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EXECUTIVE SUMMARY



EXECUTIVE SUMMARY

This report presents key figures about cardiothoracic transplantation in the UK. The period reported covers 10 years of transplant data, from 1 April 2006 to 31 March 2016. The report presents information on the number of transplants and survival analysis after first heart and/or lung transplantation; both on a national and centre-specific basis.

Key findings

- On 31 March 2016, there were 248 patients on the UK <u>active heart transplant list</u> which represents a 7% decrease in the number of patients a year earlier. The equivalent number of patients on the active lung transplant list was 330, representing a 2% decrease from the previous year.
- There were 3218 cardiothoracic **transplants** performed in the UK in the ten year period. Of these, 1488 were first heart-only transplants and 1667 were first lung or heart/lung transplants.
- Centre-specific <u>risk-adjusted survival rates</u> at 1 year post **heart** transplant are all within the 99.8% <u>confidence limits</u> of the national average survival rate, for adult recipients at all transplant centres. Risk-adjusted survival rates at 5 years post heart transplant for one centre are however below the 99.8% lower <u>confidence limit</u> of the national average survival rate and above the 99.8% upper <u>confidence limit</u> for 30 day post transplant survival at another adult centre.
- Centre-specific risk-adjusted survival rates at 90 days and 1 year post **lung** transplant are within the 99.8% <u>confidence limits</u> of the national average survival rate, for **adult** recipients at all transplant centres. Risk-adjusted survival rates at 5 years post lung transplant for one centre are however below the 99.8% lower <u>confidence limit</u> of the national average survival rate.
- The national rate of survival 30 days after first heart transplantation of adults is 88.7%. These rates vary between centres, ranging from 80.3% to 95.2% (<u>risk-adjusted</u>).
- The national rate of survival 30 days after first **heart transplantation of paediatrics** is 96%. These rates vary between centres, ranging from 95.1% to 96.8% (<u>unadjusted</u>). Centre-specific estimates of these rates must be interpreted with caution due to the small number of transplants upon which they are based.
- The national rate of survival 90 days after first lung transplantation of adults from deceased donors is 89.3%. These rates vary between centres, ranging from 79.0% to 92.9% (<u>risk-adjusted</u>).
- The national rate of survival 90 days after first **lung transplantation of paediatrics** from deceased donors is 95.5%. These rates vary between centres, ranging from 94.7% to 100% (<u>unadjusted</u>). Centre-specific estimates of these rates must be interpreted with caution due to the small number of transplants upon which they are based.

Use of the contents of this report should be acknowledged as follows: Annual Report on Cardiothoracic Transplantation 2015/16, NHS Blood and Transplant

INTRODUCTION



INTRODUCTION

This report presents information on transplant activity and patient mortality after first heart and/or lung transplantation between 1 April 2006 and 31 March 2016, for all centres performing heart and/or lung transplantation in the UK. Data were obtained from the UK Transplant Registry at NHS Blood & Transplant which holds information relating to donors, recipients and outcomes for all cardiothoracic transplants performed in the UK.

Results are described separately for hearts and lungs and also for adult (aged≥16 years) and paediatric patients (aged<16 years). There are seven cardiothoracic transplant centres in the UK (six in England and one in Scotland). Five of the seven centres specialise in transplanting adult patients, one in transplanting paediatric patients (Great Ormond Street) and one transplants both adult and paediatric patients (Newcastle). However, both adult and paediatric transplants carried out at Great Ormond Street are included in the paediatric report, and paediatric transplants carried out at non-paediatric centres are included in the adult report. Heart lung blocks are included in the lung analysis.

The centre specific results for adult first transplants are adjusted for differences in <u>risk</u> <u>factors</u> between the centres. The risk models used are described in the <u>Appendix</u> and were developed in August 2015 in collaboration with the Cardiothoracic Advisory Group (CTAG) Clinical Audit Group.

Methods used are described in the Appendix.

Patients requiring <u>multi-organ transplants</u> (other than heart/lung 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.

Figure 1.1 shows the number of patients on the <u>active transplant list</u> at 31 March each year between 2007 and 2016. The number of patients waiting for a lung transplant fell each year from 292 in 2007 to 229 in 2009 and has increased since to 330 in 2016. The number of patients waiting for a heart transplant has increased substantially from 93 in 2009 to 248 in 2016.





Figure 1.2 shows the number of adult and paediatric patients on the active transplant list at 31 March 2016 by centre. In total, there were 532 adults and 46 paediatric patients. Harefield had the largest proportion of the adult heart and lung transplant lists. Glasgow does not perform lung transplantation.



Figure 1.2 Patients on heart and lung transplant lists at 31 March 2016, by centre



The percentage of organs retrieved that were not transplanted are shown in **Figure 1.3** and **Figure 1.4** for hearts and lungs respectively. The rates are shown over the last decade. It can be seen that the non-utilisation rate of organs is generally stable and low (less than 5%) over time for hearts and has generally decreased over time for lungs reaching 7.7% in 2015/16.



Figure 1.3 Percentage of hearts retrieved that are not transplanted from deceased organ donors in the UK, 1 April 2007 to 31 March 2016



Figure 1.4 Percentage of lungs (by organ) retrieved that are not transplanted from deceased organ donors in the UK, 1 April 2007 to 31 March 2016

Figure 1.5 shows the total number of transplants performed in the last ten years. The number of heart transplants per year dropped to 128 in 2007/2008 but began increasing slightly in 2010/2011. There was a substantial increase between 2012/2013 and 2015/2016 from 145 to 195. The number of lung transplants per year has been steadily increasing since 2007/08 to 188 in 2015/2016

Figure 1.5 Number of cardiothoracic transplants in the UK, by financial year, 1 April 2006 to 31 March 2016



The number of cardiothoracic organ transplants by recipient country/Strategic Health Authority of residence is shown in **Table 1.1**. No adjustments have been made for potential demographic differences in populations. The transplant rate ranged from 4.1 to 11.8 pmp across Strategic Health Authorities and overall was 5.9 pmp. Lung transplants include the small number of heart/lung transplants performed.

Table 1.1Cardiothoracic transplant rates per million population (pmp) in the UK,1 April 2015 - 31 March 2016, by Country/ Strategic Health Authority										
Country/ Strategic Health Authority	Heart	(pmp)	DI	Lungs (BD	(pmp) D(CD	Total	(pmp)		
North East North West Yorkshire and The Humber North of England	20 25 9 54	(7.6) (3.5) (1.7) (3.6)	9 19 9 37	(3.4) (2.7) (1.7) (2.4)	2 3 4 9	(0.8) (0.4) (0.7) (0.6)	31 47 22 100	(11.8) (6.6) (4.1) (6.6)		
East Midlands West Midlands East of England Midlands and East	8 20 25 53	(1.7) (3.5) (4.2) (3.2)	11 19 20 50	(2.4) (3.3) (3.3) (3.1)	2 2 1 5	(0.4) (0.4) (0.2) (0.3)	21 41 46 108	(4.5) (7.2) (7.6) (6.6)		
London	25	(2.9)	9	(1.1)	2	(0.2)	36	(4.2)		
South East Coast South Central South West South of England	10 11 13 34	(2.2) (2.6) (2.4) (2.4)	15 9 10 34	(3.3) (2.1) (1.8) (2.4)	5 4 3 12	(1.1) (0.9) (0.6) (0.8)	30 24 26 80	(6.5) (5.6) (4.8) (5.6)		
England Isle of Man Channel Islands	166 1 0	(3.1) (12.5)	130 0 0	(2.4)	28 0 0	(0.5)	324 1 0	(6.0) (12.5)		
Wales	11	(3.6)	12	(3.9)	3	(1.0)	26	(8.4)		
Scotland	9	(1.7)	8	(1.5)	2	(0.4)	19	(3.6)		
Northern Ireland	7	(3.8)	1	(0.5)	2	(1.1)	10	(5.4)		
TOTAL ¹	194 ²	(3.0)	151	(2.3)	35	(0.5)	380	(5.9)		
¹ Excludes 3 recipients who reside in the Republic of Ireland ² Includes 19 DCD heart recipients										

Figure 1.6 details the 2814 adult cardiothoracic transplants performed in the UK in the ten year period whilst **Figure 1.7** shows similar information for 404 paediatric transplants performed during the same period. Of these, 2801 adult and 404 paediatric transplants are analysed in the following sections as <u>multi-organ transplants</u> are not included (light blue boxes). The exception to this however is that the survival analyses sections further exclude partial lung transplants, heart/lung transplants and re-transplants along with <u>multi-organ transplants</u>.

Figure 1.6 Adult cardiothoracic organ transplants performed in the UK, 1 April 2006 to 31 March 2016



¹ Includes 8 heart and kidney transplants, 1 heart and liver, 1 lung and kidney and 3 lung and liver

² Includes 3 domino donor transplants and 20 DCD heart transplants

³ Includes 1 partial lung transplant from a living donor

⁴ Survival sections are split into 1 April 2011 to 31 March 2015 for 30 day (heart) and 90 day post-transplant survival (lung) 1 April 2007 to 31 March 2011 for 1 year and 5 year survival



Figure 1.7 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2006 to 31 March 2016

¹ Includes 1 domino donor transplant and 1 DCD heart transplant

² Includes 1 partial lung transplant from a deceased donor

³ Survival sections are split into 1 April 2011 to 31 March 2015 for 30 day (heart) and 90 day post-transplant survival (lung) 1 April 2007 to 31 March 2011 for 1 year and 5 year survival

ADULT HEART TRANSPLANTATION

Transplant List



3.1 Adult heart only transplant list as at 31 March, 2007 – 2016

Figure 3.1 shows the number of adult patients on the heart transplant list at 31 March each year between 2007 and 2016. The overall number of patients actively waiting for a heart transplant increased each year from 72 in 2007 to 207 in 2016. The number of patients on the urgent list has increased from 0 in 2007 to 19 in 2016, with an average of 8.6 patients on the list on the 31st March each year.





Figure 3.2 shows the number of adult patients on the <u>active heart transplant list</u> at 31 March 2016 by centre. In total, there were 207 adult patients. Harefield had the largest proportion (32%) of the transplant list whilst Manchester and Glasgow had the smallest (8%). The number of patients on the urgent transplant list at 31 March 2016 ranged from one at Manchester to five at Harefield.





Figure 3.3 shows the number of adult patients on the transplant list at 31 March each year between 2007 and 2016 for each centre.



Figure 3.3 Adult patients on the heart transplant list at 31 March each year for the last 10 years, by year and centre

The demographic characteristics of the 207 adult patients on the <u>active heart transplant list</u> on 31 March 2016 are shown by centre and overall in **Table 3.1.** 85% of the recipients were male and the <u>median</u> age was 53 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 3.1 Demographic characteristics of adult heart transplant list patients at 31 March 2016, by centre									
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	Glasgow N (%)	TOTAL	
Number		47 (100)	38 (100)	67 (100)	21 (100)	17 (100)	17 (100)	207 (100)	
Urgency status	Non-urgent	43 (91)	36 (95)	62 (93)	18 (86)	16 (94)	13 (76)	188 (91)	
	Urgent	4 (9)	2 (5)	5 (7)	3 (14)	1 (6)	4 (24)	19 (9)	
Recipient sex	Male	40 (85)	32 (84)	57 (85)	16 (76)	16 (94)	15 (88)	176 (85)	
	Female	7 (15)	6 (16)	10 (15)	5 (24)	1 (6)	2 (12)	31 (15)	
Recipient ethnicity	White	43 (91)	32 (84)	60 (90)	18 (86)	16 (94)	16 (94)	185 (89)	
	Non-white	4 (9)	6 (16)	7 (10)	3 (14)	1 (6)	1 (6)	22 (11)	
Recipient age	Median (<u>IQR</u>)	53 (42, 58)	57 (49, 62)	51 (42, 60)	51 (41, 59)	52 (43, 58)	51 (43, 55)	53 (43, 60)	
	Missing	0	0	0	0	0	0	0	
Primary Disease	Coronary heart disease	11 (23)	7 (18)	12 (18)	4 (19)	2 (12)	5 (29)	41 (20)	
	Cardiomyopathy	21 (45)	13 (34)	35 (52)	8 (38)	6 (35)	5 (29)	88 (43)	
	Congenital heart disease	9 (19)	2 (5)	3 (4)	1 (5)	0 (0)	0 (0)	15 (7)	
	Other heart disease	5 (11)	12 (32)	7 (10)	2 (10)	7 (41)	3 (18)	36 (17)	
	Others	1 (2)	4 (11)	10 (15)	6 (29)	2 (12)	4 (24)	27 (13)	
Previous open heart surgery	None	24 (51)	22 (58)	34 (51)	6 (29)	9 (53)	12 (71)	107 (52)	
	One	8 (17)	14 (37)	23 (34)	10 (48)	6 (35)	3 (18)	64 (31)	
	More than one	5 (11)	2 (5)	10 (15)	3 (14)	1 (6)	2 (12)	23 (11)	
	Missing	10 (21)	0 (0)	0 (0)	2 (10)	1 (6)	0 (0)	13 (6)	
Previous thoracotomy	No	35 (74)	37 (97)	59 (88)	17 (81)	14 (82)	11 (65)	173 (84)	
	Yes	2 (4)	1 (3)	8 (12)	4 (19)	2 (12)	6 (35)	23 (11)	
	Missing	10 (21)	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	11 (5)	
Serum Bilirubin (umol/l)	Median (<u>IQR</u>)	16 (10, 25)	18 (12, 24)	14 (10, 19)	14 (10, 19)	21 (11, 34)	9 (7, 12)	14 (10, 21)	
	Missing	11	2	0	0	1	3	17	
Serum Creatinine	Median (<u>IQR</u>)	106 (84, 127)	116 (96, 138)	97 (76, 114)	88 (76, 119)	96 (78, 117)	94 (85, 115)	100 (81, 121)	
(umol/l)	Missing	10	0	0	0	1	2	13	

3.2 Post-registration outcomes, 1 April 2012 – 31 March 2013

An indication of outcomes for adult patients listed for a non-urgent heart transplant is summarised in **Figure 3.4** whilst outcomes for patients registered urgently are shown in **Figure 3.5**. For patients that have been registered on either the non-urgent or the urgent heart allocation scheme more than once, only the first non-urgent and the first urgent registration, respectively, is considered. **Figure 3.5** includes patients who have been urgently listed over the period, including those who have moved from the routine list. These charts show the proportion of patients transplanted or still waiting six months, one, two and three years after joining the list. They also show the proportion removed from the transplant list (typically because they become too unwell for transplant) and those who died while on the transplant while 7% died waiting. Three years after listing, 21% have received a transplant whilst 37% were moved to the urgent list.



Figure 3.4 Post-registration outcome for 147 first non-urgent heart only registrations made in the UK, 1 April 2012 to 31 March 2013

Figure 3.5 Post-registration outcome for 124 first urgent heart only registrations made in the UK, 1 April 2012 to 31 March 2013



3.3 Median waiting time to transplant, 1 April 2010 - 31 March 2013

The <u>median</u> waiting time to transplant for adult patients on the heart transplant list is shown in **Figure 3.6.** This is estimated for any heart only patient in the time period using the <u>Kaplan Meier</u> method. Overall time to transplant is the combination of time on the nonurgent transplant list and time on the urgent transplant list for all patients on the heart transplant list. **Table 3.2** shows the overall <u>median</u> waiting time and, separately, the <u>median</u> waiting time for patients that have never been registered on the urgent list and patients registered on the urgent list at any point during their registration. For 'ever urgent' patients, their waiting time includes any time spent on the routine list, as well as on the urgent list. The overall national <u>median</u> waiting time is 217 days and ranges from 57 days at Birmingham to 960 days at Harefield.



Figure 3.6 Overall median waiting time to transplant for adult patients registered on the heart only transplant list, from 1 April 2010 to 31 March 2013

Transplant centre

Transplant centre	Number of patients	Waiting	time (days)
	registered	Median	95% Confidence interval
All patients (Total			
active waiting time)			
Newcastle	104	416	96 - 736
Papworth	142	250	136 - 364
Harefield	101	960	686 - 1234
Birmingham	88	57	25 - 89
Manchester	72	123	4 - 242
Glasgow	46	112	89 - 135
UK	553	217	144 - 290
Never urgent			
patients (Routine			
active waiting time)			
1			
Newcastle	43	-	-
Papworth	57	441	358 - 524
Harefield	51	-	-
Birmingnam	42	140	42 - 238
Manchester	20	342	130 - 554
Glasgow	21	237	43 - 431
UK	240	619	83 - 1155
Ever urgent patients			
(Total active waiting			
time)			
Neuroette	C4	405	94 400
Newcastle	01 95	120	84 - 100 21 - 81
Harofield	00 50	51 117	21-01
Birmingham	50 46	114	13 - 67
Manchester	40	+0 21	8 - 54
Glasgow	25	68	8 - 128
	20	00	0 120
UK	313	68	40 - 96
¹ Median waiting time cannot	be estimated		

Table 3.2Median waiting time to deceased donor transplant for adult patients registered
on the heart transplant list, 1 April 2010 to 31 March 2013

The <u>median</u> waiting time to transplant for adult patients on the heart transplant list is also considered by pre-transplant <u>long-term</u> Left <u>VAD</u> (LVAD) support status. This is shown in **Figure 3.7a** and **Figure 3.8b** for patients who have never received long-term LVAD support and patients who have ever received long-term LVAD support, respectively. This is estimated for any heart only patient in the time period using the <u>Kaplan Meier</u> method. Overall time to transplant list for all patients on the non-urgent transplant list and time on the urgent transplant list for all patients on the heart transplant list. **Table 3.3** shows the overall <u>median</u> waiting time and, separately, the <u>median</u> waiting time for patients that have never received long-term LVAD support and patients who have ever received long-term LVAD support and patients who have ever received long-term LVAD support and patients who have ever received long-term LVAD support.

Figure 3.7a Overall median waiting time to transplant for adult patients registered on the heart only transplant list who never received long-term LVAD support, from 1 April 2010 to 31 March 2013





Figure 3.7b Overall median waiting time to transplant for adult patients registered on the heart only transplant list who ever received long-term LVAD support, from 1 April 2010 to 31 March 2013

Transplant centre	Number of patients	Waiting	time (days)
	registered	Median	95% Confidence interval
All patients			
Newcastle	104	416	96 - 736
Papworth	142	250	136 - 364
Harefield	101	960	686 - 1234
Birmingham	88	57	25 - 89
Manchester	72	123	4 - 242
Glasgow	46	112	89 - 135
UK	553	217	144 - 290
Name an Ian a tama			
Never on long-term			
Left VAD support			
Newcastle	54	103	57 - 149
Papworth	106	101	35 - 167
Harefield	50	129	0 - 272
Birmingham	81	49	12 - 86
Manchester	62	54	0 - 158
Glasgow	35	112	47 - 177
e.aoge.i			
UK	388	92	60 - 124
Ever on long-term			
Left VAD support			
Newcastle ¹	50	_	_
Papworth	36	1056	- 7/3 - 1369
Harofield	50	1870	852 - 2888
Birmingham ¹	7	1070	052 - 2000
Manchester	10	1085	- 253 - 1017
Glasgow ¹	10	1005	200 - 1917
Glasgow		-	-
UK	165	1118	847 - 1389
¹ Median waiting time cannot	be estimated		

Table 3.3Median waiting time to deceased donor transplant for adult patients registered
on the heart transplant list, 1 April 2010 to 31 March 2013

ADULT HEART TRANSPLANTATION

Response to Offers



Figure 4.1 compares individual centre adult heart offer decline rates with the national rate between 1 April 2013 and 31 March 2016. This also includes offers that were accepted and not used by a centre. Offer decline rates at Harefield, Newcastle, Birmingham and Papworth fall outside of the 99.8% <u>confidence limits</u>. This indicates that Harefield and Newcastle had a significantly higher and, Papworth and Birmingham had a significantly lower offer decline rate than the national average.

This analysis excludes fast track offers and only considers offers of hearts that were eventually transplanted. The offers included those to both urgent and non-urgent patients and first and subsequent offers.



Figure 4.1 Adult heart offer decline rates that resulted in a transplant, 1 April 2013 to 31 March 2016

Table 4.1 compares individual centre heart offer decline rates over the same period by financial year. Harefield and Newcastle have had offer decline rates that are consistently higher than national rate over the last three financial years while Papworth and Birmingham have had consistently lower rates. Overall offer decline rates increased by 10% between 2013/2014 and 2014/2015 and remained at a similar level for 2015/2016.

Centre	Financial year	Total No. Offers	Declined		Accepted, not used		Transplanted	
		N	Ν	(%)	N	(%)	Ν	(%)
Birmingham	2013/14	67	46	(69)	0	(0)	21	(31)
	2014/15	111	80	(72)	2	(2)	29	(26)
	2015/16	98	72	(73)	0	(0)	26	(27)
	Overall	276	198	(72)	2	(1)	76	(28)
Glasgow	2013/14	60	41	(68)	0	(0)	19	(32)
-	2014/15	97	84	(87)	0	(0)	13	(13)
	2015/16	118	111	(94)	0	(0)	7	(6)
	Overall	275	236	(86)	0	(0)	39	(14)
Harefield	2013/14	185	158	(85)	1	(1)	26	(14)
	2014/15	284	259	(91)	0	(0)	25	(9)
	2015/16	262	240	(92)	1	(0)	21	(8)
	Overall	731	657	(90)	2	(0)	72	(10)
Manchester	2013/14	118	88	(75)	1	(1)	29	(25)
	2014/15	142	116	(82)	0	(0)	26	(18)
	2015/16	116	85	(73)	0	(0)	31	(27)
	Overall	376	289	(77)	1	(0)	86	(23)
Newcastle	2013/14	179	146	(82)	2	(1)	31	(17)
	2014/15	229	209	(91)	0	(0)	20	(9)
	2015/16	426	393	(92)	2	(0)	31	(7)
	Overall	834	748	(90)	4	(0)	82	(10)
Papworth	2013/14	112	64	(57)	1	(1)	47	(42)
	2014/15	130	96	(74)	0	(0)	34	(26)
	2015/16	127	88	(69)	1	(1)	38	(30
	Overall	369	248	(67)	2	(1)	119	(32

Table 4.1 Adult Heart (including cardiac block) offer results by transplant centre, 1 April 2013 and 31 March 2016										
Centre	Financial year	Total No. Declined		Accepted, I	not used	Transplanted				
		Offers								
		N	N	(%)	N	(%)	N	(%)		
UK	2013/14	721	543	(75)	5	(1)	173	(24)		
	2014/15	993	844	(85)	2	(0)	147	(15)		
	2015/16	1147	989	(86)	4	(0)	154	(13)		
	Overall	2861	2376	(83)	11	(0)	474	(17)		

ADULT HEART TRANSPLANTATION Transplants



5.1 Adult heart transplants, 1 April 2006 – 31 March 2016

Figure 5.1 and **5.2** show the total number of adult heart transplants performed in the last ten years overall and by centre, respectively. The number of transplants increased steadily between 2009 and 2013, after which a substantial increase occurred, most recently due to DCD heart transplants. The number of transplants increased by 12% over the last financial year. The number of transplants in the latest financial year (2015/2016) is shown by centre in **Figure 5.3**.







Figure 5.2 Number of adult heart transplants in the UK, by financial year and centre, 1 April 2006 to 31 March 2016



Figure 5.3 Number of adult heart transplants in the UK, by centre, 1 April 2015 to 31 March 2016

Figure 5.4 and **5.5** show the total number of adult heart transplants performed in the last ten years overall and by centre, respectively, by urgency status. The number of transplants by urgency status in the latest financial year (2015/2016) is shown by centre in **Figure 5.6**. The proportion of urgent transplants performed in each financial year has increased from 28% in 2006/2007 to 79% in 2015/2016. The proportion of urgent transplants performed at each centre in 2015/2016 ranged from 59% at Papworth to 100% at Glasgow.







Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2006 to 31 March 2016




The demographic characteristics of 160 adult heart transplant recipients in the latest year are shown by centre and overall in **Table 5.1**. 75% of these recipients were male and the <u>median</u> age was 51 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 5.1 Demogra	aphic characteristi	cs of adult heart t	ransplants 1 Ap	oril 2015 to 31	March 2016, by	v centre		
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	Glasgow N (%)	TOTAL N (%)
Number		22 (100)	51 (100)	25 (100)	26 (100)	29 (100)	7 (100)	160 (100)
Urgency status at	Non-urgent	4 (18)	21 (41)	4 (16)	3 (12)	2 (7)	0 (0)	34 (21)
transplant	Urgent	18 (82)	30 (59)	21 (84)	23 (88)	27 (93)	7 (100)	126 (79)
Recipient sex	Male	16 (73)	36 (71)	19 (76)	21 (81)	23 (79)	5 (71)	120 (75)
	Female	6 (27)	15 (29)	6 (24)	4 (15)	6 (21)	2 (29)	39 (24)
	Missing	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)	1 (1)
Recipient ethnicity	White	20 (91)	36 (71)	19 (76)	21 (81)	26 (90)	6 (86)	128 (80)
	Non-white	2 (9)	15 (29)	6 (24)	5 (19)	2 (7)	1 (14)	31 (19)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Recipient age	Median (<mark>IQR</mark>)	54 (39, 57)	51 (41, 59)	50 (37, 56)	53 (37, 60)	43 (29, 55)	57 (44, 63)	51 (37, 58)
	Missing	0	0	0	0	0	0	0
Recipient weight	Median (<mark>IQR</mark>)	76 (65, 89)	72 (65, 85)	74 (63, 81)	84 (76, 89)	79 (64, 91)	76 (58, 86)	76 (66, 86)
	Missing	0	0	0	0	0	0	0
NYHA class	II	0 (0)	1 (2)	2 (8)	0 (0)	0 (0)	0 (0)	3 (2)
	III	3 (14)	26 (51)	9 (36)	1 (4)	13 (45)	3 (43)	55 (34)
	IV	17 (77)	23 (45)	14 (56)	24 (92)	16 (55)	3 (43)	97 (61)
	Missing	2 (9)	1 (2)	0 (0)	1 (4)	0 (0)	1 (14)	5 (3)
Recipient in hospital pre- transplant	No Yes Missing	18 (82) 3 (14) 1 (5)	26 (51) 25 (49) 0 (0)	3 (12) 22 (88) 0 (0)	4 (15) 22 (85) 0 (0)	2 (7) 27 (93) 0 (0)	0 (0) 6 (86) 1 (14)	53 (33) 105 (66) 2 (1)
If in hospital, recipient on ventilator	No	3 (100)	25 (100)	22 (100)	22 (100)	27 (100)	6 (100)	105 (100)

Table 5.1Demographic characteristics of adult heart transplants 1 April 2015 to 31 March 2016, by centre										
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	Glasgow N (%)	TOTAL N (%)		
If in hospital, recipient VAD	None Left Right Both	2 (67) 1 (33) 0 (0) 0 (0)	21 (84) 0 (0) 0 (0) 4 (16)	14 (64) 8 (36) 0 (0) 0 (0)	16 (73) 3 (14) 0 (0) 3 (14)	23 (85) 0 (0) 0 (0) 4 (15)	4 (67) 0 (0) 0 (0) 2 (33)	80 (76) 12 (11) 0 (0) 13 (12)		
If in hospital, recipient TAH	No	3 (100)	25 (100)	22 (100)	22 (100)	27 (100)	6 (100)	105 (100)		
If in hospital, recipient	No	3 (100)	25 (100)	22 (100)	21 (95)	27 (100)	6 (100)	104 (99)		
ECMO	Yes	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	0 (0)	1 (1)		
If in hospital, recipient on inotropes	No	1 (33)	6 (24)	6 (27)	2 (9)	3 (11)	4 (67)	22 (21)		
	Yes	2 (67)	19 (76)	16 (73)	20 (91)	24 (89)	2 (33)	83 (79)		
If in hospital, recipient IABP	No Yes Missing	2 (67) 0 (0) 1 (33)	23 (92) 2 (8) 0 (0)	22 (100) 0 (0) 0 (0)	21 (95) 1 (5) 0 (0)	23 (85) 4 (15) 0 (0)	4 (67) 2 (33) 0 (0)	95 (91) 9 (9) 1 (1)		
Recipient CMV status	No	11 (50)	23 (45)	6 (24)	12 (46)	10 (34)	3 (43)	65 (41)		
	Yes	6 (27)	13 (25)	13 (52)	9 (35)	13 (45)	2 (29)	56 (35)		
	Missing	5 (23)	15 (29)	6 (24)	5 (19)	6 (21)	2 (29)	39 (24)		
Recipient HCV status	No	17 (77)	36 (71)	19 (76)	21 (81)	23 (79)	5 (71)	121 (76)		
	Missing	5 (23)	15 (29)	6 (24)	5 (19)	6 (21)	2 (29)	39 (24)		
Recipient HBV status	No	17 (77)	36 (71)	19 (76)	21 (81)	23 (79)	5 (71)	121 (76)		
	Missing	5 (23)	15 (29)	6 (24)	5 (19)	6 (21)	2 (29)	39 (24)		
Recipient HIV status	No	17 (77)	36 (71)	19 (76)	21 (81)	23 (79)	5 (71)	121 (76)		
	Missing	5 (23)	15 (29)	6 (24)	5 (19)	6 (21)	2 (29)	39 (24)		
Recipient Serum	Median (<u>IQR</u>)	96 (82, 149)	113 (87, 140)	99 (84, 117)	99 (79, 123)	96 (78, 118)	100 (91, 118)	105 (84, 130)		
Creatinine	Missing	4	0	0	0	0	2	6		
Donor sex	Male	18 (82)	32 (63)	15 (60)	23 (88)	19 (66)	5 (71)	112 (70)		
	Female	4 (18)	19 (37)	10 (40)	3 (12)	10 (34)	2 (29)	48 (30)		

Table 5.1 Demographic characteristics of adult heart transplants 1 April 2015 to 31 March 2016, by centre									
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	Glasgow N (%)	TOTAL N (%)	
Donor ethnicity	White	17 (77)	46 (90)	23 (92)	25 (96)	26 (90)	7 (100)	144 (90)	
	Non-white	1 (5)	2 (4)	1 (4)	0 (0)	3 (10)	0 (0)	7 (4)	
	Missing	4 (18)	3 (6)	1 (4)	1 (4)	0 (0)	0 (0)	9 (6)	
Donor age	Median (<mark>IQR</mark>)	40 (28, 51)	39 (29, 51)	39 (27, 46)	35 (28, 49)	36 (26, 47)	37 (24, 53)	38 (28, 49)	
	Missing	0	0	0	0	0	0	0	
Donor BMI	Median (<mark>IQR</mark>)	26 (24, 29)	25 (23, 29)	24 (23, 28)	25 (24, 28)	25 (23, 26)	26 (23, 29)	25 (23, 28)	
	Missing	0	0	0	0	0	0	0	
Donor cause of death	CVA	15 (68)	41 (80)	14 (56)	20 (77)	25 (86)	7 (100)	122 (76)	
	Trauma	3 (14)	4 (8)	7 (28)	5 (19)	4 (14)	0 (0)	23 (14)	
	Others	4 (18)	6 (12)	4 (16)	1 (4)	0 (0)	0 (0)	15 (9)	
Donor hypotension	No	9 (41)	39 (76)	19 (76)	19 (73)	23 (79)	5 (71)	114 (71)	
	Yes	12 (55)	12 (24)	6 (24)	2 (8)	5 (17)	1 (14)	38 (24)	
	Missing	1 (5)	0 (0)	0 (0)	5 (19)	1 (3)	1 (14)	8 (5)	
Donor past diabetes	No	20 (91)	51 (100)	25 (100)	24 (92)	25 (86)	6 (86)	151 (94)	
	Yes	1 (5)	0 (0)	0 (0)	1 (4)	3 (10)	0 (0)	5 (3)	
	Missing	1 (5)	0 (0)	0 (0)	1 (4)	1 (3)	1 (14)	4 (3)	
Donor past cardiothoracic disease	No	17 (77)	35 (69)	19 (76)	21 (81)	22 (76)	5 (71)	119 (74)	
	Missing	5 (23)	16 (31)	6 (24)	5 (19)	7 (24)	2 (29)	41 (26)	
Donor past hypertension	No Yes Missing	20 (91) 1 (5) 1 (5)	44 (86) 7 (14) 0 (0)	24 (96) 1 (4) 0 (0)	23 (88) 3 (12) 0 (0)	25 (86) 3 (10) 1 (3)	4 (57) 1 (14) 2 (29)	140 (88) 16 (10) 4 (3)	
Donor past tumour	No	21 (95)	49 (96)	22 (88)	26 (100)	26 (90)	6 (86)	150 (94)	
	Yes	0 (0)	0 (0)	3 (12)	0 (0)	2 (7)	0 (0)	5 (3)	
	Missing	1 (5)	2 (4)	0 (0)	0 (0)	1 (3)	1 (14)	5 (3)	
Donor past smoker	No	15 (68)	22 (43)	11 (44)	12 (46)	11 (38)	5 (71)	76 (48)	
	Yes	6 (27)	29 (57)	14 (56)	14 (54)	17 (59)	1 (14)	81 (51)	
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	1 (3)	1 (14)	3 (2)	

5.2 Total ischaemia time, 1 April 2006 – 31 March 2016

Figure 5.7 shows the <u>median</u> total ischaemia time in adult <u>DBD</u> donor heart transplants over the last 10 years. The <u>median</u> total ischaemia time has remained fairly stable over the last 10 years.



Figure 5.7 Median total ischaemia time in adult DBD donor heart transplants, by financial year, 1 April 2006 to 31 March 2016

¹ Does not take into account use of donor organ maintenance systems

Figure 5.8 and **Figure 5.9** show the <u>median</u> total ischaemia time in adult <u>DBD</u> donor heart transplants, by centre, in the latest financial year (2015/2016) and over the last 10 years respectively. Papworth has seen an overall decrease in <u>median</u> total ischaemia time. Harefield experienced a substantial increase in <u>median</u> total ischaemia time during 2013/2014 which has led to this centre having a much higher <u>median</u> time than all other centres. However, this analysis does not take into account the use of donor organ maintenance systems for some transplants. These enable warm blood perfusion to continue ex-vivo during transportation. For such transplants, the definition of total ischaemia time used here (cross-clamp to reperfusion) overestimates the true ischaemia time because the heart is not subject to ischaemia during transportation.





Figure 5.9 Median total ischaemia time in adult DBD donor heart transplants, by transplant centre and financial year, 1 April 2006 to 31 March 2016





ADULT HEART TRANSPLANTATION

Post-Transplant Survival



The survival analysis results presented in this section exclude:

- Multi-organ transplants
- Second (or greater) graft transplants

30-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2011 to 31 March 2015 while 5-year survival rates are based on transplants performed in the period 1 April 2007 to 31 March 2011.

For the 529 adult heart transplants that were performed in the period 1 April 2011 and 31 March 2015, 30-day outcome information was known for all 529 patients. Thirty day <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these heart transplants is shown in **Table 6.1**. None of the centres apart from Papworth were statistically significantly different to the national rate, as shown in the <u>funnel plot</u> in **Figure 6.1**. 30-day survival at Papworth exceeded the 99.8% <u>confidence interval</u> indicating that their risk-adjusted post-transplant survival was significantly different to the national one.

The <u>risk factors</u> used in these models are found in **Appendix A3.1**. Please note that these models do not include ischaemia time as a risk factor. Ischaemia time is understood to be one of the most dominant factors in terms of short-term survival however the use of donor organ maintenance systems mean that ischaemia time can no longer be calculated in the traditional manner (time between cross clamp and reperfusion). It is therefore not appropriate to include a term for ischaemia time in the models until a detailed data collection process on these systems has taken place and the statistical impact of their use upon post-transplant survival has been investigated.

Donor type has not been accounted for in the model as there was only 1 DCD heart transplant over the period 1 April 2007 to 31 March 2015.

Table 6.1 30 day p 1 April 2	atient survival aft 011 and 31 March	er first ad n 2015	ult heart transpla	ants, by	centre,			
Centre	% 30 day survival (95% CI) Number of <u>Unadjusted</u> <u>Risk-adjusted</u> transplants							
Newcastle	80	80	(69.4 - 87.2)	80.3	(67.8 - 87.9)			
Papworth	133	94.7	(89.3 - 97.5)	95.2	(90.0 - 97.7)			
Harefield	81	87.7	(78.3 - 93.2)	84.5	(71.1 - 91.6)			
Birmingnam	89	89.9	(81.5 - 94.6) (85.2 - 06.5)	90.1	(81.0 - 94.8)			
Glasgow	50	78	(63.8 - 87.2)	91.0 82.5	(68.3 - 90.3)			
UK	529	88.7	(85.6 - 91.1)					
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 98.8% confidence limit								

Figure 6.1 Risk-adjusted 30 day patient survival for adult heart transplants, by centre , 1 April 2011 to 31 March 2015



For the 529 adult heart transplants that were performed in the period 1 April 2011 and 31 March 2015, one-year outcome information was known for 467 patients. One year <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these heart transplants is shown in **Table 6.2**. None of the centres were statistically significantly different to the national rate, as shown in the <u>funnel plot</u> in **Figure 6.2**. 1-year patient survival at Papworth exceeded the 95% <u>confidence limit</u>, whilst at Newcastle and Glasgow this fell below the 95% <u>confidence limit</u>, but both were within the 99.8% <u>confidence interval</u>.

Table 6.2 1 year patient survival after first adult heart transplants, by centre,1 April 2011 and 31 March 2015											
Centre	Number of transplants	% 1 year survival (95% CI) Number of <u>Unadjusted</u> <u>Risk-adjusted</u> transplants									
Newcastle Papworth Harefield Birmingham Manchester Glasgow	80 133 81 89 96 50	73.8 87.9 82.7 83.1 88.5 71.8	(62.6 - 82) (81.1 - 92.4) (72.6 - 89.4) (73.6 - 89.5) (80.3 - 93.5) (57.1 - 82.3)	72.1 90.0 82.9 82.0 86.5 70.1	(57.2 - 81.8) (83.7 - 93.9) (71.2 - 89.9) (70.1 - 89.1) (75.5 - 92.5) (49.4 - 82.3)						
UK	52982.8(79.3 - 85.7)Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 98.8% confidence limit										

Figure 6.2 Risk-adjusted one-year patient survival for adult heart transplants, by centre, 1 April 2011 to 31 March 2015



Number of transplants

For the 360 adult heart transplants that were performed in the period 1 April 2007 and 31 March 2011, 5-year outcome information was known for 325 patients. Five year <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these heart transplants is shown in **Table 6.3** and **Figure 6.3**. None of the centres apart from Glasgow were statistically significantly different to the national rate, as shown in the funnel plot in **Figure 6.3**. 5-year patient survival at Glasgow was below the 99.8% <u>confidence limit</u> indicating that their risk-adjusted post-transplant survival was significantly different to the national rate. The number of transplants performed by Glasgow over this period is however much lower than at the other five centres.

Table 6.3 5 year patient survival after first adult heart transplants, by centre,1 April 2007 and 31 March 2011										
Centre	Number of transplants	% 5 year survival (95% CI) Number of <u>Unadjusted</u> <u>Risk-adjusted</u> transplants								
Newcastle Papworth Harefield Birmingham Manchester Glasgow	72 91 54 68 47 28	77.7 79.1 63 67.6 78.7 56.9	(66.2 - 85.7) (69.2 - 86.1) (48.7 - 74.3) (55.1 - 77.3) (64 - 87.9) (36.8 - 72.8)	76.1 81.1 60.4 71.6 78.2 33.6	(61.0 - 85.4) (70.4 - 87.9) (38.6 - 74.5) (56.8 - 81.3) (59.4 - 88.2) (0 - 62.3)					
UK	36072.4(67.5 - 76.8)Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 98.8% confidence limit									



Figure 6.3 Risk-adjusted five year patient survival for adult heart transplants, by centre, 1 April 2007 to 31 March 2011

ADULT HEART TRANSPLANTATION Survival from Listing



Survival from listing was analysed for patients \geq 18 years registered for the first time for a heart transplant between 1 January 2004 and 31 December 2015. 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 <u>risk-adjusted</u> survival rates from the point of heart transplant listing are shown by centre in **Figures 7.1**, **7.2** and **7.3** respectively. These rates are also shown in **Table 7.1**.

In terms of one year survival rate, two centres fell above and two fell below the upper and lower 95% <u>confidence intervals</u>, respectively, however survival rates for Birmingham only were below the 99.8% <u>confidence limits</u>. Five and ten year survival from listing rates fell below the 99.8% <u>confidence limit</u> for Newcastle and above the 99.8% <u>confidence limit</u> for Papworth suggesting that these rates may be significantly lower than the national average.

Table 7.1	Risk-adjusted 1, 5 and 10 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2004 to 31 December 2015											
Centre		One ye	ear	Five y	<i>r</i> ear	Ten y	ear					
		N	(%)	N	(%)	N	(%)					
Birmingham		298	(72)	298	(57)	298	(45)					
Glasgow		164	(79)	164	(62)	164	(52)					
Harefield		367	(82)	367	(64)	367	(55)					
Manchester		281	(86)	281	(73)	281	(60)					
Newcastle		344	(74)	344	(51)	344	(39)					
Papworth		490	(85)	490	(72)	490	(62)					
UK		1944	(80)	1944	(64)	1944	(53)					
		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 from listing



Figure 7.2 Risk-adjusted five year patient survival from listing





Figure 7.3 Risk-adjusted ten year patient survival from listing

ADULT LUNG TRANSPLANTATION Transplant List



8.1 Adult lung and heart/lung transplant list as at 31 March, 2007 – 2016

Figure 8.1 shows the number of adult patients on the lung transplant list at 31 March each year between 2007 and 2016. The number of patients actively waiting for a lung transplant decreased from 284 in 2007 to 211 in 2011 and has since been on the increase, reaching 321 in 2016.

Figure 8.1 Adult patients on the lung transplant list at 31 March each year for the last 10 years, by year



Figure 8.2 shows the number of adult patients on the <u>active lung transplant list</u> on 31 March 2016 by centre. In total, there were 321 adult patients. Harefield had the largest proportion (40%) of the transplant list whilst Birmingham had the smallest (10%).





Figure 8.3 shows the number of adult patients on the transplant list at 31 March each year between 2007 and 2016 for each centre.



Figure 8.3 Adult patients on the lung transplant list at 31 March each year for the last 10 years, by year and centre

The demographic characteristics of the 321 adult patients on the <u>active lung transplant list</u> on 31 March 2016 are shown by centre and overall in **Table 8.1.** 45% of the recipients were male and the <u>median</u> age was 52 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 8.1 Demo	graphic characteristics of adult lu	ung transplant list	patients at 31 Ma	rch 2016, by centre			
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	TOTAL N (%)
Number		65 (100)	51 (100)	127 (100)	31 (100)	47 (100)	321 (100)
Recipient sex	Male	28 (43)	24 (47)	60 (47)	15 (48)	18 (38)	145 (45)
	Female	37 (57)	27 (53)	67 (53)	16 (52)	29 (62)	176 (55)
Recipient ethnicity	White	64 (98)	47 (92)	113 (89)	29 (94)	45 (96)	298 (93)
	Non-white	1 (2)	4 (8)	14 (11)	2 (6)	1 (2)	22 (7)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (0)
Recipient age	Median (<u>IQR</u>)	52 (35, 59)	52 (43, 63)	51 (37, 58)	52 (38, 57)	55 (45, 60)	52 (39, 59)
	Missing	0	0	0	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	18 (28)	12 (24)	41 (32)	9 (29)	7 (15)	87 (27)
	Fibrosing lung disease	22 (34)	12 (24)	31 (24)	4 (13)	14 (30)	83 (26)
	COPD and emphysema	13 (20)	3 (6)	31 (24)	3 (10)	15 (32)	65 (20)
	Primary pulmonary hypertension	2 (3)	2 (4)	2 (2)	0 (0)	5 (11)	11 (3)
	Other	10 (15)	22 (43)	22 (17)	14 (45)	6 (13)	74 (23)
	Missing	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (0)
Smoker	No	61 (94)	50 (98)	127 (100)	31 (100)	47 (100)	316 (98)
	Yes	1 (2)	1 (2)	0 (0)	0 (0)	0 (0)	2 (1)
	Missing	3 (5)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1)
Lung function - FEV1	Median (<u>IQR</u>)	0.90 (0.65, 1.35)	1.32 (0.88, 1.66)	0.97 (0.62, 1.48)	0.91 (0.70, 1.40)	1.14 (0.64, 2.37)	0.97 (0.66, 1.56)
	Missing	2	1	1	0	2	6
Lung function - FVC	Median (<u>IQR</u>)	1.80 (1.39, 2.60)	2.13 (1.65, 2.56)	1.93 (1.49, 2.40)	2.43 (1.67, 2.77)	2.54 (1.80, 3.17)	2.00 (1.56, 2.67)
	Missing	2	0	1	0	2	5

8.2 Post-registration outcomes, 1 April 2012 – 31 March 2013

An indication of outcomes for adult patients first listed for a lung transplant in the period is summarised in **Figure 8.4**. This is only for first registrations for these patients. This shows the proportion of patients transplanted or still waiting six months, one, two and three years after joining the list. It also shows the proportion removed from the transplant list (typically because they become too unwell for transplant) and those who died while on the transplant list. Within six month of listings, 41% of lung patients were transplanted while 8% died waiting. Three years after listing 69% have received a transplant.





8.3 Median waiting time to transplant, 1 April 2010 - 31 March 2013

The <u>median</u> waiting time to transplant for adult patients on the lung transplant list is shown in **Figure 8.5** and **Table 8.2**. This is estimated for any lung only patient in the time period using the <u>Kaplan Meier</u> method. The national <u>median</u> waiting time is 230 days and ranges from 209 days at Manchester to 289 days at Birmingham.





Table 8.2	Median waiting time to deceased donor transplant for adult patients registered on the lung transplant list, 1 April 2010 to 31 March 2013										
Transplant centre Number of patients Waiting time (days)											
		registered	<u>Median</u>	95% Confidence interval							
Newcastle		172	261	201 - 321							
Papworth		131	224	148 - 300							
Harefield		199	214	155 - 273							
Birmingham		62	289	159 - 419							
Manchester		105	209	132 - 286							
UK		669	230	198 - 262							

ADULT LUNG TRANSPLANTATION

Response to Offers



Figures 9.1a and **9.1b** compare individual centre adult lung offer decline rates with the national rate between 1 April 2013 and 31 March 2016 for bilateral lung offers and single lung offers, respectively. This includes offers that were accepted and then not used by centres. Offer decline rates at Harefield and Birmingham fall outside of the 99.8% confidence limits. This indicates that Birmingham had a significantly higher and Harefield had a significantly lower offer decline rate than the national average. No centres significantly differed from the national rate in terms of single lung offer decline rates however.

This analysis excludes fast track offers and considers only those offers that resulted in transplant. Heart lung blocks are treated as bilateral lungs in this analysis.







Figure 9.1b Adult single lung offer decline rates for organs that resulted in transplant, 1 April 2013 to 31 March 2016

Table 9.1 and **9.2** compare individual centre lung offer decline rates over the same period by financial year, for bilateral lung offers and single lung offers respectively. Declines and acceptances with non-use in **Table 9.1** are counted only for cases where the full bilateral lung was declined or accepted with non-use. Transplanted organs are then split by bilateral organ and single lungs.

Table 9.1 Adult	bilateral lung offer re	sults, by transplan	t centre, 1 April	2013 to 3	1 March 2016				
Centre	Financial year	Total No. Offers	Declined		Accepted, not used		Tra	ansplanted	
		Ν	Bilateral lungs	(%)	Bilateral lungs	(%)	Bilateral lungs	Single lungs	(%)
Birmingham	2013/14	65	47	(72)	0	(0)	14	4	(28)
	2014/15	41	24	(59)	0	(0)	15	2	(41)
	2015/16	43	24	(56)	0	(0)	19	0	(44)
	Overall	149	95	(64)	0	(0)	48	6	(36)
Harefield	2013/14	88	41	(47)	0	(0)	46	1	(53)
	2014/15	56	17	(30)	0	(0)	37	2	(70)
	2015/16	54	20	(37)	0	(0)	33	1	(63)
	Overall	198	78	(39)	0	(0)	116	4	(61)
Manchester	2013/14	72	45	(63)	1	(1)	20	6	(36)
	2014/15	40	23	(58)	0	(0)	12	5	(43)
	2015/16	49	26	(53)	2	(4)	16	5	(43)
	Overall	161	94	(58)	3	(2)	48	16	(40)
Newcastle	2013/14	91	44	(48)	3	(3)	40	4	(48)
	2014/15	51	18	(35)	1	(2)	30	2	(63)
	2015/16	64	37	(58)	0	(0)	25	2	(42)
	Overall	206	99	(48)	4	(2)	95	8	(50)
Papworth	2013/14	77	43	(56)	1	(1)	27	6	(43)
	2014/15	49	19	(39)	1	(2)	26	3	(59)
	2015/16	49	16	(33)	1	(2)	30	2	(65)
	Overall	175	78	(45)	3	(2)	83	11	(54)
UK	2013/14	393	220	(56)	5	(1)	147	21	(43)
	2014/15	237	101	(43)	2	(1)	120	14	(57)
	2015/16	259	123	(47)	3	(1)	123	10	(51)
	Overall	889	444	(50)	10	(1)	390	45	(49)

Table 9.2 Adult single lung offer results, by transplant centre, 1 April 2013 to 31 March 2016										
Centre	Financial year	Total No. Offers	Decline	d	Accepted, no	t used	Transplant	ted		
		N	Ν	(%)	Ν	(%)	Ν	(%)		
Birmingham	2013/14	20	19	(95)	0	(0)	1	(5)		
	2014/15	8	8	100)	0	(0)	0	(0)		
	2015/16	10	8	(80)	1	(10)	1	(10)		
	Overall	38	35	(92)	1	(3)	2	(5)		
Harefield	2013/14	24	22	(92)	0	(0)	2	(8)		
	2014/15	10	10	100)	0	(0)	0	(0)		
	2015/16	9	9	100)	0	(0)	0	(0)		
	Overall	43	41	(95)	0	(0)	2	(5)		
Manchester	2013/14	21	18	(86)	0	(0)	3	(14)		
	2014/15	14	13	(93)	0	(0)	1	(7)		
	2015/16	5	5	100)	0	(0)	0	(0)		
	Overall	40	36	(90)	0	(0)	4	(10)		
Newcastle	2013/14	20	19	(95)	0	(0)	1	(5)		
	2014/15	14	13	(93)	0	(0)	1	(7)		
	2015/16	8	8	100)	0	(0)	0	(0)		
	Overall	42	40	(95)	0	(0)	2	(5)		
Papworth	2013/14	25	24	(96)	0	(0)	1	(4)		
	2014/15	16	16	100)	0	(0)	0	(0)		
	2015/16	6	6	100)	0	(0)	0	(0)		
	Overall	47	46	(98)	0	(0)	1	(2)		
UK	2013/14	110	102	(93)	0	(0)	8	(7)		
	2014/15	62	60	(97)	0	(0)	2	(3)		
	2015/16	38	36	(95)	1	(3)	1	(3)		
	Overall	210	198	(94)	1	(0)	11	(5)		

ADULT LUNG TRANSPLANTATION

Transplants



10.1 Adult lung and heart/lung transplants, 1 April 2006 – 31 March 2016

Figure 10.1 and **10.2** show the total number of adult lung transplants performed in the last ten years overall and by centre, respectively. The number of transplants from donors after brain death (<u>DBD</u>) has generally increased since 2007 from 111 to 146 in 2015/2016. The number of transplants in the latest financial year (2015/2016) is shown by centre in **Figure 10.3**.



Figure 10.1 Number of adult lung transplants in the UK, by financial year, 1 April 2006 to 31 March 2016



Figure 10.2 Number of adult lung transplants in the UK, by financial year and centre, 1 April 2006 to 31 March 2016



Figure 10.3 Number of adult lung transplants in the UK, by centre, 1 April 2015 to 31 March 2016

Figure 10.4 and **10.5** show the total number of adult lung transplants performed in the last ten years overall and by centre, respectively, by transplant type. The number of transplants by transplant type in the latest financial year (2015/2016) is shown by centre in **Figure 10.6**. The proportion of bilateral lung transplants has increased from 69% in 2006/2007 to 88% in 2015/2016. The proportion of bilateral lung transplants as performed at each centre in 2015/2016 ranged from 65% at Manchester to 96% at Harefield.





Figure 10.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2006 to 31 March 2016



* includes 1 partial lung transplant



Figure 10.6 Number of adult lung transplants in the UK, by centre, 1 April 2015 to 31 March 2016

The demographic characteristics of 179 adult lung transplant recipients in the latest year are shown by centre and overall in **Table 10.1**. 61% of these recipients were male and the <u>median</u> age was 52 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 10.1 Demogr	Table 10.1 Demographic characteristics of adult lung transplants 1 April 2015 to 31 March 2016, by centre											
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	TOTAL					
Number		42 (100)	39 (100)	50 (100)	25 (100)	23 (100)	179 (100)					
Transplant type	Single lung	3 (7)	5 (13)	1 (2)	1 (4)	6 (26)	16 (9)					
	Bilateral lung	39 (93)	32 (82)	48 (96)	23 (92)	15 (65)	157 (88)					
	Partial lung	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)					
	Heart/lung	0 (0)	2 (5)	1 (2)	1 (4)	2 (9)	6 (3)					
Recipient sex	Male	22 (52)	27 (69)	30 (60)	16 (64)	14 (61)	109 (61)					
	Female	20 (48)	12 (31)	20 (40)	9 (36)	9 (39)	70 (39)					
Recipient ethnicity	White	40 (95)	37 (95)	48 (96)	22 (88)	21 (91)	168 (94)					
	Non-white	2 (5)	2 (5)	2 (4)	3 (12)	1 (4)	10 (6)					
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	1 (1)					
Recipient age	Median (<u>IQR</u>)	57 (44, 61)	50 (33, 62)	45 (28, 56)	52 (46, 57)	54 (50, 61)	52 (39, 61)					
	Missing	0	0	0	0	0	0					
Recipient weight	Median (<u>IQR</u>)	74 (61, 83)	64 (60, 73)	61 (50, 75)	65 (62, 84)	74 (59, 80)	66 (56, 77)					
	Missing	0	0	0	0	0	0					
NYHA class	I	0 (0)	0 (0)	0 (0)	21 (84)	1 (4)	22 (12)					
	II	0 (0)	3 (8)	12 (24)	0 (0)	0 (0)	15 (8)					
	III	3 (7)	25 (64)	32 (64)	0 (0)	22 (96)	82 (46)					
	IV	1 (2)	11 (28)	5 (10)	1 (4)	0 (0)	18 (10)					
	Missing	38 (90)	0 (0)	1 (2)	3 (12)	0 (0)	42 (24)					
Recipient in hospital pre-transplant	No	38 (90)	38 (97)	39 (78)	22 (88)	22 (96)	159 (89)					
	Yes	1 (2)	1 (3)	10 (20)	3 (12)	1 (4)	16 (9)					
	Missing	3 (7)	0 (0)	1 (2)	0 (0)	0 (0)	4 (2)					
If in hospital, recipient on ventilator	No	0 (0)	1 (100)	6 (60)	3 (100)	1 (100)	11 (69)					
	Yes	1 (100)	0 (0)	4 (40)	0 (0)	0 (0)	5 (31)					

Table 10.1 Demographic characteristics of adult lung transplants 1 April 2015 to 31 March 2016, by centre							
		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	TOTAL
If in hospital, recipient on inotropes	No	1 (100)	1 (100)	8 (80)	2 (67)	1 (100)	13 (81)
	Yes	0 (0)	0 (0)	2 (20)	1 (33)	0 (0)	3 (19)
If in hospital, recipient on ECMO	No Yes Missing	0 (0) 1 (100) 0 (0)	0 (0) 1 (100) 0 (0)	5 (50) 5 (50) 0 (0)	2 (67) 0 (0) 1 (33)	1 (100) 0 (0) 0 (0)	8 (50) 7 (44) 1 (6)
Recipient CMV status	No	22 (52)	18 (46)	23 (46)	11 (44)	11 (48)	85 (48)
	Yes	15 (36)	12 (31)	19 (38)	7 (28)	8 (35)	61 (34)
	Missing	5 (12)	9 (23)	8 (16)	7 (28)	4 (17)	33 (18)
Recipient HCV status	No	37 (88)	31 (79)	42 (84)	18 (72)	19 (83)	147 (82)
	Missing	5 (12)	8 (21)	8 (16)	7 (28)	4 (17)	32 (18)
Recipient HBV status	No	37 (88)	31 (79)	42 (84)	18 (72)	19 (83)	147 (82)
	Missing	5 (12)	8 (21)	8 (16)	7 (28)	4 (17)	32 (18)
Recipient HIV status	No	37 (88)	31 (79)	42 (84)	18 (72)	19 (83)	147 (82)
	Missing	5 (12)	8 (21)	8 (16)	7 (28)	4 (17)	32 (18)
Recipient Serum	Median (<u>IQR</u>)	67 (57, 94)	72 (60, 90)	57 (49, 74)	71 (58, 87)	70 (62, 81)	68 (56, 83)
Creatinine	Missing	7	0	3	3	0	13
Donor sex	Male	15 (36)	16 (41)	27 (54)	11 (44)	10 (43)	79 (44)
	Female	27 (64)	23 (59)	23 (46)	14 (56)	13 (57)	100 (56)
Donor ethnicity	White	37 (88)	36 (92)	41 (82)	21 (84)	20 (87)	155 (87)
	Non-white	1 (2)	1 (3)	5 (10)	2 (8)	0 (0)	9 (5)
	Missing	4 (10)	2 (5)	4 (8)	2 (8)	3 (13)	15 (8)
Donor age	Median (<u>IQR</u>)	46 (32, 55)	46 (36, 54)	40 (26, 51)	47 (25, 54)	45 (27, 52)	44 (29, 54)
	Missing	0	0	0	0	0	0
Donor BMI	Median (<u>IQR</u>)	25 (22, 29)	24 (22, 29)	24 (22, 28)	24 (22, 26)	26 (21, 29)	24 (22, 28)
	Missing	0	0	0	0	0	0
Donor cause of death	CVA	40 (95)	31 (79)	40 (80)	22 (88)	21 (91)	154 (86)
	Trauma	2 (5)	4 (10)	3 (6)	1 (4)	1 (4)	11 (6)
	Others	0 (0)	4 (10)	7 (14)	2 (8)	1 (4)	14 (8)
Table 10.1 Demographic characteristics of adult lung transplants 1 April 2015 to 31 March 2016, by centre							
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		Newcastle N (%)	Papworth N (%)	Harefield N (%)	Birmingham N (%)	Manchester N (%)	TOTAL
Donor hypotension	No	20 (48)	32 (82)	32 (64)	14 (56)	17 (74)	115 (64)
	Yes	18 (43)	6 (15)	15 (30)	6 (24)	6 (26)	51 (29)
	Missing	4 (10)	1 (3)	3 (6)	5 (20)	0 (0)	13 (7)
Donor past cardiothoracic disease	No	34 (81)	29 (74)	41 (82)	18 (72)	18 (78)	140 (78)
	Yes	3 (7)	2 (5)	1 (2)	0 (0)	0 (0)	6 (3)
	Missing	5 (12)	8 (21)	8 (16)	7 (28)	5 (22)	33 (18)
Donor past hypertension	No Yes Missing	33 (79) 6 (14) 3 (7)	27 (69) 11 (28) 1 (3)	39 (78) 10 (20) 1 (2)	19 (76) 5 (20) 1 (4)	16 (70) 7 (30) 0 (0)	134 (75) 39 (22) 6 (3)
Donor past tumour	No	37 (88)	38 (97)	46 (92)	22 (88)	21 (91)	164 (92)
	Yes	1 (2)	1 (3)	2 (4)	3 (12)	2 (9)	9 (5)
	Missing	4 (10)	0 (0)	2 (4)	0 (0)	0 (0)	6 (3)
Donor past smoker	No	24 (57)	21 (54)	27 (54)	15 (60)	13 (57)	100 (56)
	Yes	15 (36)	18 (46)	21 (42)	9 (36)	10 (43)	73 (41)
	Missing	3 (7)	0 (0)	2 (4)	1 (4)	0 (0)	6 (3)

10.2 Total ischaemia time, 1 April 2006 – 31 March 2016

Figure 10.7 shows the <u>median</u> total ischaemia time in adult <u>DBD</u> donor lung transplants over the last 10 years. The <u>median</u> total ischaemia time has remained fairly stable over the last 10 years.





Figure 10.8 and **Figure 10.9** show the <u>median</u> total ischaemia time in adult <u>DBD</u> donor lung transplants, by centre, for the latest financial year (2015/2016) and over the last 10 years respectively. This analysis does not take into account the use of donor organ maintenance systems for some transplants. These enable warm blood perfusion to continue ex-vivo during transportation. For such transplants, the definition of total ischemia time used here (cross-clamp to reperfusion) over-estimates the true ischaemia time because the lungs are not subject to ischaemia during transportation.





Figure 10.9 Median total ischaemia time in adult DBD donor lung transplants, by transplant centre and financial year, 1 April 2006 to 31 March 2016





ADULT LUNG TRANSPLANTATION

Post-Transplant Survival



The survival analysis results presented in this section exclude:

- <u>Multi-organ transplants</u> (including heart/lung transplants)
- Second (or greater) graft transplants
- Partial lung transplants

90-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2011 to 31 March 2015 while 5-year survival rates are based on transplants performed in the period 1 April 2007 to 31 March 2011.

For the 719 adult lung transplants that were performed in the period 1 April 2011 and 31 March 2015, 90-day outcome information was known for 717 patients. Ninety day <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these lung transplants is shown in **Table 11.1**. None of the centres were statistically significantly different to the national rate, as shown in the <u>funnel plot</u> in **Figure 11.1**. 90 day survival at Birmingham fell below the 95% <u>confidence interval</u> but was within the 99.8% <u>confidence limit</u>. The <u>risk factors</u> used in these models are found in **Appendix A3.2**.

Table 11.1 90 day patient survival after first adult lung transplants, by centre,1 April 2011 and 31 March 2015								
			% 90 dav survi	val (95%	CI)			
Centre	Number of transplants	<u>L</u>	Inadjusted	Ris	k-adjusted			
Newcastle	195	87.6	(82 1 - 91 5)	88.0	(82 1 - 92 0)			
Panworth	139	92.8	(87 - 96 1)	92.8	(86.7 - 96.1)			
Harefield	202	90.6	(85 7 - 93 9)	90.0	(84 3 - 93 6)			
Birmingham	76	78.9	(68 - 86 5)	79.0	(65.6 - 87.1)			
Manchester	107	92.5	(85.6 - 96.2)	92.9	(85.9 - 96.5)			
UK	719	89.3	(86.8 - 91.3)					
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 98.8% confidence limit								





For the 719 adult lung transplants that were performed in the period 1 April 2011 and 31 March 2015, one-year outcome information was known for 652 patients. One year <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these lung transplants is shown in **Table 11.2**. None of the centres were statistically significantly different to the national rate, as shown in the <u>funnel plot</u> in **Figure 11.2**. Again, survival at Birmingham fell below the 95% <u>confidence interval</u> but was within the 99.8% <u>confidence limit</u>.

95% CI)						
Risk-adjusted						
(0 (70 1 - 83 7)						
(70.1 - 03.7)						
(735-862)						
(13.3 - 00.2)						
(34.2 - 79.1)						
7 (72.8 - 88.9)						
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit						
nit						
limit						
7 4 0 9 2						

Figure 11.2 Risk-adjusted one-year patient survival for adult lung transplants, by centre, 1 April 2011 to 31 March 2015



For the 536 adult lung transplants that were performed in the period 1 April 2007 and 31 March 2011, 5-year outcome information was known for 473 patients. Five year <u>unadjusted</u> and <u>risk-adjusted</u> patient survival for these lung transplants is shown in **Table 11.3**. None of the centres apart from Birmingham were statistically significantly different to the national rate, as shown in the funnel plot in **Figure 11.3**. 5-year patient survival at Birmingham was below the 99.8% <u>confidence limit</u> indicating that their risk-adjusted post-transplant survival was significantly different to the national rate.

Table 11.3 5 year patient survival after first adult lung transplants, by centre,1 April 2007 and 31 March 2011							
Centre	Number of transplants	L	% 5 year survi <u>Inadjusted</u>	val (95% <u>Ris</u>	CI) sk-adjusted		
Newcastle Papworth Harefield Birmingham Manchester	162 103 153 35 83	62.1 57 63.8 53.8 46.9	(53.7 - 69.3) (46.8 - 65.9) (55.6 - 70.8) (36 - 68.6) (35.9 - 57.2)	59.5 62.4 62.1 39.2 57.8	(47.4 - 68.9) (48.9 - 72.3) (50.5 - 71.0) (14.0 - 57.0) (41.5 - 69.6)		
UK	536	58.5	(54.1 - 62.6)				
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 98.8% confidence limit							

Figure 11.3 Risk-adjusted five year patient survival for adult lung transplants, by centre, 1 April 2007 to 31 March 2011



ADULT LUNG TRANSPLANTATION

Survival from Listing



Survival from listing was analysed for patients \geq 18 years registered for the first time for a lung transplant between 1 January 2004 and 31 December 2015. 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 <u>risk-adjusted</u> survival rates from the point of lung transplant listing are shown by centre in **Figures 12.1**, **12.2** and **12.3** respectively. These rates are also shown in **Table 12.1**.

In terms of one year survival rate, one centre fell below the lower 95% <u>confidence</u> <u>intervals</u>, however all survival rates were within the 99.8% <u>confidence limits</u>, Five and ten year survival from listing rates at Birmingham, however, fell below the 99.8% <u>confidence</u> <u>limit</u> suggesting that these rates may be significantly lower than the national average. Ten year survival from listing rate at Papworth fell just below the 99.8% <u>confidence limit</u> whilst at Harefield, this fell above the 99.8% <u>confidence limit</u>.

Table 12.1Risk-adjusted 1, 5 and 10 year patient survival from listing for first deceased donor lung only transplant in patients registered between 1 January 2004 and 31 December 2015							
Centre		One	vear	Five	e vear	Ten	vear
		Ν	(%)	Ν	(%)	Ν	(%)
Birmingham		255	(70)	255	(34)	255	(15)
Harefield		745	(79)	745	(52)	745	(37)
Manchester		437	(78)	437	(46)	437	(28)
Newcastle		749	(75)	749	(49)	749	(34)
Papworth		476	(76)	476	(43)	476	(25)
UK		2662	(76)	2662	(47)	2662	(30)
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 one year patient survival from listing

Figure 12.2 Risk-adjusted five year patient survival from listing





Figure 12.3 Risk-adjusted ten year patient survival from listing

PAEDIATRIC HEART TRANSPLANTATION

Transplant List



13.1 Paediatric heart only transplant list as at 31 March, 2007 – 2016

Figure 13.1 shows the number of paediatric patients on the heart transplant list at 31 March each year between 2007 and 2016. The overall number of patients actively waiting for a heart transplant increased substantially from 16 in 2013 to 37 in 2016. The number of patients on the urgent transplant list has increased from 0 in 2007 to 12 in 2016, with an average of 6.1 patients on the list on the 31st March each year.

Figure 13.1 Paediatric patients on the heart transplant list at 31 March each year for the last 10 years, by year



Figure 13.2 shows the number of paediatric patients on the <u>active heart transplant list</u> at 31 March 2016 by centre. In total, there were 37 paediatric patients. Great Ormond Street Hospital (GOSH) had the largest proportion (65%) of the transplant list. Seven patients at Newcastle and five at GOSH were on the urgent list at this time.





Figure 13.3 shows the number of paediatric patients on the transplant list at 31 March each year between 2007 and 2016 for each centre.





The demographic characteristics of the 37 paediatric patients on the <u>active heart transplant list</u> on 31 March 2016 are shown by centre and overall in **Table 13.1.** 76% of the recipients were male and the <u>median</u> age was 6 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 13.1 Demographic ch by centre	naracteristics of paediatric he	eart transplant list p	oatients at 31 Marcl	n 2016,
		Newcastle N (%)	Great Ormond Street N (%)	TOTAL
Number		13 (100)	24 (100)	37 (100)
Urgency status	Urgent	6 (46)	19 (79)	25 (68)
	Non-urgent	7 (54)	5 (21)	12 (32)
Recipient sex	Male	11 (85)	17 (71)	28 (76)
	Female	2 (15)	7 (29)	9 (24)
Recipient ethnicity	White	8 (62)	17 (71)	25 (68)
	Non-white	5 (38)	7 (29)	12 (32)
Recipient age	Median (<u>IQR</u>)	5 (2, 9)	9 (2, 12)	8 (2, 11)
	Missing	0	0	0
Primary Disease	Cardiomyopathy	4 (31)	7 (29)	11 (30)
	Congenital heart disease	7 (54)	8 (33)	15 (41)
	Other heart disease	0 (0)	1 (4)	1 (3)
	Others	2 (15)	8 (33)	10 (27)
Previous open heart surgery	None One More than one Missing	0 (0) 1 (8) 4 (31) 8 (62)	16 (67) 1 (4) 6 (25) 1 (4)	16 (43) 2 (5) 10 (27) 9 (24)
Previous thoracotomy	No	3 (23)	19 (79)	22 (60)
	Yes	0 (0)	5 (21)	5 (14)
	Missing	9 (69)	0 (0)	9 (24)
Serum Bilirubin (umol/l)	Median (<u>IQR</u>)	17 (10, 28)	13 (8, 23)	13 (8, 23)
	Missing	9	11	20
Serum Creatinine (umol/l)	Median (<u>IQR</u>)	32 (25, 51)	42 (31, 62)	41 (29, 62)
	Missing	9	11	20

13.2 Post-registration outcomes, 1 April 2012 – 31 March 2013

An indication of outcomes for paediatric patients listed for a non-urgent heart transplant is summarised in **Figure 13.4** whilst outcomes for patients registered urgently are shown in **Figure 13.5**. For patients that have been registered on either the non-urgent or the urgent heart allocation scheme more than once, only the first non-urgent and the first urgent registration, respectively, is considered. **Figure 13.5** includes patients who have been urgently listed over the period, including those who have moved from the routine list. These charts show the proportion of patients transplanted or still waiting six months, one, two and three years after joining the list. They also show the proportion removed from the transplant list (typically because they become too unwell for transplant) and those who died while on the transplant list. Within six months of listing, 0% of non-urgent heart patients were transplanted while 8% died waiting. One year after listing, there were no patients actively waiting on the routine list; 75% had been moved to the urgent list, 8% had been removed and 17% had died waiting.

Figure 13.4 Post-registration outcome for 12 new non-urgent heart only registrations made in the UK, 1 April 2012 to 31 March 2013





Figure 13.5 Post-registration outcome for 34 new urgent heart only registrations made in the UK, 1 April 2012 to 31 March 2013

13.3 Median waiting time to transplant, 1 April 2010 - 31 March 2013

Table 13.2 shows the overall <u>median</u> waiting time and, separately, the median waiting time for patients that have never been registered on the urgent list and patients registered on the urgent list at any point during their registration. This is estimated for any heart only patient in the time period using the <u>Kaplan Meier</u> method. For ever urgent patients, their waiting time includes any time spent on the routine list, as well as on the urgent list. The national median waiting time is 96 days.

Table 13.2	Median w on the he	vaiting time to deceased do art transplant list, 1 April 2	nor transplant for p 010 to 31 March 201	aediatric patients registered 3
Transplant ce	entre	Number of patients registered	Waitin <u>Median</u>	g time (days) 95% <u>Confidence interval</u>
All patients (active waitin	Total g time)			
Newcastle Great Ormone	d Street	63 76	64 145	32 - 96 113 - 177
UK		139	96	61 - 131
Never urgent (Routine acti waiting time)	t ive)			
Newcastle ¹ Great Ormone	d Street	5 23	357	- 0 - 793
UK		28	357	0 - 839
Ever urgent (active waitin	(Total g time)			
Newcastle Great Ormone	d Street	58 53	64 91	33 - 95 29 - 153
UK		111	81	56 - 106
¹ <u>Median</u> waitin	ng time cann	ot be estimated		

PAEDIATRIC HEART TRANSPLANTATION

Response to Offers



Table 14.1 compares individual centre paediatric heart offer decline rates over time by financial year. Over the three year period 1 April 2013 to 31 March 2016, offer decline rates at Newcastle were slightly lower than at Great Ormond Street.

Table 14.1 Paedia	atric Heart (including	g cardiac block)	offer results	by transpl	ant centre, betw	een 1 April 2	2013 and 31 Ma	rch 2016
Centre	ntre Financial year Total Offer		Declined		Accepted, not used		Transplanted	
		Ν	Ν	(%)	Ν	(%)	Ν	(%)
London, Great	2013/14	18	12	(67)	0	(0)	6	(33)
Ormond Street	2014/15	26	18	(69)	0	(0)	8	(31)
	2015/16	58	49	(84)	1	(2)	8	(14)
	Overall	102	79	(77)	1	(1)	22	(22)
Newcastle	2013/14	27	19	(70)	0	(0)	8	(30)
	2014/15	26	13	(50)	0	(0)	13	(50)
	2015/16	66	58	(88)	0	(0)	8	(12)
	Overall	119	90	(76)	0	(0)	29	(24)
UK	2013/14	45	31	(69)	0	(0)	14	(31)
	2014/15	52	31	(60)	0	(0)	21	(40)
	2015/16	124	107	(86)	1	(1)	16	(13)
	Overall	221	169	(76)	1	ÌO	51	(23)

PAEDIATRIC HEART TRANSPLANTATION

Transplants



15.1 Paediatric heart only transplants, 1 April 2006 – 31 March 2016

Figure 15.1 and **15.2** show the total number of paediatric heart transplants performed in the last ten years overall and by centre, respectively. The number of transplants fell from 40 in 2010/2011 to 24 in 2012/2013 and has since risen to 34 in 2015/2016 All paediatric heart only transplants performed in 2015/2016 were <u>DBD</u> transplants.



Figure 15.1 Number of paediatric heart transplants in the UK, by financial year, 1 April 2006 to 31 March 2016

Figure 15.2 Number of paediatric heart transplants in the UK, by financial year and centre, 1 April 2006 to 31 March 2016



Figure 15.3 and **15.4** show the total number of paediatric heart transplants performed in the last ten years overall and by centre, respectively, by urgency status. The number of transplants by urgency status in the latest financial year (2015/2016) is shown by centre in **Figure 15.5**. The proportion of urgent transplants performed in each financial year has increased from 41% in 2006/2007 to 88% in 2015/2016. The proportion of urgent transplants performed at both Newcastle and Great Ormond Street Hospital (GOSH) was over 80%.

Figure 15.3 Number of paediatric heart transplants in the UK, by financial year and urgency status, 1 April 2006 to 31 March 2016



Figure 15.4 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2006 to 31 March 2016





Figure 15.5 Number of paediatric heart transplants in the UK, by centre, 1 April 2015 to 31 March 2016

The demographic characteristics of 34 paediatric heart transplant recipients in the latest year are shown by centre and overall in **Table 15.1**. 35% of these recipients were male and the <u>median</u> age was 6 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 15.1 Demographic characteristics of paediatric heart transplants 1 April 2015 to 31 March 2016,by centre						
		Newcastle N (%)	Great Ormond Street N (%)	TOTAL		
Number		19 (100)	15 (100)	34 (100)		
Urgency status at transplant	Urgent	18 (95)	12 (80)	30 (88)		
	Non-urgent	1 (5)	3 (20)	4 (12)		
Recipient sex	Male	7 (37)	5 (33)	12 (35)		
	Female	12 (63)	10 (67)	22 (65)		
Recipient ethnicity	White	15 (79)	9 (60)	24 (71)		
	Non-white	4 (21)	5 (33)	9 (27)		
	Missing	0 (0)	1 (7)	1 (3)		
Recipient age	Median (<u>IQR</u>)	6 (1, 12)	7 (3, 13)	6 (3, 12)		
	Missing	0	0	0		
Recipient weight	Median (<u>IQR</u>)	20 (14, 42)	18 (12, 25)	19 (13, 29)		
	Missing	1	0	1		
NYHA class	III	1 (5)	0 (0)	1 (3)		
	IV	18 (95)	2 (13)	20 (59)		
	Missing	0 (0)	13 (87)	13 (38)		
Recipient in hospital pre-transplant	No	4 (21)	1 (7)	5 (15)		
	Yes	15 (79)	3 (20)	18 (53)		
	Missing	0 (0)	11 (73)	11 (32)		
If in hospital, recipient on ventilator	No	6 (40)	2 (67)	8 (44)		
	Yes	9 (60)	1 (33)	10 (56)		
If in hospital, recipient VAD	None	6 (40)	2 (67)	8 (44)		
	Left	3 (20)	0 (0)	3 (17)		
	Right	2 (13)	0 (0)	2 (11)		
	Both	4 (27)	1 (33)	5 (28)		
If in hospital, recipient TAH	No	15 (100)	3 (100)	18 (100)		
If in hospital, recipient ECMO	No	10 (67)	3 (100)	13 (72)		
	Yes	5 (33)	0 (0)	5 (28)		
If in hospital, recipient on inotropes	No	1 (7)	3 (100)	4 (22)		
	Yes	14 (93)	0 (0)	14 (78)		
If in hospital, recipient IABP	No	13 (87)	3 (100)	16 (89)		
	Yes	2 (13)	0 (0)	2 (11)		
Recipient CMV status	No	7 (37)	8 (53)	15 (44)		
	Yes	4 (21)	4 (27)	8 (24)		
	Missing	8 (42)	3 (20)	11 (32)		
Recipient HCV status	No	11 (58)	12 (80)	23 (68)		
	Missing	8 (42)	3 (20)	11 (32)		

by centre				
		Newcastle N (%)	Great Ormond Street N (%)	TOTAL
Recipient HBV status	No	11 (58)	12 (80)	23 (68)
	Missing	8 (42)	3 (20)	11 (32)
Recipient HIV status	No	11 (58)	12 (80)	23 (68)
	Missing	8 (42)	3 (20)	11 (32)
Recipient Serum Creatinine	Median (<u>IQR</u>)	46 (31, 64)	28 (22, 36)	37 (24, 62)
	Missing	1	11	12
Donor sex	Male	6 (32)	6 (40)	12 (35)
	Female	13 (68)	9 (60)	22 (65)
Donor ethnicity	White	13 (68)	8 (53)	21 (62)
	Non-white	2 (11)	2 (13)	4 (12)
	Missing	4 (21)	5 (33)	9 (27)
Donor age	Median (<u>IQR</u>)	15 (7, 42)	12 (11, 36)	14 (11, 37)
	Missing	0	0	0
Donor BMI	Median (<u>IQR</u>)	22 (15, 24)	19 (16, 21)	20 (16, 23)
	Missing	0	0	0
Donor cause of death	CVA	14 (74)	11 (73)	25 (74)
	Trauma	2 (11)	2 (13)	4 (12)
	Others	3 (16)	2 (13)	5 (15)
Donor hypotension	No	8 (42)	3 (20)	11 (32)
	Yes	10 (53)	1 (7)	11 (32)
	Missing	1 (5)	11 (73)	12 (35)
Donor past diabetes	No	18 (95)	3 (20)	21 (62)
	Yes	1 (5)	1 (7)	2 (6)
	Missing	0 (0)	11 (73)	11 (32)
Donor past cardiothoracic disease	No	11 (58)	11 (73)	22 (65)
	Missing	8 (42)	4 (27)	12 (35)
Donor past hypertension	No	18 (95)	3 (20)	21 (62)
	Yes	1 (5)	1 (7)	2 (6)
	Missing	0 (0)	11 (73)	11 (32)
Donor past tumour	No	19 (100)	3 (20)	22 (65)
	Yes	0 (0)	1 (7)	1 (3)
	Missing	0 (0)	11 (73)	11 (32)
Donor past smoker	No	13 (68)	3 (20)	16 (47)
	Yes	6 (32)	1 (7)	7 (21)
	Missing	0 (0)	11 (73)	11 (32)

Table 15.1 Demographic characteristics of paediatric heart transplants 1 April 2015 to 31 March 2016, by centre

15.2 Total ischaemia time, 1 April 2006 – 31 March 2016

Figure 15.6 shows the <u>median</u> total ischaemia time in paediatric <u>DBD</u> donor heart transplants over the last 10 years. The <u>median</u> total ischaemia time has remained fairly stable over the last 10 years.

Figure 15.6 Median total ischaemia time in paediatric DBD donor heart transplants, by financial year, 1 April 2006 to 31 March 2016



Table 15.2 shows the <u>median</u> total ischaemia time, where reported, in paediatric <u>DBD</u> donor heart transplants, by centre, over the last 10 years. This analysis does not take into account the use of donor organ maintenance systems for some transplants. These enable warm blood perfusion to continue ex-vivo during transportation. For such transplants, the definition of total ischemia time used here (cross-clamp to reperfusion) over-estimates the true ischaemia time because the heart is not subject to ischaemia during transportation.

Median total inchesmis time for peopletric DDI

..

by c	entre and financial year, ²	1 April 2006 - 31 Marc	ch 2016	
		Total i	schaemia time (ł	nours)
Transplant centre	e Financial year	Number of transplants with total ischaemia time reported	<u>Median</u>	Interquartile range
Newcastle	2006/2007 2007/2008 2008/2009 2009/2010 2010/2011 2011/2012 2012/2013 2013/2014 2014/2015 2015/2016 Total	11 10 13 13 17 15 13 10 18 18 18 138	3.6 3.2 3.5 3.6 3.3 3.8 3.4 3.3 3.4 3.7 3.5	(3.3 - 4.3) (3 - 3.6) (2.9 - 3.9) (3.5 - 4.3) (2.8 - 4.3) (3.4 - 4.1) (3 - 3.6) (3.2 - 3.5) (2.9 - 3.8) (3.2 - 4.2) (3.1 - 4)
London, Great Ormond Street	2006/2007 2007/2008 2008/2009 2009/2010 2010/2011 2011/2012 2012/2013 2013/2014 2014/2015 2015/2016 Total	15 13 12 18 7 6 4 10 4 3 92	4 4.3 3.9 4 4.1 3 3.6 3.9 3.6 3.7 3.9	$\begin{array}{c} (3.6 - 4.6) \\ (2.6 - 4.5) \\ (3.4 - 4.3) \\ (2.3 - 4.3) \\ (3.8 - 4.6) \\ (2.3 - 4) \\ (2.9 - 4.7) \\ (3.7 - 5.3) \\ (3.3 - 3.9) \\ (2.4 - 5.5) \\ \textbf{(3.3 - 4.4)} \end{array}$
Overall	Total	230	3.6	(3.2 - 4.2)

PAEDIATRIC HEART TRANSPLANTATION

Post-Transplant Survival



The survival analysis results presented in this section exclude:

- <u>Multi-organ transplants</u>
- Second (or greater) graft transplants

30-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2011 to 31 March 2015 while 5-year survival rates are based on transplants performed in the period 1 April 2007 to 31 March 2011.

For the 124 paediatric heart transplants that were performed in the period 1 April 2011 and 31 March 2015, 30-day outcome information was known for all 124 patients. Thirty day <u>unadjusted</u> patient survival for these heart transplants is shown in **Table 16.1**. As the 95% <u>confidence limits</u> for Great Ormond Street and Newcastle overlap, this suggests that there is no statistically significant difference between the two centres.

Table 16.1 30 day patient survival after first paediatric heart transplants, by centre,1 April 2011 and 31 March 2015							
Centre	Number of transplants	Number of deaths	% 30 day s (un:	survival (95% CI) adjusted)			
Newcastle	61	3	95.1	(85.5 - 98.4)			
London, Great Ormond Street	63	2	96.8	(87.9 - 99.2)			
ик	124	5	96	(90.6 - 98.3)			

For the 124 paediatric heart transplants that were performed in the period 1 April 2011 and 31 March 2015, 1-year outcome information was known for 113 patients. One year <u>unadjusted</u> patient survival for these heart transplants is shown in **Table 16.2**. As the 95% <u>confidence limits</u> for Great Ormond Street and Newcastle overlap, this suggests that there is no statistically significant difference between the two centres.

Table 16.2 1 year patient survival after first paediatric heart transplants, by centre,1 April 2011 and 31 March 2015							
Centre	Number of transplants	Number of deaths	% 1 year survival (95% CI) (unadjusted)				
Newcastle	61	7	88.5	(77.4 - 94.4)			
London, Great Ormond Street	63	6	90.5	(80 - 95.6)			
υκ	124	13	89.5	(82.6 - 93.8)			

For the 133 paediatric heart transplants that were performed in the period 1 April 2007 and 31 March 2011, 5-year outcome information was known for 116 patients. Five year <u>unadjusted</u> patient survival for these heart transplants is shown in **Table 16.3**. As the 95% <u>confidence limits</u> for Great Ormond Street and Newcastle overlap, this suggests that there is no statistically significant difference between the two centres.

Table 16.3 5 year patient survival after first paediatric heart transplants, by centre,1 April 2007 and 31 March 2011						
Centre	Number of transplants	Number of deaths	% 5 year survival (95% CI) (unadjusted)			
Newcastle	61	10	83.6	(71.7 - 90.8)		
London, Great Ormond Street	72	11	84.4	(73.6 - 91.1)		
υκ	133	21	84.1	(76.7 - 89.3)		

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List



17.1 Paediatric lung and heart/lung transplant list as at 31 March, 2007 – 2016

Figure 17.1 shows the number of paediatric patients on the lung transplant list at 31 March each year between 2007 and 2016. The number of patients actively waiting for a lung transplant increased each year from 7 in 2007 to 17 in 2013 but has dropped to 9 in 2016.

Figure 17.1 Paediatric patients on the lung transplant list at 31 March each year for the last 10 years, by year



Figure 17.2 shows the number of paediatric patients on the <u>active lung transplant list</u> at 31 March 2016 by centre. In total, there were 9 paediatric patients. All of these patients were at Great Ormond Street Hospital.





Transplant centre
Figure 17.3 shows the number of paediatric patients on the transplant list at 31 March each year between 2007 and 2016 for each centre.





The demographic characteristics of the 9 paediatric patients on the <u>active lung transplant list</u> on 31 March 2016 are shown by centre and overall in **Table 17.1**. 44% of the recipients were male and the <u>median</u> age was 10 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 17.1 Demograpl by centre	hic characteristics of paediatric lung	transplant list p	atients at 31 March	2016,
		Newcastle	Great Ormond Street	TOTAL
		N (%)	N (%)	N (%)
Number		0	9 (100)	9 (100)
Recipient sex	Male	-	4 (44)	4 (44)
	Female	-	5 (56)	5 (56)
Recipient ethnicity	White	-	7 (78)	7 (78)
	Non-white	-	2 (22)	2 (22)
Recipient age	Median (<u>IQR</u>)	-	10 (5, 15)	10 (5, 15)
	Missing	-	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	-	2 (22)	2 (22)
	Fibrosing lung disease	-	1 (11)	1 (11)
	Primary pulmonary hypertension	-	2 (22)	2 (22)
	Other	-	4 (44)	4 (44)
Smoker	No	-	9 (100)	9 (100)
Lung function - FEV1	Median (<u>IQR</u>) Missing	-	0.50 (0.42, 0.57) 7	0.50 (0.42, 0.57) 7
Lung function - FVC	Median (<u>IQR</u>) Missing	-	0.73 (0.69, 0.76) 7	0.73 (0.69, 0.76) 7

17.2 Post-registration outcomes, 1 April 2012 – 31 March 2013

An indication of outcomes for paediatric patients listed for a lung transplant is summarised in **Figure 17.4**. This is only for first registrations for these patients. This shows the proportion of patients transplanted or still waiting six months, one, two and three years after joining the list. It also shows the proportion removed from the transplant list (typically because they become too unwell for transplant) and those who died while on the transplant list. Within six month of listings, all 6 patients were still waiting on the list. Three years after listing 50% have received a transplant.



Figure 17.4 Post-registration outcome for 6 new lung only registrations made in the UK, 1 April 2012 to 31 March 2013

17.3 Median waiting time to transplant, 1 April 2010 - 31 March 2013

The <u>median</u> waiting time to transplant for paediatric patients on the lung transplant list is shown in **Figure 17.5** and **Table 17.2**. This is estimated for any lung only patient in the time period using the <u>Kaplan Meier</u> method. The national median waiting time is 527 days.

Table 17.2Median waiting time to deceased donor transplant for paediatric patients registered on the lung transplant list, 1 April 2010 to 31 March 2013								
Transplant ce	entre	Number of patients	Waitin	g time (davs)				
		registered	Median	95% Confidence interval				
Newcastle		4	256	39 - 473				
London, Grea Ormond Stre	at et	26	650	331 - 969				
UK		30	527	128 - 926				

PAEDIATRIC LUNG TRANSPLANTATION

Response to Offers



Table 18.1 compares individual centre paediatric lung offer decline rates over the period 1 April 2013 to 31 March 2016 by financial year, for bilateral lung offers and single lung offers respectively. This analysis excludes fast track offers and considers only those offers that resulted in transplant. Heart-lung blocks are treated as bilateral lungs in the analysis. Declines and acceptances with non-use in **Table 18.1** are counted only for cases where the full bilateral lung was declined or accepted with non-use. Transplanted organs are then split by bilateral organ and single lungs.

Table 18.1 Paedi	atric bilateral lung o	ffer results by trans	splant centre, 1	April 201	3 to 31 March 20	16			
Centre	Financial year	Total Offer	Decline Bilateral	d	Accepted, no Bilateral	t used	Tra Bilateral	ansplanted Single	
		Ν	lungs	(%)	lungs	(%)	lungs	lungs	(%)
London, Great	2013/14	4	0	(0)	0	(0)	4	0	100)
Ormond Street	2014/15	11	7	(64)	0	(0)	4	0	(36)
	2015/16	14	12	(86)	0	(0)	2	0	(14)
	Overall	29	19	(66)	0	(0)	10	0	(34)
Newcastle	2013/14	5	4	(80)	0	(0)	1	0	(20)
	2014/15	13	12	(92)	0	(0)	1	0	(8)
	2015/16	15	10	(67)	0	(0)	5	0	(33)
	Overall	33	26	(79)	0	(0)	7	0	(21)
UK	2013/14	9	4	(44)	0	(0)	5	0	(56)
	2014/15	24	19	(79)	0	ÌO	5	0	(21)
	2015/16	29	22	(76)	0	ÌÓ	7	0	(24)
	Overall	62	45	(73)	0	Ì0́)	17	0	(27)

Transplanted organs are then split into bilateral and single lungs.

PAEDIATRIC LUNG TRANSPLANTATION

Transplants



19.1 Paediatric lung and heart/lung transplants, 1 April 2006 – 31 March 2016

Figure 19.1 and **19.2** show the total number of paediatric lung transplants performed in the last ten years overall 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 9 in 2015/2016. The number of transplants in the latest financial year (2015/2016) is shown by centre in **Figure 19.3**.





Figure 19.2 Number of paediatric lung transplants in the UK, by financial year and centre, 1 April 2006 to 31 March 2016





Figure 19.3 Number of paediatric lung transplants in the UK, by centre, 1 April 2015 to 31 March 2016

Figure 19.4 and **19.5** show the total number of paediatric lung transplants performed in the last ten years overall and by centre, respectively, by transplant type. The number of transplants by transplant type in the latest financial year (2015/2016) is shown by centre in **Figure 19.6**.







Figure 19.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2006 to 31 March 2016

Figure 19.6 Number of paediatric lung transplants in the UK, by centre, 1 April 2015 to 31 March 2016



The demographic characteristics of 9 paediatric lung transplant recipients in the latest year are shown by centre and overall in **Table 19.1**. 56% of these recipients were male and the <u>median</u> age was 14 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 19.1 Demographic characteristics of paediatric lung transplants 1 April 2015 to 31 March 2016,by centre							
		Newcastle	Great Ormond Street	TOTAL			
Number		2 (100)	7 (100)	9 (100)			
Recipient sex	Male	2 (100)	3 (43)	5 (56)			
	Female	0 (0)	4 (57)	4 (44)			
Recipient ethnicity	White	2 (100)	6 (86)	8 (89)			
	Non-white	0 (0)	1 (14)	1 (11)			
Recipient age	Median (IQR)	13 (11, 15)	14 (10, 15)	14 (11, 15)			
	Missing	0	0	0			
Recipient weight	Median (IQR)	34 (28, 40)	40 (29, 46)	40 (29, 40)			
	Missing	0	0	0			
NYHA class	Missing	2 (100)	7 (100)	9 (100)			
Recipient in hospital pre-transplant	No	1 (50)	1 (14)	2 (22)			
	Missing	1 (50)	6 (86)	7 (78)			
If in hospital, recipient on ventilator	No	0 (0)	0 (0)	0 (0)			
If in hospital, recipient on inotropes	No	0 (0)	0 (0)	0 (0)			
Recipient CMV status	No	1 (50)	2 (29)	3 (33)			
	Yes	1 (50)	5 (71)	6 (67)			
Recipient HCV status	No	2 (100)	7 (100)	9 (100)			
Recipient HBV status	No	2 (100)	7 (100)	9 (100)			
Recipient HIV status	No	2 (100)	7 (100)	9 (100)			
Recipient Serum Creatinine	Median (IQR)	60 (60, 60)	28 (28, 28)	44 (28, 60)			
	Missing	1	6	7			
Donor sex	Male	2 (100)	2 (29)	4 (44)			
	Female	0 (0)	5 (71)	5 (56)			
Donor ethnicity	White	2 (100)	4 (57)	6 (67)			
	Non-white	0 (0)	1 (14)	1 (11)			
	Missing	0 (0)	2 (29)	2 (22)			
Donor age	Median (IQR)	8 (7, 9)	15 (11, 43)	12 (9, 42)			
	Missing	0	0	0			
Donor BMI	Median (IQR)	14 (13, 15)	19 (19, 27)	19 (18, 23)			
	Missing	0	0	0			
Donor cause of death	CVA	1 (50)	6 (86)	7 (78)			
	Trauma	1 (50)	1 (14)	2 (22)			

Table 19.1 Demographic characteristics of paediatric lung transplants 1 April 2015 to 31 March 2016,
by centre

		Newcastle	Great Ormond Street	TOTAL
		N (%)	N (%)	
Donor hypotension	Yes	1 (50)	1 (14)	2 (22)
	Missing	1 (50)	6 (86)	7 (78)
Donor past cardiothoracic disease	No	2 (100)	7 (100)	9 (100)
Donor past hypertension	No	1 (50)	1 (14)	2 (22)
	Missing	1 (50)	6 (86)	7 (78)
Donor past tumour	No	1 (50)	1 (14)	2 (22)
	Missing	1 (50)	6 (86)	7 (78)
Donor past smoker	No	1 (50)	1 (14)	2 (22)
	Missing	1 (50)	6 (86)	7 (78)

19.2 Total ischaemia time, 1 April 2006 – 31 March 2016

Table 19.2 shows the <u>median</u> total ischaemia time, where reported, in paediatric <u>DBD</u> donor lung transplants, by centre, over the last 10 years. This analysis does not take into account the use of donor organ maintenance systems for some transplants. These enable warm blood perfusion to continue ex-vivo during transportation. For such transplants, the definition of total ischemia time used here (cross-clamp to reperfusion) over-estimates the true ischaemia time because the lungs are not subject to ischaemia during transportation.

Table 19.2	Median to by centre	otal ischaemia time f and financial year, 1	or paediatric DBD lur I April 2006 - 31 Marc	ng transplants, h 2016	
			Total is	schaemia time (h	ours)
Transplant	t centre	Financial year	Number of transplants with total ischaemia time reported	<u>Median</u>	Interquartile range
Newcastle		2006/2007	1	48	_
Newcastie		2000/2007	1	5.8	-
		2010/2011	1	4.8	-
		2011/2012	1	7.8	-
		2012/2013	1	8.8	-
		2013/2014	2	5.4	(4.4 - 6.3)
		2014/2015	1	5.2	-
		2015/2016	1	4.5	-
		Total	9	5.2	(4.8 - 6.3)
London, Grea	at	2006/2007	8	4.1	(3.9 - 5.6)
Ormond Stree	et	2007/2008	5	4.3	(4.3 - 4.4)
		2008/2009	8	4.4	(3.8 - 4.8)
		2009/2010	7	4.6	(2.8 - 5)
		2010/2011	5	4.9	(3.9 - 5)
		2011/2012	4	6	(5.1 - 6.5)
		2012/2013	2	5.2	(4.1 - 6.3)
		2013/2014	4	4.7	(4.5 - 5.6)
		2014/2015	4	4.3	(3.2 - 4.7)
		2015/2016	0	0	(0 - 0)
		Total	47	4.5	(4 - 5)
Overall		Total	56	4.5	(4.1 - 5.4)

PAEDIATRIC LUNG TRANSPLANTATION

Post-Transplant Survival



The survival analysis results presented in this section exclude:

- <u>Multi-organ transplants</u> (including heart/lung transplants)
- Second (or greater) graft transplants
- Partial lung transplants

90-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2011 to 31 March 2015 while 3-year and 5-year survival rates are based on transplants performed in the period 1 April 2007 to 31 March 2011.

For the 22 paediatric heart transplants that were performed in the period 1 April 2011 and 31 March 2015, 90-day outcome information was known for 21 patients. Ninety day <u>unadjusted</u> patient survival for these lung transplants is shown in **Table 20.1**.

Table 20.1 90 day patient survival after first paediatric lung transplants, by centre,1 April 2011 and 31 March 2015									
Centre	Number of transplants	Number of deaths	% 90 day s (un:	survival (95% CI) adjusted)					
Newcastle	3	0	100	(-)					
London, Great Ormond Street	19	1	94.7	(68.1 - 99.2)					
ик	22	1	95.5	(71.9 - 99.3)					

For the 22 paediatric heart transplants that were performed in the period 1 April 2011 and 31 March 2015, 1-year outcome information was known for 19 patients. One year <u>unadjusted</u> patient survival for these heart transplants is shown in **Table 20.2**.

Table 20.2 1 year patient survival after first paediatric lung transplants, by centre,1 April 2011 and 31 March 2015									
Centre	Number ofNumber% 1 year survival (95% CItransplantsof deaths(unadjusted)								
Newcastle	3	0	100	(-)					
London, Great Ormond Street	19	1	94.7	(68.1 - 99.2)					
UK	22	1	95.5	(71.9 - 99.3)					

For the 29 paediatric heart transplants that were performed in the period 1 April 2007 and 31 March 2011, 5-year outcome information was known for 26 patients. Five year <u>unadjusted</u> patient survival for these lung transplants is shown in **Table 20.3**. As the 95% <u>confidence limits</u> for Great Ormond Street and Newcastle overlap, this suggests that there is no statistically significant difference between the two centres.

Table 20.3 5 year patient survival after first paediatric lung transplants, by centre,1 April 2007 and 31 March 2011									
Centre	Number of transplants	Number of deaths	r % 5 year survival (95% CI) is (unadjusted)						
Newcastle	3	1	66.7	(5.4 - 94.5)					
London, Great Ormond Street	26	8	68.6	(46.8 - 82.9)					
υκ	29	9	68.4	(48 - 82.2)					

FORM RETURN RATES



21.1 Adult heart form return rates, 1 January – 31 December 2015

Form return rates are reported in **Table 21.1** for the cardiothoracic transplant record, 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 2015 for the transplant record, and all requests for follow up forms issued in this time period. Centres highlighted are transplant centres.

Table 21.1 Form return rates for ac	lult hear	t transplants	, 1 Janu	ary 2015 to 3	1 Decer	nber 2015		
Centre	Transp	blant record %	3 mon	th follow-up %	1 yea	r follow-up %	Lifetime follow- %	
	Ν	Returned	Ν	Returned	Ν	Returned	Ν	Returned
Aberdeen Royal Infirmary	-	-	-	-	-	-	1	0
Birmingham, Queen Elizabeth Hospital	29	100	26	96	27	100	196	100
Glasgow, Golden Jubilee National Hospital	8	100	6	100	10	90	142	91
Harefield, Harefield Hospital	24	100	23	100	16	100	553	93
Manchester, Wythenshawe Hospital	29	100	27	100	25	100	227	97
Newcastle, Freeman Hospital	21	95	19	95	14	100	299	99
Oxford, John Radcliffe Hospital	-	-	-	-	-	-	1	0
Papworth, Papworth Hospital	45	100	41	100	32	100	519	100
Sheffield, Northern General Hospital	-	-	-	-	-	-	62	100
Overall	156	99	142	99	124	99	2000	97

21.2 Adult lung form return rates, 1 January – 31 December 2015

Form return rates are reported in **Table 21.1** for the cardiothoracic transplant record, 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 2015 for the transplant record, and all requests for follow up forms issued in this time period. Centres highlighted are transplant centres.

Table 21.2 Form return rates for adult	t lung tra	nsplants, 1	January	/ 2015 to 31	Decem	nber 2015		
Centre	Transp	lant record	3 fol	month llow-up	fo	1 year Illow-up	Lif	etime ow-up
	Ν	% returned	Ν	% returned	Ν	% returned	Ν	% returned
Birmingham, Queen Elizabeth Hospital	22	100	17	100	19	100	78	100
Harefield, Harefield Hospital	57	100	52	100	43	100	371	96
Manchester, Wythenshawe Hospital	26	100	22	100	22	100	146	100
Newcastle, Freeman Hospital	44	95	41	98	35	100	322	98
Papworth, Papworth Hospital	44	100	45	100	40	100	264	100
Sheffield, Northern General Hospital	-	-	-	-	-	-	5	80
Overall	193	99	177	99	159	100	1186	98

21.3 Paediatric heart form return rates, 1 January – 31 December 2015

Form return rates are reported in **Table 21.3** for the cardiothoracic transplant record, 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 2015 for the transplant record, and all requests for follow up forms issued in this time period. Centres highlighted are transplant centres.

Table 21.3	Form return rates for pae	diatric hea	art transplan	its, 1 Ja	nuary 2015	to 31 [December 20	15	
Centre		Transp	lant record	3 ı fol	month llow-up	fo	l year llow-up	Lif foll	etime ow-up
		Ν	% returned	Ν	% returned	Ν	% returned	Ν	% returned
London, Grea Newcastle, Fr	at Ormond Street Hospital reeman Hospital	15 19	93 84	15 16	100 100	14 15	100 100	135 166	99 96
Overall		34	88	31	100	29	100	301	97

21.4 Paediatric lung form return rates, 1 January – 31 December 2015

Form return rates are reported in **Table 21.4** for the cardiothoracic transplant record, 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 2015 for the transplant record, and all requests for follow up forms issued in this time period. Centres highlighted are transplant centres.

Table 21.4 Form return rates for paed	diatric lur	ng transplant	s, 1 Ja	nuary 2015 f	to 31 D	ecember 201	15	
Centre	Transplant record		3 month follow-up		1 year follow-up		Lifetime follow-up	
	Ν	% returned	Ν	% returned	Ν	% returned	Ν	% returned
London, Great Ormond Street Hospital Newcastle, Freeman Hospital	7 2	100 50	6 0	100 0	6 1	100 100	19 13	95 92
Overall	9	89	6	100	7	100	32	94

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 2006 – 31 March 2016	Introduction	None	1196	1618
1 April 2006 – 31 March 2016	Transplants	<u>Multi-organ</u> transplants	1187	1614
1 April 2011 – 31 March 2015	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ</u> <u>transplants</u> (including heart/lung txs) Partial lung transplants Second (or more) graft transplants 	529	719
1 April 2007 – 31 March 2011	Post-transplant survival – • 5-year survival	 <u>Multi-organ</u> <u>transplants</u> (including heart/lung txs) Partial lung transplants Second (or more) graft transplants 	360	536

Table A1.2 Paediatric transplants analysed				
Time period	Report Section	Exclusion criteria	No.heart transplants	No. lung (+ heart/lung) transplants
1 April 2006 – 31 March 2016	Introduction	None	330	74
1 April 2006 – 31 March 2016	Transplants	 <u>Multi-organ</u> transplants 	330	74
1 April 2011 – 31 March 2015	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ</u> <u>transplants</u> (including heart/lung txs) Partial lung transplants Second (or more) graft transplants 	124	22
1 April 2007 – 31 March 2011	Post-transplant survival – • 5-year survival	 <u>Multi-organ</u> <u>transplants</u> (including heart/lung txs) Partial lung transplants Second (or more) graft transplants 	133	29

A2: Methods

Offer Decline rates

The offer decline rate analysis was limited to heart-only (or lung/heart-lung only) offers from <u>DBD</u> donors who had at least one heart (or lung /heart-lung) retrieved and resulted in transplantation. Any from donations after circulatory death donors were excluded.

<u>Funnel plots</u> 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 <u>unadjusted</u> offer decline rate is shown by the solid line while the 95% and 99.8% confidence lines are indicated via a thin and thick dotted line, respectively. Each dot in the plot represents an individual transplant centre. Centres that are positioned above the upper limits indicate on offer decline rate that is higher than the national rate, while centres positioned below the lower limits indicates on offer decline

Unadjusted post-transplant survival rates

Kaplan-Meier methods were used to estimate the <u>unadjusted</u> 30-day patient <u>survival rates</u> for hearts and 90-day patient <u>survival rates</u> for lungs. 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 <u>survival rate</u> 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 <u>Cox Proportional Hazards model</u> 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 the tables below.

The <u>funnel plot</u> 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 <u>confidence limits</u> around this national rate superimposed. In this report, 95% and 99.8% <u>confidence limits</u> were used. Units that lie within the <u>confidence limits</u> 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.

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 2004 and 31 December 2015. 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 27 May 2016 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 <u>multi-organ transplant</u>
- 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 <u>risk-adjusted</u> 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

<u>Survival rates</u> at one, five and ten years post registration were calculated from the risk adjusted survival rate (RASR), obtained as $1 - \{\text{observed number of deaths in follow up period/expected number}\}$ x national mortality rate}. The expected survival rates were estimated from fitting a <u>Cox model</u> 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	<u>Risk factors</u> and categories used in t year survival models	he adult heart risk adjusted 30-day, 1-year and 5-
Donor cause	of death	Vascular Trauma Hypoxic Other
Donor BMI		(modelled as continuous variable)
Donor age		(modelled as continuous variable)
Respiratory a	rrest	Yes
		No
Recipient BMI		(modelled as continuous variable)
Recipient creatinine at transplant		Non-linear spline with knots at 57, 89, 118, 180
ECMO at trar	nsplant (30 day model only)	Yes No
VAD at trans	plant (1 and 5 year models only)	Short-term (including ECMO) Long-term (including total artificial hearts) None
Hospital statu	us at transplant	In hospital Not in hospital
Primary disea	ase	Dilated cardiomyopathy Coronary heart disease Congenital heart disease Other
Sex Mismatc	h	RM:DM RM:DF RF:DM RF:DF

Table A3.2

Risk factors and categories used in the adult lung risk adjusted 90-day. 1- year and 5-year survival model

Donor CMV	Negative
Donor history of smoking	No
	Yes
Recipient daily dose of prednisolone at registration	0
	1-14
	≥ 15
Donor:recipient predicted 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 63.
Ischaemia time (hours)	Non-linear spline with knots at 3, 5, 7 and 11
Transplant type	Single lung Bilateral lung
Primary disease group	COPD and emphysema
	Cystic fibrosis and bronchiectasis
	Fibrosing lung disease
	Primary pulmonary hypertension
	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.

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 <u>survival rate</u> 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 <u>confidence interval</u> 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 <u>confidence interval</u> includes the true value of the quantity we wish to estimate.

Confidence limit

The upper and lower bounds of a <u>confidence interval</u>.

Cox Proportional Hazards model

A statistical model that relates the instantaneous risk (hazard) of an event occurring at a given time point to the <u>risk factors</u> 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 <u>survival rates</u> 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 <u>confidence limits</u> around this national rate superimposed. In this report, 95% and 99.8% <u>confidence limits</u> were used. Units that lie within the <u>confidence limits</u> 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 <u>survival rates</u>. For example, when estimating one year <u>patient survival rates</u>, 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 <u>median</u> 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 <u>survival rates</u> 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 <u>risk</u> <u>factors</u>, among patients. A risk-adjusted <u>survival rate</u> for a centre is the expected survival rate for that centre given the <u>case mix</u> of their patients. Adjusting for <u>case mix</u> 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 <u>survival rates</u> do not take account of <u>risk factors</u> 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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