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REPORT FOR 2020/2021 (1 APRIL 2011 – 31 MARCH 2021)

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EXECUTIVE SUMMARY



1. Executive Summary

This report presents key figures and information about cardiothoracic organ transplantation in the UK. The period reported covers 10 years of heart and lung transplant data, from 1 April 2011 to 31 March 2021. The data include number of patients listed for a transplant, number of transplants performed and <u>survival rates</u> following heart and lung transplantation; both on a national and centre-specific basis. Data were extracted on 15 August 2021.

Key findings

- In the last financial year, 2020/2021, 161 heart transplants were performed across the UK; a 7% decrease from the previous year. The number of lung transplants performed was 91; 43% lower than the previous year and substantially lower than any of the last 10 years, due to the impact of the COVID-19 pandemic. These numbers, which are for adult and paediatric patients combined, represent 2.4 heart transplants per million population and 1.4 lung transplants per million population in the UK.
- Overall, the number of patients waiting for a heart or lung transplant was lower on 31 March 2021 compared with the same time last year, however, when broken down by age group, the number of paediatric patients waiting had increased. The fall in the adult heart and lung lists, by 13% and 27%, respectively, reflects the fact that fewer patients than usual were added to the transplant list during the COVID-19 pandemic.
- During 2020/2021, 77% of adult heart transplants were urgent or super-urgent and 12% were from <u>DCD</u> donors. For paediatric heart transplantion, 81% were urgent or super-urgent and 22% were from <u>DCD</u> donors. For adult lung transplantation, 21% were urgent or super-urgent and 22% were from <u>DCD</u> donors. There were only three paediatric lung transplants.
- The national 30 day rate of survival following adult heart transplantation was 91.4%, which ranged from 81.8% to 95.6% across centres (<u>risk-adjusted</u>). The national 90 day survival rate was 88.3%, ranging from 77.2% to 91.5% across centres (<u>risk-adjusted</u>). The national 1 year survival rate was 84.3%, ranging from 77.7% to 88.9% across centres (<u>risk-adjusted</u>). The national 5 year survival rate was 70.0%, ranging from 63.3% to 79.1% across centres (<u>risk-adjusted</u>). At 5 years, there was some evidence of a significantly higher rate at Papworth in comparison to the national rate.
- The national 90 day rate of survival following adult lung transplantation was 89.9%, which ranged from 86.0% to 97.4% across centres (risk-adjusted), with evidence that the survival rate at Manchester was higher than the national average. The national 1 year survival rate was 81.3%, ranging from 76.4% to 86.7% across centres (risk-adjusted). The national 5 year survival rate was 56.2%, ranging from 31.0% to 62.8% across centres (risk-adjusted), with evidence of a significantly lower rate at Birmingham.
- The national rate of **survival following paediatric heart transplantation** was 96.3% at 30 days, 96.3% at 90 days, 91.7% at 1 year and 82.1% at 5 years. Great Ormond Street Hospital had no deaths within 1 year post-transplant in the analysis cohort.
- The national rate of **survival following paediatric lung transplantation** was 96.0% at 90 days, 84.0% at 1 year, and 70.4% at 5 years. Due to small numbers of transplants, no comparisons were made across centres.

Use of the contents of this report should be acknowledged as follows: Annual Report on Cardiothoracic Organ Transplantation 2020/2021, NHS Blood and Transplant

INTRODUCTION



2. Introduction

This report presents data on activity and outcomes of heart and lung transplant candidates and recipients between 1 April 2011 and 31 March 2021, for all centres performing heart and/or lung transplantation in the UK. Data were obtained from the UK Transplant Registry at NHS Blood and Transplant which holds information relating to donors, recipients and outcomes for all cardiothoracic organ transplants performed in the UK.

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

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

Methods used are described in the <u>Appendix</u>. The centre specific adult <u>survival rates</u> are adjusted for differences in <u>risk 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.

Changes were made to the listing and allocation policies for lung transplantation on 18 May 2017, when certain patients with the greatest clinical need could be registered urgently or super-urgently on the lung transplant list. The year before, in October 2016, a new super-urgent heart registration tier was introduced for adult candidates only, and this was extended to paediatric patients in October 2020.

2.1 Overview

Figure 2.1 shows the number of patients on the <u>active transplant lists</u> at financial year end between 2012 and 2021. The number of patients waiting for a lung transplant generally increased each year up to 2017, when it reached a peak of 378, it then fell slightly in the next three years and then dropped substantially to 271 on 31 March 2021. The number of patients waiting for a heart transplant doubled between 2012 and 2020, from 169 to 340. In the latest year the number has fallen to 311.





Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the <u>active</u> <u>transplant lists</u> at 31 March 2021 at each centre. In total, there were 522 adult and 60 paediatric patients waiting for a heart or lung transplant. Newcastle had the highest number of adult patients on the heart transplant list and Harefield had the highest number of adult patients on the lung transplant list. Note that Glasgow does not perform lung transplantation. Great Ormond Street Hospital had the highest number of paediatric patients on both the heart and lung transplant lists. These numbers include 2 patients waiting for a multi-organ transplant (1 heart and liver and 1 lung and liver).

Compared with the previous year (see <u>Sections 3.1</u> and <u>9.1</u>), most adult centres have seen a decrease in their heart and lung waiting lists, while paediatric centres have seen an increase (see <u>Sections 15.1</u> and <u>20.1</u>).



Figure 2.2 Number of adult patients on the active heart and lung transplant lists at 31 March 2021, by centre

Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists at 31 March 2021, by centre



Figure 2.4 shows the total number of transplants performed in each of the last ten financial years. The number of heart transplants last year was 161, 7% lower than in 2019/2020. The number of lung transplants last year also fell, by 43% to 91, the lowest it has been over the last 10 years.





Figure 2.5 and **Figure 2.6** show the number of adult and paediatric transplants carried out in the most recent financial year at each centre. Papworth performed the highest number of adult heart transplants and Harefield performed the highest number of adult lung transplants. Great Ormond Street Hospital performed the highest number of paediatric heart and lung transplants. Compared with the previous year (see <u>sections 5.1</u> and <u>17.1</u>), all adult centres performed fewer adult heart and adult lung transplants, except Glasgow who performed more heart transplants. In paediatric transplantation, Great Ormond Street Hospital performed both more heart and more lung transplants in 2020/2021 compared with the previous year, whereas Newcastle performed fewer, with no paediatric lung transplants in 2020/2021 (see <u>sections 11.1</u> and <u>22.1</u>).





Figure 2.6 Number of paediatric cardiothoracic organ transplants in the UK, by centre, 1 April 2020 to 31 March 2021



Figure 2.7 shows a breakdown of the 3,181 adult cardiothoracic organ transplants performed in the UK in the ten year period while **Figure 2.8** shows a similar breakdown for the 367 paediatric transplants performed during the same period. In the remainder of this report, <u>multi-organ transplants</u> are excluded, hence 3,165 adult and all paediatric transplants are analysed further (those in the light blue boxes). In the survival sections, first transplants from deceased donors only are analysed (those in the pink boxes) and the time period of transplants is restricted to allow time for follow-up data to be reported to the registry.



Figure 2.7 Adult cardiothoracic organ transplants performed in the UK, 1 April 2011 to 31 March 2021

¹ Includes 7 heart and kidney, 5 heart and liver, 3 lung and liver and 1 lung and kidney transplant

² Includes 125 DCD heart transplants and 3 domino donor transplants



Figure 2.8 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2011 to 31 March 2021

¹ Includes 10 DCD heart transplants

² Deceased donor transplant

2.2 Geographical variation in registration and transplant rates

Figure 2.9 shows rates of registration to the heart transplant list per million population (pmp) between 1 April 2020 and 31 March 2021 compared with heart transplant rates pmp for the same time period, by recipient country/NHS region of residence. **Table 2.1** shows the actual numbers as well as rates. If a patient has had more than one registration/transplant in the period, each registration/transplant is considered. Note that this analysis only considers NHS Group 1 patients. The UK heart registration and transplant rates are 3.9 pmp and 2.4 pmp respectively.

Since there will inevitably be some random variation in rates between areas, the systematic component of variation (SCV) was used to identify if the variation is more (or less) than a random effect for the different NHS regions in England only. Only first registrations and transplants in the period were considered. The larger the SCV the greater the evidence of a high level of systematic variation between areas. Registration and transplant rates yielded an SCV of 0.02 (p-value = 0.06) and 0.04 (p-value = 0.07), respectively. The p-value shows the probability that an SCV of this size (or higher) would be observed by chance if only random variation existed and therefore, there is weak evidence of geographical variation beyond what would be expected at random for registrations and transplants. No adjustment has been made for area-specific demographic characteristics that may impact the rates of registration to the transplant list and transplantation such as age and sex. Therefore, these results should be interpreted with caution.

Figure 2.10 and **Table 2.2** shows the same information but for registrations to the lung transplant list and lung transplants. The UK lung registration and transplant rates are 2.1 pmp and 1.4 pmp respectively. For lungs, registration and transplant rates yielded a SCV of 0.04 (p-value = 0.06) and 0 (p-value >0.999), respectively, and therefore there was weak evidence of geographical variation beyond what would be expected at random for registrations but not transplants.



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

Country/ NHS region	Registration	Registrations (pmp)		Transplants (pmp)			
North East and Yorkshire North West	48 26	(5.6) (3.7)	21 15	(2.4) (2.1)			
Midlands East of England	49 29	(4.6) (4.4)	34 18	(3.2) (2.8)			
London South East South West	30 27 15	(3.3) (3.0) (2.7)	13 21 5	(1.5) (2.4) (0.9)			
England Isle of Man Channel Islands	224 1 0	(4.0) (12.5) (0.0)	127 0 0	(2.3) (0.0) (0.0)			
Wales	5	(1.6)	6	(1.9)			
Scotland	19	(3.5)	21	(3.8)			
Northern Ireland	13	(6.9)	4	(2.1)			
TOTAL	263 ¹	(3.9)	159 ²	(2.4)			

Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2020 – 31 March 2021, by Country/NHS region Table 2.1

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



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

1 April 2020		i y/iiio region			
Country/ NHS region	Registrat	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire North West Midlands East of England London South East South West	26 13 30 17 9 13 13	(3.0) (1.8) (2.8) (2.6) (1.0) (1.5) (2.3)	12 8 10 10 17 11 9	(1.4) (1.1) (0.9) (1.5) (1.9) (1.2) (1.6)	
England Isle of Man Channel Islands	121 1 1	(2.1) (12.5) (5.9)	77 0 0	(1.4) (0.0) (0.0)	
Wales	9	(2.9)	4	(1.3)	
Scotland	8	(1.5)	7	(1.3)	
Northern Ireland	3	(1.6)	3	(1.6)	
TOTAL	143	(2.1)	91	(1.4)	

Table 2.2Lung registration and transplant rates per million population (pmp) in the UK,
1 April 2020 – 31 March 2021, by Country/NHS region

ADULT HEART TRANSPLANTATION Transplant List



3.1 Adult heart only transplant list as at 31 March, 2012 – 2021

Figure 3.1 shows the number of adult patients on the heart transplant list on 31 March each year between 2012 and 2021, split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list generally increased each year, from 142 in 2012 up to 271 in 2020, and has since decreased to 243 in 2021. The number of patients on the urgent list increased from 9 in 2012 to 16 in 2021. There were 4 patients on the super-urgent list on 31 March 2021. There has also been a recent increase in the number of suspended patients.





Figure 3.2 shows the number of adult patients on the <u>active heart transplant list</u> at 31 March 2021, by centre and urgency. **Figure 3.3** provides a similar breakdown by centre and mechanical circulatory support (MCS) status. In total, there were 263 adult patients waiting. The number of patients on the urgent transplant list at 31 March 2021 ranged from 0 at Glasgow to 7 at Birmingham. Birmingham, Harefield, Manchester and Papworth had 1 patient each on the super-urgent transplant list. A total of 147 patients were on long term MCS (including left-, right- and bi-ventricular assist devices and total artificial hearts), representing 56% of the national waiting list, but varying between 8% and 80% across centres.



Figure 3.2 Number of adult patients on the active heart transplant list at 31 March 2021, by centre and urgency

Figure 3.3 Number of adult patients on the active heart transplant list at 31 March 2021, by centre and mechanical circulatory support status



Figure 3.4 shows the trend over time in the number of adult patients on the heart transplant list at 31 March each year across centres. Birmingham, Manchester and Newcastle have experienced substantial increases in their heart lists over the decade, whilst Glasgow has had a smaller increase. Papworth's list has generally decreased except for an increase between 2018 and 2020, and Harefield's list has remained relatively stable. Manchester have had a noticeable increase in suspended patients in recent years.





3.2 Demographic characteristics, 1 April 2020 – 31 March 2021

There were 217 adult patient registrations onto the heart transplant list between 1 April 2020 and 31 March 2021. Demographic characteristics of these patients are shown by centre and overall, in **Table 3.1**. Nationally, 70% of patients were male and the <u>median</u> age was 50 years. Note that there were 35 super-urgent heart registrations in this period. For some characteristics, due to rounding, percentages may not add up to 100.

Table 3.1 Demographic characteristics of adult patients registered onto the heart transplant list between 1 April 2020 and 31 March 2021, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		38 (100)	17 (100)	39 (100)	29 (100)	49 (100)	45 (100)	217 (100)
Highest urgency during registration	Non-urgent	13 (34)	9 (53)	9 (23)	17 (59)	19 (39)	22 (49)	89 (41)
	Urgent	15 (39)	6 (35)	22 (56)	9 (31)	26 (53)	15 (33)	93 (43)
	Super-urgent	10 (26)	2 (12)	8 (21)	3 (10)	4 (8)	8 (18)	35 (16)
Recipient sex	Male	23 (61)	10 (59)	30 (77)	22 (76)	33 (67)	34 (76)	152 (70)
	Female	15 (39)	7 (41)	9 (23)	7 (24)	16 (33)	11 (24)	65 (30)
Recipient ethnicity	White	35 (92)	15 (88)	31 (79)	28 (97)	47 (96)	34 (76)	190 (88)
	Non-white	3 (8)	2 (12)	7 (18)	1 (3)	2 (4)	10 (22)	25 (12)
	Missing	0 (0)	0 (0)	1 (3)	0 (0)	0 (0)	1 (2)	2 (1)
Recipient age (years)	Median (<u>IQR</u>)	51 (39, 57)	50 (44, 57)	53 (34, 57)	51 (33, 58)	50 (40, 59)	46 (39, 55)	50 (38, 57)
Primary Disease	Coronary heart disease	16 (42)	1 (6)	6 (15)	7 (24)	5 (10)	8 (18)	43 (20)
	Cardiomyopathy	17 (45)	16 (94)	28 (72)	19 (66)	29 (59)	33 (73)	142 (65)
	Congenital heart disease	2 (5)	0 (0)	2 (5)	0 (0)	11 (22)	0 (0)	15 (7)
	Graft failure/Rejection	0 (0)	0 (0)	1 (3)	0 (0)	1 (2)	1 (2)	3 (1)
	Other	3 (8)	0 (0)	2 (5)	3 (10)	3 (6)	3 (7)	14 (7)
Previous open heart surgery	None	19 (50)	9 (53)	27 (69)	18 (62)	17 (35)	33 (73)	123 (57)
	One	14 (37)	1 (6)	8 (21)	10 (34)	22 (45)	8 (18)	63 (29)
	More than one	5 (13)	0 (0)	3 (8)	1 (3)	7 (14)	1 (2)	17 (8)
	Missing	0 (0)	7 (41)	1 (3)	0 (0)	3 (6)	3 (7)	14 (7)
Serum Bilirubin (umol/l)	Median (<u>IQR</u>)	16 (10, 21)	10 (7, 13)	14 (9, 20)	16 (10, 28)	19 (12, 25)	22 (14, 32)	17 (10, 26)
	Missing	0	1	1	0	3	0	5
Serum Creatinine	Median (<u>IQR</u>)	86 (79, 101)	90 (76, 118)	86 (71, 127)	84 (61, 112)	113 (86, 169)	82 (71, 109)	92 (73, 124)
(umol/l)	Missing	0	1	1	0	3	0	5

3.3 Post-registration outcomes, 1 April 2016 – 31 March 2018

The registration outcomes of adult patients listed for a heart transplant between 1 April 2016 and 31 March 2018 are summarised in **Figures 3.5** - **3.9**, nationally and by centre, for non-urgent, urgent and super-urgent registrations respectively. The possible outcomes for patients on the list include receiving a transplant, removal from the list, moving lists, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted". If a patient moved lists, e.g. from the non-urgent to the urgent list, they would be included in both the non-urgent and the urgent charts.

Figure 3.5 shows the non-urgent post-registration outcomes; within six months of listing 10% of non-urgent heart patients had been transplanted and 4% had died on the list, while after three years 17% had been transplanted and 10% had died on the list. Also, 19% had been moved to the urgent heart list within 6 months, reaching 31% by three years. Removals from the list were for a variety of reasons, most commonly due to deteriorating condition or contra-indication to transplant.



Figure 3.5 Post-registration outcome for 305 non-urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2018

Figure 3.6 shows the three year non-urgent registration outcomes by centre. The nonurgent transplant rate at three years was highest at Papworth (44%) and lowest at Birmingham (5%).





Figure 3.7 shows outcomes on the urgent heart list. The chance of transplant is much higher from the urgent list compared with the non-urgent list; within 6 months, 67% had been transplanted, 2% had died on the list and 18% were removed. Removals from the urgent heart list were due to a variety of reasons, including deteriorating condition or the patient being fitted with an LVAD.

Figure 3.7 Post-registration outcome for 297 urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2018



Figure 3.8 shows the one month urgent registration outcomes by centre. The urgent transplant rate at one month was highest at Papworth (59%) and lowest at Glasgow (18%).



Figure 3.8 One month registration outcomes by centre, for urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2018

Figure 3.9 shows outcomes on the super-urgent patients list. The chance of transplant is much higher from the super-urgent list compared with the non-urgent and urgent lists; within 3 months, 72% had been transplanted, 22% were removed and 4% had died on the list. Please note that there is no figure breaking down super-urgent registration outcomes by centre due to the small numbers.





3.4 Median waiting time to transplant, 1 April 2014 - 31 March 2018

The <u>median</u> waiting time to heart transplant from registration for adult patients is shown in **Figure 3.10** and **Table 3.2**. This is estimated for patients registered on the heart only transplant list between 1 April 2014 and 31 March 2018 using the <u>Kaplan Meier</u> method. This is split by the urgency of the patient at initial registration; non-urgent, urgent or superurgent. All waiting time from initial registration is considered, regardless of any change in urgency. Any suspended time is discounted.

The overall national <u>median</u> waiting time to transplant from non-urgent registration was 831 days (2.3 years) and ranged from 135 days at Papworth to 1843 days at Birmingham, but could not be calculated for Harefield or Newcastle as not enough patients had been transplanted within a reasonable timeframe. For urgent registrations, the national <u>median</u> waiting time was 38 days, and ranged from 10 days at Papworth to 57 days at Harefield. The national <u>median</u> waiting time for super-urgent registrations was 9 days. The 95% <u>confidence intervals</u> for some of these medians are very wide, indicating the variation in individual waiting times within groups. The national <u>median</u> waiting for super-urgent registrations is also shown in **Table 3.2** (but not in **Figure 3.10**), which was 9 days in this cohort (this is not split by centre due to small number).





Note: Median waiting times could not be estimated for non-urgent patients at Harefield or Newcastle

Transplant centre	Number of patients	Number	Wai	ting time (days)
	registered	transplanted	<u>Median</u>	95% Confidence interval
Overall				
Birmingham	135	73	159	0 - 325
Glasgow	66	37	262	9 - 515
Harefield	159	83	276	127 - 425
Manchester	110	75	97	46 - 148
Newcastle	148	66	693	62 - 1324
Papworth	156	127	51	25 - 77
UK	774	461	153	109 - 197
Non-urgent at initial re	gistration			
Birmingham	66	21	10/2	1006 2690
Closgow	20	2 I 1 2	1043	F71 1045
Glasgow Herefield ¹	50	12	1200	571 - 1945
Manahastar	04	33	-	-
Newcestle1	49	20	000	400 - 1200
Newcastle ¹	00	30	-	-
Papworth	100	78	135	90 - 180
UK	417	200	831	580 - 1082
Urgent at initial registra	ation			
Birmingham	61	46	39	23 - 55
Glasgow	27	18	49	14 - 84
Harefield	62	46	57	30 - 84
Manchester	51	40	37	18 - 56
Newcastle	60	36	41	24 - 58
Papworth	46	41	10	1 - 19
UK	307	227	38	32 - 44
Super-urgent at initial	registration			
UK	50	34	9	4 - 14
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Table 3.2 Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and centre, 1 April 2015 to 31 March 2018

¹ Medians and 95% confidence intervals could not be calculated as not enough patients had been transplanted within a reasonable timeframe at time of analysis

The <u>median</u> waiting time to heart transplant for adult patients is also considered by blood group. This is shown in **Figure 3.11** and **Table 3.3** by both blood group and urgency status at registration. For both urgent and non-urgent registrations, blood group O patients have the longest average wait compared with the other blood groups.

Figure 3.11 Median waiting time to heart transplant for adult patients registered on the transplant list between 1 April 2015 and 31 March 2018, by blood group and urgency at registration



Table 3.3Median active waiting time to heart transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2015 to 31 March 2018									
Blood Group	Number of patients registered	Number transplanted	Wa <u>Median</u>	iting time (days) 95% <u>Confidence interval</u>					
Overall									
О А В АВ UK	320 335 93 26 774	171 210 63 17 461	275 106 104 82 153	166 - 384 62 - 150 41 - 167 8 - 156 109 - 197					
Non-urgent at init	ial registration								
О А В АВ UK	181 179 45 12 417	82 88 25 5 200	869 826 375 693 831	495 - 1243 360 - 1292 128 - 622 666 - 720 580 - 1082					
Urgent at initial re	gistration								
O 123 81 49 36 - 62 A 131 103 29 20 - 38 B 40 32 40 18 - 62 AB 13 11 27 14 - 40 UK 307 227 38 32 - 44									
UK	50	34	9	4 - 14					

The median waiting time to heart transplant for adult patients is shown by VAD status in **Figure 3.12** and **Table 3.4**. This considers whether a patient ever had an implantable leftventricular assist device (LVAD) as a bridge to heart transplant compared with not and is restricted to those who were initially non-urgent. Median waiting time for those on LVAD support could not be estimated for most centres, or on a national basis, as not enough patients had been transplanted in this group at time of analysis. However, the national median for those not on LVAD support (276 days) was substantially lower than the overall median for non-urgent patients (831 days).





Note: Median waiting times for patients on LVAD support could only be estimated for Manchester and Papworth

Table 3.4

Median active waiting time to heart transplant for adult patients registered on the non-urgent transplant list 1 April 2015 to 31 March 2018, by centre and whether the patient had an implantable left-ventricular assist device (LVAD)

Transplant centre	Number of patients Number		Wadian	aiting time (days)
	registered	transplanteu	INICULATI	35% Confidence Interval
Never on LVAD support	t			
Birmingham	33	15	427	0 - 882
Glasgow	26	10	1258	-
Harefield	33	22	370	113 - 627
Manchester	29	17	542	0 - 1213
Newcastle	37	20	497	163 - 831
Papworth	85	70	112	62 - 162
UK	243	154	276	168 - 384
Ever on LVAD support				
Birmingham ¹	33	6	-	-
Glasgow ²	4	2	-	-
Harefield ¹	51	11	-	-
Manchester	20	9	1731	1225 - 2237
Newcastle ¹	51	10	-	-
Papworth	15	8	526	255 - 797
UK ¹	174	46	-	-

¹ Medians and 95% confidence intervals could not be calculated as not enough patients had been transplanted within a reasonable timeframe at time of analysis

² Median waiting time for groups with less than 10 patients are not presented due to small numbers

ADULT HEART TRANSPLANTATION

Response to Offers



4. Response to Offers

This section presents an analysis of adult DBD donor heart offer decline rates. This only considers offers of hearts between 1 April 2018 and 31 March 2021 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. In this analysis, adjustments have been made to count any centre who is ranked above the accepting centre in the allocation sequence for that donor as declining the heart, even if they did not respond to the group offer, and any declines recorded for a centre ranked below the accepting centre were discounted.

Figure 4.1 compares individual centre decline rates with the national rate using a <u>funnel</u> <u>plot</u>. The offer decline rate for Harefield is above the upper 99.8% <u>confidence limit</u>, indicating that they have a significantly higher decline rate than the national rate. The offer decline rate for Newcastle is above the 95% <u>confidence limit</u>, providing some evidence of a higher than average decline rate. The offer decline rates for both Birmingham and Papworth are below the lower 99.8% <u>confidence limit</u>, indicating that they have a significantly have national rate.





Table 4.1 shows a breakdown of each centre's decline rate across the three years analysed.Nationally, the number of offers has remained similar (for hearts that were eventually
transplanted), but the offer decline rates was highest in the latest year.

Table 4.1UK adult DBD donor heart offer decline rates by transplant centre and year, between 1 April 2018 and 31 March 2021									
Centre	2018/19		2019/20		2020/21		Overall		
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	
Birmingham	62	(59.7)	68	(58.8)	61	(62.3)	191	(60.2)	
Glasgow	50	(84.0)	67	(86.6)	41	(68.3)	158	(81.0)	
Harefield	146	(82.2)	105	(85.7)	137	(89.8)	388	(85.8)	
Manchester	78	(74.4)	73	(74.0)	69	(79.7)	220	(75.9)	
Newcastle	96	(80.2)	93	(75.3)	123	(85.4)	312	(80.8)	
Papworth	42	(40.5)	41	(53.7)	41	(48.8)	124	(47.6)	
UK	474	(74.1)	447	(74.7)	472	(78.2)	1393	(75.7)	
	Centre has reached the upper 99.8% confidence limit								
Centre has reached the upper 95% confidence limit									
Centre has reached the lower 95% confidence limit									
Centre has reached the lower 99.8% confidence limit									

ADULT HEART TRANSPLANTATION Transplants


5.1 Adult heart transplants, 1 April 2011 – 31 March 2021

Figure 5.1 shows the number of adult heart transplants performed per year over the last ten years, by donor type. Last year there were 132 adult heart transplants nationally, 17 lower than the previous year and 35 less than the most active year over the last decade, which was 2013/2014, but 23% higher than the beginning of the decade. Comparing 2020/21 with the previous year, we see there were fewer DBD heart transplants and also fewer DCD heart transplants.





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



Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2011 to 31 March 2021

Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants, performed by 3 centres in this time period, represented 12% of last year's adult heart transplant activity. The highest number of transplants, both DBD and DCD, were performed by Papworth.





Figure 5.4 and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time, the proportion of urgent transplants has increased; from 57% in 2011/2012 to 77% in 2020/2021, including 26 super-urgent transplants. Papworth performed the highest number of non-urgent transplants over the time period.



Figure 5.4 Number of adult heart transplants in the UK, by financial year and urgency status, 1 April 2011 to 31 March 2021





Last year's activity is shown by centre and urgency status in **Figure 5.6**. Birmingham performed the highest number of super-urgent transplants.



Figure 5.6 Number of adult heart transplants in the UK, by centre and urgency status, 1 April 2020 to 31 March 2021

5.2 Demographic characteristics of transplants, 1 April 2020 – 31 March 2021

The demographic characteristics of the 132 adult heart transplant recipients and donors in the latest year are shown by centre and overall, in **Table 5.1**. Nationally, 66% of heart recipients were male and the <u>median</u> age was 49 years while the median age for donors was 34 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2020 to 31 March 2021, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		25 (100)	20 (100)	13 (100)	15 (100)	22 (100)	37 (100)	132 (100)
Urgency status at transplant	Non-urgent Urgent Super-urgent	4 (16) 11 (44) 10 (40)	6 (30) 12 (60) 2 (10)	0 (0) 12 (92) 1 (8)	2 (13) 11 (73) 2 (13)	4 (18) 15 (68) 3 (14)	14 (38) 15 (41) 8 (22)	30 (23) 76 (58) 26 (20)
Recipient sex	Male	15 (60)	12 (60)	10 (77)	10 (67)	14 (64)	26 (70)	87 (66)
	Female	10 (40)	8 (40)	3 (23)	5 (33)	8 (36)	11 (30)	45 (34)
Recipient ethnicity	White	20 (80)	20 (100)	7 (54)	13 (87)	22 (100)	28 (76)	110 (83)
	Non-white	5 (20)	0 (0)	6 (46)	2 (13)	0 (0)	9 (24)	22 (17)
Recipient age (years)	Median (<u>IQR</u>)	43 (34, 57)	49 (40, 58)	51 (40, 56)	50 (28, 55)	48 (32, 59)	51 (37, 56)	49 (35, 57)
	Missing	0	0	0	0	0	0	0
Recipient weight (kg)	Median (<u>IQR</u>)	76 (69, 86)	84 (73, 94)	72 (58, 80)	70 (60, 83)	69 (56, 81)	76 (61, 89)	75 (63, 87)
	Missing	0	0	0	3	0	0	3
Recipient primary disease	Coronary heart disease Cardiomyopathy Congenital heart disease	6 (24) 16 (64) 2 (8)	2 (10) 16 (80) 0 (0)	0 (0) 11 (85) 1 (8)	5 (33) 10 (67) 0 (0)	1 (5) 18 (82) 2 (9)	8 (22) 24 (65) 1 (3)	22 (17) 95 (72) 6 (5)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
	Other	1 (4)	2 (10)	1 (8)	0 (0)	1 (5)	3 (8)	8 (6)
NYHA class	l	2 (8)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (2)
	II	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	2 (5)	3 (2)
	III	11 (44)	5 (25)	5 (38)	4 (27)	4 (18)	18 (49)	47 (36)
	IV	4 (16)	6 (30)	8 (62)	11 (73)	16 (73)	17 (46)	62 (47)
	Missing	8 (32)	9 (45)	0 (0)	0 (0)	1 (5)	0 (0)	18 (14)

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2020 to 31 March 2021, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Recipient in hospital pre-transplant	No	7 (28)	5 (25)	2 (15)	3 (20)	5 (23)	16 (43)	38 (29)
	Yes	18 (72)	12 (60)	11 (85)	12 (80)	16 (73)	21 (57)	90 (68)
	Missing	0 (0)	3 (15)	0 (0)	0 (0)	1 (5)	0 (0)	4 (3)
If in hospital, recipient on ventilator	No	17 (94)	12 (100)	11 (100)	12 (100)	16 (100)	20 (95)	88 (98)
	Yes	1 (6)	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	2 (2)
If in hospital, recipient on VAD	None Left Right Both	9 (50) 2 (11) 0 (0) 7 (39)	11 (92) 1 (8) 0 (0) 0 (0)	10 (91) 1 (9) 0 (0) 0 (0)	8 (67) 2 (17) 0 (0) 2 (17)	12 (75) 3 (19) 0 (0) 1 (6)	13 (62) 0 (0) 1 (5) 7 (33)	63 (70) 9 (10) 1 (1) 17 (19)
If in hospital, recipient on TAH	No	18 (100)	12 (100)	11 (100)	12 (100)	16 (100)	21 (100)	90 (100)
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
If in hospital, recipient on ECMO	No	17 (94)	11 (92)	10 (91)	12 (100)	15 (94)	19 (90)	84 (93)
	Yes	1 (6)	1 (8)	1 (9)	0 (0)	1 (6)	2 (10)	6 (7)
If in hospital, recipient on inotropes	No	8 (44)	2 (17)	1 (9)	4 (33)	2 (13)	9 (43)	26 (29)
	Yes	10 (56)	10 (83)	10 (91)	8 (67)	14 (88)	12 (57)	64 (71)
If in hospital, recipient on IABP	No	18 (100)	7 (58)	11 (100)	11 (92)	16 (100)	20 (95)	83 (92)
	Yes	0 (0)	5 (42)	0 (0)	1 (8)	0 (0)	1 (5)	7 (8)
Recipient CMV status	No	12 (48)	12 (60)	12 (92)	8 (53)	8 (36)	24 (65)	76 (58)
	Yes	13 (52)	7 (35)	1 (8)	7 (47)	13 (59)	12 (32)	53 (40)
	Missing	0 (0)	1 (5)	0 (0)	0 (0)	1 (5)	1 (3)	3 (2)
Recipient HCV status	No	25 (100)	19 (95)	13 (100)	15 (100)	22 (100)	37 (100)	131 (99)
	Missing	0 (0)	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient HBV status	No	25 (100)	19 (95)	13 (100)	15 (100)	22 (100)	37 (100)	131 (99)
	Missing	0 (0)	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient HIV status	No	25 (100)	19 (95)	13 (100)	15 (100)	22 (100)	37 (100)	131 (99)
	Missing	0 (0)	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient serum creatinine (umol/I)	Median (<mark>IQR</mark>)	84 (66, 100)	105 (90, 118)	99 (91, 118)	82 (66, 107)	108 (84, 138)	82 (70, 100)	91 (76, 116)
	Missing	0	7	0	0	1	0	8

Table 5.1 Demographic characteristics of adult heart transplants, 1 April 2020 to 31 March 2021, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor sex	Male	13 (52)	12 (60)	9 (69)	9 (60)	15 (68)	23 (62)	81 (61)
	Female	12 (48)	8 (40)	4 (31)	6 (40)	7 (32)	14 (38)	51 (39)
Donor ethnicity	White	22 (88)	17 (85)	11 (85)	13 (87)	18 (82)	35 (95)	116 (88)
	Non-white	3 (12)	3 (15)	2 (15)	1 (7)	3 (14)	1 (3)	13 (10)
	Missing	0 (0)	0 (0)	0 (0)	1 (7)	1 (5)	1 (3)	3 (2)
Donor age (years)	Median (<u>IQR</u>)	36 (24, 48)	41 (27, 47)	30 (28, 36)	32 (20, 42)	33 (25, 46)	35 (24, 47)	34 (26, 47)
	Missing	0	0	0	0	0	0	0
Donor BMI (kg/m²)	Median (<u>IQR</u>)	27 (23, 32)	26 (23, 28)	24 (21, 26)	25 (20, 30)	26 (23, 31)	25 (22, 29)	26 (22, 29)
	Missing	0	0	0	0	0	0	0
Donor cause of death	CVA	23 (92)	15 (75)	12 (92)	14 (93)	17 (77)	31 (84)	112 (85)
	Trauma	1 (4)	1 (5)	0 (0)	1 (7)	2 (9)	4 (11)	9 (7)
	Others	1 (4)	4 (20)	1 (8)	0 (0)	3 (14)	2 (5)	11 (8)
Donor hypotension	No	18 (72)	8 (40)	10 (77)	12 (80)	3 (14)	29 (78)	80 (61)
	Yes	6 (24)	3 (15)	3 (23)	2 (13)	9 (41)	7 (19)	30 (23)
	Missing	1 (4)	9 (45)	0 (0)	1 (7)	10 (45)	1 (3)	22 (17)
Donor past diabetes	No	25 (100)	19 (95)	12 (92)	15 (100)	22 (100)	37 (100)	130 (99)
	Yes	0 (0)	1 (5)	1 (8)	0 (0)	0 (0)	0 (0)	2 (2)
Donor past cardiothoracic disease	No	24 (96)	19 (95)	13 (100)	14 (93)	22 (100)	37 (100)	129 (98)
	Missing	1 (4)	1 (5)	0 (0)	1 (7)	0 (0)	0 (0)	3 (2)
Donor past	No	22 (88)	18 (90)	11 (85)	14 (93)	19 (86)	35 (95)	119 (90)
hypertension	Yes	3 (12)	2 (10)	2 (15)	1 (7)	3 (14)	2 (5)	13 (10)
Donor past tumour	No	25 (100)	19 (95)	13 (100)	14 (93)	21 (95)	37 (100)	129 (98)
	Yes	0 (0)	1 (5)	0 (0)	1 (7)	1 (5)	0 (0)	3 (2)
Donor past smoker	No	6 (24)	10 (50)	2 (15)	6 (40)	9 (41)	15 (41)	48 (36)
	Yes	19 (76)	10 (50)	11 (85)	9 (60)	13 (59)	22 (59)	84 (64)
Total ischaemia time	Median (<mark>IQR</mark>)	3.1 (2.4, 3.6)	2.9 (2.7, 3.1)	4.5 (3.1, 5.3)	3.5 (3.1, 3.8)	3.6 (3.2, 4.1)	3.4 (2.6, 4.2)	3.5 (2.7, 4.2)
(hours)	Missing	7	11	1	0	1	0	20

5.3 Total ischaemia time, 1 April 2011 – 31 March 2021

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



Figure 5.7 Boxplots of total ischaemia time for DBD donor hearts transplanted into adult recipients, by financial year, 1 April 2011 to 31 March 2021

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

Figure 5.8 and **Figure 5.9** show <u>boxplots</u> of total ischaemia time by centre in the latest financial year (2020/2021) and over the last 10 years, respectively. The increase in observed <u>median</u> total ischaemia time at Harefield from 2013/2014 onwards is explained by their use of the Organ Care System (OCS); between 2013/2014 and 2019/2020, 100% of DBD hearts transplanted by Harefield used OCS compared with 1%-6% for other centres. In 2020/2021, the OCS was only used in 45% of Harefield's DBD heart transplants, 4% of Birmingham's and 0% for other centres.



Figure 5.8 Boxplots of total ischaemia time in DBD donor hearts transplanted into

Includes time on the Organ Care System (OCS), where centres used the OCS in a variable proportion of transplants: Birmingham 4%, Glasgow 0%, Harefield 45%, Manchester 0%, Newcastle 0% and Papworth 0%





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

ADULT HEART TRANSPLANTATION

Post-Transplant Survival



6. Post-Transplant Survival

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

The survival analyses exclude <u>multi-organ transplants</u> and include first time transplants only. Thirty-day, 90-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2020 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2012 to 31 March 2016. <u>Survival rates</u> are presented by transplant centre in **Tables 6.1-6.4** and **Figures 6.1-6.4** as well as disease group in **Tables 6.5-6.6**. DCD heart transplants are excluded but separate tables (**Table 6.7** and **6.8**) at the end of this section provide <u>unadjusted survival rates</u> for the small number of DCD heart transplant recipients between 1 January 2015 and 31 March 2020.

6.1 Survival by centre

Table 6.1 and **Figure 6.1** show the 30-day post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 537 first adult <u>DBD</u> heart only transplants in the period 1 April 2016 to 31 March 2020. All of the centres' rates were statistically consistent with the national rate of survival which was 91.4%.

Table 6.1 30 day patient survival rates after first adult DBD heart transplant, by centre, 1 April 2016 to 31 March 2020							
Centre	Number of		% 30 day survi	val (95%	o CI)		
	transplants	<u>L</u>	Inadjusted	<u>Ris</u>	sk-adjusted		
Birmingham	101	93.1	(86.0 - 96.6)	93.1	(85.5 - 96.7)		
Glasgow	45	91.1	(78.0 - 96.6)	81.8	(51.6 - 93.2)		
Harefield	96	84.4	(75.4 - 90.3)	88.7	(81.3 - 93.2)		
Manchester	82	96.3	(89.1 - 98.8)	95.6	(86.2 - 98.6)		
Newcastle	92	91.3	(83.4 - 95.6)	93.6	(87.2 - 96.8)		
Papworth	121	92.6	(86.2 - 96.1)	89.8	(80.4 - 94.7)		
UK	537	91.4	(88.7 - 93.5)				
	Centre has reached	d the lower	99.8% confidence li	mit			
	Centre has reached	d the lower	95% confidence limi	it			
	Centre has reached the upper 95% confidence limit						
	Centre has reached the upper 99.8% confidence limit						

Figure 6.1 Risk-adjusted 30 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2016 to 31 March 2020



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Table 6.2 and **Figure 6.2** show the 90-day post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 537 first adult <u>DBD</u> heart only transplants in the period 1 April 2016 to 31 March 2020. All of the centres' rates were statistically consistent with the national rate of survival which was 88.3%.

Table 6.2 90 day patient survival after first adult DBD heart transplant, by centre,1 April 2016 and 31 March 2020							
Centre	Number of transplants	ι	% 90 day survi Inadjusted	val (95% Ris	sk-adjusted		
Birmingham Glasgow Harefield Manchester Newcastle Papworth	101 45 96 82 92 121	91.1 88.9 78.1 92.7 88.0 90.9	(83.6 - 95.3) (75.3 - 95.2) (68.5 - 85.1) (84.4 - 96.6) (79.5 - 93.2) (84.2 - 94.9)	90.4 77.2 85.1 91.5 91.0 87.5	(81.5 - 95.0) (45.3 - 90.5) (77.1 - 90.3) (81.0 - 96.2) (83.7 - 95.0) (77.5 - 93.1)		
UK	537	88.3	(85.2 - 90.7)				
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit							

Figure 6.2 Risk-adjusted 90 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2016 to 31 March 2020



Number of transplants

Table 6.3 and **Figure 6.3** show the 1-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 537 first adult <u>DBD</u> heart only transplants in the period 1 April 2016 to 31 March 2020. The national rate of survival was 84.3%. The centre specific rates were consistent with the national rate.

Table 6.3	year patient survival centre, 1 April 2016 to	rates after 31 March 2	first adult DBD h 020	eart tran	splant, by
Centre	Number of		% 1 year survi	val (95%	CI)
	transplants	<u> </u>	<u>Jnadjusted</u>	<u>Ris</u>	sk-adjusted
Birmingham	101	86.0	(77.5 - 91.5)	86.1	(76.6 - 91.8)
Glasgow	45	88.9	(75.3 - 95.2)	77.7	(46.5 - 90.7)
Harefield	96	71.8	(61.6 - 79.7)	80.8	(72.0 - 86.8)
Manchester	82	90.2	(81.4 – 95.0)	88.9	(77.9 - 94.5)
Newcastle	92	80.3	(70.6 - 87.1)	84.3	(75.1 - 90.1)
Papworth	121	90.1	(83.2 - 94.2)	85.6	(74.6 - 91.8)
UK	537	84.3	(80.9 - 87.1)		
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit					





Number of transplants

Table 6.4 and **Figure 6.4** show the 5-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 562 first adult <u>DBD</u> heart only transplants in the period 1 April 2012 to 31 March 2016. The national rate of survival was 70.0%. The rate for Papworth lies between the upper 95% and 99.8% <u>confidence limits</u>, providing some evidence that it is significantly higher than the national rate.

Table 6.4 5 year pa centre 1	atient survival rate April 2012 to 31 N	es after firs March 2010	st adult DBD hea ວິ	rt transı	olant, by
Centre	Number of		% 5 year survi	val (95%	CI)
	transplants	<u>L</u>	<u>Inadjusted</u>	<u>Ris</u>	sk-adjusted
Birmingham	93	65.4	(54.7 - 74.1)	63.3	(48.0 - 74.0)
Glasgow	48	66.7	(51.5 - 78.1)	66.3	(45.1 - 79.4)
Harefield	93	70.9	(60.5 – 79.0)	69.8	(55.9 - 79.3)
Manchester	107	66.3	(56.5 - 74.4)	66.0	(52.8 - 75.5)
Newcastle	85	71.7	(60.8 - 80.1)	66.4	(49.9 - 77.5)
Papworth	136	75.5	(67.3 - 81.9)	79.1	(70.6 - 85.2)
ик	562	70.0	(66.0 - 73.6)		
	Centre has reache	d the lower	99.8% confidence li	mit	
	Centre has reache	d the lower	95% confidence limi	t	
	Centre has reache	d the upper	95% confidence lim	it	
	Centre has reache	d the upper	99.8% confidence li	mit	





6.2 Survival by disease group

Tables 6.5 and **6.6** present <u>unadjusted</u> and <u>risk-adjusted survival rates</u> by primary disease group, at 1 year and 5 years post-transplant, respectively. The <u>risk factors</u> used to produce the <u>risk-adjusted survival rates</u> are listed in <u>Appendix A3.1</u>, except centre was used in place of disease group. Patients with congenital heart disease had a lower than average <u>risk-adjusted survival rate</u> at 1 year.

Table 6.51 year patient survival rates after first adult DBD heart transplant, by disease
group, 1 April 2016 and 31 March 2020

Disease group	Number of		% 1 year survival (95% CI)			
	transplants	<u>U</u>	nadjusted	<u>Ris</u>	k-adjusted	
		70.0				
Congenital heart disease	36	72.0	(54.2 - 83.9)	68.6	(41.6 - 83.1)	
Coronary heart disease	66	90.9	(80.9 - 95.8)	89.2	(76.0 - 95.2)	
Dilated cardiomyopathy	308	84.0	(79.4 - 87.7)	85.9	(81.3 - 89.3)	
Other	127	85.0	(77.5 - 90.2)	81.0	(70.3 - 87.9)	
UK	537	84.3	(80.9 - 87.1)			

Table 6.6 5 year patient survival rates after first adult DBD heart transplant, by diseasegroup, 1 April 2012 and 31 March 2016							
Disease group	Number of transplants	<u>L</u>	% 5 year surviv Inadjusted	val (95% <u>Ris</u>	CI) sk-adjusted		
Congenital heart disease Coronary heart disease Dilated cardiomyopathy Other	40 85 333 104	72.4 64.5 71.3 69.2	(55.7 - 83.7) (53.3 - 73.7) (66.1 - 75.9) (59.4 - 77.1)	72.4 67.7 70.7 68.8	(50.1 - 84.7) (53.8 - 77.4) (64.2 - 76.0) (55.9 - 77.9)		
UK	562	70.0	(66 - 73.6)				

6.3 Survival by VAD status

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

Table 6.7 Unadjusted patient survival rates after first adult DBD heart transplant, by mechanical supportstatus, 1 April 2016 and 31 March 2020							
Mechanical support status	Number of transplants	% 30 (<u>Ur</u>	day survival 95% CI) <u>nadjusted</u>	90 % 90 (۱ <u>Un</u>	day survival 95% CI) <u>adjusted</u>	% 1 (<u>U</u>	year survival (95% CI) <u>nadjusted</u>
Short-term support Long-term support No support	82 84 371	89.0 78.6 94.9	(80.0 - 94.1) (68.2 - 85.9) (92.1 - 96.7)	86.6 72.6 92.2	(77.1 - 92.3) (61.7 - 80.9) (88.9 - 94.5)	80.5 69 88.6	(70.1 - 87.6) (57.9 - 77.7) (84.9 - 91.4)
ик	537	91.4	(88.7 - 93.5)	88.3	(85.2 - 90.7)	84.3	(80.9 - 87.1)

6.4 Survival post DCD heart transplant

Tables 6.8 - 6.10 present short-term patient <u>survival rates</u> following DCD heart only transplant, by centre and nationally. During the time period 1 January 2015 (the start of the UK DCD heart programme) to 31 March 2020 transplants were performed by five of the six adult centres, and there were 16 deaths within 1 year.

Table 6.830 day patient survival rates after first adult DCD heart only transplant, by centre, 1 January 2015 and 31 March 2020									
Centre	Number of patients	Number of deaths	% 30 day (<mark>u</mark>	survival (95% CI) <u>nadjusted</u>)					
Glasgow ¹ Harefield Manchester ¹ Newcastle ¹ Papworth	1 19 9 1 78	0 1 0 2	94.7 - 97.4	- (68.1 - 99.2) - - (90.1 - 99.4)					
UK	108	3	97.2	(91.6 – 99.1)					

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

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

Table 6.990 day patient survival rates after first adult DCD heart only transplant, by centre, 1 January 2015 and 31 March 2020									
Centre	Number of patients	Number of deaths	% 90 day (<u>ur</u>	survival (95% CI) nadjusted)					
Glasgow ¹	1	0	-	-					
Harefield	19	3	84.2	(58.7 - 94.6)					
Manchester ¹	9	2	-	-					
Newcastle ¹	1	0	-	-					
Papworth	78	5	93.6	(85.3 - 97.3)					
UK	108	10	90.7	(83.5 - 94.3)					
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers									
This table excludes 1 patient at Harefield who received a DCD heart transplant as a re-graft and died within 30 days									

Table 6.10) 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 January 2015 and 31 March 2020							
Centre		Number of patients	Number of deaths	% 1 year survival (95% CI) (<u>unadjusted</u>)				
Glasgow ¹		1	0	-	-			
Harefield		19	5	73.7	(47.9 – 88.1)			
Manchester	1	9	3	-	-			
Newcastle ¹		1	0	-	-			
Papworth		78	8	89.7	(80.5 – 94.7)			
UK		108	16	85.2	(77.0 - 90.6)			
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers								

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

ADULT HEART TRANSPLANTATION Survival from Listing



7. Survival from Listing

Survival from listing was analysed for patients 18 years or older registered for the first time for a heart transplant between 1 January 2009 and 31 December 2020. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The <u>risk factors</u> used to produce the <u>risk-adjusted survival rates</u> are listed in <u>Appendix A2.1</u>.

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

The one year survival rate for Manchester fell above the upper 99.8% <u>confidence limits</u>, indicating significantly high survival from listing at this centre. There is also some evidence of higher survival at five years at Manchester, and also at Papworth. Newcastle's five year survival rate fell below the lower 99.8% <u>confidence limits</u>, indicating significantly low survival from listing at this time point, and there was also some evidence of lower survival at one year for this centre.

Table 7.1Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2009 to 31 December 2020									
		One year Five year							
Centre	Number at risk ¹ at day 0	Survival rate (%)	(95% CI)	Number at risk ¹	Survival rate (%)	(95% CI)	Number at risk ¹		
Birmingham	390	81.0	(76.2 - 84.9)	261	64.5	(57.5 - 70.3)	107		
Glasgow	200	84.3	(78.4 - 88.6)	130	69.2	(60.5 - 76.0)	44		
Harefield	421	85.3	(81.4 - 88.4)	307	67.7	(61.5 - 72.8)	117		
Manchester	337	90.7	(86.7 - 93.5)	271	74.1	(68.0 - 79.1)	107		
Newcastle	447	79.8	(75.0 - 83.7)	313	55.4	(47.6 - 62.1)	109		
Papworth	537	86.8	(83.5 - 89.4)	417	72.7	(67.7 - 77.0)	173		
UK	2332	84.7	(83.1 – 86.1)	1699	67.2	(64.9 – 69.5)	657		
Centre has reached the lower 99.8% confidence limit									
Centre has reached the lower 95% confidence limit									
Centre has reached the upper 95% confidence limit									
Centre has reached the upper 99.8% confidence limit									
¹ Number of patients with reported follow-up beyond this time point									



Figure 7.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2009 – 31 December 2020

Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2009 – 31 December 2020



ADULT HEART TRANSPLANTATION Form Return Rates



8. Adult heart form return rates, 1 January 2020 – 31 December 2020

Form return rates are reported in **Table 8.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult heart transplants between 1 January and 31 December 2020 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. All active centres have a 93% or greater return rate for this period. Note that any skipped follow-up forms are counted as not returned.

Centre	Transpla No. required	nt record % returned	3 month No. required	follow-up % returned	1 year f No. required	ollow-up % returned	Lifetime No. required	follow-up % returned
Birmingham Queen Elizabeth Hospital	28	100	31	100	26	100	240	98
Royal Derby Hospital	-	-	-	-	-	-	1	0
Royal Devon and Exeter Hospital	-	-	-	-	-	-	2	0
Glasgow Golden Jubilee Hospital	18	100	17	94	11	100	151	97
Harefield Hospital	19	100	16	100	18	100	527	95
Manchester Wythenshawe Hospital	16	100	21	100	17	100	262	100
Newcastle Freeman Hospital	24	96	21	100	20	100	312	98
Oxford, John Radcliffe Hospital	-	-	-	-	-	-	1	100
Royal Papworth Hospital	38	100	38	100	41	100	610	93
Plymouth, Derriford Hospital	-	-	-	-	-	-	1	0
Sheffield Northern General Hospital	-	-	-	-	-	-	40	98
Truro, Royal Cornwall Hospital	-	-	-	-	-	-	1	100
Overall	143	99	144	99	133	100	2148	96

Table 8.1 Form return rates for adult heart transplants, 1 January 2020 to 31 December 2020

ADULT LUNG TRANSPLANTATION Transplant List



9.1 Adult lung and heart-lung transplant list as at 31 March, 2012 – 2021

Figure 9.1 shows the number of adult patients on the lung and heart-lung transplant lists at 31 March each year between 2012 and 2021 split by urgency status of the patient. The number of patients on the active non-urgent lung transplant list generally increased year on year, until 2017 when it remained relatively stable for a few years and then dropped substantially to 246 on 31 March 2021. The number of patients on the heart-lung list has also reduced in the last two years. On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2021, there were five adult patients on the urgent list and none on the super-urgent list. There has also been a recent increase in suspended patients.





Figure 9.2 shows the number of adult patients on the <u>active lung and heart-lung transplant</u> <u>lists</u> on 31 March 2021, by centre and urgency. In total, there were 257 adult patients waiting, including 5 urgent lung patients. Harefield had the highest number of patients on the transplant list while Papworth had the lowest.



Figure 9.2 Number of adult patients on the active lung and heart-lung transplant lists at 31 March 2021, by centre

Figure 9.3 shows the trend over time in the number of adult patients on the lung transplant list at 31 March each year across centre. Harefield experienced a marked increase in their lung list between 2012 and 2017, but have since seen a substantial decrease.



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

9.2 Demographic characteristics, 1 April 2020 – 31 March 2021

There were 128 adult patient registrations onto the lung or heart-lung transplant lists between 1 April 2020 and 31 March 2021. Demographic characteristics of these patients are shown by centre and overall in **Table 9.1**. Nationally, 61% of patients were male and the <u>median</u> age was 56 years. Note that 17 of these registrations were urgent and none were super-urgent. For some characteristics, due to rounding, percentages may not add up to 100.

Table 9.1 Demographic characteristics of adult patients registered onto the lung transplant list between 1 April 2020 and 31 March 2021, by centre									
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)		
Number of registrations		23 (100)	23 (100)	23 (100)	24 (100)	35 (100)	128 (100)		
Highest urgency on the	Non-urgent	22 (96)	19 (83)	21 (91)	18 (75)	31 (89)	111 (87)		
lung list during	Urgent	1 (4)	4 (17)	2 (9)	6 (25)	4 (11)	17 (13)		
registration	Super-urgent	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
Recipient sex	Male	17 (74)	13 (57)	10 (43)	18 (75)	20 (57)	78 (61)		
	Female	6 (26)	10 (43)	13 (57)	6 (25)	15 (43)	50 (39)		
Recipient ethnicity	White	17 (74)	21 (91)	20 (87)	23 (96)	32 (91)	113 (88)		
	Non-white	6 (26)	2 (9)	3 (13)	1 (4)	3 (9)	15 (12)		
Recipient age (years)	Median (<u>IQR</u>)	57 (50, 61)	49 (38, 55)	56 (41, 60)	58 (52, 62)	57 (50, 60)	56 (47, 60)		
	Missing	0	0	0	0	0	0		
Primary Disease	Cystic fibrosis and bronchiectasis	2 (9)	6 (26)	1 (4)	1 (4)	2 (6)	12 (9)		
	Fibrosing lung disease	8 (35)	10 (43)	12 (52)	17 (71)	14 (40)	61 (48)		
	COPD and emphysema	8 (35)	3 (13)	4 (17)	2 (8)	8 (23)	25 (20)		
	Primary pulmonary hypertension	0 (0)	0 (0)	1 (4)	3 (13)	4 (11)	8 (6)		
	Other	3 (13)	4 (17)	5 (22)	1 (4)	7 (20)	20 (16)		
	Missing	2 (9)	0 (0)	0 (0)	0 (0)	0 (0)	2 (2)		
Smoker	No	21 (91)	23 (100)	23 (100)	23 (96)	35 (100)	125 (98)		
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
	Missing	2 (9)	0 (0)	0 (0)	1 (4)	0 (0)	3 (2)		
Lung function - FEV1	Median (<mark>IQR</mark>)	1.39 (0.78, 1.85)	1.14 (1.03, 1.83)	1.15 (0.83, 1.73)	1.81 (1.18, 2.63)	1.33 (0.82, 1.74)	1.36 (0.93, 1.85)		
(litres)	Missing	2	0	1	3	0	6		
Lung function – FVC	Median (<u>IQR</u>)	2.15 (1.77, 2.61)	2.18 (1.68, 2.87)	1.92 (1.43, 2.41)	2.42 (2.00, 3.26)	1.81 (1.51, 3.10)	2.20 (1.62, 2.88)		
(litres)	Missing	2	0	1	3	0	6		

9.3 Post-registration outcomes, 1 April 2016 – 31 March 2018

The registration outcomes of adult patients listed for a lung only transplant between 1 April 2016 and 31 March 2018 are summarised in **Figures 9.4** – **9.6**, nationally and by centre, for non-urgent and urgent registrations respectively. The possible outcomes for patients on the list include receiving a transplant, removal from the list, moving lists, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted". If a patient moved lists, e.g. from the non-urgent to the urgent list, they would be included in both the non-urgent and the urgent charts.

Nationally, within six months of non-urgent registration, 26% of lung patients had received a transplant and 10% had died. Three years after listing, 46% has received a transplant and 19% had died. By centre (**Figure 9.5**), within 1 year of registration, the proportion transplanted ranged from 22% at Newcastle to 58% at Papworth. Removals from the non-urgent list were predominantly due to deteriorating condition.





Figure 9.5 1 year registration outcomes by centre, for non-urgent lung only registrations made in the UK, 1 April 2016 to 31 March 2018



Figure 9.6 shows outcomes on the urgent lung list. The chance of transplant is much higher from the urgent list compared with the non-urgent list; within six months, 74% had received a transplant. A centre breakdown is not provided for urgent registrations, nor is a super-urgent registration figure, due to small numbers.





9.4 Median waiting time to transplant, 1 April 2015 - 31 March 2018

The <u>median</u> waiting time to non-urgent lung transplant from registration for adult patients is shown in **Figure 9.7** and **Table 9.2**. This is estimated for patients registered initially as non-urgent between 1 April 2015 and 31 March 2018 using the <u>Kaplan Meier</u> method. The national non-urgent <u>median</u> waiting time was 422 days and ranged from 196 days at Papworth to 656 days at Newcastle (log-rank p<0.0001). Median waiting time is not presented for urgent or super-urgent registrations, as only a small number of patients start off on these urgency schemes (most are initially on the non-urgent scheme) and this analysis is based on initial registration status.



Figure 9.7 Median waiting time to non-urgent lung transplant for adult patients registered between 1 April 2015 and 31 March 2018, by centre

Table 9.2 Median active waiting time to lung transplant for adult patients registered on the
transplant list, by centre, 1 April 2015 to 31 March 2018

Transplant centre	Number of patients	Number	Waiting time (days)						
	registered	transplanted	Median	95% Confidence interval					
	0	-							
Non-urgent at initial registration									
Birmingham	114	60	457	275 - 639					
Harefield	272	144	646	523 - 769					
Manchester	113	80	302	218 - 386					
Newcastle	180	88	656	543 - 769					
Papworth	169	130	196	139 - 253					
·									
UK	848	502	422	340 - 504					
-									

The <u>median</u> waiting time to non-urgent lung transplant for adult patients is also considered by blood group. This is shown in **Figure 9.8** and **Table 9.3**. Blood group B patients had the longest average wait (732 days) compared with the other blood groups (log-rank p<0.0001).



Figure 9.8 Median waiting time to non-urgent lung transplant for adult patients registered between 1 April 2015 and 31 March 2018, by blood group

Table 9.3 Median active waiting time to lung transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2015 to 31 March 2018								
Blood Group	Number of patients Number Waiting time (days)							
•	registered	transplanted	<u>Median</u>	95% Confidence interval				
Non-urgent at initial registration								
0	395	218	561	470 - 652				
А	340	222	304	221 - 387				
В	82	39	732	285 - 1179				
AB	31	23	171	29 - 313				
UK	848	502	422	340 - 504				

ADULT LUNG TRANSPLANTATION

Response to Offers



10. Response to Offers

This section presents an analysis of adult DBD donor lung offer decline rates. This only considers offers of bilateral lungs between 1 April 2018 and 31 March 2021 that were eventually transplanted and excludes all fast track offers. A bilateral lung offer is counted as accepted if either both the lungs were accepted or just a single lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lungs were declined as well as cases where both the heart and lungs were declined. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients but acceptance is determined by a centre's position in the allocation sequence. In this analysis, adjustments have been made to count any centre who is ranked above the accepting centre in the allocation sequence for that donor as declining the heart, even if they did not respond to the group offer, and any declines recorded for a centre ranked below the accepting centre were discounted.

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



Figure 10.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2018 to 31 March 2021
Table 10.1 shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the number of offers for lungs that were eventually transplanted was much lower in 2020/2021 due to fewer transplants being performed.

Table 10.1UK adult DBD donor bilateral lung offer decline rates by transplant centre and year, between 1 April 2018 and 31 March 2021								
201	8/19	201	19/20	202	20/21	0/21 Overall		
No.	Decline	No.	Decline	No.	Decline	No.	Decline	
offers	rate (%)	offers	rate (%)	offers	rate (%)	offers	rate (%)	
oners	1410 (70)	onero	1410 (70)	onero	Tate (70)	onero	1410 (70)	
40	(72.5)	46	(67.4)	20	(75.0)	106	(70.8)	
68	(51.5)	88	(727)	28	(35.7)	184	(59.2)	
40	(60.0)	46	(63.0)	21	(57.1)	107	(60.7)	
62	(00.0)	-0 60	(03.0)	69	(37.1)	200	(74.0)	
46	(11.4)	46	(71.0)	00	(79.4)	200	(49.2)	
40	(41.3)	40	(50.0)	20	(57.7)	110	(40.3)	
257	(59.1)	295	(66.4)	163	(65.0)	715	(63.5)	
Centre ha	as reached th	ne upper 9	9.8% confide	ence limit				
Centre ha	as reached th	ne upper 9	5% confiden	ce limit				
Centre ha	as reached th	ne lower 9	5% confidenc	ce limit				
Centre ha	as reached th	ne lower 9	9.8% confide	nce limit				
Contro He		10 10 10 10						
	It DBD of n 1 April 201 No. offers 40 68 40 63 40 63 46 257 Centre ha Centre ha Centre ha Centre ha	It DBD donor bilate 1 April 2018 and 2018/19 No. Decline offers rate (%) 40 (72.5) 68 (51.5) 40 (60.0) 63 (71.4) 46 (41.3) 257 (59.1) Centre has reached th Centre has reached th	It DBD donor bilateral lung n 1 April 2018 and 31 March2018/19207No.DeclineNo.offersrate (%)offers40(72.5)4668(51.5)8840(60.0)4663(71.4)6946(41.3)46Centre has reached the upper 9Centre has reached the upper 9Centre has reached the lower 95Centre has reached the lower 95	It DBD donor bilateral lung offer decline 1 April 2018 and 31 March 2021 2018/19 2019/20 No. Decline No. Decline offers rate (%) offers rate (%) 40 (72.5) 46 (67.4) 68 (51.5) 88 (72.7) 40 (60.0) 46 (63.0) 63 (71.4) 69 (71.0) 46 (41.3) 46 (50.0) 257 (59.1) 295 (66.4) Centre has reached the upper 99.8% confide Centre has reached the lower 95% confide	40 (72.5) 46 (67.4) 20 40 (72.5) 46 (67.4) 20 40 (60.0) 46 (63.0) 21 40 (60.0) 46 (63.0) 21 63 (71.4) 69 (71.0) 68 46 (41.3) 46 (50.0) 26 257 (59.1) 295 (66.4) 163 Centre has reached the upper 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 95% confidence limit	Lt DBD donor bilateral lung offer decline rates by transplateral 2018 and 31 March 2021 2018/19 2019/20 2020/21 No. Decline No. Decline offers rate (%) offers rate (%) 40 (72.5) 46 (67.4) 20 (75.0) 68 (51.5) 88 (72.7) 28 (35.7) 40 (60.0) 46 (63.0) 21 (57.1) 63 (71.4) 69 (71.0) 68 (79.4) 46 (41.3) 46 (50.0) 26 (57.7) 257 (59.1) 295 (66.4) 163 (65.0) Centre has reached the upper 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 99.8% confidence limit	Lt DBD donor bilateral lung offer decline rates by transplant centre n 1 April 2018 and 31 March 2021 2018/19 2019/20 2020/21 Over the constraint of the co	

ADULT LUNG TRANSPLANTATION

Transplants



11.1 Adult lung and heart-lung transplants, 1 April 2011 – 31 March 2021

Figure 11.1 and **11.2** show the number of adult lung transplants performed per year over the last ten years, by donor type, nationally and by centre, respectively. The number of transplants increased over the first few years of the decade, reaching a peak of 210 in 2013/2014. The number has since fallen (except in 2017/2018 which was another peak year), with only 87 transplants last year. **Figure 11.2** shows that all centres performed fewer transplants in 2020/2021 compared with the previous year. Last year DCD lung transplantation represented 22% of the total activity. Last year's activity is shown by centre and donor type in **Figure 11.3**. The highest number of transplants were performed by Harefield.







Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2011 to 31 March 2021



Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2010 to 31 March 2021

Figure 11.4 and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. The number of transplants by transplant type in the latest financial year (2010/2021) is shown by centre in **Figure 11.6**. There was a total of 45 heart-lung block transplants, and no partial lung transplants, over the decade. The overall proportion of single lung transplants has decreased from 18% in 2011/2012 to 8% in 2020/2021. When broken down by centre, it can be seen that Newcastle, Manchester and Birmingham have reduced their use of single lungs. In the last financial year Papworth was the highest user of single lungs and Manchester and Birmingham were the only centres that performed heart-lung block transplants (**Figure 11.6**).







Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2011 to 31 March 2021



Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2020 to 31 March 2021

On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. The number of lung only transplants per year by urgency status is shown in **Figure 11.7**; the proportion of urgent or super-urgent lung transplants was 21% in 2020/2021.



Figure 11.7 Number of adult lung only transplants in the UK, by financial year and urgency status, 1 April 2011 to 31 March 2021

Figure 11.8 shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 17 urgent lung only transplants (ranging from 1 at Manchester to 5 at both Newcastle and Papworth) and 1 super-urgent lung only transplant, performed at Harefield. Of the two adult heart-lung transplants in 2020/2021, one was urgent and one was non-urgent.





Non-urgent Urgent Super-urgent

11.2 Demographic characteristics of transplants, 1 April 2020 – 31 March 2021

The demographic characteristics of the 87 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 64% of lung recipients were male and the <u>median</u> age was 53 years while the median age of donors was 46 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2020 to 31 March 2021, by centre									
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)		
Number of transplants		7 (100)	28 (100)	13 (100)	21 (100)	18 (100)	87 (100)		
Urgency status at transplant	Non-urgent	4 (57)	23 (82)	12 (92)	16 (76)	13 (72)	68 (78)		
	Urgent	3 (43)	4 (14)	1 (8)	5 (24)	5 (28)	18 (21)		
	Super-urgent	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	1 (1)		
Transplant type	Single lung	1 (14)	1 (4)	1 (8)	0 (0)	4 (22)	7 (8)		
	Bilateral lung	5 (71)	27 (96)	11 (85)	21 (100)	14 (78)	78 (90)		
	Heart-lung	1 (14)	0 (0)	1 (8)	0 (0)	0 (0)	2 (2)		
Recipient sex	Male	4 (57)	15 (54)	8 (62)	16 (76)	13 (72)	56 (64)		
	Female	3 (43)	13 (46)	5 (38)	5 (24)	5 (28)	31 (36)		
Recipient ethnicity	White	7 (100)	21 (75)	12 (92)	20 (95)	18 (100)	78 (90)		
	Non-white	0 (0)	7 (25)	1 (8)	1 (5)	0 (0)	9 (10)		
Recipient age (years)	Median (<u>IQR</u>)	60 (56, 62)	52 (36, 57)	49 (44, 56)	55 (49, 62)	57 (50, 61)	53 (47, 60)		
	Missing	0	0	0	0	0	0		
Recipient weight (kg)	Median (<u>IQR</u>)	74 (53, 91)	63 (59, 78)	72 (62, 84)	77 (66, 88)	69 (57, 79)	70 (59, 81)		
	Missing	0	0	0	0	0	0		
Recipient primary disease	Cystic fibrosis and bronchiectasis Fibrosing lung disease COPD and emphysema Primary pulmonary hypertension Other	0 (0) 2 (29) 3 (43) 0 (0) 2 (29)	8 (29) 5 (18) 11 (39) 0 (0) 4 (14)	0 (0) 4 (31) 6 (46) 1 (8) 2 (15)	3 (14) 12 (57) 4 (19) 1 (5) 1 (5)	1 (6) 4 (22) 8 (44) 2 (11) 3 (17)	12 (14) 27 (31) 32 (37) 4 (5) 12 (14)		
NYHA class	I	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)		
	II	0 (0)	5 (18)	0 (0)	4 (19)	0 (0)	9 (10)		
	III	2 (29)	14 (50)	9 (69)	17 (81)	8 (44)	50 (58)		
	IV	2 (29)	2 (7)	4 (31)	0 (0)	10 (56)	18 (21)		
	Missing	2 (29)	7 (25)	0 (0)	0 (0)	0 (0)	9 (10)		

Table 11.1 Demog	Table 11.1Demographic characteristics of adult lung transplants, 1 April 2020 to 31 March 2021, by centre								
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)		
Recipient in hospital	No	3 (43)	24 (86)	13 (100)	20 (95)	18 (100)	78 (90)		
pre-transplant	Yes	4 (57)	4 (14)	0 (0)	1 (5)	0 (0)	9 (10)		
If in hospital, recipient on ventilator	No	4 (100)	3 (75)	0	1 (100)	0	8 (89)		
	Yes	0 (0)	1 (25)	0	0 (0)	0	1 (11)		
If in hospital, recipient on inotropes	No	4 (100)	4 (100)	0	1 (100)	0	9 (100)		
	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
If in hospital, recipient on ECMO	No	4 (100)	3 (75)	0	1 (100)	0	8 (89)		
	Yes	0 (0)	1 (25)	0	0 (0)	0	1 (11)		
Recipient CMV status	No	5 (71)	15 (54)	7 (54)	11 (52)	13 (72)	51 (59)		
	Yes	2 (29)	13 (46)	6 (46)	10 (48)	4 (22)	35 (40)		
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (6)	1 (1)		
Recipient HCV status	No	7 (100)	28 (100)	13 (100)	21 (100)	18 (100)	87 (100)		
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
Recipient HBV status	No	7 (100)	28 (100)	13 (100)	21 (100)	18 (100)	87 (100)		
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
Recipient HIV status	No	7 (100)	28 (100)	13 (100)	21 (100)	18 (100)	87 (100)		
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)		
Recipient serum	Median (<u>IQR</u>)	57 (46, 82)	63 (55, 71)	70 (65, 80)	67 (55, 78)	62 (58, 73)	65 (55, 75)		
creatinine (umol/l)	Missing	0	1	0	0	0	1		
Donor sex	Male	3 (43)	13 (46)	7 (54)	8 (38)	9 (50)	40 (46)		
	Female	4 (57)	15 (54)	6 (46)	13 (62)	9 (50)	47 (54)		
Donor ethnicity	White	6 (86)	22 (79)	8 (62)	18 (86)	14 (78)	68 (78)		
	Non-white	0 (0)	5 (18)	3 (23)	3 (14)	4 (22)	15 (17)		
	Missing	1 (14)	1 (4)	2 (15)	0 (0)	0 (0)	4 (5)		
Donor age (years)	Median (<u>IQR</u>)	56 (29, 63)	48 (25, 55)	47 (40, 53)	37 (23, 47)	46 (28, 55)	46 (28, 55)		
	Missing	0	0	0	0	0	0		
Donor BMI (kg/m ²)	Median (<u>IQR</u>)	23 (21, 26)	24 (22, 28)	25 (24, 27)	23 (22, 26)	25 (21, 27)	24 (22, 27)		
	Missing	0	0	0	0	0	0		

Table 11.1 Demographic characteristics of adult lung transplants, 1 April 2020 to 31 March 2021, by centre								
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)	
Donor cause of death	CVA	6 (86)	27 (96)	13 (100)	16 (76)	15 (83)	77 (89)	
	Trauma	0 (0)	0 (0)	0 (0)	1 (5)	1 (6)	2 (2)	
	Others	1 (14)	1 (4)	0 (0)	4 (19)	2 (11)	8 (9)	
Donor hypotension	No	5 (71)	22 (79)	11 (85)	3 (14)	15 (83)	56 (64)	
	Yes	2 (29)	4 (14)	2 (15)	6 (29)	2 (11)	16 (18)	
	Missing	0 (0)	2 (7)	0 (0)	12 (57)	1 (6)	15 (17)	
Donor past cardiothoracic disease	No	6 (86)	28 (100)	13 (100)	21 (100)	16 (89)	84 (97)	
	Yes	1 (14)	0 (0)	0 (0)	0 (0)	2 (11)	3 (3)	
Donor past hypertension	No	4 (57)	19 (68)	12 (92)	20 (95)	15 (83)	70 (81)	
	Yes	2 (29)	9 (32)	1 (8)	1 (5)	3 (17)	16 (18)	
	Missing	1 (14)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	
Donor past tumour	No	7 (100)	27 (96)	13 (100)	21 (100)	18 (100)	86 (99)	
	Yes	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	1 (1)	
Donor past smoker	No	4 (57)	17 (61)	9 (69)	9 (43)	9 (50)	48 (55)	
	Yes	3 (43)	11 (39)	4 (31)	12 (57)	9 (50)	39 (45)	
Total ischaemia time	Median (IQR)	5.9 (4.4, 6.8)	8.3 (6.9, 10.2)	5.4 (5.3, 7.0)	5.8 (5.1, 6.2)	7.5 (6.4, 8.9)	6.9 (5.7, 8.3)	
(hours)	Missing	1	1	0	1	1	4	

11.3 Total ischaemia time, 1 April 2011 – 31 March 2021

Figure 11.9 shows <u>boxplots</u> of the total ischaemia time for <u>DBD</u> donor lungs transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion (of second lung if applicable) and can be considered the out of body time. In cases where organ maintenance systems were used (3%), not all of this time duration is ischaemic, and no adjustment has been made for this. The national <u>median</u> total ischaemia time has increased from 5.6 hours to 6.4 hours over the last decade.





Figure 11.10 and **Figure 11.11** show <u>boxplots</u> of total ischaemia time by centre in the latest financial year (2020/2021) and over the last 10 years, respectively. The median ischaemia time for lung transplants in 2020/2021 was longest for Harefield and shortest for Manchester. Over time, several centres have experienced increases in ischaemia times.



Figure 11.10 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2020 to 31 March 2021

Figure 11.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2011 to 31 March 2021



ADULT LUNG TRANSPLANTATION

Post-Transplant Survival



12. Post-Transplant Survival

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

The survival analyses exclude <u>multi-organ transplants</u> and include first time transplants only. Ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2020 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2012 to 31 March 2016. Both DBD and DCD lung transplants are included. <u>Survival rates</u> are presented by transplant centre in **Tables 12.1-12.3** and **Figures 12.1-12.3**, by disease group in **Tables 12.4-12.5**, and by transplant type (single or bilateral lungs) in **Table 12.6**. Heart-lung transplants are excluded but separate tables (**Table 12.7** and **12.8**) at the end of this section provide <u>unadjusted survival rates</u> for the small number of heart-lung transplant recipients between 1 April 2012 and 31 March 2020.

12.1 Survival by centre

Table 12.1 and **Figure 12.1** show the 90-day post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient survival rate for each centre and nationally for the 656 first adult lung only transplants in the period 1 April 2016 to 31 March 2020. Manchester's survival rate at 90 days falls above the 99.8% upper <u>confidence limit</u>, indicating that the survival rate is higher than the national average at this time point. All other centres were statistically consistent with the national rate of survival which was 89.9%.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre,1 April 2016 to 31 March 2020								
Centre	Number of		% 90 day survi	val (95%	o CI)			
	transplants	<u>L</u>	<u>Inadjusted</u>	<u>Ris</u>	sk-adjusted			
Birmingham	64	84.4	(72.9 - 91.3)	86.0	(73.9 - 92.5)			
Harefield	183	89.1	(83.6 - 92.8)	88.6	(82.4 - 92.7)			
Manchester	111	97.3	(91.9 - 99.1)	97.4	(92.1 - 99.2)			
Newcastle	132	86.4	(79.2 - 91.2)	86.5	(78.5 - 91.5)			
Papworth	166	91.0	(85.5 - 94.5)	90.5	(84.3 - 94.3)			
UK	656	89.9	(87.4 - 92)					
	Centre has reache	d the lower	99.8% confidence li	mit				
	Centre has reache	d the lower	95% confidence limi	t 				
	Centre nas reache	a the upper	95% confidence lim	IT .,				
	Centre has reache	a the upper	99.8% confidence li	mit				

Figure 12.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2016 to 31 March 2020



Table 12.2 and **Figure 12.2** show the 1-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 656 first adult lung only transplants in the period 1 April 2016 to 31 March 2020. The national rate of survival was 81.3%. The rates for all centres were statistically consistent with the national rate.

Table 12.2 1 year patient survival rates after first adult lung transplant, by centre,1 April 2016 to 31 March 2020									
Centre	Number of % 1 year survival (95% CI)								
	transplants	<u>L</u>	Inadjusted	<u>Ris</u>	sk-adjusted				
Birmingham	64	76.5	(64 - 85.1)	76.4	(60.8 - 85.8)				
Harefield	183	82.5	(76.2 - 87.3)	81.2	(73.4 - 86.7)				
Manchester	111	85.5	(77.4 - 90.8)	86.7	(78.2 - 91.8)				
Newcastle	132	79.4	(71.4 - 85.4)	79.6	(70.2 - 86.0)				
Papworth	166	80.7	(73.8 - 85.9)	80.9	(73.0 - 86.5)				
UK	656	81.3	(78.1 - 84.1)						
	Centre has reache	d the lower	99.8% confidence li	mit					
	Centre has reache	d the lower	95% confidence limi	t					
	Centre has reache	d the upper	95% confidence lim	it					
	Centre has reache	d the upper	99.8% confidence li	mit					

Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2016 to 31 March 2020



Table 12.3 and **Figure 12.3** show the 5-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 722 first adult lung only transplants in the period 1 April 2012 to 31 March 2016. Birmingham's survival rate at 5 years falls below the 99.8% lower <u>confidence limit</u>, indicating lower than average survival at this time point. All other centres were statistically consistent with the national rate of survival of 56.2%.

Table 12.3 5 year patient survival rates after first adult lung transplant, by centre,1 April 2012 to 31 March 2016								
Centre	Number of transplants	<u>L</u>	% 5 year surviv Inadjusted	val (95% <u>Ris</u>	s <mark>cI)</mark> sk-adjusted			
Birmingham Harefield Manchester Newcastle Papworth	84 200 102 193 143	39.2 65.0 50.0 56.2 58.5	(28.8 - 49.5) (57.9 - 71.1) (40 - 59.2) (48.8 - 62.9) (49.9 - 66.1)	31.0 62.8 54.0 57.2 60.7	(9.1 - 47.5) (53.0 - 70.6) (39.4 - 65.0) (46.9 - 65.4) (49.3 - 69.6)			
UK	722	56.2	(52.5 - 59.7)					
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit								

Figure 12.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2012 to 31 March 2016



12.2 Survival by disease group

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

Table 12.4 1 year patient survival rates after first adult lung transplant, by disease group,1 April 2016 to 31 March 2020

Disease group	Number of % 1 year survival (95% C				CI)
	transplants	<u>L</u>	Inadjusted	Risk-adjusted	
Cystic fibrosis and bronchiectasis	197	85.8	(80.1 - 89.9)	80.7	(72.1 - 86.7)
COPD and emphysema	184	79.7	(73.1 - 84.8)	82.3	(75.6 - 87.2)
Fibrosing lung disease	153	77.6	(70.1 - 83.4)	79.5	(71.3 - 85.3)
Other	122	81.1	(73.0 - 87.0)	82.7	(74.0 - 88.5)
UK	656	81.3	(78.1 - 84.1)		

Table 12.55 year patient survival rates after first adult lung transplant, by disease group,
1 April 2012 to 31 March 2016

Disease group	Number of	val (95%	(95% CI)		
	transplants	plants <u>Unadjuste</u>		Risk-adjusted	
Cystic fibrosis and bronchiectasis	213	61.9	(55.0 - 68.0)	61.1	(51.6 - 68.7)
COPD and emphysema	224	59.4	(52.6 - 65.5)	54.5	(44.2 - 63.0)
Fibrosing lung disease	158	51.1	(43.0 - 58.6)	59.1	(48.9 - 67.3)
Other	127	47.4	(38.5 - 55.9)	46.1	(31.4 - 57.7)
UK	722	56.2	(52.5 - 59.7)		

12.3 Survival by transplant type

Table 12.6 presents <u>unadjusted survival rates</u> by transplant type (single lung against bilateral lung), at 90 days,1 year and 5 years post-transplant, respectively. Survival rates at 90 days and 1 year are based on transplants performed between 1 April 2016 and 31 March 2020 whereas the 5 year survival rates are for transplants performed between 1 April 2012 and 31 March 2016. Survival rates across transplant types were comparable at 90 days and 1 year, however a significant difference was found at 5 years (log-rank p=0.01).

Table 12.6Unadjusted patient survival rates after first adult lung transplant, by transplant type,1 April 2016 to 31 March 2020 (90 day and 1 year) and 1 April 2012 to 31 March 2016 (5 year)									
Transplant type	N*	90 c % surv <u>Ur</u>	lay ival (95% CI) nadjusted	N*	1 ye % sur\ <u>Ur</u>	ar /ival (95% CI) nadjusted	N*	5 y % sur <u>U</u>	ear vival (95% CI) <u>nadjusted</u>
Single lung Bilateral lung	73 583	91.8 89.7	(82.6 - 96.2) (86.9 - 91.9)	73 583	79.4 81.6	(68.1 - 87.0) (78.2 - 84.5)	97 625	42.9 58.3	(32.9 - 52.5) (54.3 - 62.0)
UK * Number of transpla	656 ants	89.9	(87.4 - 92.0)	656	81.3	(78.1 - 84.1)	722	56.2	(52.5 - 59.7)

12.4 Survival post heart-lung transplant

Table 12.7 and **Table 12.8** present short-term patient <u>survival rates</u> following combined heart-lung transplant, by centre and nationally. During the time period 1 April 2012 to 31 March 2020, a small number of transplants were performed, with the highest number being performed at Papworth, hence centre-specific rates are only reported for Papworth. The national rates of survival were 81.1% at 90 days and 69.9% at one year.

Table 12.7 90 day patient survival after first adult heart-lung transplant, by centre,1 April 2012 and 31 March 2020							
Centre	Number of transplants	Number of deaths	% 90 day s (<u>un</u>	survival (95% CI) <u>adjusted</u>)			
Birmingham ¹	6	1	-	-			
Harefield ¹	6	3	-	-			
Manchester ¹	6	0	-	-			
Newcastle ¹	6	1	-	-			
Papworth	13	2	84.6	(51.2 - 95.9)			
UK	37	7	81.1	(64.4 - 90.5)			
¹ Survival rates for groups with le	¹ Survival rates for groups with less than 10 patients are not presented due to small numbers						

Table 12.8 1 year patient survival after first adult heart-lung transplant, by centre,1 April 2012 and 31 March 2020							
Centre	Number of transplants	Number of deaths	% 1 year si (<u>una</u>	urvival (95% CI) adjusted)			
Birmingham ¹	6	1	-	-			
Harefield ¹	6	5	-	-			
Manchester ¹	6	1	-	-			
Newcastle ¹	6	2	-	-			
Papworth	13	2	84.6	(51.2 - 95.9)			
UK	37	11	69.9	(52.2 - 82.1)			
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers							

ADULT LUNG TRANSPLANTATION

Survival from Listing



13. Survival from Listing

Survival from listing was analysed for patients 18 years or older registered for the first time for a lung transplant between 1 January 2009 and 31 December 2020. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. Survival time was censored at either date of removal from the list, or at the last known follow-up date post-transplant when no death date was recorded, or at time of analysis if the patient was still active on the transplant list. The risk factors used to produce the risk-adjusted survival rates are listed in Appendix A2.1.

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

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

Table 13.1Risk-adjusted 1 and 5 year patient survival from listing for first lung only transplants in patients registered between 1 January 2009 to 31 December 2020								
Centre	Number at risk ¹ at day 0	Survival rate (%)	One year (95% CI)	Number at risk ¹	Survival rate (%)	Five year (95% CI)	Number at risk ¹	
Birmingham Harefield Manchester Newcastle Papworth UK	360 826 420 728 559 2893	70.7 82.0 83.6 73.5 79.0 78.0	(64.4 - 75.9) (78.6 - 84.8) (79.2 - 87.1) (69.6 - 77.0) (74.9 - 82.4) (76.5 - 79.5)	233 653 325 502 403 2116	32.2 56.8 51.0 47.0 51.0 49.4	(21.9 - 41.2) (51.6 - 61.4) (43.3 - 57.6) (41.0 - 52.4) (44.3 - 56.9) (47.3 - 51.5)	54 239 98 191 140 722	
¹ Number of pat	Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit ents with reported follow-up beyond this time point							

Figure 13.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2009 – 31 December 2020



Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2009 – 31 December 2020



ADULT LUNG TRANSPLANTATION Form Return Rates



14. Adult lung form return rates, 1 January – 31 December 2020

Form return rates are reported in Table 14.1 for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all adult lung and heart-lung transplants between 1 January and 31 December 2020 for the transplant record, and all follow up forms issued in this time period. Centres highlighted are the currently active transplant centres. All active centres have a form return rate of 94% or greater for this period. Note that any skipped follow-up forms are counted as not returned.

Table 14.1 Form return rates for adult lung transplants, 1 January 2020 to 31 December 2020								
Centre	Transpla No. required	nt record % returned	3 month No. required	follow-up % returned	1 year fo No. required	ollow-up % returned	Lifetime No. required	follow-up % returned
Birmingham Queen Elizabeth Hospital	9	100	8	100	15	100	108	100
Glasgow Golden Jubilee Hospital	-	-	-	-	-	-	1	100
Harefield Hospital	30	100	25	100	28	100	447	96
London King's College Hospital	-	-	-	-	-	-	1	0
Manchester Wythenshawe Hospital	16	100	18	100	28	100	177	100
Newcastle Freeman Hospital	22	100	17	100	27	100	327	98
Royal Papworth Hospital	21	100	26	96	38	100	305	94
Sheffield Northern General Hospital	-	-	-	-	-	-	5	100
Overall	98	100	94	99	136	100	1371	97

PAEDIATRIC HEART TRANSPLANTATION

Transplant List



15.1 Paediatric heart only transplant list as at 31 March, 2012 – 2021

Figure 15.1 shows the number of paediatric patients on the heart transplant list at 31 March each year between 2012 and 2021 split by urgency status of the patient. The number of patients on the active non-urgent heart transplant list increased substantially during the last financial year, reaching 34 on 31 March 2021. There has also been an upward trend in the number of patients on the urgent transplant list, with 13 urgent paediatric patients waiting on 31 March 2021.





Figure 15.2 shows the number of paediatric patients on the <u>active heart transplant list</u> at 31 March 2021 by centre and urgency. In total, there were 47 paediatric patients waiting. Great Ormond Street Hospital had the largest overall number of paediatric patients on the transplant list. **Figure 15.3** shows the number of patients split by centre and mechanical circulatory support (MCS) status where MCS includes ventricular assist devices and extracorporeal membrane oxygenation. A total of 9 (19%) of the paediatric heart list were on MCS on 31 March 2021.





Figure 15.3 Number of paediatric patients on the active heart transplant list at 31 March 2021, by centre and mechanical circulatory support status



Figure 15.4 shows the trend over time in the number of paediatric patients on the heart transplant list on 31 March each year across each centre. Both centres had a relatively high number of patients on their non-urgent lists as at 31 March 2021, with 17 each. Great Ormond Street Hospital's urgent list has increased in recent years, while Newcastle's urgent list has remained reasonably stable.





15.2 Demographic characteristics, 1 April 2020 – 31 March 2021

There were 43 paediatric patient registrations onto the heart transplant list between 1 April 2020 and 31 March 2021. Demographic characteristics of these patients are shown by centre and overall, in **Table 15.1**. Nationally, 47% of the patients were male and the <u>median</u> age was 4 years. One of these registrations was super-urgent. For some characteristics, due to rounding, percentages may not add up to 100.

Table 15.1 Demographic characteristics of paediatric patients registered onto the heart transplant list between 1 April 2020 and 31 March 2021, by centre						
		Great Ormond Street Hospital	Newcastle	TOTAL		
		N (%)	N (%)	N (%)		
Number of registrations		20 (100)	23 (100)	43 (100)		
Highest urgency during registration	Non-urgent	11 (55)	11 (48)	22 (51)		
	Urgent	9 (45)	11 (48)	20 (47)		
	Super-urgent	0 (0)	1 (4)	1 (2)		
Recipient sex	Male	9 (45)	11 (48)	20 (47)		
	Female	11 (55)	12 (52)	23 (54)		
Recipient ethnicity	White	17 (85)	19 (83)	36 (84)		
	Non-white	3 (15)	4 (17)	7 (16)		
Recipient age (years)	Median (<u>IQR</u>)	6 (2, 11)	3 (0, 12)	4 (0, 12)		
	Missing	0	0	0		
Recipient height (cm)	Median (<u>IQR</u>)	114 (80, 140)	88 (68, 142)	95 (70, 142)		
	Missing	0	0	0		
Recipient weight (kg)	Median (<u>IQR</u>)	18 (10, 30)	13 (8, 36)	14 (8, 33)		
	Missing	0	0	0		
Primary Disease	Coronary heart disease	1 (5)	0 (0)	1 (2)		
	Cardiomyopathy	12 (60)	10 (43)	22 (51)		
	Congenital heart disease	4 (20)	12 (52)	16 (37)		
	Graft failure/rejection	3 (15)	0 (0)	3 (7)		
	Others	0 (0)	1 (4)	1 (2)		
Previous open heart surgery	None One More than one Missing	10 (50) 6 (30) 4 (20) 0 (0)	5 (23) 5 (23) 10 (45) 2 (9)	15 (36) 11 (26) 14 (33) 2 (5)		
Serum Bilirubin (umol/l)	Median (<u>IQR</u>)	10 (6, 13)	11 (8, 19)	10 (7, 17)		
	Missing	0	7	7		
Serum Creatinine (umol/l)	Median (<u>IQR</u>)	39 (25, 53)	27 (25, 44)	30 (25, 51)		
	Missing	0	6	6		

15.3 Post-registration outcomes, 1 April 2016 – 31 March 2018

The registration outcomes of paediatric patients listed for a heart transplant between 1 April 2016 and 31 March 2018 are summarised in **Figure 15.5** and **Figure 15.6**, for non-urgent and urgent registrations, respectively. The possible outcomes for patients on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted". If a patient moved lists, e.g. from the non-urgent to the urgent list, they would be included in both the non-urgent and the urgent charts.

Within the first 6 months of listing, it is shown that 23% had received a transplant, 3% had died and 29% had been moved to the urgent list. At 3 years, 29% had been transplanted, however, now 49% of non-urgent recipients have been added to the urgent list. As can be seen in **Figure 15.6**, recipients have a greater chance of transplant on the urgent heart list comparative to the non-urgent list, with 51% receiving a transplant by 6 months. Removals from the urgent list were for a mixture of improved and deteriorating condition.

Figure 15.5 Post-registration outcome for 35 new non-urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2018





Figure 15.6 Post-registration outcome for 73 new urgent heart only registrations made in the UK, 1 April 2016 to 31 March 2018

15.4 Median waiting time to transplant, 1 April 2015 - 31 March 2018

Table 15.2 shows the <u>median</u> waiting time to heart transplant from listing for paediatric patients registered between 1 April 2015 and 31 March 2018. This is estimated using the <u>Kaplan Meier</u> method and is split by the urgency of the patient at initial registration; nonurgent or urgent. All waiting time from initial registration is considered for patients, regardless of any change in urgency. Any suspended time is discounted.

The national <u>median</u> waiting time to paediatric heart transplant was 447 days from nonurgent registration and 104 days from urgent registration. There was some evidence of longer waiting times at Great Ormond Street Hospital compared with Newcastle across both non-urgent and urgent registrations. The <u>median</u> waiting time to heart transplant for paediatric patients is also considered by blood group in **Table 15.3**.

Table 15.2 Median active waiting time to heart transplant for paediatric patients registered on the
transplant list, by urgency at registration and centre, 1 April 2015 to 31 March 2018

Transplant centre	Number of patients	Number	Waiting time (days)				
	registered	transplanted	<u>Median</u>	95% Confidence interval			
Overall							
Great Ormond Street Hospital	68	40	219	49 - 389			
Newcastle	77	53	106	66 - 146			
UK	145	93	159	117 - 201			
Non-urgent at initial registration							
Great Ormond Street Hospital	33	20	662	108 - 1216			
Newcastle	20	13	176	42 - 310			
UK	53	33	447	124 - 770			
Urgent at initial registration							
Great Ormond Street Hospital	35	20	151	56 - 246			
Newcastle	57	40	87	26 - 148			
UK	92	60	104	65 - 143			

transplant list, by urgency at registration and blood group, 1 April 2015 to 31 March 2018							
Blood Group	Number of patients registered	Number transplanted	W <u>Median</u>	aiting time (days) 95% <u>Confidence interval</u>			
Overall							
O A B AB ¹	74 42 25 4	40 31 18 4	196 104 129 -	123 - 269 49 - 159 54 - 204 -			
UK	145	93	159	117 - 201			
Non-urgent at initial registration							
O A B AB ¹	27 17 9 0	15 13 5 -	813 137 662 -	263 - 1363 14 - 260 0 - 1747 -			
υκ	53	33	447	124 - 770			
Urgent at initial registration							
O A B AB ¹	47 25 16 4	25 18 13 4	151 87 102 -	101 - 201 38 - 136 3 - 201 -			
UK	92	60	104	65 - 143			
¹ Median waiting time for groups with less than 10 patients are not presented due to small numbers							

Table 15.3 Median active waiting time to heart transplant for paediatric patients registered on the
transplant list, by urgency at registration and blood group, 1 April 2015 to 31 March 2018

PAEDIATRIC HEART TRANSPLANTATION

Response to Offers


16. Response to Offers

Table 16.1 compares individual centre paediatric heart offer decline rates over the three years between 1 April 2018 and 31 March 2021. This only considers offers of UK DBD donor hearts that were eventually transplanted and excludes fast track offers. Hearts offered as part of a cardiac block are considered, this includes cases where just the heart is declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients, but acceptance is determined by a centre's position in the allocation sequence. In this analysis, adjustments have been made to count any centre who is ranked above the accepting centre in the allocation sequence for that donor as declining the heart, even if they did not respond to the group offer, and any declines recorded for a centre ranked below the accepting centre were discounted.

The number of offers received per year from paediatric donors whose heart was donated, is small. In 2020/2021, there was an overall decline rate for paediatric offers, of 63.6%.

Table 16.1	UK paediatri 1 April 2018	ic DBD 8 to 31 N	donor hea March 2021	rt offer d	ecline rate	s by tran	splant cen	tre and y	ear,
Centre		201	8/19	201	19/20	202	20/21	Ov	/erall
		No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)
GOSH		16	(50.0)	14	(78.6)	15	(53.3)	45	(60.0)
Newcastle		8	(25.0)	15	(46.7)	7	(85.7)	30	(50.0)
UK		24	(41.7)	29	(62.1)	22	(63.6)	75	(56.0)

PAEDIATRIC HEART TRANSPLANTATION

Transplants



17.1 Paediatric heart transplants, 1 April 2011 – 31 March 2021

Figure 17.1 and **17.2** show the number of paediatric heart transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants was highest in 2014/2015 and lowest in 2019/20. Last year's activity is shown by centre in **Figure 17.3**. The 27 transplants carried out in 2020/2021 comprised of 20 at Great Ormond Street Hospital and 7 at Newcastle, and there were a total of six DCD transplants.





Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2011 to 31 March 2021



Figure 17.3 Number of paediatric heart transplants in the UK, by centre and donor type, 1 April 2020 to 31 March 2021



Figure 17.4 and **17.5** show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. The majory of transplants were urgent, but in the last year, there were three super-urgent transplants. Last year's activity is shown by centre and urgency status in **Figure 17.6**, indicating that the three super-urgent transplants were all at Great Ormond Street Hospital.









Figure 17.6 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2020 to 31 March 2021



17.2 Demographic characteristics of transplants, 1 April 2020 – 31 March 2021

The demographic characteristics of the 27 paediatric heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 17.1**. Nationally, 52% of heart recipients were female and the <u>median</u> age was 10 years, while the median age of donors was 19 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 17.1 Demographic by centre	characteristics of paediatrie	c heart transplants	1 April 2020 to 31	March 2021,
		Great Ormond	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		20 (100)	7 (100)	27 (100)
Urgency status at transplant	Non-urgent	3 (15)	2 (29)	5 (19)
	Urgent	14 (70)	5 (71)	19 (70)
	Super-urgent	3 (15)	0 (0)	3 (11)
Recipient sex	Male	12 (60)	1 (14)	13 (48)
	Female	8 (40)	6 (86)	14 (52)
Recipient ethnicity	White	14 (70)	5 (71)	19 (70)
	Non-white	5 (25)	2 (29)	7 (26)
	Missing	1 (5)	0 (0)	1 (4)
Recipient age	Median (IQR)	11 (5, 13)	10 (2, 13)	10 (4, 13)
	Missing	0	0	0
Recipient weight	Median (IQR)	26 (13, 33)	24 (12, 36)	25 (13, 33)
	Missing	0	0	0
Recipient primary disease	Coronary heart disease	1 (5)	0 (0)	1 (4)
	Cardiomyopathy	17 (85)	2 (29)	19 (70)
	Congenital heart disease	1 (5)	3 (43)	4 (15)
	Graft failure/Rejection	0 (0)	2 (29)	2 (7)
	Other	1 (5)	0 (0)	1 (4)
NYHA class	II	1 (5)	0 (0)	1 (4)
	III	5 (25)	2 (29)	7 (26)
	IV	9 (45)	5 (71)	14 (52)
	Missing	5 (25)	0 (0)	5 (19)
Recipient in hospital	No	9 (45)	1 (14)	10 (37)
	Yes	10 (50)	6 (86)	16 (59)
	Missing	1 (5)	0 (0)	1 (4)
If in hospital, recipient on ventilator	No	8 (80)	3 (50)	11 (69)
	Yes	2 (20)	3 (50)	5 (31)
If in hospital, recipient on VAD	None Left Both	4 (40) 4 (40) 2 (20)	4 (67) 2 (33) 0 (0)	8 (50) 6 (38) 2 (13)
If in hospital, recipient on TAH	No	10 (100)	6 (100)	16 (100)
If in hospital, recipient on ECMO	No	8 (80)	5 (83)	13 (81)
	Yes	2 (20)	1 (17)	3 (19)
If in hospital, recipient on inotropes	No	6 (60)	0 (0)	6 (38)
	Yes	4 (40)	6 (100)	10 (63)

Table 17.1 Demographic by centre	characteristics of paediat	ric heart transplants	1 April 2020 to 31	March 2021,
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
If in hospital, recipient on IABP	No	9 (90)	6 (100)	15 (94)
	Yes	1 (10)	0 (0)	1 (6)
Recipient CMV status	No	11 (55)	5 (71)	16 (59)
	Yes	7 (35)	2 (29)	9 (33)
	Missing	2 (10)	0 (0)	2 (7)
Recipient HCV status	No	18 (90)	7 (100)	25 (93)
	Missing	2 (10)	0 (0)	2 (7)
Recipient HBV status	No	18 (90)	7 (100)	25 (93)
	Missing	2 (10)	0 (0)	2 (7)
Recipient HIV status	No	18 (90)	7 (100)	25 (93)
	Missing	2 (10)	0 (0)	2 (7)
Recipient Serum Creatinine	Median (IQR)	37 (29, 57)	39 (30, 109)	38 (30, 57)
	Missing	1	0	1
Donor sex	Male	12 (60)	1 (14)	13 (48)
	Female	8 (40)	6 (86)	14 (52)
Donor ethnicity	White	18 (90)	7 (100)	25 (93)
	Missing	2 (10)	0 (0)	2 (7)
Donor age	Median (IQR)	18 (10, 34)	19 (13, 29)	19 (11, 32)
	Missing	0	0	0
Donor BMI	Median (IQR)	20 (18, 23)	18 (16, 20)	19 (17, 23)
	Missing	0	0	0
Donor cause of death	CVA	15 (75)	5 (71)	20 (74)
	Trauma	1 (5)	0 (0)	1 (4)
	Others	4 (20)	2 (29)	6 (22)
Donor hypotension	No	14 (70)	3 (43)	17 (63)
	Yes	3 (15)	0 (0)	3 (11)
	Missing	3 (15)	4 (57)	7 (26)
Donor past diabetes	No	20 (100)	6 (86)	26 (96)
	Yes	0 (0)	1 (14)	1 (4)
Donor past cardio disease	No	18 (90)	7 (100)	25 (93)
	Missing	2 (10)	0 (0)	2 (7)
Donor past hypertension	No	20 (100)	6 (86)	26 (96)
	Yes	0 (0)	1 (14)	1 (4)
Donor past tumour	No	19 (95)	6 (86)	25 (93)
	Yes	1 (5)	1 (14)	2 (7)
Donor past smoker	No	14 (70)	4 (57)	18 (67)
	Yes	6 (30)	3 (43)	9 (33)
Total ischaemia time	Median (IQR)	4.0 (3.2, 5.2)	3.8 (3.2, 3.9)	4.0 (3.2, 4.9)
	Missing	1	2	3

17.3 Total ischaemia time, 1 April 2011 – 31 March 2021

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





Figure 17.8 and **Figure 17.9** show <u>boxplots</u> of total ischaemia time by centre in the latest financial year (2020/2021) and over the last 10 years, respectively. Generally, the median ischaemia times for Newcastle were marginally shorter than the median ischaemia times for Great Ormond Street Hospital.





Figure 17.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2011 to 31 March 2021



PAEDIATRIC HEART TRANSPLANTATION

Post-Transplant Survival



18. Post-Transplant Survival

The survival analyses presented in this section exclude <u>multi-organ transplants</u> and <u>DCD</u> heart transplants and include first time transplants only. Thirty-day, ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2020 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2012 to 31 March 2016.

The 30-day post-transplant <u>unadjusted</u> patient survival rate for each centre and nationally are shown in **Table 18.1** for the 109 first DBD paediatric heart only transplants in the period 1 April 2016 to 31 March 2020. There were no deaths within 30 days at Great Ormond Street Hospital. The 90 day <u>survival rates</u> are identical to the 30 day rates, as shown in **Table 18.2**, as there were no additional deaths.

Table 18.1 30 day patient survival rates after first DBD paediatric heart only transplant, by centre, 1 April 2016 to 31 March 2020					
Centre	Number of patients	Number of deaths	% 30 day s (un	survival (95% CI) adjusted)	
Great Ormond Street Hospital Newcastle	52 57	0 4	100.0 93	(-) (82.4 - 97.3)	
υκ	109	4	96.3	(90.5 - 98.6)	

Table 18.2 90 day patient survival rates after first DBD paediatric heart only transplant, by	y
centre, 1 April 2016 to 31 March 2020	

Centre	Number of	Number	% 90 day s	urvival (95% CI)
	patients	of deaths	(una	adjusted)
Great Ormond Street Hospital	52	0	100.0	(-)
Newcastle	57	4	93	(82.4 - 97.3)
UK	109	4	96.3	(90.5 - 98.6)

The one year post-transplant <u>unadjusted survival rates</u> are shown in **Table 18.3**. There were no deaths within 1 year at Great Ormond Street Hospital.

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Table 18.3 1 year patient survival after first DBD paediatric heart only transplant, by centre,1 April 2016 to 31 March 2020					
Centre	Number of	Number	% 1 year s	urvival (95% CI)	
	patients	of deaths	(un	adjusted)	
Great Ormond Street Hospital	52	0	100.0	(-)	
Newcastle	57	9	84.2	(71.9 - 91.5)	
υκ	109	9	91.7	(84.7 - 95.6)	

Five year <u>survival rates</u> were estimated from the 121 first DBD paediatric heart only transplants performed in the period 1 April 2012 to 31 March 2016. The <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 18.4**. There was no statistically significant difference between the two centres' rates.

Table 18.4 5 year patient survival after first DBD paediatric heart only transplant, by centre,1 April 2012 to 31 March 2016					
Centre	Number of	Number	% 5 year s	urvival (95% CI)	
	patients	of deaths	(un:	adjusted)	
Great Ormond Street Hospital	59	9	84.2	(71.8 - 91.5)	
Newcastle	62	12	80.2	(67.8 - 88.3)	
ик	121	21	82.1	(73.8 - 88.0)	

PAEDIATRIC HEART TRANSPLANTATION

Form Return Rates



19. Paediatric heart form return rates, 1 January – 31 December 2020

Form return rates are reported in **Table 19.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric heart transplants between 1 January and 31 December 2020 for the transplant record, and all follow up forms issued in this time period. There was a small number of lifetime follow-up forms outstanding for Newcastle.

Table 19.1 Form return rat	es for paed	iatric hear	t transplant	s, 1 Janua	ry 2020 to 3	1 Decemb	er 2020	
Centre	Transpla	nt record	3 month f	follow-up	1 year fo	bllow-up	Lifetime f	ollow-up
	requested	% returned	requested	% returned	requested	% returned	requested	% returned
Great Ormond Street Hospital	24	100	22	100	8	100	107	100
Newcastle, Freeman Hospital	10	100	9	100	11	100	204	99
Overall	34	100	31	100	19	100	311	99

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List



20.1 Paediatric lung and heart/lung transplant list as at 31 March, 2011 – 2021

Figure 20.1 shows the number of paediatric patients on the lung transplant list at 31 March each year between 2012 and 2021 split by urgency status. The number of patients on the active lung transplant list was highest in 2013, with 15 on the non-urgent list and 2 active for a heart-lung transplant. It has since decreased to 3 as at 31 March 2020 (2 non-urgent, 1 urgent) and has risen to 13 (6 non-urgent, 4 heart-lung and 3 urgent) as at 31 March 2021.



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

Figure 20.2 shows the number of paediatric patients on the <u>active lung transplant list</u> at 31 March 2021 by centre. In total, there were 13 paediatric patients waiting; 10 at Great Ormond Street Hospital and 3 at Newcastle. Two patients at Great Ormond Street Hospital and one patient at Newcastle were on the urgent list, and no patients were on the super-urgent list.





Figure 20.3 shows the trend over time in the number of paediatric patients on the lung transplant list at each centre at 31 March each year between 2012 and 2021. Great Ormond Street Hospital experienced a decrease in their list between 2015 and 2018 but after remaining low for several years it has now increased slightly to 10 active patients on 31 March 2021. Newcastle had a peak of five patients on their list in 2017, but this has now decreased to 3 (1 urgent, 1 non-urgent, 1 heart-lung).





20.2 Demographic characteristics, 1 April 2019 – 31 March 2021

There were 19 paediatric registrations onto the lung transplant list between 1 April 2019 and 31 March 2021 (two years analysed due to small numbers). Demographic characteristics of these patients are shown by centre and overall in **Table 20.1**. Nationally, 63% of the patients were female and the <u>median</u> age was 10 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 20.1 Demographi 1 April 2019	c characteristics of paediatric pati and 31 March 2021, by centre	ents registered ont	o the lung trans	splant list between
		Great Ormond	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		15 (100)	4 (100)	19 (100)
Year of registration	2019/2020	3 (20)	1 (25)	4 (21)
	2020/2021	12 (80)	3 (75)	15 (79)
Highest urgency during registration	Non-urgent	12 (80)	2 (50)	14 (74)
	Urgent	3 (20)	1 (25)	4 (21)
	Super-Urgent	0 (0)	1 (25)	1 (5)
Recipient sex	Male	4 (27)	3 (75)	7 (37)
	Female	11 (73)	1 (25)	12 (63)
Recipient ethnicity	White	13 (87)	4 (100)	17 (90)
	Non-white	2 (13)	0 (0)	2 (11)
Recipient age (years)	Median (<mark>IQR</mark>) ¹	8 (3, 14)	-	10 (4, 14)
	Missing	0	0	0
Height (cm)	Median (<mark>IQR</mark>) ¹	122 (95, 162)	-	132 (98, 162)
	Missing	0	0	0
Weight (kg)	Median (<mark>IQR</mark>) ¹	22 (13, 55)	-	25 (16, 55)
	Missing	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	0 (0)	0 (0)	0 (0)
	Fibrosing lung disease	0 (0)	2 (50)	2 (11)
	Primary pulmonary hypertension	8 (53)	1 (25)	9 (47)
	Other heart/lung disease	5 (33)	1 (25)	6 (32)
	Missing	2 (13)	0 (0)	2 (11)
Lung function - FEV1	Median (<mark>IQR</mark>)¹	1.56 (1.04, 1.93)	-	1.15 (0.75, 1.68)
(litres)	Missing	11	2	13
Lung function – FVC	Median (<mark>IQR</mark>)¹	2.04 (1.84, 2.32)	-	1.84 (1.35, 2.08)
(litres)	Missing	11	2	13
¹ Medians for groups with le	ess than 5 registrations are not presented	due to small numbers		

20.3 Post-registration outcomes, 1 April 2016 – 31 March 2018

The registration outcomes of paediatric patients listed for a non-urgent lung transplant between 1 April 2016 and 31 March 2018 are summarised in **Figure 20.4**. The possible outcomes for patients on the list include receiving a transplant, removal from the list, dying on the list, or the patient may still be waiting at a given time point post-registration. In these figures, a patients *first* outcome is used, so if a patient was transplanted then died their registration outcome would be "transplanted".

Within six months of listing, 36% of patients were transplanted, 7% had died, 7% had been moved to the urgent list and the remaining 50% were still waiting. After three years, the transplant rate had increased slightly to 50% and the percentage moved to the urgent list had increased substantially to 36%. Due to small numbers, outcomes on the urgent or super-urgent paediatric lists are not presented.





20.4 Median waiting time to transplant, 1 April 2015 - 31 March 2018

The <u>median</u> waiting time to lung transplant from non-urgent registration for paediatric patients registered between 1 April 2015 and 31 March 2018 is shown in **Table 20.2**. This is estimated using the <u>Kaplan Meier</u> method. Any suspended time is discounted, but any time on the urgent list, which was introduced in May 2017, is included. The national median waiting time to paediatric lung transplant was 210 days.

Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the
transplant list, by centre, 1 April 2015 to 31 March 2018

Transplant centre	Number of patients	Number	Waiting time (days)			
	registered	transplanted	<u>Median</u>	95% Confidence interval		
Non-urgent at initial registration						
Great Ormond Street Hospital	15	10	161	0 - 330		
Newcastle ¹	8	7	-	-		
UK	23	17	210	116 - 304		
¹ Median waiting time for groups with less than 10 patients are not presented due to small numbers						

PAEDIATRIC LUNG TRANSPLANTATION

Response to Offers



21. Response to Offers

Table 21.1 compares individual centre paediatric bilateral lung offer decline rates between 1 April 2018 and 31 March 2021. This only considers offers of UK DBD donor lungs that were eventually transplanted and excludes fast track offers. A bilateral lung offer is counted as accepted if both lungs or just one lung was accepted. Lungs offered as part of a cardiac block are considered, this includes cases where just the lung(s) is/are declined as well as cases where both the heart and lung(s) are declined. Urgent and non-urgent offers are all considered. Offers to adult patients at Newcastle are excluded.

On 22 June 2017, group offering for non-urgent cardiothoracic organ offers was introduced, where all centres receive a simultaneous offer for their non-urgent patients, but acceptance is determined by a centre's position in the allocation sequence. In this analysis, adjustments have been made to count any centre who is ranked above the accepting centre in the allocation sequence for that donor as declining the heart, even if they did not respond to the group offer, and any declines recorded for a centre ranked below the accepting centre were discounted.

The national decline rate was 88.9% and was the same at both centres.

Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2018 to 31 March 2021						
Centre	Number of offers	Decline rate (%)				
Great Ormond Street Hospital Newcastle	9 9	(89.9) (88.9)				
UK	18	(88.9)				

PAEDIATRIC LUNG TRANSPLANTATION

Transplants



22.1 Paediatric lung and heart-lung transplants, 1 April 2011 – 31 March 2021

Figure 22.1 and **22.2** show the number of paediatric lung and heart-lung transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants increased between 2013/2014 and 2016/2017 but has since decreased to 3 in 2020/2021. The majority of paediatric lung transplants over the decade were performed by Great Ormond Street Hospital. The number of transplants in the latest financial year (2020/2021) is shown by centre and donor type in **Figure 22.3**. All transplants used DBD donor lungs.





Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2011 to 31 March 2021





Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2020 to 31 March 2021

Figure 22.4 and **22.5** show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period there have been three paediatric heart-lung block transplants. Newcastle performed one partial lung transplant in 2012/2013.





Figure 22.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2011 to 31 March 2021



On 18 May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. **Figure 22.6** displays the number of paediatric lung only transplants performed in the last 10 financial years by urgency. The number of lung only transplants by urgency status in the latest financial year (2020/2021) is shown by centre in **Figure 22.7**. There was one urgent lung only transplant last year and no super-urgent transplants.





Figure 22.7 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2020 to 31 March 2021



22.2 Demographic characteristics of transplants, 1 April 2019 – 31 March 2021

The demographic characteristics of the 7 paediatric lung transplant recipients and donors in the last two years are shown by centre and overall in **Table 22.1**. Nationally, 71% of lung recipients were female and the <u>median</u> age was 9 years, while the median age of donors was 11 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2019 to 31 March 2021,by centre					
		Great Ormond Street Hospital	Newcastle	TOTAL	
		N (%)	N (%)	N (%)	
Number of transplants		5 (100)	2 (100)	7 (100)	
Year of transplant	2019/2020	2 (40)	2 (100)	4 (57)	
	2020/2021	3 (60)	0 (0)	3 (43)	
Urgency status at transplant	Non-urgent Urgent Super-urgent	4 (80) 1 (20) 0 (0)	1 (50) 0 (0) 1 (50)	5 (71) 1 (14) 1 (14)	
Recipient sex	Male	1 (20)	1 (50)	2 (29)	
	Female	4 (80)	1 (50)	5 (71)	
Recipient ethnicity	White	5 (100)	2 (100)	7 (100)	
	Non-white	0 (0)	0 (0)	0 (0)	
Recipient age (years)	Median (<u>IQR</u>)¹	13 (7, 15)	-	9 (4, 15)	
	Missing	0	0	0	
Recipient weight (kg)	Median (<u>IQR</u>)¹	41 (11, 55)	-	20 (11, 55)	
	Missing	0	0	0	
Recipient primary disease	Cystic fibrosis and bronchiectasis Fibrosing lung disease Primary pulmonary hypertension Other heart/lung disease	1 (20) 1 (20) 2 (40) 1 (20)	0 (0) 1 (50) 1 (50) 0 (0)	1 (14) 2 (29) 3 (43) 1 (14)	
NYHA class	l	0 (0)	0 (0)	0 (0)	
	II	0 (0)	0 (0)	0 (0)	
	III	0 (0)	1 (50)	1 (14)	
	IV	4 (80)	1 (50)	5 (71)	
	Missing	1 (20)	0 (0)	1 (14)	
Recipient in hospital pre-transplant	No	3 (60)	1 (50)	4 (57)	
	Yes	2 (40)	1 (50)	3 (43)	
If in hospital, recipient on ventilator	No	1 (50)	0 (0)	1 (33)	
	Yes	1 (50)	1 (100)	2 (67)	
If in hospital, recipient on inotropes	No	1 (50)	0 (0)	1 (33)	
	Yes	1 (50)	1 (100)	2 (67)	
Recipient CMV status	No	2 (40)	1 (50)	3 (43)	
	Yes	2 (40)	0 (0)	2 (29)	
	Missing	1 (20)	1 (50)	2 (29)	

Table 22.1 Demographic characteristics of paediatric lung transplants, 1 April 2019 to 31 March 2021,by centre						
		Great Ormond Street Hospital	Newcastle	TOTAL		
		N (%)	N (%)	N (%)		
Recipient HCV status	No	4 (80)	1 (50)	5 (71)		
	Missing	1 (20)	1 (50)	2 (29)		
Recipient HBV status	No	4 (80)	1 (50)	5 (71)		
	Missing	1 (20)	1 (50)	2 (29)		
Recipient HIV status	No	4 (80)	1 (50)	5 (71)		
	Missing	1 (20)	1 (50)	2 (29)		
Recipient serum	Median (<u>IQR</u>)¹	50 (45, 62)	-	45 (23, 62)		
creatinine (umol/l)	Missing	0	0	0		
Donor sex	Male	2 (40)	2 (100)	4 (57)		
	Female	3 (60)	0 (0)	3 (43)		
Donor ethnicity	White	4 (80)	4 (80) 1 (50)			
	Non-white	0 (0)	0 (0) 0 (0)			
	Missing	1 (20)	1 (20) 1 (50)			
Donor age (years)	Median (<u>IQR</u>) ¹	14 (11, 19)	-	11 (3, 19)		
	Missing	0	0	0		
Donor BMI (kg/m²)	Median (<u>IQR</u>)¹	17 (16, 21)	-	17 (16, 21)		
	Missing	0	0	0		
Donor cause of death	CVA	2 (40)	1 (50)	3 (43)		
	Others	3 (60)	1 (50)	4 (57)		
Donor hypotension	No	4 (80)	1 (50)	5 (71)		
	Yes	1 (20)	0 (0)	1 (14)		
	Missing	0 (0)	1 (50)	1 (14)		
Donor past	No	4 (80)	1 (50)	5 (71)		
cardiothoracic disease	Missing	1 (20)	1 (50)	2 (29)		
Donor past hypertension	No	5 (100)	1 (50)	6 (86)		
	Missing	0 (0)	1 (50)	1 (14)		
Donor past tumour	No	5 (100)	1 (50)	6 (86)		
	Missing	0 (0)	1 (50)	1 (14)		
Donor past smoker	No	4 (80)	2 (100)	6 (86)		
	Yes	1 (20)	0 (0)	1 (14)		
Total ischaemia time	Median (<u>IQR</u>)¹	6.1 (5.8, 6.9)	-	6.1 (5.8, 6.9)		
(hours)	Missing	0	1	1		
¹ Medians for groups with les	ss than 5 observations are not presented	d due to small numbers	3			

22.3 Total ischaemia time, 1 April 2011 – 31 March 2021

Figure 22.8 shows <u>boxplots</u> of total ischaemia time for <u>DBD</u> donor lungs transplanted into paediatric recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion and can be considered the out of body time. The <u>median</u> total ischaemia time varied quite substantially over the decade, however these are based on a very small number of transplants per year (≤ 10). No further breakdown by centre is shown due to small numbers.





PAEDIATRIC LUNG TRANSPLANTATION

Post-Transplant Survival



23. Post-Transplant Survival

The survival analyses presented in this section exclude heart-lung transplants and other <u>multi-organ transplants</u> and include first time transplants only. Partial lung transplants are also excluded. Both DBD and DCD lung transplants are included. Ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2020 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2016 to 31 March 2012 to 31 March 2016.

The 90-day post-transplant <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 23.1** for the 25 first paediatric lung only transplants in the period 1 April 2016 to 31 March 2020. Only 7 of these transplants were performed by Newcastle so it was not possible to generate a robust survival rate, however there were no reported deaths within 90 days for these patients. Nationally, the 90 day survival rate following first paediatric lung transplant was 96.0%.

Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre,1 April 2016 to 31 March 2020							
Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)				
Great Ormond Street Hospital Newcastle ¹	18 7	1 0	94.4	(66.6 - 99.2) -			
UK	25	1	96.0	(74.8 - 99.4)			
¹ Survival rates for groups with less than 1	0 patients are no	ot presented due	e to small numb	ers			

There were three additional deaths between 90 days and 1 year for the 25 paediatric lung only transplants performed in the period 1 April 2016 to 31 March 2020; one from Great Ormond Street Hospital and two from Newcastle.

Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre,1 April 2016 to 31 March 2020							
Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)				
Great Ormond Street Hospital Newcastle ¹	18 7	2 2	88.9 -	(62.4 - 97.1) -			
UK	25	4	84.0	(62.8 - 93.7)			
¹ Survival rates for groups with less than	10 patients are no	ot presented due	e to small numb	bers			

Five year <u>survival rates</u> were estimated from the 26 first lung only transplants performed in the period 1 April 2012 to 31 March 2016. The unadjusted patient <u>survival rates</u> are shown in **Table 23.3**.

Table 23.3 5 year patient survival rates after first paediatric lung transplants, by centre,1 April 2012 to 31 March 2016						
Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)			
Great Ormond Street Hospital Newcastle ¹	22 4	5 2	77.0 -	(53.2 - 89.7) -		
UK	26	7	70.4	(47.5 - 84.7)		
¹ Survival rates for groups with less tha	in 10 patients are no	ot presented due	e to small num	pers		

PAEDIATRIC LUNG TRANSPLANTATION Form Return Rates



24. Paediatric lung form return rates, 1 January – 31 December 2020

Form return rates are reported in **Table 24.1** for the cardiothoracic transplant record and the three month and 1 year follow up form, along with lifetime follow up (2 years or more). These include all paediatric lung and heart-lung transplants between 1 January and 31 December 2020 for the transplant record, and all follow up forms issued in this time period. There are no outstanding forms for this period for either centre.

Table 24.1 Form return rates for paediatric lung transplants, 1 January 2020 to 31 December 2020								
Centre	Transplai No. requested	nt record % returned	3 month f No. requested	follow-up % returned	1 year fo No. requested	ollow-up % returned	Lifetime f No. requested	ollow-up % returned
Great Ormond Street Hospital Newcastle, Freeman Hospital	2 0	100 -	2 1	100 100	5 3	100 100	17 14	100 100
Overall	2	100	3	100	8	100	31	100
APPENDIX



A1: Number of patients analysed

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

Table A1.1 Adult transplants analysed					
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants	
1 April 2011 – 31 March 2021	Introduction	None	1473	1708	
1 April 2011 – 31 March 2021	Transplants	<u>Multi-organ transplants</u>	1461	1659	
1 April 2016 – 31 March 2020	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ transplants</u> DCD heart transplants excluded from main analysis Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants 	537	656	
1 April 2012 – 31 March 2016	Post-transplant survival – • 5-year survival	 <u>Multi-organ transplants</u> DCD heart transplants excluded from main analysis Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants 	562	722	

Table A1.2 Paediatric transplants analysed					
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants	
1 April 2011 – 31 March 2021	Introduction	None	301	66	
1 April 2011 – 31 March 2021	Transplants	<u>Multi-organ transplants</u>	301	66	
1 April 2016 – 31 March 2020	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ transplants</u> Heart-lung transplants Partial lung transplants Second (or more) transplants DCD heart transplants 	109	25	
1 April 2012 – 31 March 2016	Post-transplant survival – • 5-year survival	 <u>Multi-organ transplants</u> (including heart-lung transplants) Partial lung transplants Second (or more) transplants DCD heart transplants 	121	26	

Geographical variation analysis

Registration rates

All NHS group 1 patients who were registered onto the heart or lung transplant list with an active status between 1 April 2020 and 31 March 2021 were extracted from the UK Transplant Registry on 9 July 2021 (numerator). Patients registered for a heart-lung block were are included in the lung figures. Patients were assigned to NHS regions in England using their postcode of residence, as reported at registration. The number of registrations per million population (pmp) by NHS region was obtained using mid-2019 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No NHS region- age- or sex-specific standardisation of rates was performed.

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

Transplant rates

Transplant rates pmp were obtained as the number of heart transplants on NHS group 1 recipients between 1 April 2020 and 31 March 2021 (numerator), divided by the mid-2019 population estimates from the ONS (denominator). Patients who received a heart-lung block transplant were included in the lung figures. Transplant rates pmp were categorised and visualised in a map as done for the registration rates.

Systematic component of variation

Only registrations or transplants in England between 1 April 2020 and 31 March 2021 were included. If a patient was re-registered during the time period, only the first registration was considered. If a patient underwent more than one heart transplant in the time period, only the first transplant was considered.

A2: Methods

Offer decline rates

The offer decline rate analysis was limited to heart or lung offers from <u>DBD</u> donors who died at a UK hospital and the heart or lung was eventually accepted and transplanted. Any offers from DCD 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 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> patient <u>survival rates</u>. 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 <u>survival rates</u> of interest. The factors included in the models are shown in <u>A3</u>.

Missing values were imputed using multiple imputation where data were missing for less than 11% of the cohort, for each <u>risk factor</u>. Multiple imputation was implemented in SAS Enterprise Guide, using chained equations. The form of the imputation model used to estimate missing values consisted of a list of transplant related variables as well as the outcome variables (survival time and censoring indicator). Twenty imputations were run with 50 burn-in iterations before each imputation. Post-transplant survival models were fitted to the resulting 20 datasets and estimates were obtained for each parameter in the model by analysing the results of these 20 models collectively.

Funnel plots

The funnel plot is a graphical method to show how consistent the <u>survival rates</u> 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.

Systematic component of variation

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

To allow for the possibility that, even after allowing for area-specific Poisson rates, area differences remain, introduce an additional multiplicative rate factor which varies from area to area. Postulate a non-parametric distribution for the multiplicative factor, with variance σ^2 . If the factor is one for all areas, then area differences are fully explained by the area-specific Poisson rate. If the factor varies with a nonzero variance, σ^2 , then we conclude that there are unexplained area differences.

The systematic component of variation (SCV; McPherson *et al., N Engl J Med* 1982, **307**: 1310-4) is the moment estimator of σ^2 . Under the null hypothesis of homogeneity across areas, the SCV would be zero. The SCV, therefore, allows us to detect variability across areas beyond that expected by chance; the larger the SCV, the greater the evidence of systematic variation across areas.

Survival from listing

Data were obtained for all patients \geq 18 years registered for the first time for a heart or lung transplant between 1 January 2009 and 31 December 2020. 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 16 July 2021 if the patient was on the transplant list at time of analysis.

Exclusions from the analysis:

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

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

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

A3: Risk models

Table A3.1	<u>Risk factors</u> and categories used in the adult heart risk adjusted 30-day, 90-day, 1-year and 5-year survival models		
Donor cause of death		Vascular Trauma Hypoxic Other	
Donor BMI		(modelled as continuous variable)	
Donor age		(modelled as continuous variable)	
Respiratory arrest		Yes No	
Recipient BMI		(modelled as continuous variable)	
Recipient creatinine at transplant		Non-linear spline with knots at 54, 85, 112, 176	
VAD at trans	plant	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	
Ischaemia tin	ne (hours)	(modelled as continuous variable)	
OCS used or	heart	Yes No	
Interaction be	tween ischaemia time and OCS		

Table A3.2Risk factors
and categories used in the adult lung risk adjusted 90-day. 1- year and
5-year survival model

Donor CMV	Negative Positive
Donor history of smoking	No Yes
Recipient daily dose of prednisolone at registration	0 1-14 ≥ 15
Donor:recipient calculated TLC mismatch (recipient – donor)	(modelled as continuous variable)
Recipient FVC at registration	(modelled as continuous variable)
Recipient bilirubin at registration	(modelled as continuous variable)
Recipient cholesterol at registration	(modelled as continuous variable)
Recipient age at transplant	Non-linear spline with knots at 23, 46, 57, 65
Transplant type	Single lung Bilateral lung
Primary disease group	COPD and emphysema Cystic fibrosis and bronchiectasis Fibrosing lung disease Other

A4: Glossary of terms

Active transplant list

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

Boxplots

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

Case mix

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

Confidence interval (CI)

When an estimate of a quantity such as a <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)

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

Donor after circulatory death (DCD)

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

Funnel plot

A graphical method that shows how consistent the rates, such as <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. A mechanical pump used to increase the amount of blood that flows through the body, relieving the symptoms of advanced heart failure.

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