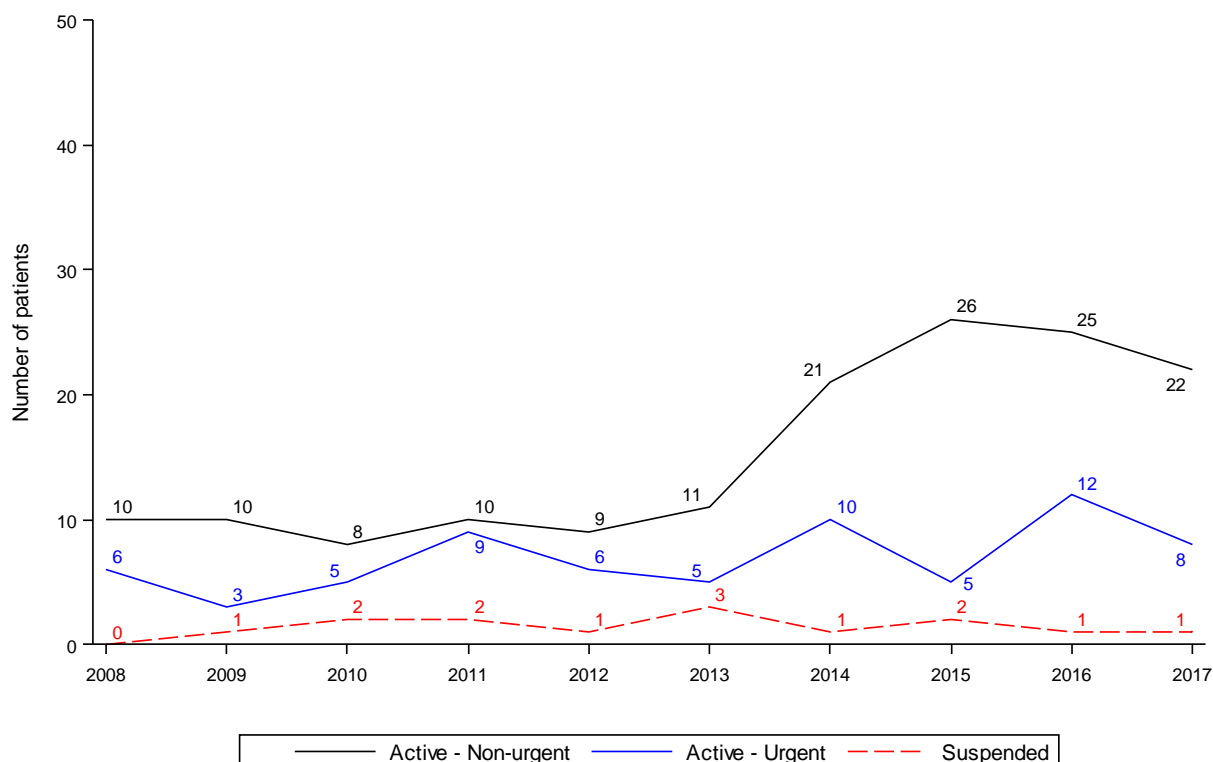
## **Transplant List**



## 15.1 Paediatric heart only transplant list as at 31 March, 2008 – 2017

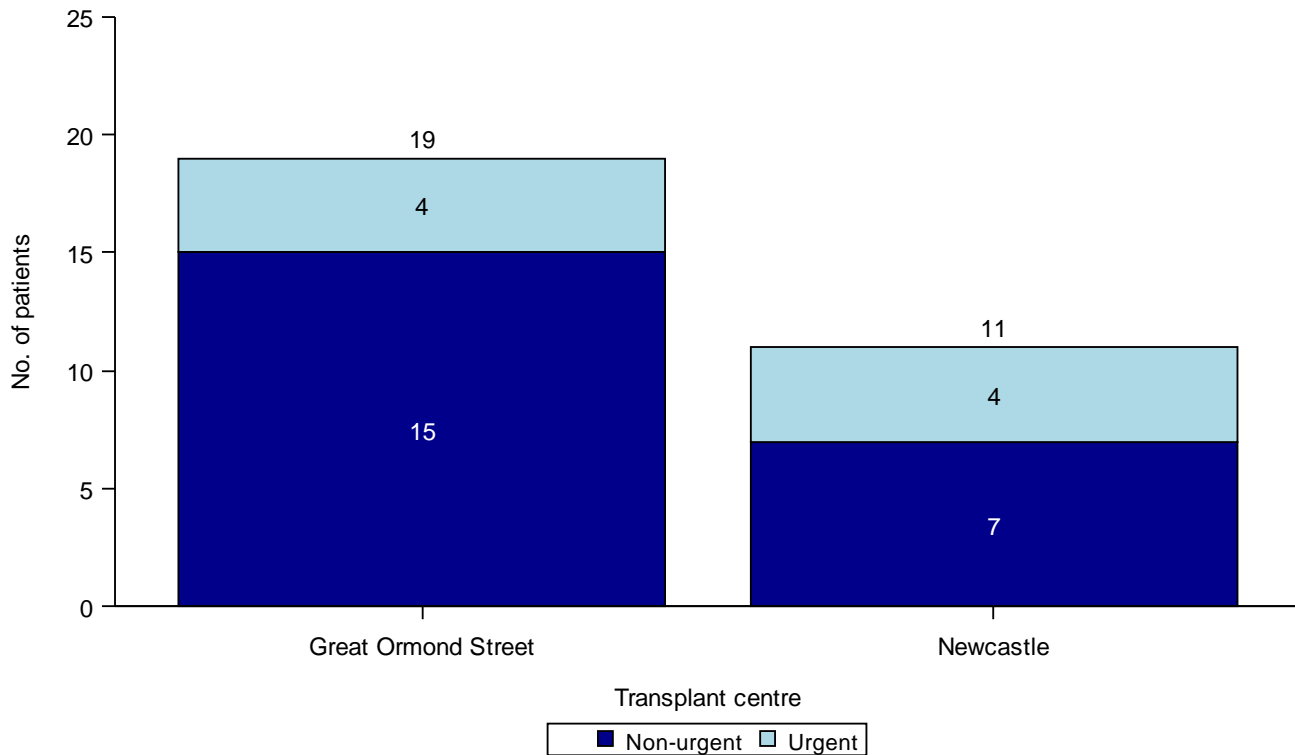
**Figure 15.1** shows the number of paediatric patients on the heart transplant list at 31 March each year between 2008 and 2017 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased significantly in 2014 to 21 and then increased further to 26 in 2015. On 31 March 2017 it was 22. The number of patients on the urgent transplant list has varied between 3 in 2009 and 12 in 2016. On 31 March 2017 it was 8. The number of patients on the urgent transplant list has varied between 3 in 2009 and 12 in 2016. On 31 March 2017 it was 8.

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



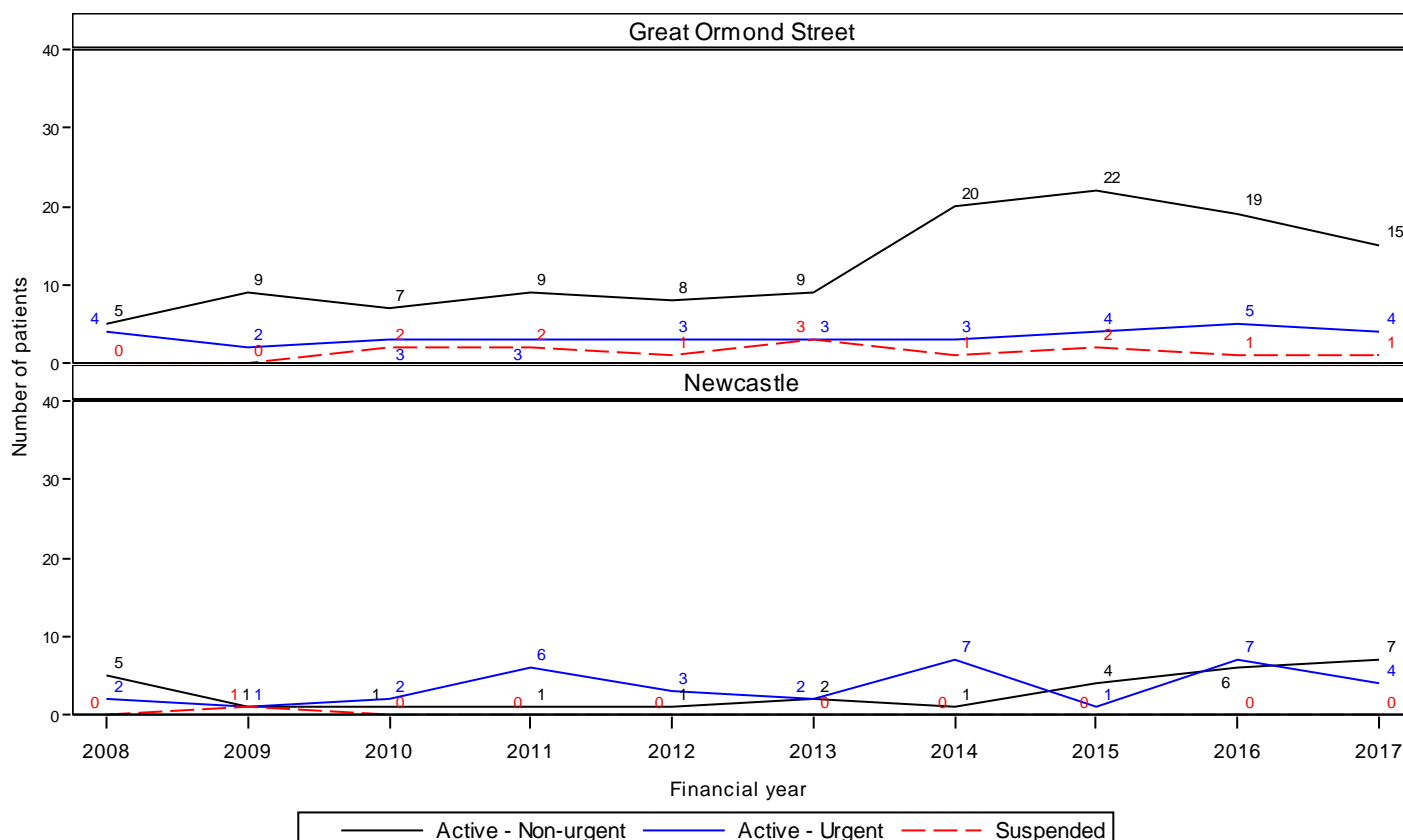
**Figure 15.2** shows the number of paediatric patients on the [active heart transplant list](#) at 31 March 2017 by centre. In total, there were 30 paediatric patients. Great Ormond Street Hospital had the largest overall number on the transplant list but both centres had the same number of urgent patients.

**Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2017, by centre**



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

**Figure 15.3 Number of paediatric patients on the heart transplant list at 31 March each year for the last 10 years, by centre**





## 15.2 Demographic characteristics, 1 April 2016 – 31 March 2017

There were 48 paediatric patient registrations onto the heart transplant list between 1 April 2016 and 31 March 2017. Demographic characteristics of these patients are shown by centre and overall in **Table 15.1**. Nationally, 56% of the patients were male and the [median](#) age was 3 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 2016 and 31 March 2017, by centre**

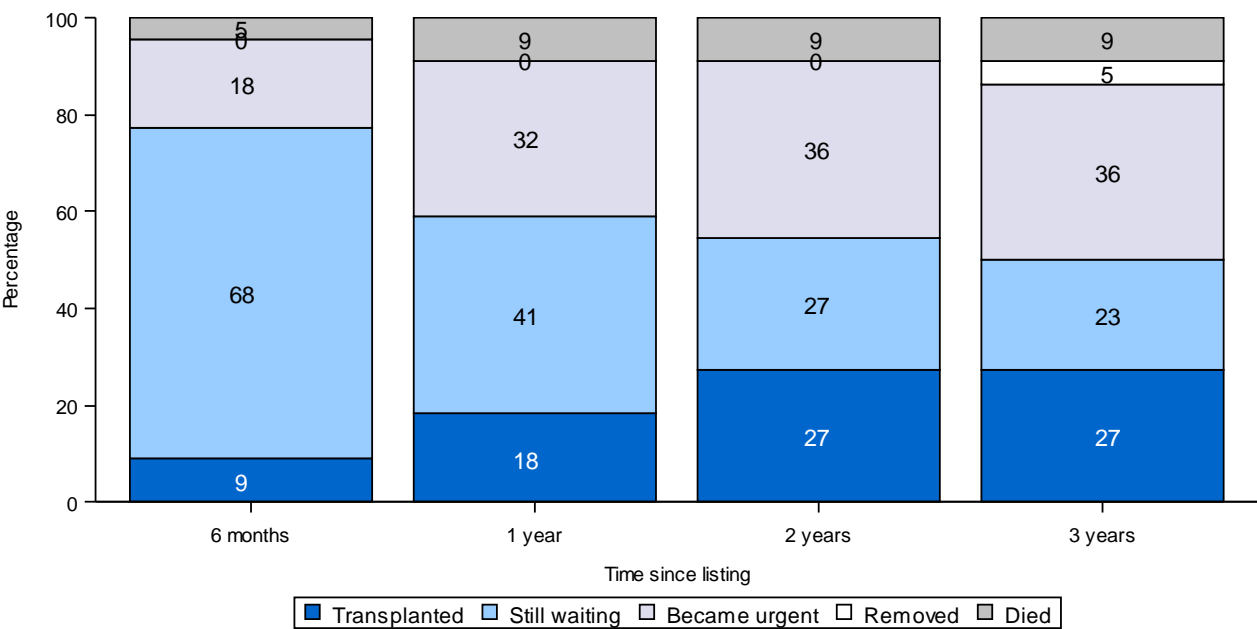
		Great Ormond Street N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		21 (100)	27 (100)	<b>48 (100)</b>
Highest urgency during registration	Non-urgent	7 (33)	6 (22)	<b>13 (27)</b>
	Urgent	14 (67)	21 (78)	<b>35 (73)</b>
Recipient sex	Male	11 (52)	16 (59)	<b>27 (56)</b>
	Female	10 (48)	11 (41)	<b>21 (44)</b>
Recipient ethnicity	White	13 (62)	21 (78)	<b>34 (71)</b>
	Non-white	8 (38)	6 (22)	<b>14 (29)</b>
Recipient age (years)	Median ( <a href="#">IQR</a> )	2 (0, 4)	4 (1, 10)	<b>3 (1, 8)</b>
	Missing	0	0	<b>0</b>
Primary Disease	Coronary heart disease	0 (0)	1 (4)	<b>1 (2)</b>
	Cardiomyopathy	9 (43)	10 (37)	<b>19 (40)</b>
	Congenital heart disease	3 (14)	13 (48)	<b>16 (33)</b>
	Graft failure/Rejection	0 (0)	1 (4)	<b>1 (2)</b>
	Others	9 (43)	2 (7)	<b>11 (23)</b>
Previous open heart surgery	None	16 (76)	7 (26)	<b>23 (48)</b>
	One	3 (14)	9 (33)	<b>12 (25)</b>
	More than one	2 (10)	11 (41)	<b>13 (27)</b>
Previous thoracotomy	No	21 (100)	26 (96)	<b>47 (98)</b>
	Missing	0 (0)	1 (4)	<b>1 (2)</b>
Serum Bilirubin (umol/l)	Median ( <a href="#">IQR</a> )	10 (4, 22)	13 (5, 21)	<b>13 (5, 21)</b>
	Missing	8	0	<b>8</b>
Serum Creatinine (umol/l)	Median ( <a href="#">IQR</a> )	30 (26, 38)	38 (28, 57)	<b>32 (28, 53)</b>
	Missing	3	0	<b>3</b>

15.3 Post-registration outcomes, 1 April 2013 – 31 March 2014

The transplant list outcomes of paediatric patients listed for a non-urgent heart transplant between 1 April 2013 and 31 March 2014 are summarised in **Figure 15.4**. The same information is presented in **Figure 15.5** for those listed for an urgent heart transplant between 1 April 2013 and 31 March 2014 (including those previously on the non-urgent list). These charts show the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one, two and three years after joining the list.

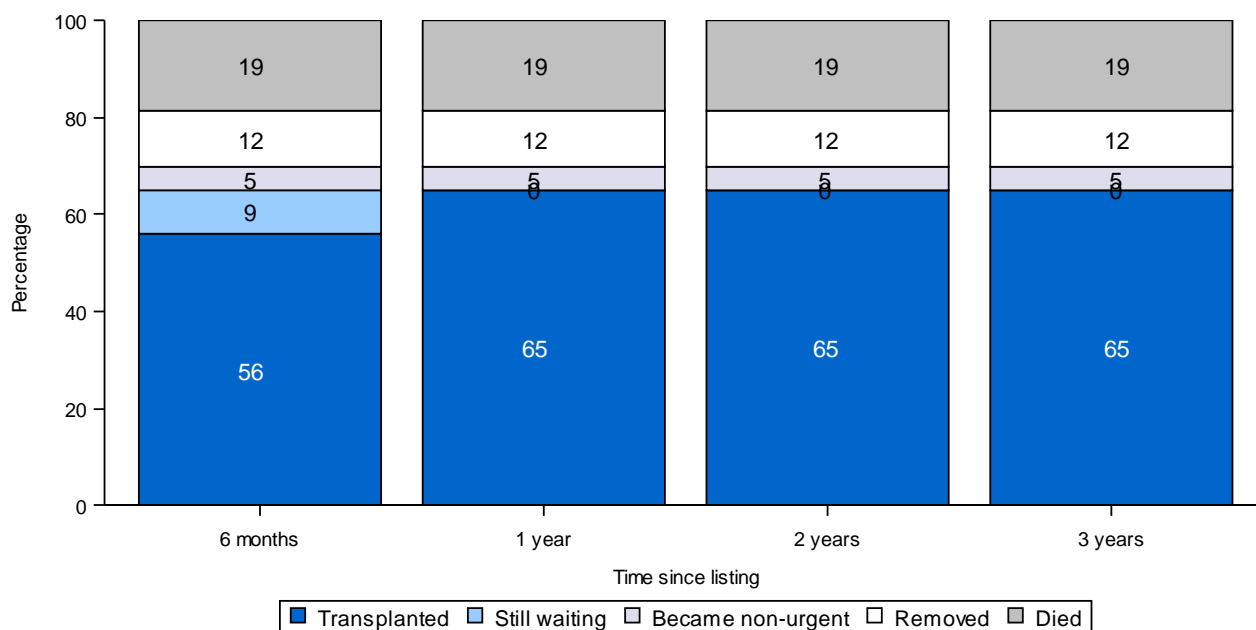
Within 6 month of listing 9% of non-urgent heart patients had been transplanted and 5% had died, while after three years 27% had been transplanted and 9% had died. Also, 18% had been moved to the urgent heart list within 6 months, reaching 36% by three years.

**Figure 15.4 Post-registration outcome for 22 new non-urgent heart only registrations made in the UK, 1 April 2013 to 31 March 2014**



In comparison to **Figure 15.4**, **Figure 15.5** shows that within six months of listing, 56% of urgent heart patients were transplanted and 19% had died. Between 6 months and 1 year a further 9% had been transplanted, but all other patients had already reached an outcome. Removals from the list were mainly due to deteriorating condition.

**Figure 15.5 Post-registration outcome for 43 new urgent heart only registrations made in the UK, 1 April 2013 to 31 March 2014**



## 15.4 Median waiting time to transplant, 1 April 2011 - 31 March 2014

**Table 15.2** shows the [median](#) waiting time to heart transplant from listing for paediatric patients registered between 1 April 2011 and 31 March 2014. This is estimated using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. The analysis separates never urgent registrations from ever urgent registrations where only urgent waiting time is counted for any patients who changed between the urgent and non-urgent lists. Any suspended time is discounted. The national median waiting time to paediatric heart transplant is 463 days for non-urgent registrations and 70 days for urgent registrations.

The [median](#) waiting time to heart transplant for paediatric patients is also considered by blood group. This is shown in **Table 15.3** for ever urgent patients only due to small numbers of never urgent patients. Blood group A patients had the highest waiting time, but this is not a significantly longer wait compared to the other blood groups (log-rank  $p=0.7$ ).

<b>Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the transplant list, by urgency and centre, 1 April 2011 to 31 March 2014</b>			
Transplant centre	Number of patients registered	<a href="#">Median</a>	Waiting time (days) 95% <a href="#">Confidence interval</a>
<b>Never urgent</b>			
Great Ormond Street	25	463	0 - 1448
Newcastle <sup>1</sup>	2	-	-
<b>UK</b>	<b>27</b>	<b>463</b>	<b>0 - 1361</b>
<b>Ever urgent patients (urgent time only)</b>			
Great Ormond Street	55	72	44 - 100
Newcastle	63	60	20 - 100
<b>UK</b>	<b>118</b>	<b>70</b>	<b>41 - 99</b>

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

<b>Table 15.3 Median active waiting time to heart transplant for paediatric patients registered on the urgent transplant list, by blood group, 1 April 2011 to 31 March 2014</b>			
Transplant centre	Number of patients registered	<a href="#">Median</a>	Waiting time (days) 95% <a href="#">Confidence interval</a>
A	36	97	29 - 165
AB <sup>1</sup>	9	-	-
B	24	66	21 - 111
O	49	70	35 - 105
<b>UK</b>	<b>118</b>	<b>70</b>	<b>41 - 99</b>

<sup>1</sup> 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 2014 and 31 March 2017. This only considers offers of UK DBD donor hearts that were eventually transplanted and excludes fast track offers. Hearts offered as part of a cardiac block offer are considered, as are all urgent and non-urgent patient offers. Offers to adult patients at Newcastle are excluded. The number of offers received per year has varied considerably which is due to a number of factors including how many urgent patients each centre had on their list during the year. Generally, Newcastle declined fewer offers than Great Ormond Street Hospital.

<b>Table 16.1 UK paediatric DBD donor heart offer decline rates by transplant centre and year, 1 April 2014 to 31 March 2017</b>								
Centre	2014/15		2015/16		2016/17		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Great Ormond Street	20	(80.0)	51	(88.2)	7	(57.1)	78	(83.3)
Newcastle	9	(11.1)	49	(85.7)	18	(55.6)	76	(69.7)
<b>UK</b>	<b>29</b>	<b>(58.6)</b>	<b>100</b>	<b>(87.0)</b>	<b>25</b>	<b>(56.0)</b>	<b>154</b>	<b>(76.6)</b>

# **PAEDIATRIC HEART TRANSPLANTATION**

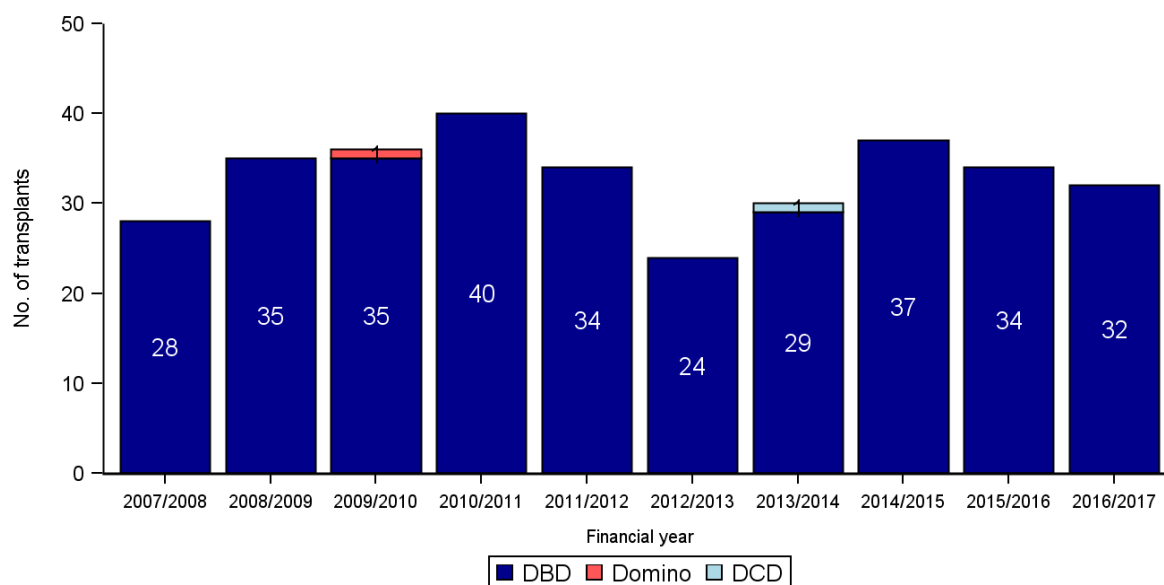
## **Transplants**



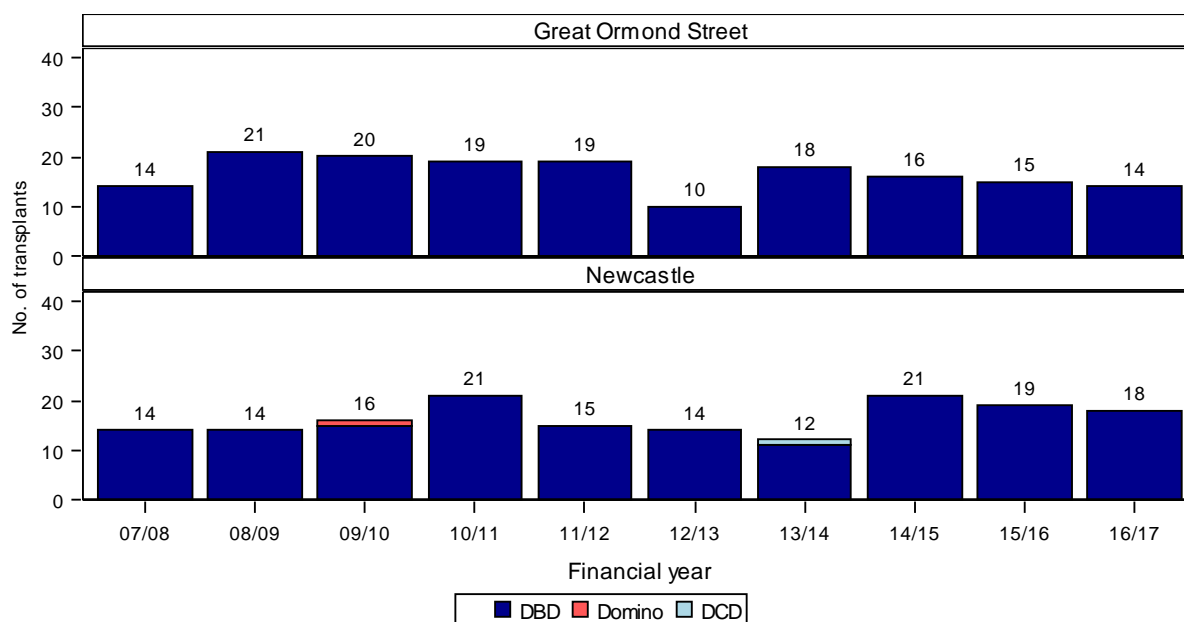
## 17.1 Paediatric heart transplants, 1 April 2007 – 31 March 2017

**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. Last year it was 32, comprising 18 at Newcastle and 14 at Great Ormond Street Hospital; all of which were from DBD donors.

**Figure 17.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2007 to 31 March 2017**



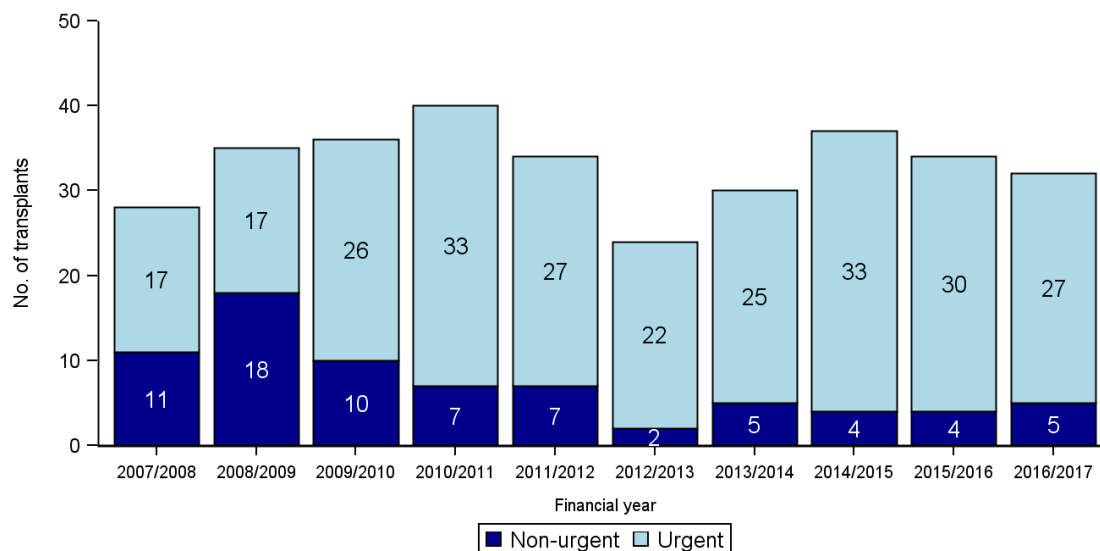
**Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2007 to 31 March 2017**



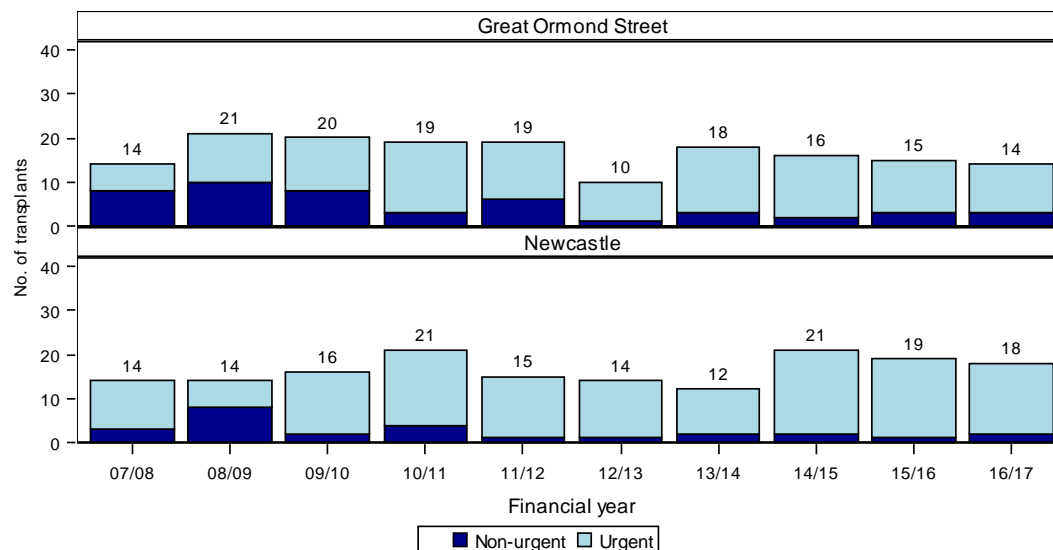


**Figure 17.3** and **17.4** show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time the proportion of urgent transplants has increased; from 61% in 2007/2008 to 84% in 2016/2017. Last year's activity is shown by centre and urgency status in **Figure 17.5**.

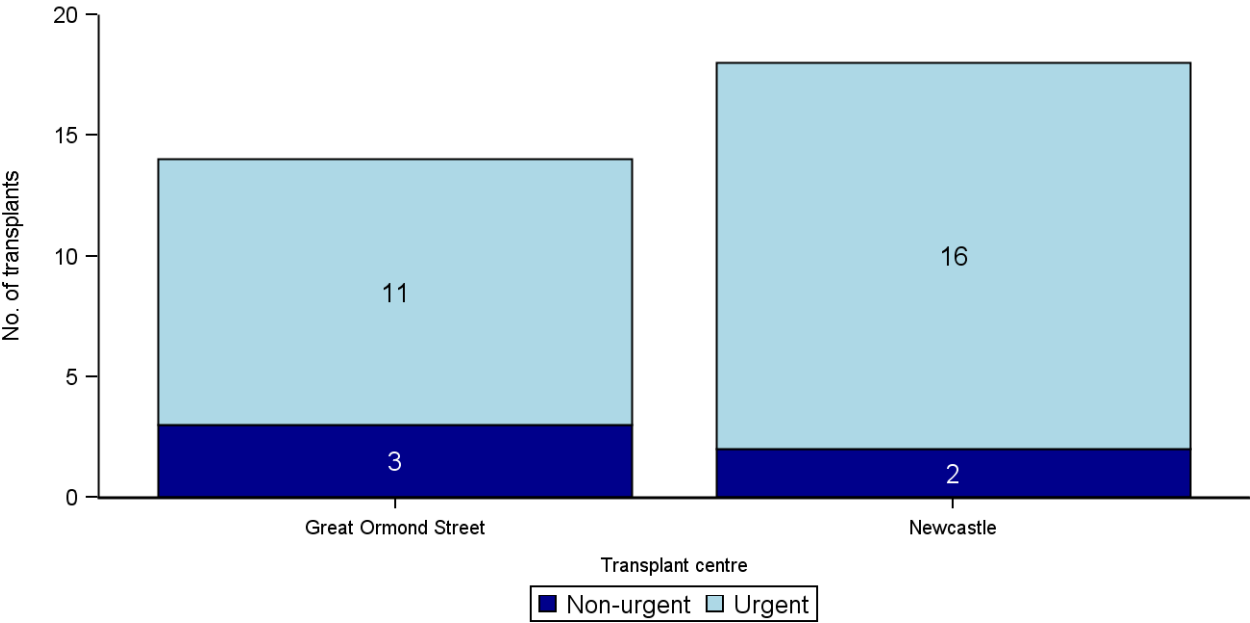
**Figure 17.3 Number of paediatric heart transplants in the UK, by financial year and urgency status, 1 April 2007 to 31 March 2017**



**Figure 17.4 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2007 to 31 March 2017**



**Figure 17.5 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2016 to 31 March 2017**



## 17.2 Demographic characteristics of transplants, 1 April 2016 – 31 March 2017

The demographic characteristics of the 32 paediatric heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 17.1**. Nationally, 47% of heart recipients were male and the [median](#) age was 7 years. For some characteristics, due to rounding, percentages may not add up to 100.

<b>Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2016 to 31 March 2017, by centre</b>				
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		14 (100)	18 (100)	<b>32 (100)</b>
Urgency status at transplant	Non-urgent	3 (21)	2 (11)	<b>5 (16)</b>
	Urgent	11 (79)	16 (89)	<b>27 (84)</b>
Recipient sex	Male	5 (36)	10 (56)	<b>15 (47)</b>
	Female	9 (64)	8 (44)	<b>17 (53)</b>
Recipient ethnicity	White	9 (64)	14 (78)	<b>23 (72)</b>
	Non-white	5 (36)	4 (22)	<b>9 (28)</b>
Recipient age (years)	Median ( <a href="#">IQR</a> )	10 (4, 12)	5 (2, 9)	<b>7 (3, 11)</b>
	Missing	0	0	<b>0</b>
Recipient weight (kg)	Median ( <a href="#">IQR</a> )	17 (11, 46)	14 (7, 32)	<b>15 (10, 37)</b>
	Missing	0	0	<b>0</b>
Recipient primary disease	Coronary heart disease	0 (0)	1 (6)	<b>1 (3)</b>
	Cardiomyopathy	5 (36)	8 (44)	<b>13 (41)</b>
	Congenital heart disease	3 (21)	7 (39)	<b>10 (31)</b>
	Others	6 (43)	2 (11)	<b>8 (25)</b>
NYHA class	III	0 (0)	6 (33)	<b>6 (19)</b>
	IV	8 (57)	10 (56)	<b>18 (56)</b>
	Missing	6 (43)	2 (11)	<b>8 (25)</b>
Recipient in hospital pre-transplant	No	2 (14)	4 (22)	<b>6 (19)</b>
	Yes	10 (71)	12 (67)	<b>22 (69)</b>
	Missing	2 (14)	2 (11)	<b>4 (13)</b>
If in hospital, recipient on ventilator	No	7 (70)	8 (67)	<b>15 (68)</b>
	Yes	2 (20)	4 (33)	<b>6 (27)</b>
	Missing	1 (10)	0 (0)	<b>1 (5)</b>
If in hospital, recipient on VAD	None	2 (20)	8 (67)	<b>10 (46)</b>
	Left	3 (30)	3 (25)	<b>6 (27)</b>
	Right	0 (0)	1 (8)	<b>1 (5)</b>
	Both	2 (20)	0 (0)	<b>2 (9)</b>
	Missing	3 (30)	0 (0)	<b>3 (14)</b>
If in hospital, recipient on TAH	No	7 (70)	12 (100)	<b>19 (86)</b>
	Missing	3 (30)	0 (0)	<b>3 (14)</b>
If in hospital, recipient on ECMO	No	7 (70)	11 (92)	<b>18 (82)</b>
	Yes	0 (0)	1 (8)	<b>1 (5)</b>
	Missing	3 (30)	0 (0)	<b>3 (14)</b>

**Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2016 to 31 March 2017, by centre**

		Great Ormond Street N (%)	Newcastle N (%)	TOTAL N (%)
If in hospital, recipient on inotropes	No	5 (50)	1 (8)	<b>6 (27)</b>
	Yes	2 (20)	11 (92)	<b>13 (59)</b>
	Missing	3 (30)	0 (0)	<b>3 (14)</b>
If in hospital, recipient on IABP	No	7 (70)	11 (92)	<b>18 (82)</b>
	Yes	0 (0)	1 (8)	<b>1 (5)</b>
	Missing	3 (30)	0 (0)	<b>3 (14)</b>
Recipient CMV status	No	5 (36)	4 (22)	<b>9 (28)</b>
	Yes	5 (36)	8 (44)	<b>13 (41)</b>
	Missing	4 (29)	6 (33)	<b>10 (31)</b>
Recipient HCV status	No	10 (71)	12 (67)	<b>22 (69)</b>
	Missing	4 (29)	6 (33)	<b>10 (31)</b>
Recipient HBV status	No	10 (71)	12 (67)	<b>22 (69)</b>
	Missing	4 (29)	6 (33)	<b>10 (31)</b>
Recipient HIV status	No	10 (71)	12 (67)	<b>22 (69)</b>
	Missing	4 (29)	6 (33)	<b>10 (31)</b>
Recipient serum creatinine (umol/l)	Median ( <a href="#">IQR</a> )	42 (30, 69)	53 (30, 82)	<b>44 (30, 80)</b>
	Missing	4	6	<b>10</b>
Donor sex	Male	6 (43)	8 (44)	<b>14 (44)</b>
	Female	8 (57)	10 (56)	<b>18 (56)</b>
Donor ethnicity	White	9 (64)	8 (44)	<b>17 (53)</b>
	Non-white	1 (7)	3 (17)	<b>4 (13)</b>
	Missing	4 (29)	7 (39)	<b>11 (34)</b>
Donor age (years)	Median ( <a href="#">IQR</a> )	14 (3, 36)	9 (3, 14)	<b>10 (3, 26)</b>
	Missing	0	0	<b>0</b>
Donor BMI (kg/m <sup>2</sup> )	Median ( <a href="#">IQR</a> )	21 (16, 24)	18 (14, 21)	<b>19 (15, 22)</b>
	Missing	0	1	<b>1</b>
Donor cause of death	CVA	5 (36)	9 (50)	<b>14 (44)</b>
	Trauma	3 (21)	1 (6)	<b>4 (13)</b>
	Others	6 (43)	8 (44)	<b>14 (44)</b>
Donor hypotension	No	7 (50)	7 (39)	<b>14 (44)</b>
	Yes	1 (7)	7 (39)	<b>8 (25)</b>
	Missing	6 (43)	4 (22)	<b>10 (31)</b>
Donor past diabetes	No	11 (79)	17 (94)	<b>28 (88)</b>
	Missing	3 (21)	1 (6)	<b>4 (13)</b>
Donor past cardiothoracic disease	No	10 (71)	11 (61)	<b>21 (66)</b>
	Missing	4 (29)	7 (39)	<b>11 (34)</b>
Donor past hypertension	No	11 (79)	17 (94)	<b>28 (88)</b>
	Missing	3 (21)	1 (6)	<b>4 (13)</b>
Donor past tumour	No	10 (71)	17 (94)	<b>27 (84)</b>
	Yes	1 (7)	0 (0)	<b>1 (3)</b>
	Missing	3 (21)	1 (6)	<b>4 (13)</b>

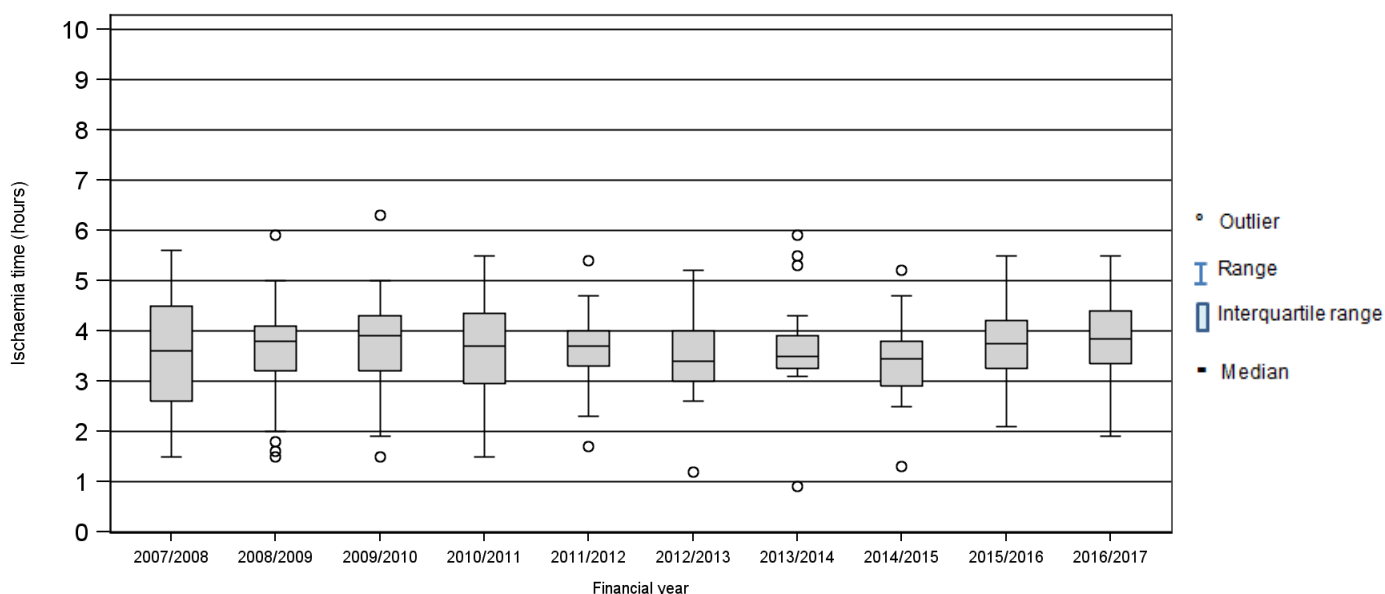
**Table 17.1 Demographic characteristics of paediatric heart transplants, 1 April 2016 to 31 March 2017, by centre**

		Great Ormond Street N (%)	Newcastle N (%)	TOTAL N (%)
Donor past smoker	No	9 (64)	13 (72)	<b>22 (69)</b>
	Yes	2 (14)	3 (17)	<b>5 (16)</b>
	Missing	3 (21)	2 (11)	<b>5 (16)</b>
Total ischaemia time (hours)	Median ( <a href="#">IQR</a> )	3.9 (3.4, 4.4)	3.7 (3.3, 4.4)	<b>3.9 (3.4, 4.4)</b>
	Missing	5	3	<b>8</b>

### 17.3 Total ischaemia time, 1 April 2007 – 31 March 2017

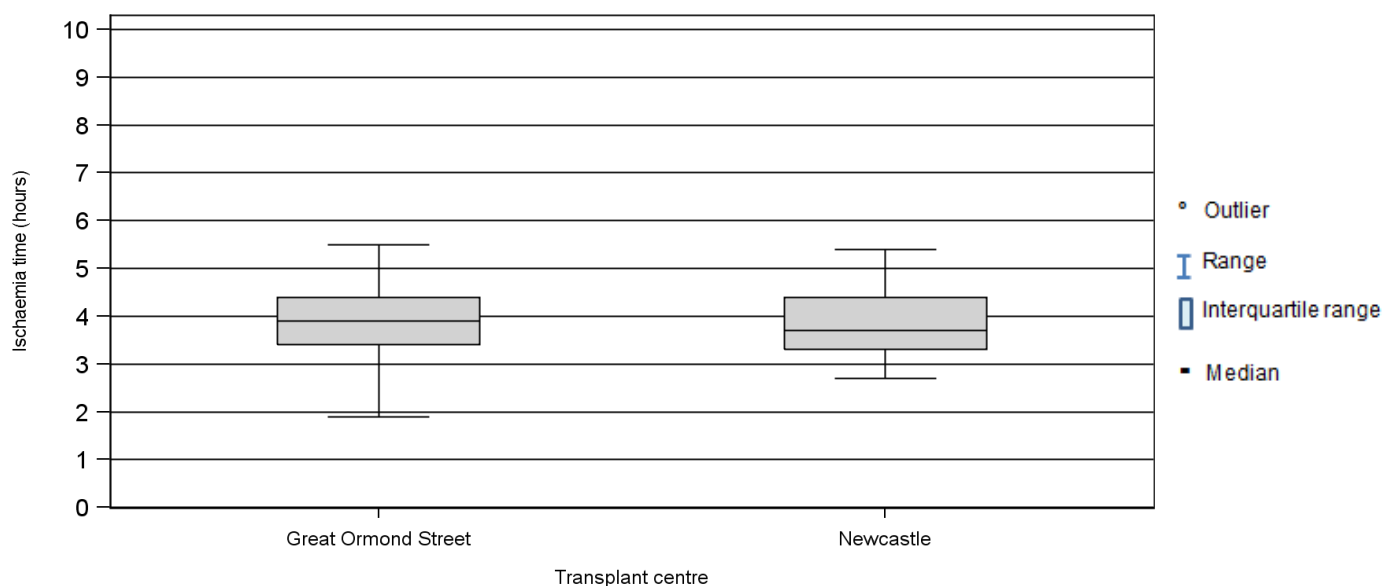
**Figure 17.6** shows [boxplots](#) of total ischaemia time for [DBD](#) donor hearts transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The national [median](#) total ischaemia time varied over the decade with no upward or downward trend.

**Figure 17.6** Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by financial year, 1 April 2007 to 31 March 2017

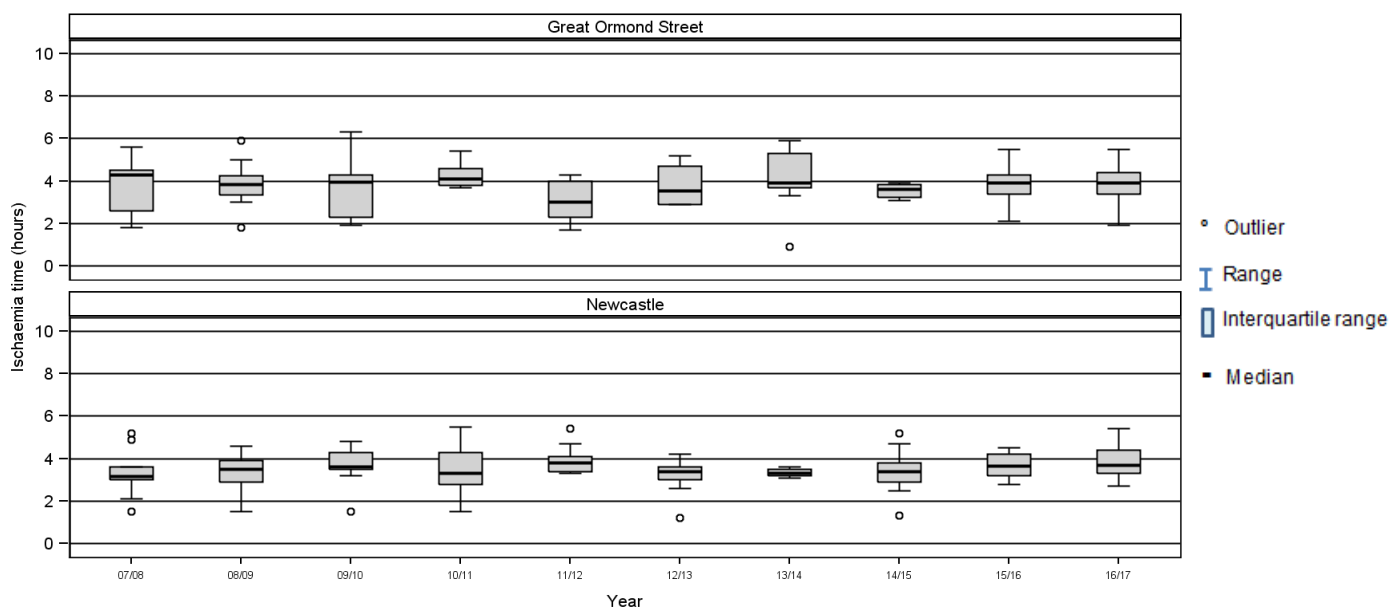


**Figure 17.7** and **Figure 17.8** show [boxplots](#) of total ischaemia time by centre in the latest financial year (2016/2017) and over the last 10 years, respectively. Generally, the median ischaemia times for Newcastle were slightly lower than the median ischaemia times for Great Ormond Street Hospital.

**Figure 17.7** Boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients, by transplant centre, 1 April 2016 to 31 March 2017



**Figure 17.8** Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2007 to 31 March 2017



# **PAEDIATRIC HEART TRANSPLANTATION**

## **Post-Transplant Survival**





## 18. Post-Transplant Survival

The survival analyses presented in this section exclude [multi-organ transplants](#) and include first time transplants only. Thirty-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2012 to 31 March 2016 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2008 to 31 March 2012.

The 30-day post-transplant [unadjusted](#) patient survival rate for each centre and nationally are shown in **Table 18.1** for the 121 first paediatric heart only transplants in the period 1 April 2012 to 31 March 2016. 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.

<b>Table 18.1 30 day patient survival rates after first paediatric heart only transplant, by centre, 1 April 2012 to 31 March 2016</b>				
Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)	
Great Ormond Street	59	2	96.6	(87.1 - 99.1)
Newcastle	62	3	95.2	(85.7 - 98.4)
<b>UK</b>	<b>121</b>	<b>5</b>	<b>95.9</b>	<b>(90.4 - 98.3)</b>

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

<b>Table 18.2 1 year patient survival rates after first paediatric heart only transplant, by centre, 1 April 2012 to 31 March 2016</b>				
Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street	59	4	93.2	(82.8 - 97.4)
Newcastle	62	5	91.9	(81.7 - 96.6)
<b>UK</b>	<b>121</b>	<b>9</b>	<b>92.5</b>	<b>(86.1 - 96.0)</b>

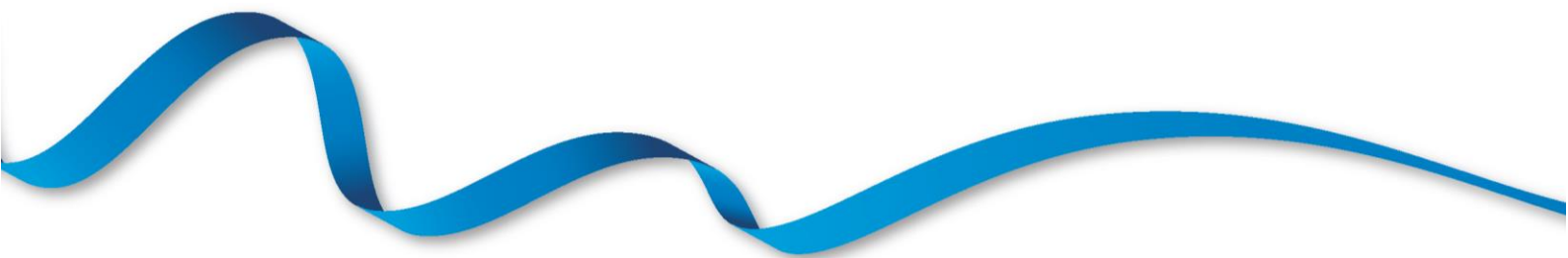
Five year [survival rates](#) were estimated from the 140 first paediatric heart only transplants performed in the period 1 April 2008 to 31 March 2012. The [unadjusted](#) patient [survival rates](#) are shown in **Table 18.3**. There is no statistically significant difference between the two centres' rates.

**Table 18.3 5 year patient survival after first paediatric heart only transplant, by centre,  
1 April 2008 to 31 March 2012**

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street	77	14	81.6	(70.9 - 88.7)
Newcastle	63	10	83.8	(71.9 – 90.9)
<b>UK</b>	<b>140</b>	<b>24</b>	<b>82.6</b>	<b>(75.2 - 88.0)</b>

# **PAEDIATRIC HEART TRANSPLANTATION**

**Form Return Rates**



## 19. Paediatric heart form return rates, 1 January – 31 December 2016

Form return rates are reported in **Table 19.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (more than 2 years). These include all paediatric heart transplants between 1 January and 31 December 2016 for the transplant record, and all follow up forms issued in this time period. A number of forms are outstanding for this period.

**Table 19.1 Form return rates for paediatric heart transplants, 1 January 2016 to 31 December 2016**

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	17	88	16	88	18	100	137	91
Newcastle, Freeman Hospital	20	95	22	100	17	100	178	96
<b>Overall</b>	<b>37</b>	<b>92</b>	<b>38</b>	<b>95</b>	<b>35</b>	<b>100</b>	<b>315</b>	<b>94</b>

# **PAEDIATRIC LUNG TRANSPLANTATION**

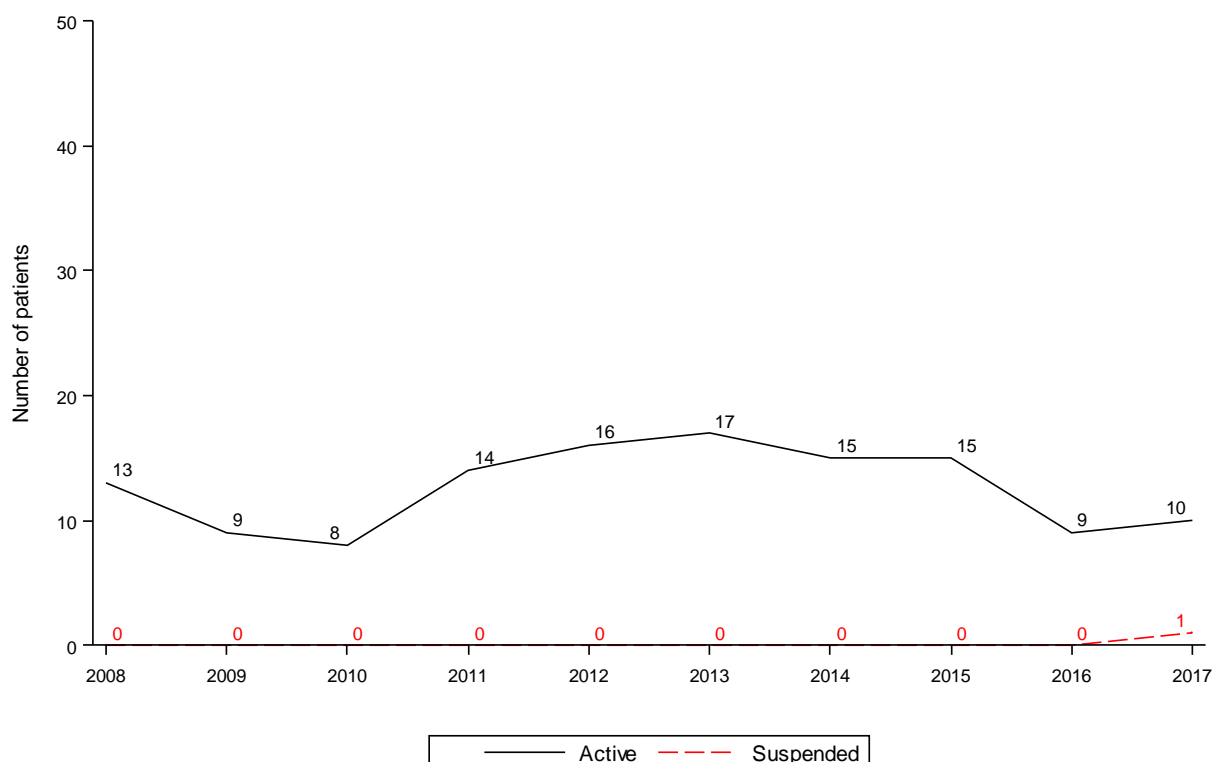
## **Transplant List**



## 20.1 Paediatric lung and heart/lung transplant list as at 31 March, 2008 – 2017

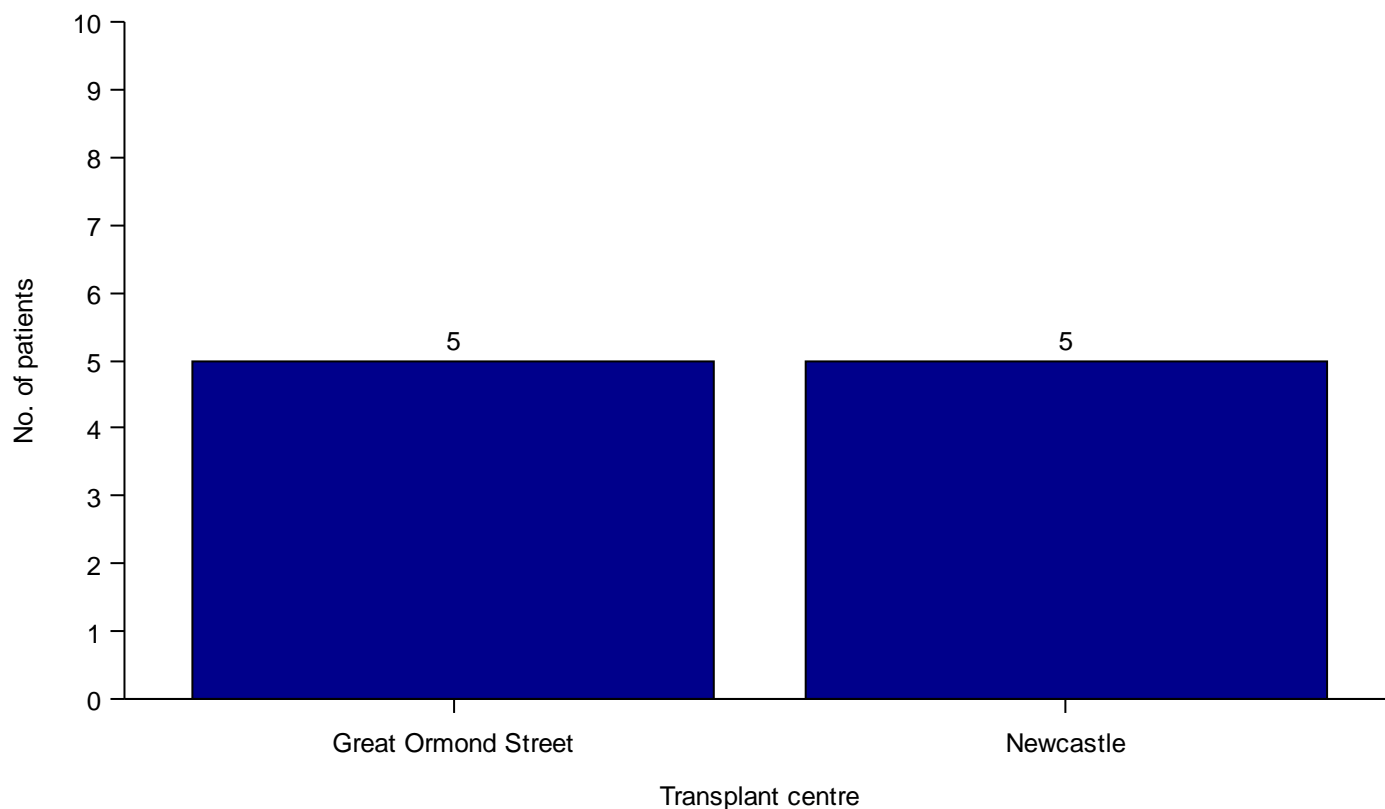
**Figure 20.1** shows the number of paediatric patients on the lung transplant list at 31 March each year between 2008 and 2017 split by active/suspended status. The number of patients on the active lung transplant list was highest in 2013. It has since decreased to 10 as at 31 March 2017.

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



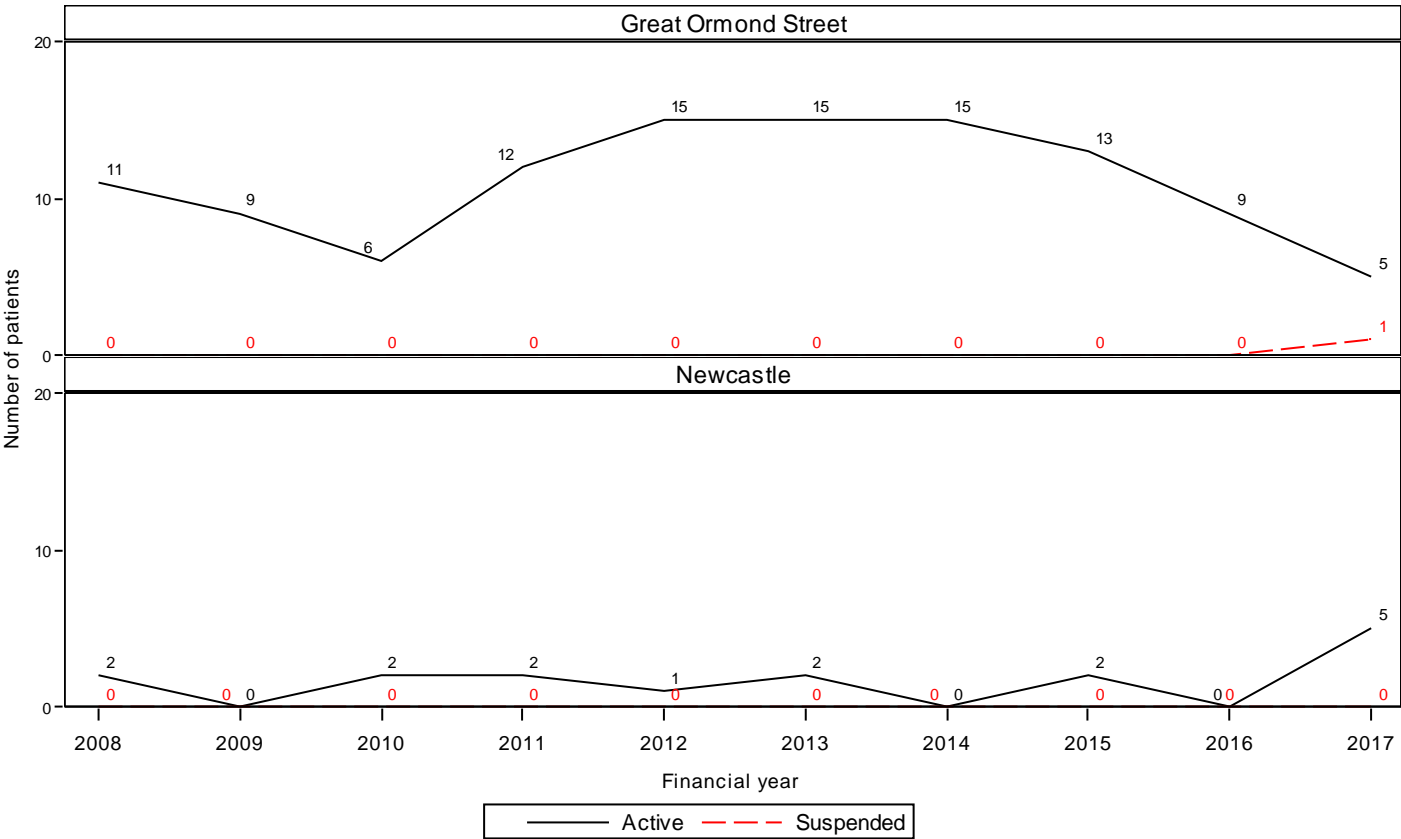
**Figure 20.2** shows the number of paediatric patients on the [active lung transplant list](#) at 31 March 2017 by centre. In total, there were 10 paediatric patients. Each centre had five patients on the list.

**Figure 20.2** Number of paediatric patients on the active lung transplant list at 31 March 2017, by centre



**Figure 20.3** shows the trend over time in the number of paediatric patients on the lung transplant list at each centre at 31 March each year between 2008 and 2017. Great Ormond Street Hospital experienced an increase in their list between 2010 and 2012 but after remaining high for three years it has now decreased to just 5 on 31 March 2017. In contrast, for Newcastle the list was the highest it has been over the decade on 31 March 2017.

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





## 20.2 Demographic characteristics, 1 April 2016 – 31 March 2017

There were 13 paediatric registrations onto the lung transplant list between 1 April 2016 and 31 March 2017. Demographic characteristics of these patients are shown by centre and overall in **Table 20.1**. Nationally, 44% of the patients were male and the [median](#) age was 11 years. For some characteristics, due to rounding, percentages may not add up to 100.

**Table 20.1 Demographic characteristics of paediatric patients registered onto the lung transplant list between 1 April 2016 and 31 March 2017, by centre**

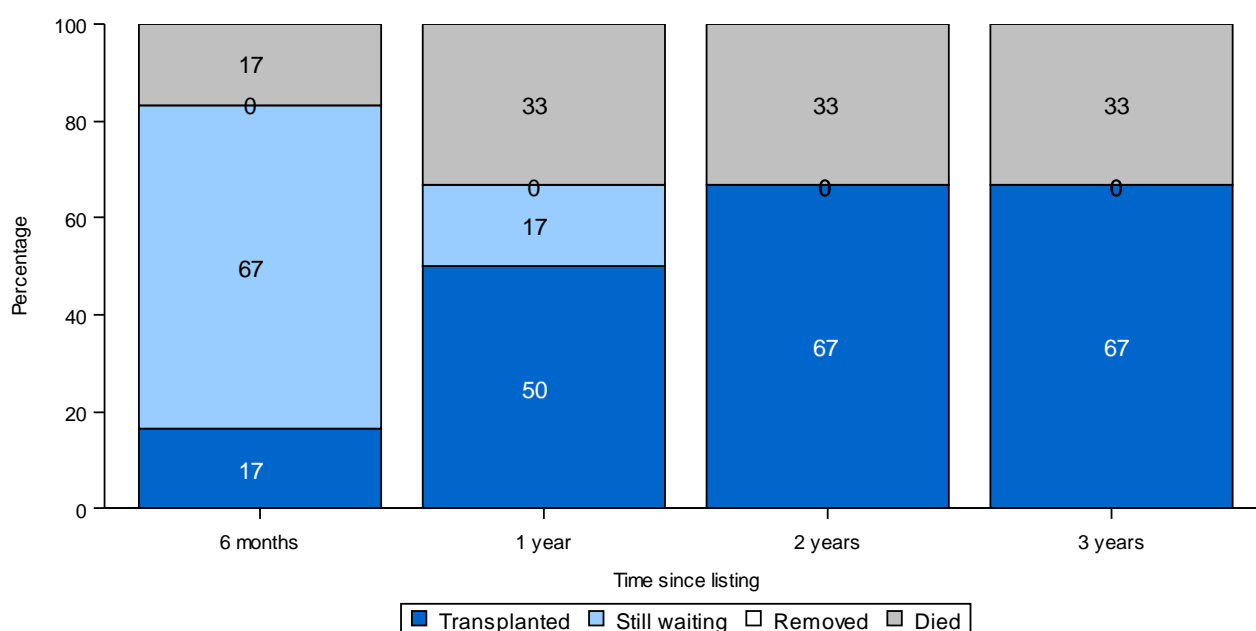
		Great Ormond Street N (%)	Newcastle N (%)	TOTAL N (%)
Number of registrations		7 (100)	6 (100)	<b>13 (100)</b>
Recipient sex	Male	2 (29)	3 (50)	<b>5 (39)</b>
	Female	5 (71)	3 (50)	<b>8 (62)</b>
Recipient ethnicity	White	7 (100)	6 (100)	<b>13 (100)</b>
Recipient age (years)	Median ( <a href="#">IQR</a> )	6 (4, 15)	13 (10, 14)	<b>11 (6, 14)</b>
	Missing	0	0	<b>0</b>
Primary Disease	Cystic fibrosis and bronchiectasis	4 (57)	5 (83)	<b>9 (69)</b>
	Primary pulmonary hypertension	1 (14)	1 (17)	<b>2 (15)</b>
	Other heart/lung disease	2 (29)	0 (0)	<b>2 (15)</b>
Lung function - FEV1 (litres)	Median ( <a href="#">IQR</a> )	0.86 (0.86, 0.86)	0.74 (0.63, 1.02)	<b>0.83 (0.65, 0.86)</b>
	Missing	6	2	<b>8</b>
Lung function – FVC (litres)	Median ( <a href="#">IQR</a> )	1.59 (1.59, 1.59)	1.40 (1.13, 1.57)	<b>1.45 (1.35, 1.59)</b>
	Missing	6	2	<b>8</b>

### 20.3 Post-registration outcomes, 1 April 2013 – 31 March 2014

The transplant list outcomes of paediatric patients listed for a lung transplant between 1 April 2013 and 31 March 2014 are summarised in **Figure 20.4**. This shows the proportion of patients transplanted, still waiting, removed from the list and who died without transplant, within six months, one year, two years and three years after joining the list.

Within six month of listings 17% of patients were transplanted and 17% had died, whilst after three years 67% were transplanted and 33% had died. Please note this is only based on 6 patients.

**Figure 20.4 Post-registration outcome for 6 new lung only registrations made in the UK, 1 April 2013 to 31 March 2014**



## 20.4 Median waiting time to transplant, 1 April 2011 - 31 March 2014

The [median](#) waiting time to lung transplant from listing for paediatric patients registered between 1 April 2011 and 31 March 2014 is shown in **Table 20.2**. This is estimated using the [Kaplan Meier](#) method and takes a patient's first registration within the period if they were registered more than once. Any suspended tie is discounted. The national median waiting time to paediatric lung transplant is 545 days.

<b>Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the transplant list, by centre, 1 April 2011 to 31 March 2014</b>			
Transplant centre	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Great Ormond Street	22	650	468 - 832
Newcastle <sup>1</sup>	3	-	-
<b>UK</b>	<b>25</b>	<b>545</b>	<b>498 – 592</b>

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

# **PAEDIATRIC LUNG TRANSPLANTATION**

## **Response to Offers**



## 21. Response to Offers

**Table 21.1** compares individual centre paediatric bilateral lung offer decline rates over the three years between 1 April 2014 and 31 March 2017. This only considers offers of UK DBD donor lungs that were eventually transplanted and excludes fast track offers. A bilateral lung offer is counted as accepted if both lungs or just one lung was accepted. Lungs offered as part of a cardiac block offer are included and offers to adult patients at Newcastle are excluded. Overall, Great Ormond Street had a slightly lower decline rate than Newcastle.

<b>Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre and year, 1 April 2014 to 31 March 2017</b>								
Centre	2014/15		2015/16		2016/17		Overall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
Great Ormond Street	11	(63.6)	14	(85.7)	5	(60.0)	30	(73.3)
Newcastle	8	(100.0)	9	(66.7)	7	(71.4)	24	(79.2)
<b>UK</b>	<b>19</b>	<b>(78.9)</b>	<b>23</b>	<b>(78.3)</b>	<b>12</b>	<b>(66.7)</b>	<b>54</b>	<b>(75.9)</b>

# **PAEDIATRIC LUNG TRANSPLANTATION**

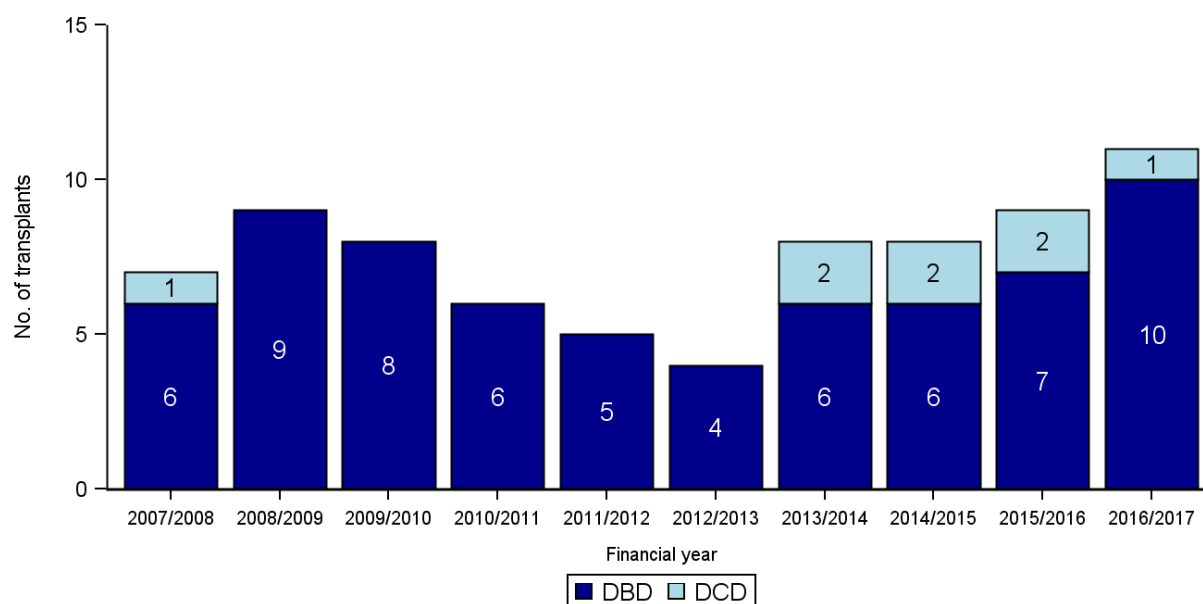
## **Transplants**



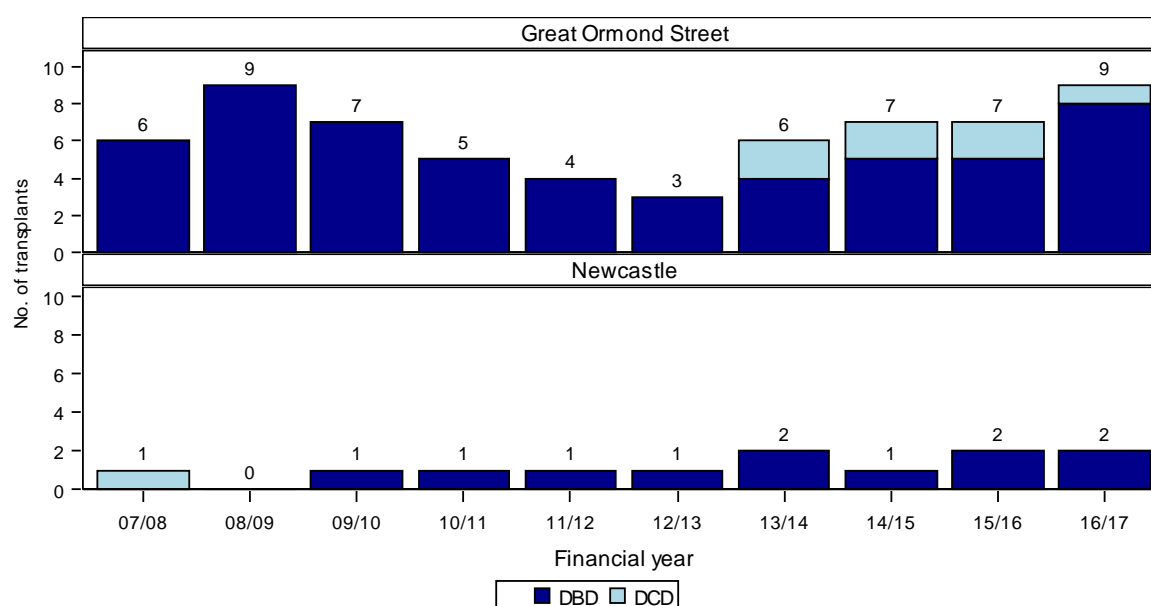
## 22.1 Paediatric lung and heart-lung transplants, 1 April 2007 – 31 March 2017

**Figure 22.1** and **22.2** show the number of paediatric lung transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants decreased each year from 9 in 2008/2009 to 4 in 2012/2013 and has since risen to 11 in 2016/2017. 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 (2016/2017) is shown by centre in **Figure 22.3**. All but one transplant used DBD donor lungs.

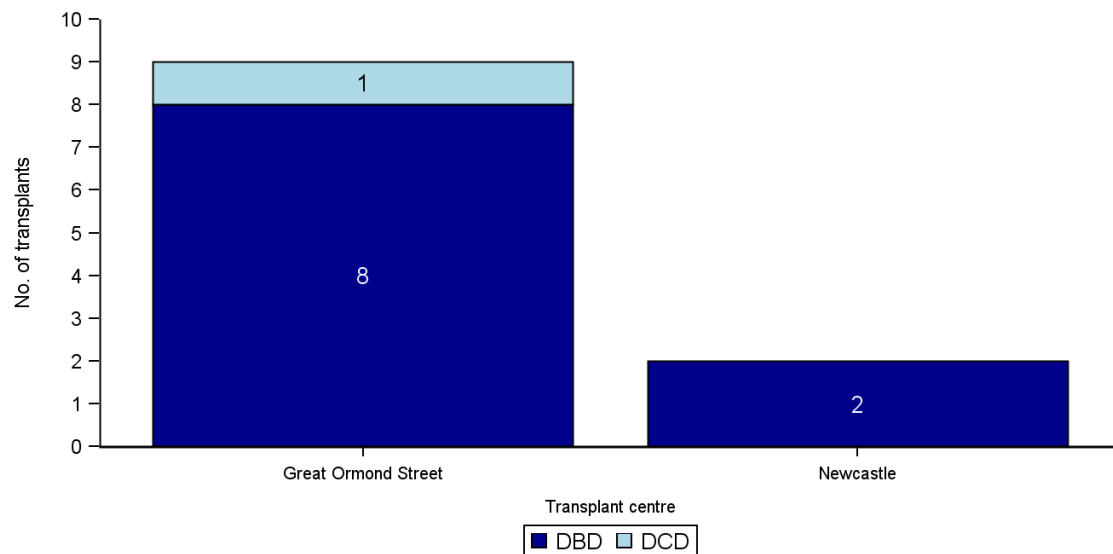
**Figure 22.1 Number of paediatric lung transplants in the UK, by financial year and donor type, 1 April 2007 to 31 March 2017**



**Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2007 to 31 March 2017**

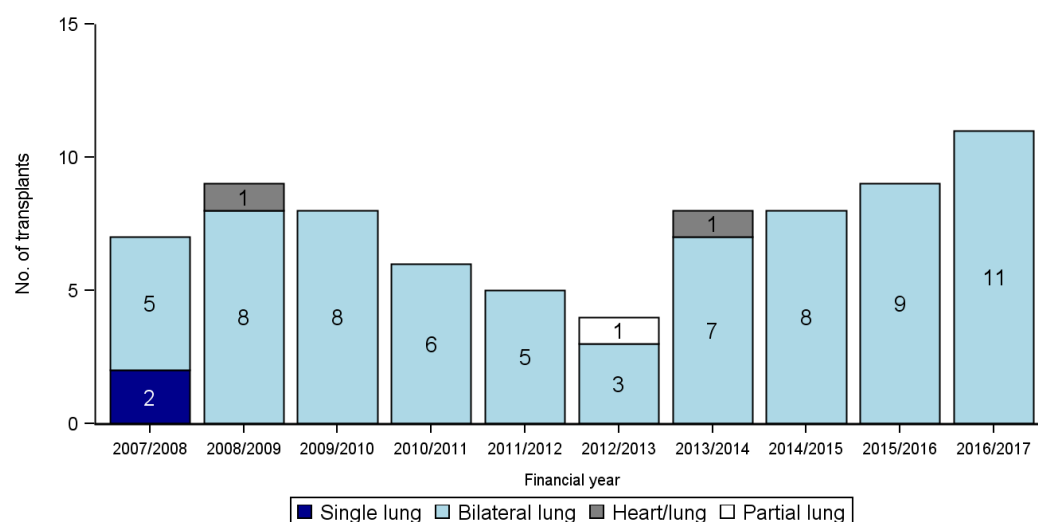


**Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2016 to 31 March 2017**



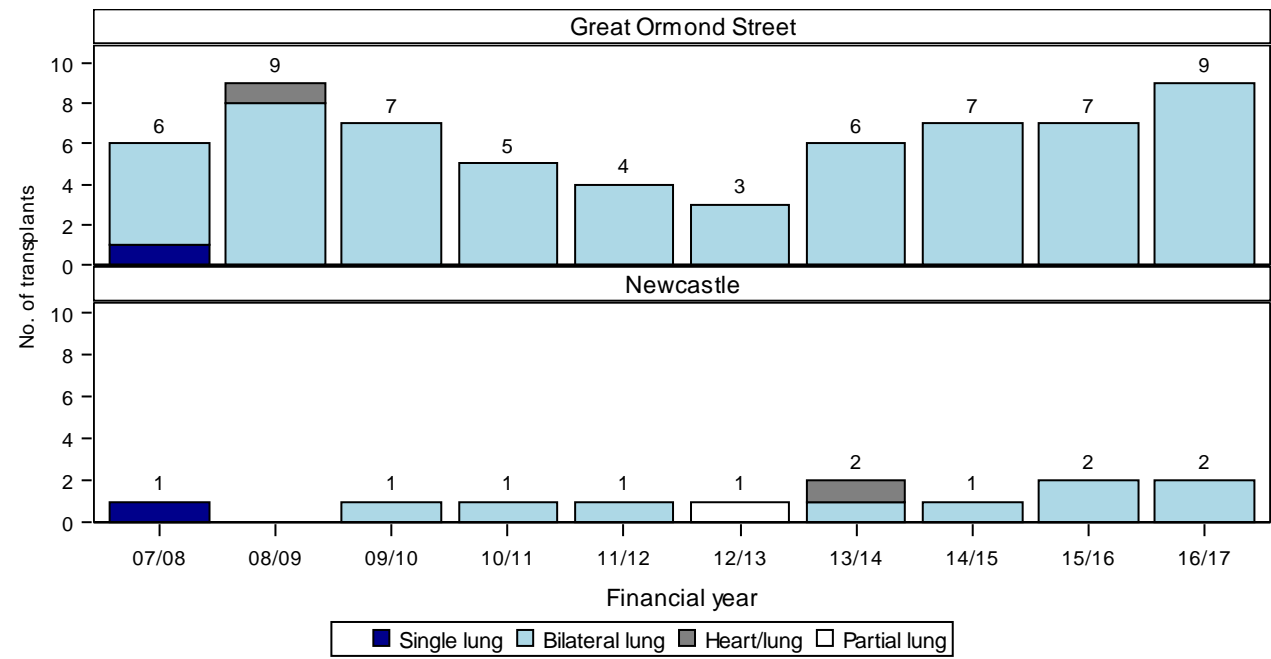
**Figure 22.4 and 22.5** show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period there have been two paediatric heart-lung block transplants; one performed by each centre. Newcastle performed one partial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

**Figure 22.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2007 to 31 March 2017**





**Figure 22.5** Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2007 to 31 March 2017



## 22.2 Demographic characteristics of transplants, 1 April 2016 – 31 March 2017

The demographic characteristics of the 11 paediatric lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 22.1**. Nationally, 45% of lung recipients were male and the [median](#) age was 11 years. For some characteristics, due to rounding, percentages may not add up to 100.

<b>Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2016 to 31 March 2017, by centre</b>				
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		9 (100)	2 (100)	11 (100)
Recipient sex	Male	3 (33)	2 (100)	5 (45)
	Female	6 (67)	0 (0)	6 (55)
Recipient ethnicity	White	9 (100)	2 (100)	11 (100)
	Non-white	0 (0)	0 (0)	0 (0)
Recipient age (years)	Median ( <a href="#">IQR</a> )	10 (5, 14)	15 (14, 15)	11 (5, 15)
	Missing	0	0	0
Recipient weight (kg)	Median ( <a href="#">IQR</a> )	23 (13, 29)	41 (40, 41)	27 (13, 41)
	Missing	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	3 (33)	2 (100)	5 (46)
	Primary pulmonary hypertension	2 (22)	0 (0)	2 (18)
	Other heart/lung disease	4 (44)	0 (0)	4 (36)
NYHA class	IV	4 (44)	0 (0)	4 (36)
	Missing	5 (56)	2 (100)	7 (64)
Recipient in hospital pre-transplant	No	5 (56)	1 (50)	6 (55)
	Yes	3 (33)	1 (50)	4 (36)
	Missing	1 (11)	0 (0)	1 (9)
If in hospital, recipient on ventilator	No	3 (100)	1 (100)	4 (100)
If in hospital, recipient on inotropes	No	1 (33)	0 (0)	1 (25)
	Yes	0 (0)	1 (100)	1 (25)
	Missing	2 (67)	0 (0)	2 (50)
Recipient CMV status	No	1 (11)	2 (100)	3 (27)
	Yes	5 (56)	0 (0)	5 (46)
	Missing	3 (33)	0 (0)	3 (27)
Recipient HCV status	No	6 (67)	2 (100)	8 (73)
	Missing	3 (33)	0 (0)	3 (27)
Recipient HBV status	No	6 (67)	2 (100)	8 (73)
	Missing	3 (33)	0 (0)	3 (27)
Recipient HIV status	No	6 (67)	2 (100)	8 (73)
	Missing	3 (33)	0 (0)	3 (27)
Recipient serum creatinine (umol/l)	Median ( <a href="#">IQR</a> )	30 (27, 35)	53 (50, 55)	32 (27, 50)
	Missing	1	0	1

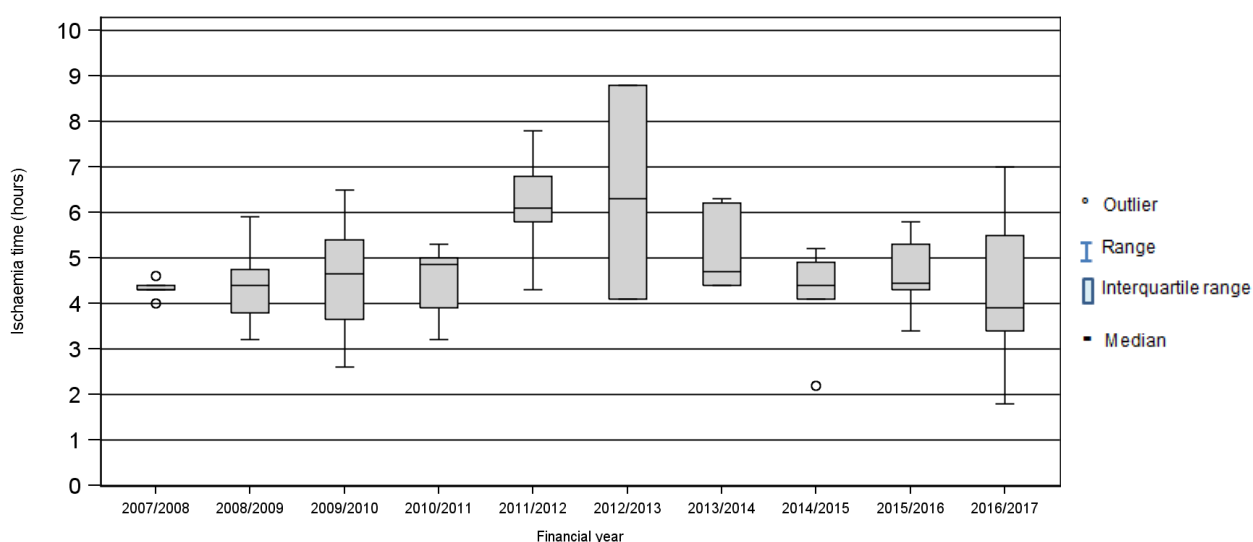
**Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2016 to 31 March 2017, by centre**

		Great Ormond Street N (%)	Newcastle N (%)	TOTAL N (%)
Donor sex	Male	4 (44)	0 (0)	<b>4 (36)</b>
	Female	5 (56)	2 (100)	<b>7 (64)</b>
Donor ethnicity	White	4 (44)	1 (50)	<b>5 (46)</b>
	Non-white	1 (11)	1 (50)	<b>2 (18)</b>
	Missing	4 (44)	0 (0)	<b>4 (36)</b>
Donor age (years)	Median ( <a href="#">IQR</a> )	6 (4, 23)	14 (13, 14)	<b>11 (4, 23)</b>
	Missing	0	0	<b>0</b>
Donor BMI (kg/m <sup>2</sup> )	Median ( <a href="#">IQR</a> )	18 (14, 25)	21 (20, 22)	<b>20 (14, 25)</b>
	Missing	0	0	<b>0</b>
Donor cause of death	CVA	3 (33)	1 (50)	<b>4 (36)</b>
	Others	6 (67)	1 (50)	<b>7 (64)</b>
Donor hypotension	No	3 (33)	2 (100)	<b>5 (46)</b>
	Missing	6 (67)	0 (0)	<b>6 (55)</b>
Donor past cardiothoracic disease	No	5 (56)	2 (100)	<b>7 (64)</b>
	Missing	4 (44)	0 (0)	<b>4 (36)</b>
Donor past hypertension	No	6 (67)	2 (100)	<b>8 (73)</b>
	Missing	3 (33)	0 (0)	<b>3 (27)</b>
Donor past tumour	No	5 (56)	2 (100)	<b>7 (64)</b>
	Yes	1 (11)	0 (0)	<b>1 (9)</b>
	Missing	3 (33)	0 (0)	<b>3 (27)</b>
Donor past smoker	No	3 (33)	2 (100)	<b>5 (46)</b>
	Yes	3 (33)	0 (0)	<b>3 (27)</b>
	Missing	3 (33)	0 (0)	<b>3 (27)</b>
Total ischaemia time (hours)	Median ( <a href="#">IQR</a> )	3.9 (3.1, 5.7)	4.5 (3.4, 5.5)	<b>3.9 (3.4, 5.5)</b>
	Missing	1	0	<b>1</b>

## 22.3 Total ischaemia time, 1 April 2007 – 31 March 2017

**Figure 22.7** shows [boxplots](#) of total ischaemia time for [DBD](#) donor lungs transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The [median](#) total ischaemia time has varied quite substantially over the decade, however these are based on a very small number of transplants per year ( $\leq 11$ ). No further breakdown by centre is shown due to small numbers.

**Figure 22.7 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2007 to 31 March 2017**



# **PAEDIATRIC LUNG TRANSPLANTATION**

## **Post-Transplant Survival**



## 23. Post-Transplant Survival

The survival analyses presented in this section exclude [multi-organ transplants](#) (including heart-lung block transplants) and include first time transplants only. Partial lung transplants are also excluded. Ninety-day and 1-year [survival rates](#) are based on transplants performed in the period 1 April 2012 to 31 March 2016 while 5-year [survival rates](#) are based on transplants performed in the period 1 April 2008 to 31 March 2012.

The 90-day post-transplant [unadjusted](#) patient [survival rates](#) are shown in **Table 23.1** for the 26 first paediatric lung only transplants in the period 1 April 2012 to 31 March 2016. Only 4 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 92%.

**Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre, 1 April 2012 to 31 March 2016**

Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)	
Great Ormond Street	22	2	90.9	(68.3 - 97.6)
Newcastle <sup>1</sup>	4	0	-	-
<b>UK</b>	<b>26</b>	<b>2</b>	<b>92.0</b>	<b>(71.6 - 97.9)</b>

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

There were no additional deaths between 90 days and 1 year for the 26 paediatric lung only transplants performed in the period 1 April 2012 to 31 March 2016, therefore the 1-year [survival rates](#) in **Table 23.2** are identical to those in **Table 23.1**.

**Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2012 to 31 March 2016**

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)	
Great Ormond Street	22	2	90.9	(68.3 - 97.6)
Newcastle <sup>1</sup>	4	0	-	-
<b>UK</b>	<b>26</b>	<b>2</b>	<b>92.0</b>	<b>(71.6 - 97.9)</b>

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

Five year [survival rates](#) were estimated from the 27 first lung only transplants performed in the period 1 April 2008 to 31 March 2012. 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 2008 to 31 March 2012**

Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)	
Great Ormond Street	24	7	70.6	(48 - 84.8)
Newcastle <sup>1</sup>	3	0	-	-
<b>UK</b>	<b>27</b>	<b>7</b>	<b>73.9</b>	<b>(52.9 - 86.6)</b>

<sup>1</sup> 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 2016

Form return rates are reported in **Table 24.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (more than 2 years). These include all paediatric lung and heart-lung transplants between 1 January and 31 December 2016 for the transplant record, and all follow up forms issued in this time period. A small number of forms are outstanding for this period.

**Table 24.1 Form return rates for paediatric lung transplants, 1 January 2016 to 31 December 2016**

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	7	86	7	71	6	100	21	90
Newcastle, Freeman Hospital	2	100	4	100	2	50	14	93
<b>Overall</b>	<b>9</b>	<b>89</b>	<b>11</b>	<b>82</b>	<b>8</b>	<b>88</b>	<b>35</b>	<b>91</b>

# 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 2007 – 31 March 2017	• Introduction	None	1238	1659
1 April 2007 – 31 March 2017	• Transplants	• <a href="#">Multi-organ transplants</a>	1229	1657
1 April 2012 – 31 March 2016	Post-transplant survival – • 30/90-day • 1-year survival	• <a href="#">Multi-organ transplants</a> (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	562	723
1 April 2008 – 31 March 2012	Post-transplant survival – • 5-year survival	• <a href="#">Multi-organ transplants</a> (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	368	597

Table A1.2 Paediatric transplants analysed				
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2007 – 31 March 2017	• Introduction	None	330	75
1 April 2007 – 31 March 2017	• Transplants	• <a href="#">Multi-organ transplants</a>	330	75
1 April 2012 – 31 March 2016	Post-transplant survival – • 30/90-day • 1-year survival	• <a href="#">Multi-organ transplants</a> (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	121	26
1 April 2008 – 31 March 2012	Post-transplant survival – • 5-year survival	• <a href="#">Multi-organ transplants</a> (including heart-lung transplants) • Partial lung transplants • Second (or more) transplants	140	27

## **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 2016 and 31 March 2017 were extracted from the UK Transplant Registry on 12 June 2017 (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-2015 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 2016 and 31 March 2017 (numerator), divided by the mid-2015 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 2016 and 31 March 2017 were included. If a patient was re-registered during the time period, only the first registration was considered. If a patient underwent more than one heart or lung transplant in the time period, only the first transplant was considered.

## A2: Methods

### Offer decline rates

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

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

### Unadjusted post-transplant survival rates

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

### Risk-adjusted post-transplant survival rates

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

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

Missing values were imputed using multiple imputation where missing values for heart transplants ranged from 0% for several variables to 8.7% for respiratory arrest, and for lung transplants ranged from 0% for several variables to 7.8% for recipient cholesterol at registration. Multiple imputation was implemented in SAS Enterprise Guide, using chained equations. The form of the imputation model used to estimate missing values consisted of a list of transplant related variables as well as the outcome variables (survival time and censoring indicator). Twenty imputations were run with 50 burn-in iterations before each imputation. Post-transplant survival models were fitted to the resulting 20 datasets and estimates were obtained for each parameter in the model by analysing the results of these 20 models collectively.

## Funnel plots

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

## Systematic component of variation

For a given individual who is a resident in a given English Strategic Health Authority (SHA), registration to the transplant list is modelled as a Bernoulli trial. At the whole area level, this becomes a Binomial process which can be approximated by a Poisson distribution when rare events are modelled. Transplant counts follow similar assumptions.

To allow for the possibility that, even after allowing for area-specific Poisson rates, area differences remain, introduce an additional multiplicative rate factor which varies from area to area. Postulate a non-parametric distribution for the multiplicative factor, with variance  $\sigma^2$ . 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,  $\sigma^2$ , 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  $\sigma^2$ . 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  $\geq 18$  years registered for the first time for a heart or lung transplant between 1 January 2005 and 31 December 2016. 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 30 May 2017 if the patient was on the transplant list at time of analysis.

Exclusions from the analysis:

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

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

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

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

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

### A3: Risk models

Table A3.1 <b>Risk factors</b> 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 57, 88, 117, 176
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 <a href="#">Risk factors</a> and categories used in the adult lung risk adjusted 90-day, 1- year and 5-year survival model	
Donor CMV	Negative Positive
Donor history of smoking	No Yes
Recipient daily dose of prednisolone at registration	0 1-14 ≥ 15
Donor:recipient calculated TLC mismatch (recipient – donor)	(modelled as continuous variable)
Recipient FVC at registration	(modelled as continuous variable)
Recipient bilirubin at registration	(modelled as continuous variable)
Recipient cholesterol at registration	(modelled as continuous variable)
Recipient age at transplant	Non-linear spline with knots at 22, 45, 56, and 64.
Transplant type	Single lung Bilateral lung
Primary disease group	COPD and emphysema Cystic fibrosis and bronchiectasis Fibrosing lung disease Other

## A4: Glossary of terms

### Active transplant list

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

### Boxplots

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

### Case mix

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

### Confidence interval (CI)

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

### Confidence limit

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

### Cox Proportional Hazards model

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

**Donor after brain death (DBD)**

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

**Donor after circulatory death (DCD)**

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

**Funnel plot**

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

**Inter-quartile range**

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

**Kaplan-Meier method**

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

**Long-term device**

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

**Median**

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

**Multi-organ transplant**

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

**Patient survival rate**

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

***p* value**

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

**Risk-adjusted survival rate**

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

**Risk factors**

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

**Unadjusted survival rate**

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

**VAD**

Ventricular Assist Device

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