

ANNUAL REPORT ON CARDIOTHORACIC ORGAN TRANSPLANTATION

REPORT FOR 2021/2022 (1 APRIL 2012 – 31 MARCH 2022)

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EXECUTIVE SUMMARY

1. Executive Summary

This report presents key data about cardiothoracic organ transplantation in the UK. The period reported covers 10 years, from 1 April 2012 to 31 March 2022. The data include number of people 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 14 July 2022.

Key findings

ADULT HEART TRANSPLANTATION

- On 31 March 2022 there were 274 adults waiting for a heart transplant: 248 non-urgent, 22 urgent and 4 super-urgent. This was similar to 31 March 2021. 58% of those waiting were on long-term <u>VAD</u> support. 1 year mortality was 6% on the non-urgent waiting list, 2% on the urgent waiting list and 6% on the super-urgent waiting list. Nationally, median waiting time to transplant was 845 days, 47 days and 18 days across these three urgency types, respectively.
- During 2021/2022 there were 145 adult heart transplants performed of which 26% came from DCD donors. This was 10% higher than the previous year in which there were 132 transplants. 72% of transplants were urgent or super-urgent.
- The national rate of patient survival following adult heart transplant was 91.4% at 30 days, 88.2% at 90 days, 84.5% at 1 year and 72.3% at 5 years.

ADULT LUNG TRANSPLANTATION

- On 31 March 2022 there were 256 adults waiting for a lung or heart-lung transplant: 247 non-urgent and 9 urgent. This was similar to 31 March 2021 which was a significant drop from 31 March 2020 (27% reduction). 1 year mortality was 13% on the non-urgent waiting list and 7% on the urgent waiting list. Median waiting time to transplant was 594 days from non-urgent registration.
- During 2021/2022 there were 106 adult lung transplants including 3 heart-lung transplants. This was 22% higher than the previous year which was low historically (87 transplants). 30% of transplants were urgent or super-urgent; the highest proportion since these schemes began in 2017.
- The national rate of patient survival following adult lung transplant was 90.3% at 90 days, 82.5% at 1 year and 55.4% at 5 years.

PAEDIATRIC HEART TRANSPLANTATION

- On 31 March 2022 there were 45 paediatric patients waiting for a heart transplant: 31 non-urgent, 13 urgent and 1 super-urgent. The number has increased over the decade and 20% of those waiting were on mechanical circulatory support. Median waiting time to transplant was 762 days from non-urgent registration and 193 days from urgent registration; this has increased from 447 and 104 days, respectively, in the 2020/2021 report.
- During 2021/2022 there were 30 paediatric heart transplants (3 more than the previous year) of which 6 came from DCD donors. 20 of the 30 transplants were either urgent or super-urgent.
- The national rate of patient survival following paediatric heart transplant was 97.9% at 30 days, 95.9% at 90 days, 90.7% at 1 year and 81.8% at 5 years.

PAEDIATRIC LUNG TRANSPLANTATION

- On 31 March 2022 there were 11 paediatric patients waiting for a lung or heart-lung transplant: 9 non-urgent, 1 urgent lung only and 1 urgent heart-lung. Median waiting time to transplant was 225 days from non-urgent registration.
- During 2021/2022 there were just 2 paediatric lung transplants, 1 less than the previous year; both were performed at Great Ormond Street Hospital, and both were urgent.
- The national rate of patient survival following paediatric lung transplant was 94.4% at 90 days, 72.2% at 1 year and 68.3% at 5 years.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Cardiothoracic Organ Transplantation 2021/2022, 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 2012 and 31 March 2022, 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 adults (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 recipients aged 16 or over are included in the paediatric analysis, and any transplants carried out at adult only centres in recipients less than 16 are included in the adult analysis.

Heart-lung block transplant activity is included within the adult and paediatric lung sections. Other <u>multi-organ transplants</u> are presented separately in <u>Section 6.5</u> and <u>Section 12.5</u> and are excluded from the rest of the main report. 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).

The time period of analysis covers the introduction of the super-urgent heart allocation scheme in October 2016 (later expanded to paediatric patients in October 2020) and the introduction of the urgent and super-urgent lung allocation schemes in May 2017.

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>. The adult lung risk model was developed in August 2015 in collaboration with the former Cardiothoracic Advisory Group (CTAG) Clinical Audit Group and will be reviewed in 2023. The adult heart risk model was revised in August 2022 in consultation with the clinical community.

2.1 Overview

Figure 2.1 shows the number of transplant candidates on the <u>active transplant lists</u> at financial year end between 2013 and 2022. The number of people 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. In the latest year the number fell slightly again to 267. The number of people waiting for a heart transplant increased significantly between 2013 and 2020, from 200 to 340. The number fell to 311 in 2021, increasing again to 327 on 31 March 2022.

Figure 2.1 Number of people on the national active heart and lung transplant lists on 31 March each year, 2013 to 2022

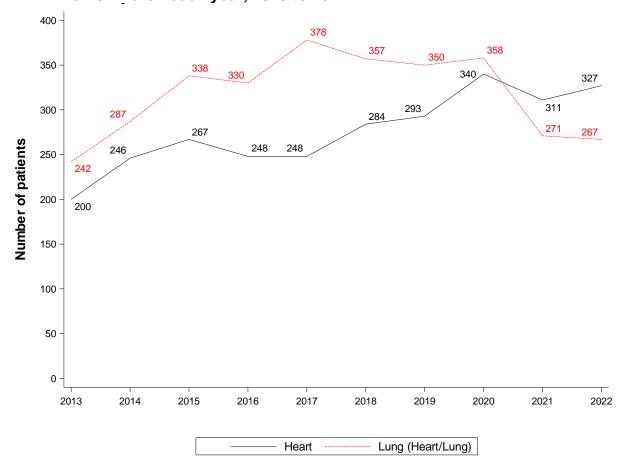


Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the <u>active transplant lists</u> on 31 March 2022 at each centre. In total, there were 537 adults and 57 paediatric patients waiting for a heart or lung transplant. Newcastle had the highest number of adults on both the heart and lung transplant lists. Note that Glasgow does not perform lung transplantation. Newcastle had the highest number of paediatric patients on the heart transplant list and Great Ormond Street Hospital had the highest number of paediatric patients on the lung transplant list. These numbers include 8 people waiting for a multi-organ transplant (6 heart and liver and 2 heart and kidney).

Figure 2.2 Number of adults on the active heart and lung transplant lists on 31 March 2022, by centre

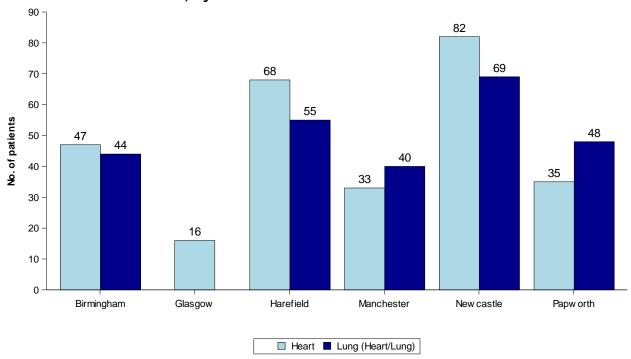


Figure 2.3 Number of paediatric patients on the active heart and lung transplant lists on 31 March 2022, by centre

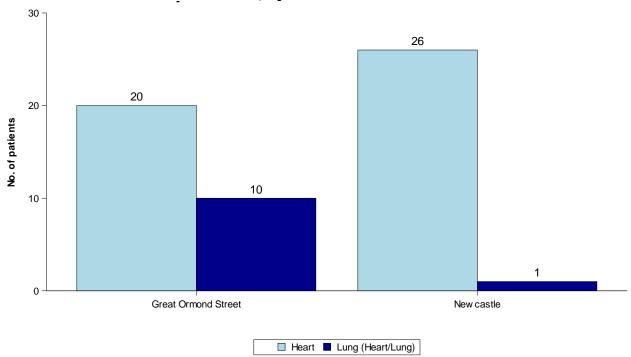


Figure 2.4 shows the total number of transplants performed in each of the last ten financial years. The number of heart transplants last year was 179, 11% higher than in 2020/2021. The number of lung transplants last year also increased, by 20% to 109, but remained significantly lower than pre COVID-19 pandemic.

Figure 2.4 Number of cardiothoracic organ transplants in the UK, by financial year, 1 April 2012 to 31 March 2022

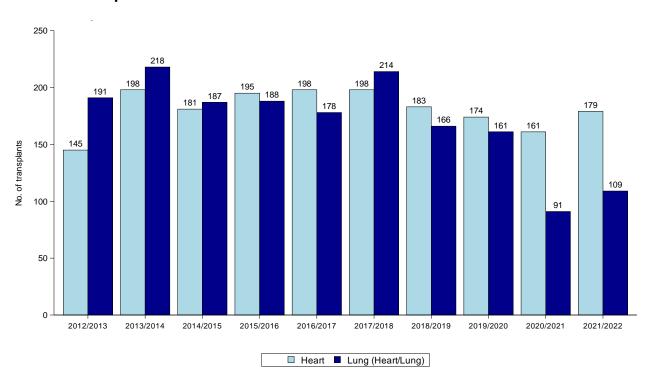


Figure 2.5 and **Figure 2.6** show the number of adult and paediatric transplants carried out in the most recent financial year at each centre. Papworth performed the highest number of adult heart transplants and adult lung transplants. Great Ormond Street Hospital performed the highest number of paediatric heart and lung transplants. For the second year running, Newcastle performed no paediatric lung transplants.

Figure 2.5 Number of adult cardiothoracic organ transplants in the UK, by centre, 1 April 2021 to 31 March 2022

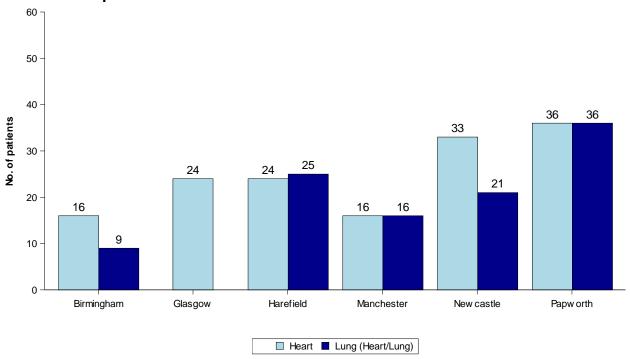


Figure 2.6 Number of paediatric cardiothoracic organ transplants in the UK, by centre, 1 April 2021 to 31 March 2022

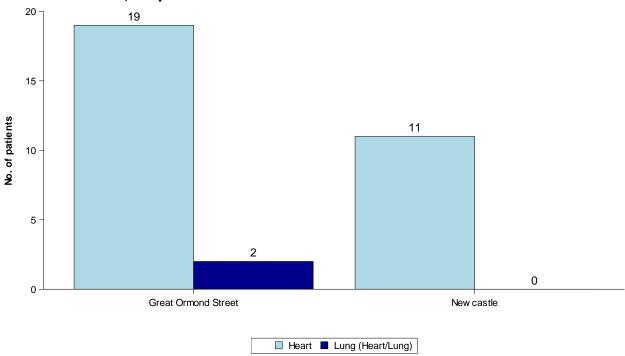
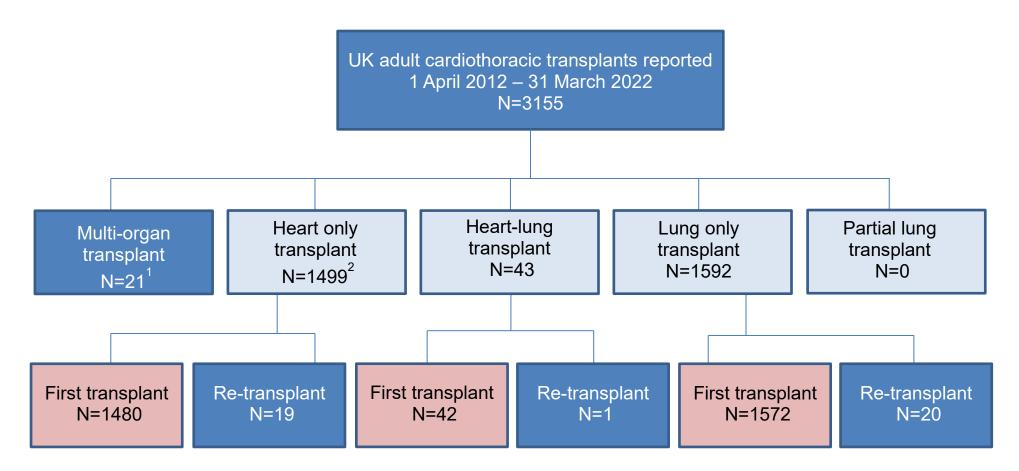


Figure 2.7 shows a breakdown of the 3,155 adult cardiothoracic organ transplants performed in the UK in the ten-year period while **Figure 2.8** shows a similar breakdown for the 360 paediatric transplants performed during the same period. Re-transplants are included in the transplant activity sections of this report but excluded from the survival analysis sections. Multi-organ transplants are excluded from the rest of the report apart from the separate multi-organ outcome sections (Sections 6.5 and 12.5).

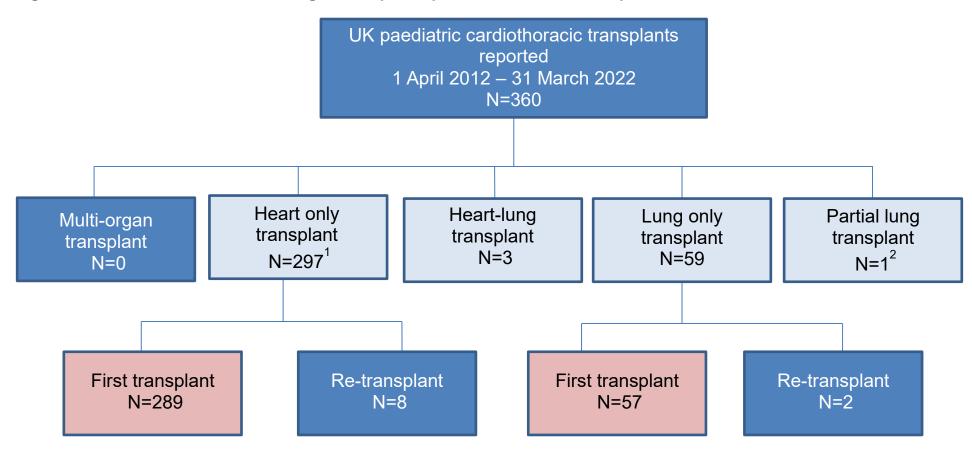
Figure 2.7 Adult cardiothoracic organ transplants performed in the UK, 1 April 2012 to 31 March 2022



¹ Includes 9 heart and kidney, 7 heart and liver, 4 lung and liver and 1 lung and kidney transplant

² Includes 163 DCD heart transplants

Figure 2.8 Paediatric cardiothoracic organ transplants performed in the UK, 1 April 2012 to 31 March 2022



¹ Includes 16 DCD heart transplants

² Deceased donor transplant

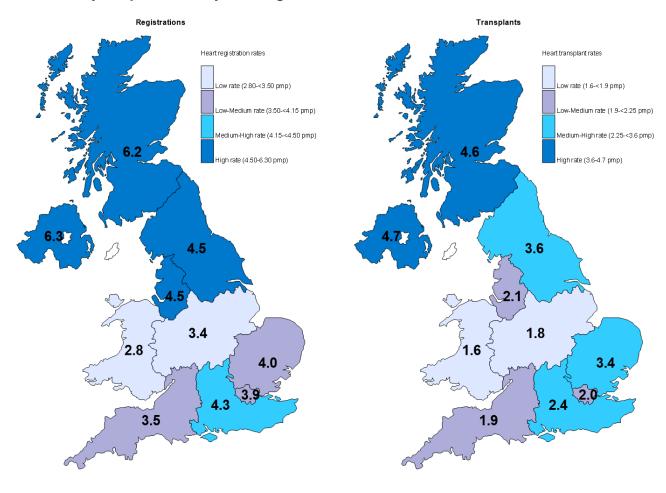
2.2 Geographical variation in registration and transplant rates

Figure 2.9 shows rates of registration to the heart transplant list per million population (pmp) between 1 April 2021 and 31 March 2022 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 an individual 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 4.2 pmp and 2.7 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 (p-value = 0.999) and 0.0233 (p-value = 0.1), 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 no evidence of geographical variation beyond what would be expected at random. 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 0.0302 (p-value = 0.07) and 0.0832 (p-value = 0.03), respectively, and therefore indicating mild to moderate evidence of geographical variation beyond what would be expected at random, with areas such as the East of England having higher rates than other areas.

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

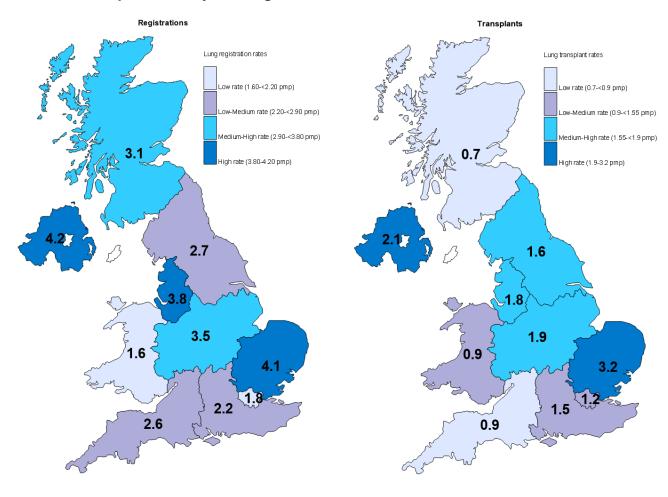


Heart registration and transplant rates per million population (pmp) in the UK, 1 April 2021 - 31 March 2022, by Country/NHS region Table 2.1

Country/ NHS region	Registrations	s (pmp)	Transplants	(pmp)
North East and Yorkshire	39	(4.5)	31	(3.6)
North West	32	(4.5)	15	(2.1)
Midlands	36	(3.4)	19	(1.8)
East of England	26	(4.0)	22	(3.4)
London	35	(3.9)	18	(2.0)
South East	38	(4.3)	21	(2.4)
South West	20	(3.5)	11	(1.9)
England Isle of Man Channel Islands	226 0 1	(4.0) (0.0) (5.9)	137 1 0	(2.4) (12.5) (0.0)
Wales	9	(2.8)	5	(1.6)
Scotland	34	(6.2)	25	(4.6)
Northern Ireland	12	(6.3)	9	(4.7)
TOTAL ^{1,2}	282	(4.2)	178	(2.7)

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



Lung registration and transplant rates per million population (pmp) in the UK, Table 2.2 1 April 2021 - 31 March 2022, by Country/NHS region Country/ Registrations (pmp) Transplants (pmp) **NHS** region North East and Yorkshire 23 14 (2.7)(1.6)North West 27 (3.8)13 (1.8)Midlands 37 20 (3.5)(1.9)East of England 27 (4.1)21 (3.2)London (1.8)(1.2)16 11 South East 20 (2.2)13 (1.5)South West 15 (2.6)5 (0.9)**England** 165 (2.9)97 (1.7)Isle of Man (0.0)(12.5)0 1 **Channel Islands** 0 (0.0)0 (0.0)Wales 5 (1.6)3 (0.9)**Scotland** 17 (0.7)(3.1)4 **Northern Ireland** 8 (4.2)4 (2.1)**TOTAL** 195 (2.9)109 (1.6)

ADULT HEART TRANSPLANTATION Transplant List

3.1 Adult heart only transplant list on 31 March, 2013 – 2022

Figure 3.1 shows the number of adult patients on the heart transplant list on 31 March each year between 2013 and 2022, split by urgency status of the patient. The number of adults on the active non-urgent heart transplant list has increased over the decade, from 165 in 2013 up to 271 in 2020, and has since decreased to 248 in 2022. The number of adults on the urgent list increased from 16 in 2013 to 22 in 2022. The super-urgent list was introduced in October 2016 and there were 4 adults waiting on this list on 31 March 2022. There has been a recent increase in the number of adults suspended from the heart waiting list.

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

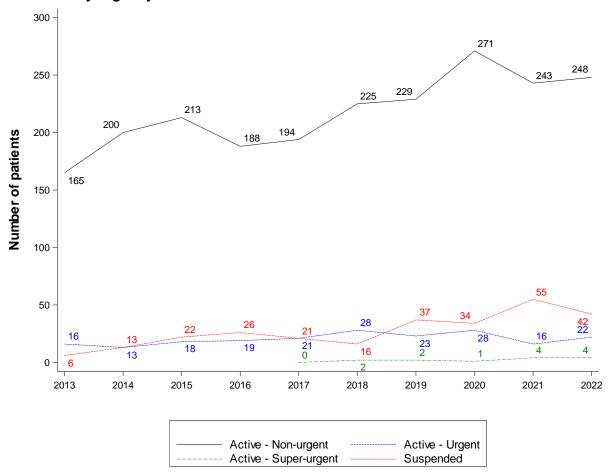


Figure 3.2 shows the number of adults on the <u>active heart transplant list</u> on 31 March 2022, by centre and urgency. **Figure 3.3** provides a similar breakdown by centre and mechanical circulatory support (MCS) status. In total, there were 274 adults waiting for a heart. The number on the urgent transplant list on 31 March 2022 ranged from 2 at Glasgow and Manchester to 8 at Newcastle. Harefield had 2 adults on the super-urgent transplant list, while Papworth and Manchester had 1 each. A total of 158 patients were on long-term MCS (including implantable <u>VADs</u> for left, right and biventricular support and total artificial hearts), representing 58% of the national waiting list, but varying between 19% and 85% across centres.

Figure 3.2 Number of adults on the active heart transplant list on 31 March 2022, by centre and urgency

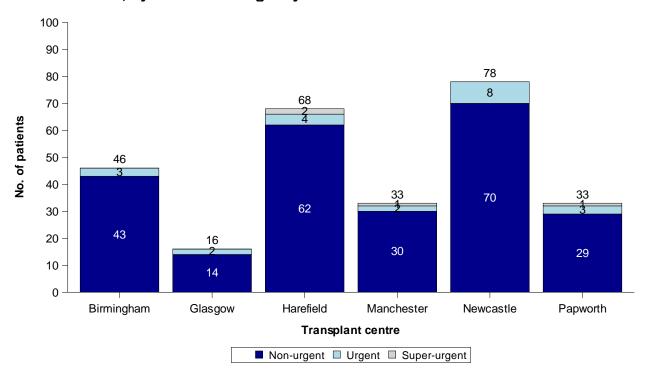


Figure 3.3 Number of adults on the active heart transplant list on 31 March 2022, by centre and mechanical circulatory support status

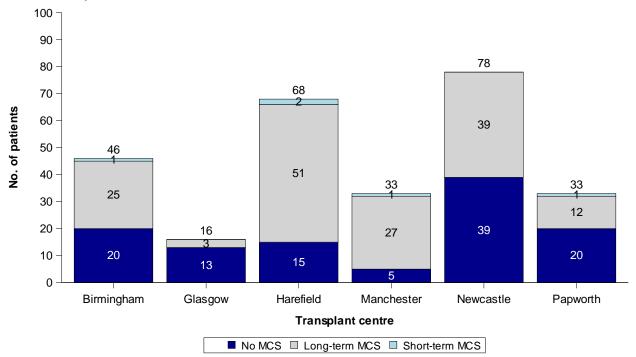
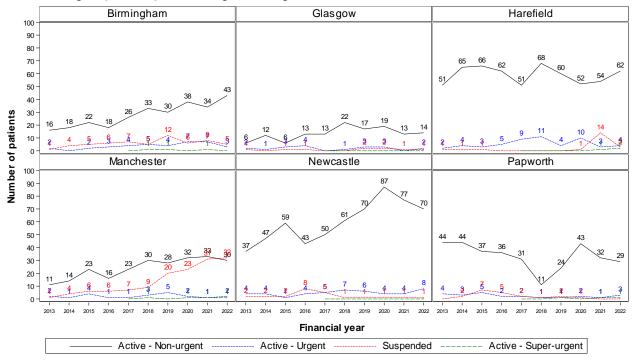


Figure 3.4 shows the trend over time in the number of adults on the heart transplant list on 31 March each year across centres. Birmingham, Manchester and Newcastle have experienced substantial increases in their heart lists over the decade, whilst Glasgow has had a smaller increase. Papworth's list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

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



3.2 Demographic characteristics, 1 April 2021 – 31 March 2022

There were 219 adult registrations onto the heart transplant list between 1 April 2021 and 31 March 2022. Demographic characteristics of these patients are shown by centre and overall, in **Table 3.1**. Nationally, 71% were male and the <u>median</u> age was 49 years. The most common primary disease group was cardiomyopathy. For some characteristics, due to rounding, percentages may not add up to 100.

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		21 (100)	30 (100)	58 (100)	29 (100)	40 (100)	41 (100)	219 (100)
Highest urgency during registration	Non-urgent	13 (62)	12 (40)	32 (55)	10 (34)	17 (43)	16 (39)	100 (46)
	Urgent	5 (24)	15 (50)	15 (26)	13 (45)	21 (53)	12 (29)	81 (37)
	Super-urgent	3 (14)	3 (10)	11 (19)	6 (21)	2 (5)	13 (32)	38 (17)
Recipient sex	Male	16 (76)	21 (70)	45 (78)	18 (62)	28 (70)	28 (68)	156 (71)
	Female	4 (19)	9 (30)	13 (22)	11 (38)	12 (30)	13 (32)	62 (28)
	Missing	1 (5)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient ethnicity	White	12 (57)	29 (97)	42 (72)	25 (86)	34 (85)	28 (68)	170 (78)
	Asian	3 (14)	0 (0)	7 (12)	3 (10)	2 (5)	8 (20)	23 (11)
	Black	3 (14)	0 (0)	3 (5)	1 (3)	1 (3)	1 (2)	9 (4)
	Other	2 (10)	0 (0)	1 (2)	0 (0)	0 (0)	2 (5)	5 (2)
	Missing	1 (5)	1 (3)	5 (9)	0 (0)	3 (8)	2 (5)	12 (6)
Recipient age (years)	Median (IQR)	49 (41, 57)	57 (48, 62)	53 (40, 59)	45 (32, 51)	47 (40, 55)	49 (45, 57)	49 (40, 58)
	Missing	0	0	0	0	0	0	0
Primary disease	Coronary heart disease	3 (14)	5 (17)	14 (24)	7 (24)	8 (20)	4 (10)	41 (19)
	Cardiomyopathy	15 (71)	25 (83)	41 (71)	21 (72)	21 (53)	35 (85)	158 (72)
	Congenital heart disease	2 (10)	0 (0)	3 (5)	0 (0)	10 (25)	0 (0)	15 (7)
	Graft failure/Rejection	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (0)
	Other/Not reported	1 (5)	0 (0)	0 (0)	1 (3)	0 (0)	2 (5)	4 (2)
Previous open-heart surgery	None One More than one Missing	11 (52) 9 (43) 1 (5) 0 (0)	13 (43) 1 (3) 0 (0) 16 (53)	31 (53) 19 (33) 6 (10) 2 (3)	20 (69) 9 (31) 0 (0) 0 (0)	18 (45) 11 (28) 7 (18) 4 (10)	35 (85) 3 (7) 1 (2) 2 (5)	128 (58 52 (24 15 (7 24 (11

Table 3.1 Demographic characteristics of adults registered onto the heart transplant list between 1 April 2021 and 31 March 2022, by centre								
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Serum Bilirubin (umol/l)	Median (IQR)	15 (10, 21)	11 (5, 17)	18 (11, 28)	16 (9, 23)	19 (11, 29)	15 (11, 22)	16 (10, 26)
	Missing	0	3	2	0	4	4	13
Serum Creatinine	Median (IQR)	104 (78, 118)	98 (85, 113)	108 (75, 131)	82 (64, 99)	102 (82, 121)	89 (70, 119)	97 (75, 118)
(umol/l)	Missing	0	3	1	0	4	2	10

3.3 Post-registration outcomes, 1 April 2017 – 31 March 2019

The registration outcomes of adults listed for a heart transplant between 1 April 2017 and 31 March 2019 are summarised in **Figures 3.5** - **3.9**, nationally and by centre, for non-urgent, urgent and super-urgent registrations respectively. The possible outcomes on the list include receiving a transplant, removal from the list, moving lists, dying on the list, or remaining on the list at a given time point post-registration. In these figures, the *first* outcome is considered, so if an individual was transplanted then died their registration outcome would be "transplanted". If they 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 11% of non-urgent heart registrations resulted in transplant and 5% had died on the list, while after three years 18% had been transplanted and 10% had died on the list. Also, 15% had moved to the urgent heart list within 6 months, reaching 28% by three years. Removals from the list were for a variety of reasons, most commonly due to deteriorating condition or contra-indication to transplant.

Percentage 6 months 1 year 2 years 3 years Time since listing ■ Transplanted □ Still waiting □ Became urgent ■ Became super-urgent □ Removed □ Died

Figure 3.5 Post-registration outcome for 302 non-urgent heart only registrations made in the UK, 1 April 2017 to 31 March 2019

Figure 3.6 shows the three year non-urgent registration outcomes by centre. The non-urgent transplant rate at three years was highest at Papworth (49%) and lowest at Birmingham (3%). The mortality rate was highest at Newcastle (26%) and lowest at Glasgow (0%).

Figure 3.6 3 year post-registration outcomes for 302 non-urgent heart only registrations made in the UK, by centre, 1 April 2017 to 31 March 2019

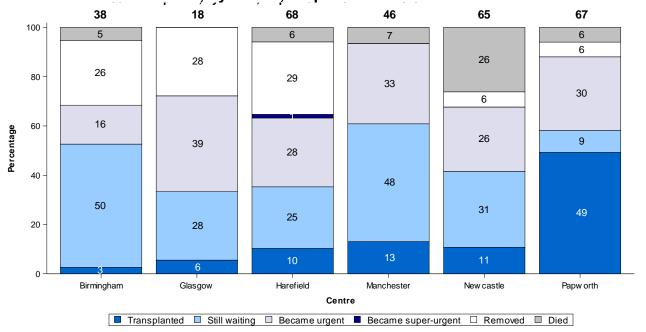


Figure 3.7 shows outcomes on the urgent heart list. The chance of transplant is much higher from the urgent list compared with the non-urgent list; within 6 months, 62% had been transplanted, 2% had died on the list and 18% were removed. Removals from the urgent heart list were due to a variety of reasons, including deteriorating condition or the patient receiving an LVAD.

Figure 3.7 Post-registration outcome for 271 urgent heart only registrations made in the UK, 1 April 2017 to 31 March 2019

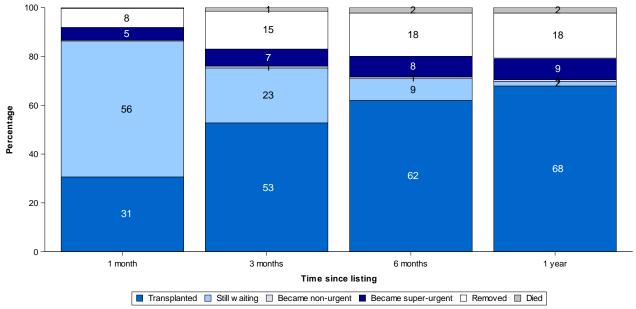


Figure 3.8 shows the one month urgent registration outcomes by centre. The urgent transplant rate at one month was highest at Papworth (60%) and lowest at Glasgow (11%).

Figure 3.8 1 month post-registration outcomes for 271 urgent heart only registrations made in the UK, by centre, 1 April 2017 to 31 March 2019

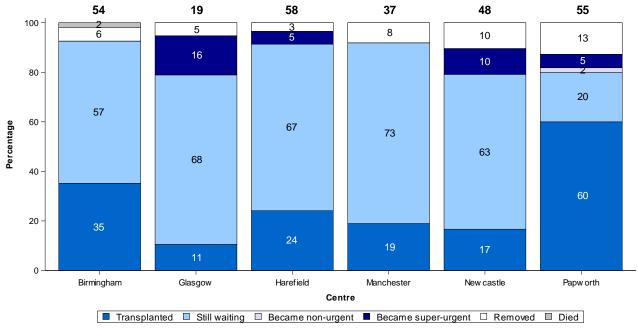
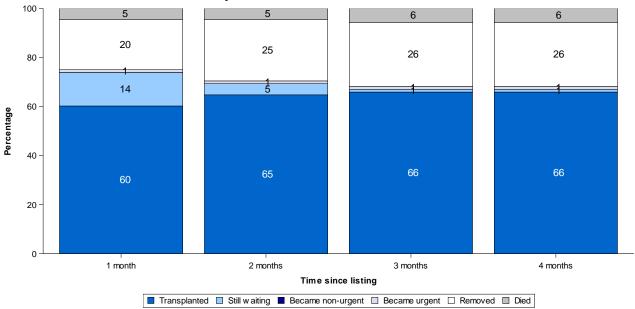


Figure 3.9 shows outcomes on the super-urgent list. The chance of transplant is much higher from the super-urgent list compared with the non-urgent and urgent lists; within 3 months, 66% had been transplanted, 26% were removed and 6% had died on the list. Please note that there is no break down by centre due to the small numbers.

Figure 3.9 Post-registration outcome for 88 super-urgent heart only registrations made in the UK, 1 April 2017 to 31 March 2019

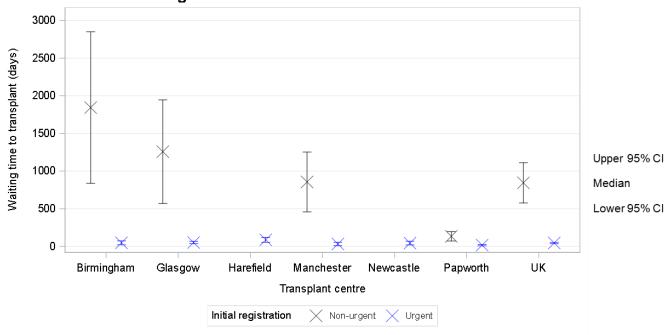


3.4 Median waiting time to transplant, 1 April 2015 - 31 March 2021

The <u>median</u> waiting time to heart transplant from registration for adults is shown in **Figure 3.10** and **Table 3.2**. This is estimated using the <u>Kaplan Meier</u> method for non-urgent registrations onto the heart only transplant list between 1 April 2015 and 31 March 2018 and urgent and super-urgent registrations between 1 April 2018 and 31 March 2021. The urgency groups are defined by urgency at initial registration and 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 845 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 due to low transplant rates. For urgent registrations, the national <u>median</u> waiting time was 47 days and ranged from 18 days at Papworth to 89 days at Harefield. The national <u>median</u> waiting time for super-urgent registrations was 18 days. The 95% <u>confidence intervals</u> for some of these medians are very wide, indicating the variation in individual waiting times within groups.

Figure 3.10 Median active waiting time to heart transplant for adults registered on the non-urgent transplant list (1 April 2015 to 31 March 2018) or urgent transplant list (1 April 2018 to 31 March 2021), by centre and urgency status at registration



Note: Median waiting times could not be estimated for non-urgent registrations at Harefield or Newcastle due to low transplant rates

Table 3.2 Median active waiting time to heart transplant for adults registered on the non-urgent transplant list (1 April 2015 to 31 March 2018) or urgent/super-urgent transplant list (1 April 2018 to 31 March 2021), by centre

Transplant centre	Number	Number	\//:	aiting time (days)
Transplant centre	registered	transplanted	Median	95% Confidence interva
	J	•		
Non-urgent at initial regis	stration			
Birmingham	65	20	1843	838 - 2848
Glasgow	30	13	1258	571 - 1945
Harefield¹	84	35	-	-
Manchester	49	28	856	459 - 1253
Newcastle ¹	87	30	-	-
Papworth	99	77	135	73 - 197
uk	414	203	845	578 - 1112
Urgent at initial registrati	on			
Birmingham	57	45	49	23 - 75
Glasgow	24	20	53	38 - 68
Harefield	56	33	89	56 - 122
Manchester	29	18	34	11 - 57
Newcastle	52	34	45	20 - 70
Papworth	39	29	18	9 - 27
uk	257	179	47	39 - 55
Super-urgent at initial re	gistration			
Birmingham	18	13	22	14 - 30
Glasgow ¹	3	1	-	-
Harefield	19	9	22	16 - 28
Manchester	13	11	18	0 - 36
Newcastle	12	4	12	7 - 17
Papworth	16	12	12	7 - 17
	81	50	18	11 - 25

The <u>median</u> waiting time to heart transplant for adults 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 non-urgent registrations, blood group O has the longest average wait compared with the other blood groups and for urgent registrations, blood group B has the longest wait.

Figure 3.11 Median active waiting time to heart transplant for adults registered on the non-urgent transplant list (1 April 2015 to 31 March 2018) or urgent transplant list (1 April 2018 to 31 March 2021), by blood group and urgency at registration

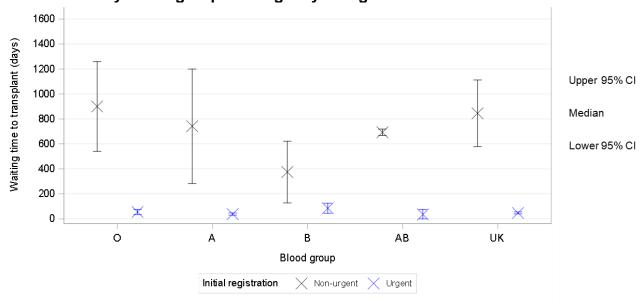
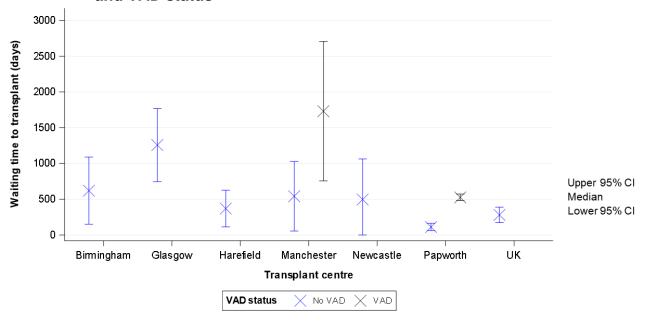


Table 3.3 Median active waiting time to heart transplant for adults registered on the non-urgent transplant list (1 April 2015 to 31 March 2018) or urgent/super-urgent transplant list (1 April 2018 to 31 March 2021), by blood group **Blood Group** Number Number Waiting time (days) 95% Confidence interval registered transplanted Median Non-urgent at initial registration O 81 900 540 - 1260 179 Α 179 91 742 284 - 1200 27 375 128 - 622 В 45 AΒ 693 667 - 719 11 4 UK 414 203 845 578 - 1112 Urgent at initial registration 0 103 66 34 - 76 55 78 38 29 - 47 Α 107 В 30 22 85 45 - 125 AΒ 13 35 17 0 - 75 UK 257 179 47 39 - 55 Super-urgent at initial registration 0 34 18 22 10 - 34 Α 30 22 11 5 - 17 В 14 7 23 14 - 32 ΑB 3 3 UK 81 50 18 11 - 25

The <u>median</u> waiting time to heart transplant for adults is shown by <u>VAD</u> status in **Figure 3.12** and **Table 3.4**. This considers whether a patient ever had an implantable left-ventricular assist device (LVAD) as a bridge to heart transplant compared with not and is restricted to those who were initially non-urgent. 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 (281 days) was substantially lower than the overall median for non-urgent patients (845 days).

Figure 3.12 Median waiting time to heart transplant for adults registered on the non-urgent list between 1 April 2015 and 31 March 2018, by centre and VAD status



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

Table 3.4 Median active waiting time to heart transplant for adults registered on the nonurgent transplant list, by centre and left-ventricular assist device (LVAD) status, 1 April 2015 to 31 March 2018 Transplant centre Number Waiting time (days) Number transplanted 95% Confidence interval registered Median **Never on LVAD support** 32 620 Birmingham 14 151 - 1089 Glasgow 26 11 1258 748 - 1768 Harefield 33 22 370 113 - 627 Manchester 29 56 - 1028 17 542 Newcastle 20 0 - 1064 36 497 Papworth 85 70 62 - 162 112 UK 241 154 281 173 - 389 **Ever on LVAD support** Birmingham¹ 33 6 Glasgow² 4 2 Harefield1 51 13 20 Manchester 11 1731 756 - 2706 Newcastle¹ 51 10 Papworth 526 479 - 573 14 7 UK^1 173 49

¹ Medians and 95% confidence intervals could not be calculated due to low transplant rate

² Median waiting time for groups with less than 10 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 2019 and 31 March 2022 that were eventually transplanted and excludes all fast track offers. Hearts offered as part of a heart-lung block are included. Super-urgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

In 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 plot</u>. The offer decline rates for Harefield and Newcastle are above the upper 99.8% <u>confidence limit</u>, indicating a significantly higher decline rate than the national rate. The offer decline rates for both Birmingham and Papworth are below the lower 99.8% <u>confidence limit</u>, indicating a significantly lower decline rate than the national rate.

Figure 4.1 UK adult DBD donor heart offer decline rates by centre, 1 April 2019 to 31 March 2022

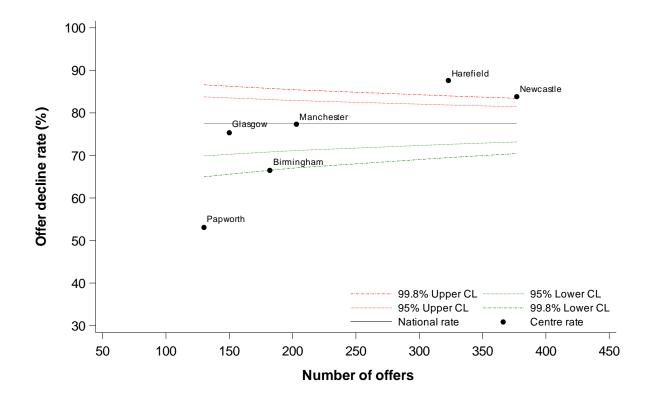


Table 4.1 shows a breakdown of each centre's decline rate across the three years analysed. Nationally, the number of offers has remained similar (for hearts that were eventually transplanted), but the offer decline rate was highest in the latest year.

Table 4.1 UK adult DBD donor heart offer decline rates by transplant centre and year, between 1 April 2019 and 31 March 2022										
Centre	201	19/20	202	20/21	2021/22		Overall			
	No.	Decline	No.	Decline	No.	Decline	No.	Decline		
	offers	rate (%)	offers	rate (%)	offers	rate (%)	offers	rate (%)		
		, ,		, ,		,		()		
Birmingham	68	(58.8)	61	(62.3)	53	(81.1)	182	(66.5)		
Glasgow	67	(86.6)	41	(68.3)	42	(64.3)	150	(75.3)		
Harefield	105	(85.7)	137	(89.8)	81	(86.4)	323	(87.6)		
Manchester	73	(74.0)	69	(79.7)	61	(78.7)	203	(77.3)		
Newcastle	93	(75.3)	123	(85.4)	161	(87.6)	377	(83.8)		
Papworth	41	(53.7)	41	(48.8)	48	(56.3)	130	(53.1)		
UK	447	(74.7)	472	(78.2)	446	(79.8)	1365	(77.6)		
Centre has reached the upper 99.8% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 99.8% confidence limit										

ADULT HEART TRANSPLANTATION Transplants

5.1 Adult heart transplants, 1 April 2012 – 31 March 2022

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 145 adult heart transplants nationally, 13 more than the previous year and 22 less than the most active year over the last decade, which was 2013/2014. Comparing 2021/2022 with the previous year, we see there were fewer DBD heart transplants but more DCD heart transplants.

Figure 5.1 Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2012 to 31 March 2022

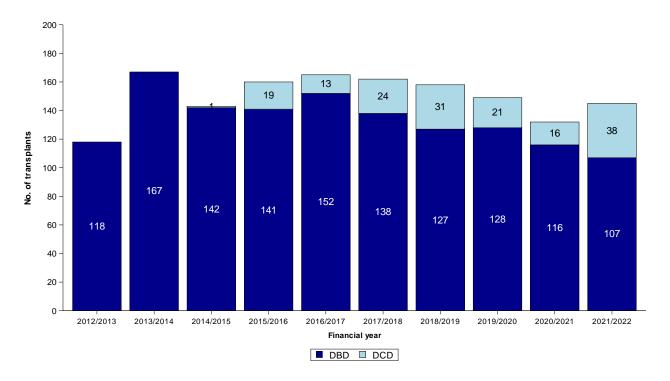
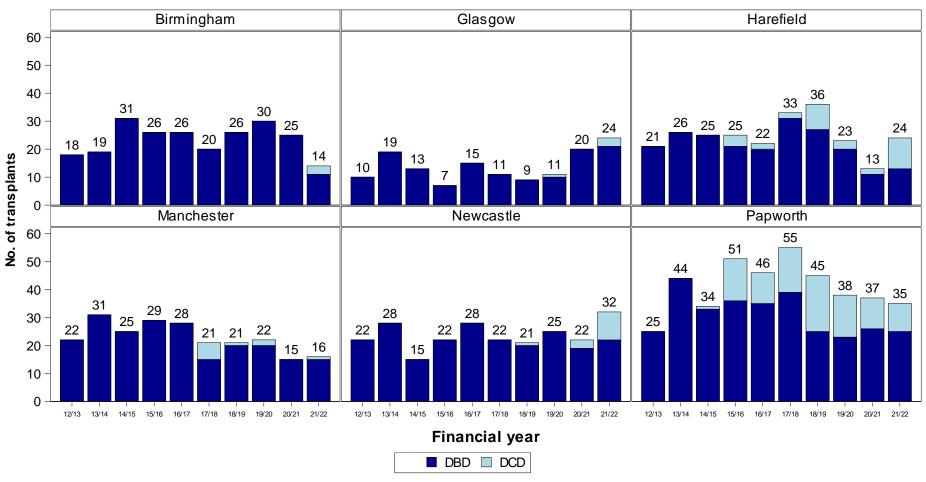


Figure 5.2 shows the number of adult heart transplants performed per centre, per year, over the last ten years, by donor type.

Figure 5.2 Number of adult heart transplants in the UK, by financial year, centre and donor type, 1 April 2012 to 31 March 2022



Last year's activity is shown by centre and donor type in **Figure 5.3**. DCD heart transplants represented 26% of last year's adult heart transplant activity The highest number of DBD transplants were performed by Papworth and the highest number of DCD transplants were performed by Harefield.

Figure 5.3 Number of adult heart transplants in the UK, by centre and donor type, 1 April 2021 to 31 March 2022

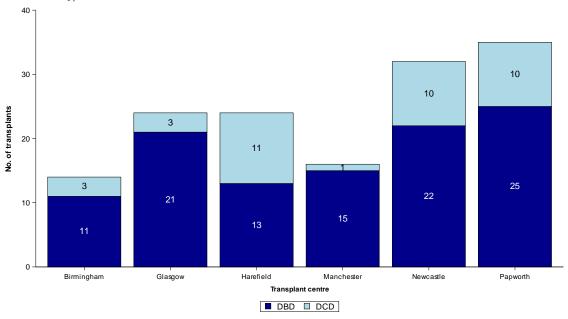


Figure 5.4 and **5.5** show the number of adult heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. Over time, the proportion of urgent transplants has increased slightly; from 68% in 2012/2013 to 72% in 2021/2022, including 28 super-urgent 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 2012 to 31 March 2022

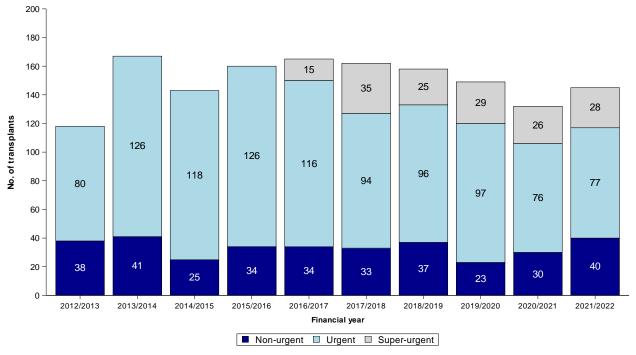
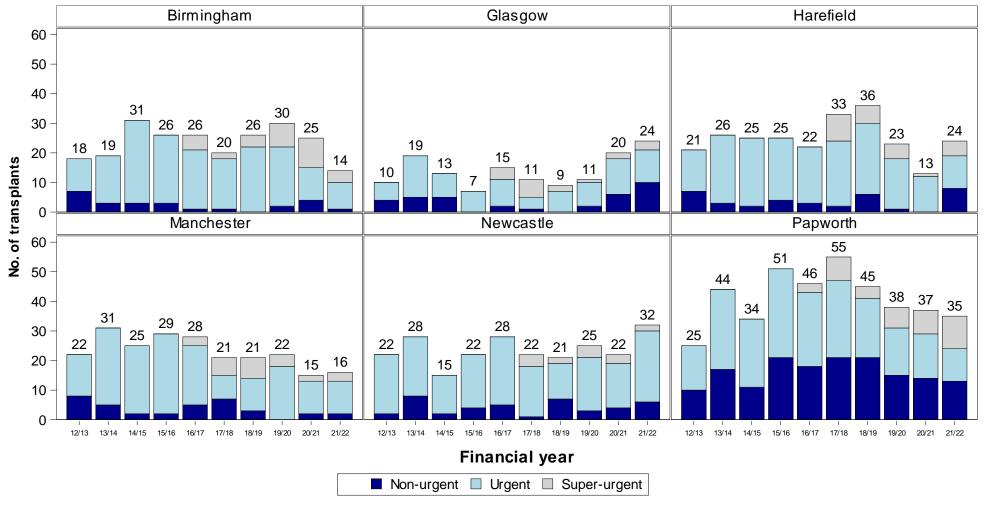
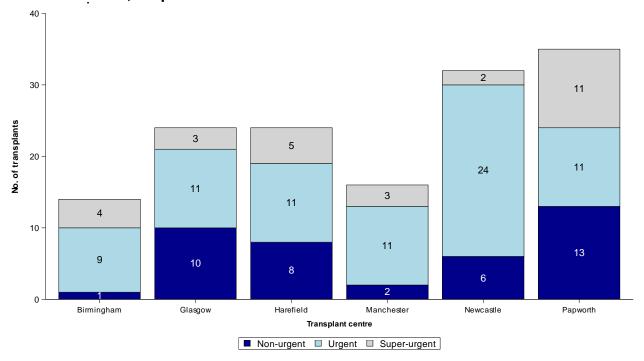


Figure 5.5 Number of adult heart transplants in the UK, by financial year, centre and urgency status, 1 April 2012 to 31 March 2022



Last year's activity is shown by centre and urgency status in **Figure 5.6**. Papworth 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 2021 to 31 March 2022



5.2 Demographic characteristics of transplants, 1 April 2021 – 31 March 2022

The demographic characteristics of the 145 adult heart transplant recipients and donors in the latest year are shown by centre and overall, in **Table 5.1**. Nationally, 68% of heart recipients were male and the <u>median</u> age was 49 years while the median age for donors was 33 years. For some characteristics, due to rounding, percentages may not add up to 100.

		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		14 (100)	24 (100)	24 (100)	16 (100)	32 (100)	35 (100)	145 (100)
Urgency status at	Non-urgent	1 (7)	10 (42)	8 (33)	2 (13)	6 (19)	13 (37)	40 (28)
transplant	Urgent	9 (64)	11 (46)	11 (46)	11 (69)	24 (75)	11 (31)	77 (53)
	Super-urgent	4 (29)	3 (13)	5 (21)	3 (19)	2 (6)	11 (31)	28 (19)
Recipient sex	Male	12 (86)	15 (63)	21 (88)	6 (38)	19 (59)	25 (71)	98 (68)
	Female	2 (14)	9 (38)	3 (13)	10 (63)	13 (41)	10 (29)	47 (32)
Recipient ethnicity	White	12 (86)	24 (100)	19 (79)	14 (88)	30 (94)	30 (86)	129 (89
	Asian	0 (0)	0 (0)	1 (4)	2 (13)	2 (6)	3 (9)	8 (6
	Black	1 (7)	0 (0)	2 (8)	0 (0)	0 (0)	0 (0)	3 (2
	Other	1 (7)	0 (0)	1 (4)	0 (0)	0 (0)	1 (3)	3 (2
	Missing	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)	1 (3)	2 (1
Recipient age (years)	Median (IQR)	47 (41, 55)	55 (48, 59)	55 (49, 60)	46 (36, 56)	43 (34, 52)	48 (44, 57)	49 (40, 57
	Missing	0	0	0	0	0	0	(
Recipient weight (kg)	Median (IQR)	87 (77, 94)	86 (74, 92)	78 (66, 84)	74 (63, 83)	66 (58, 79)	75 (67, 90)	77 (66, 88
1 3 (3/	Missing	Ó	Ó	Ó	Ó	Ó	Ó	` (
Recipient primary	Coronary heart disease	4 (29)	4 (17)	7 (29)	5 (31)	4 (13)	6 (17)	30 (21
disease	Cardiomyopathy	8 (57)	20 (83)	16 (67)	11 (69)	19 (59)	27 (77)	101 (70
	Congenital heart disease	1 (7)	0 (0)	0 (0)	0 (0)	9 (28)	1 (3)	11 (8
	Graft failure/Rejection	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	1 (1
	Other	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	2 (1

		Birmingham	Glasgow	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
IYHA class	1	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
		0 (0)	2 (8)	0 (0)	0 (0)	0 (0)	0 (0)	2 (1
	III	3 (21)	7 (29)	13 (54)	9 (56)	6 (19)	10 (29)	48 (33
	IV	2 (14)	15 (63)	11 (46)	6 (38)	25 (78)	25 (71)	84 (58
	Missing	8 (57)	0 (0)	0 (0)	1 (6)	1 (3)	0 (0)	10 (7
ecipient in hospital	No	3 (21)	10 (42)	8 (33)	2 (13)	8 (25)	15 (43)	46 (32
	Yes	11 (79)	14 (58)	16 (67)	14 (88)	23 (72)	20 (57)	98 (68
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1
n hospital, recipient	No	11 (100)	14 (100)	16 (100)	14 (100)	22 (96)	20 (100)	97 (99
n ventilator	Yes	0 (0)	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1
n hospital, recipient	None	8 (73)	14 (100)	11 (69)	7 (50)	20 (87)	7 (35)	67 (68
'AD	Left	0 (0)	0 (0)	4 (25)	4 (29)	3 (13)	1 (5)	12 (12
	Both	3 (27)	0 (0)	1 (6)	3 (21)	0 (0)	12 (60)	19 (19
n hospital, recipient	No	11 (100)	14 (100)	16 (100)	14 (100)	23 (100)	20 (100)	98 (100
AH	Yes	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0
n hospital, recipient	No	11 (100)	12 (86)	16 (100)	14 (100)	21 (91)	19 (95)	93 (95
CMO	Yes	0 (0)	1 (7)	0 (0)	0 (0)	2 (9)	1 (5)	4 (4
	Missing	0 (0)	1 (7)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1
hospital, recipient	No	2 (18)	1 (7)	2 (13)	5 (36)	0 (0)	13 (65)	23 (24
n inotropes	Yes	9 (82)	13 (93)	14 (88)	9 (64)	23 (100)	7 (35)	75 (77
n hospital, recipient	No	11 (100)	3 (21)	16 (100)	14 (100)	23 (100)	19 (95)	86 (88
ABP	Yes	0 (0)	11 (79)	0 (0)	0 (0)	0 (0)	1 (5)	12 (12
ecipient CMV status	Negative	7 (50)	15 (63)	12 (50)	8 (50)	14 (44)	25 (71)	81 (56
	Positive	7 (50)	9 (38)	12 (50)	8 (50)	18 (56)	10 (29)	64 (44
ecipient HCV status	Negative	14 (100)	23 (96)	24 (100)	16 (100)	30 (94)	35 (100)	142 (98
•	Positive	`O (O)	1 (4)	`0 (0)	`O (O)	0 (0)	`O (O)	ì (
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (6)	0 (0)	2 (

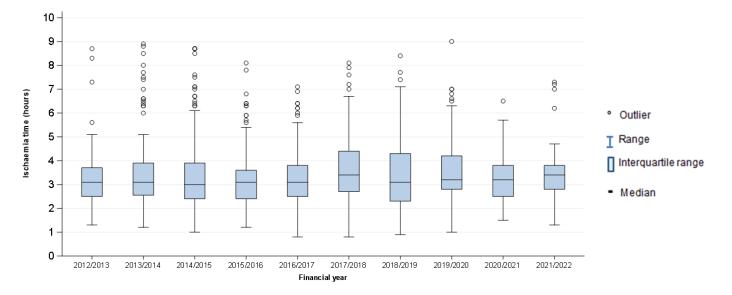
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Recipient HBV status	Negative	14 (100)	23 (96)	24 (100)	16 (100)	30 (94)	35 (100)	142 (98)
	Positive	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (6)	0 (0)	2 (1)
Recipient HIV status	Negative	14 (100)	23 (96)	24 (100)	16 (100)	30 (94)	35 (100)	142 (98)
	Positive	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (6)	0 (0)	2 (1)
Recipient Serum	Median (IQR)	88 (66, 124)	89 (78, 100)	108 (88, 136)	83 (64, 107)	98 (86, 118)	95 (75, 133)	91 (77, 122)
Creatinine (umol/l)	Missing	0	1	0	0	2	1	4
Donor sex	Male	11 (79)	11 (46)	19 (79)	6 (38)	20 (63)	19 (54)	86 (59)
	Female	3 (21)	13 (54)	5 (21)	10 (63)	12 (38)	16 (46)	59 (41)
Donor ethnicity	White	12 (86)	21 (88)	18 (75)	16 (100)	30 (94)	28 (80)	125 (86)
	Asian	1 (7)	1 (4)	1 (4)	0 (0)	0 (0)	4 (11)	7 (5)
	Black	0 (0)	1 (4)	1 (4)	0 (0)	0 (0)	0 (0)	2 (1)
	Other	1 (7)	1 (4)	3 (13)	0 (0)	2 (6)	2 (6)	9 (6)
	Missing	0 (0)	0 (0)	1 (4)	0 (0)	0 (0)	1 (3)	2 (1)
Donor age (years)	Median (IQR)	40 (27, 47)	41 (29, 48)	32 (25, 40)	28 (23, 33)	28 (20, 33)	40 (32, 48)	33 (25, 44)
	Missing	0	0	0	0	0	0	0
Donor BMI	Median (IQR)	28 (24, 32)	28 (23, 30)	25 (24, 29)	26 (21, 31)	26 (23, 29)	25 (24, 28)	26 (24, 29)
	Missing	0	0	0	0	0	0	0
Donor cause of death	CVA	12 (86)	16 (67)	22 (92)	14 (88)	29 (91)	28 (80)	121 (83)
	Trauma	1 (7)	3 (13)	1 (4)	0 (0)	1 (3)	1 (3)	7 (5)
	Others	1 (7)	5 (21)	1 (4)	2 (13)	2 (6)	6 (17)	17 (12)
Donor hypotension	No	11 (79)	17 (71)	17 (71)	14 (88)	3 (9)	28 (80)	90 (62)
	Yes	3 (21)	5 (21)	6 (25)	2 (13)	5 (16)	7 (20)	28 (19)
	Missing	0 (0)	2 (8)	1 (4)	0 (0)	24 (75)	0 (0)	27 (19)

		Dissipator	01	1 1 C . I . I	NA L t	NId.	D	TOTAL
		Birmingham N (%)	Glasgow N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor past diabetes	No	14 (100)	24 (100)	23 (96)	16 (100)	27 (84)	33 (94)	137 (95)
	Yes	0 (0)	0 (0)	1 (4)	0 (0)	4 (13)	2 (6)	7 (5)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Donor past cardio	No	13 (93)	23 (96)	24 (100)	16 (100)	32 (100)	33 (94)	141 (97)
disease	Yes	1 (7)	0 (0)	0 (0)	0 (0)	O (O)	2 (6)	3 (2)
	Missing	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Donor past	No	12 (86)	20 (83)	22 (92)	16 (100)	30 (94)	29 (83)	129 (89)
nypertension	Yes	2 (14)	4 (17)	2 (8)	(O)	1 (3)	6 (17)	15 (10)
,	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Donor past tumour	No	14 (100)	24 (100)	24 (100)	15 (94)	30 (94)	33 (94)	140 (97)
•	Yes	0 (0)	0 (0)	0 (0)	1 (6)	1 (3)	0 (0)	2 (1)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	2 (6)	3 (2)
Donor past smoker	No	9 (64)	13 (54)	10 (42)	6 (38)	19 (59)	15 (43)	72 (50)
·	Yes	5 (36)	11 (46)	14 (58)	10 (63)	12 (38)	20 (57)	72 (50)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	0 (0)	1 (1)
Total ischaemia time	Median (IQR)	3.3 (2.8, 7.3)	3.6 (2.9, 3.7)	4.4 (3.6, 5.0)	3.1 (2.8, 3.4)	3.7 (2.8, 4.2)	3.8 (3.2, 4.8)	3.6 (3.1, 4.4)
(hours)	Missing	0	10	8	1	2	O ,	2 1

5.3 Total ischaemia time, 1 April 2012 – 31 March 2022

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

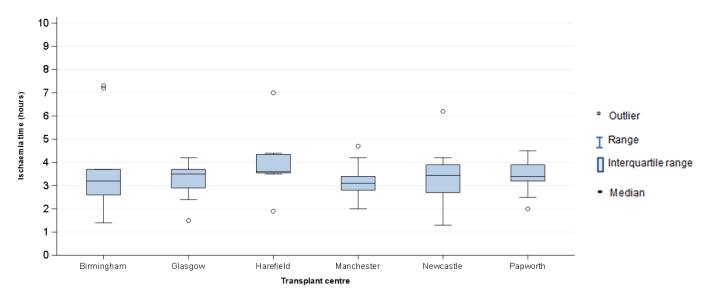
Figure 5.7 Boxplots of total ischaemia time for DBD donor hearts transplanted into adult recipients, by financial year, 1 April 2012 to 31 March 2022



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

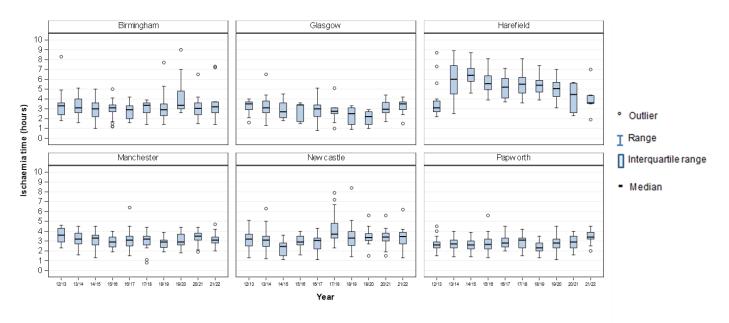
Figure 5.8 and **Figure 5.9** show <u>boxplots</u> of total ischaemia time by centre in the latest financial year and over the last 10 years, respectively. The increase in observed <u>median</u> total ischaemia time at Harefield from 2013/2014 onwards is explained by their use of the Organ Care System (OCS); between 2013/2014 and 2019/2020, 100% of DBD hearts transplanted by Harefield used OCS compared with 1%-6% for other centres. In 2021/2022, the OCS was not used in any DBD heart transplants.

Figure 5.8 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre, 1 April 2021 to 31 March 2022



The Organ Care System (OCS) was not used in any DBD heart transplants in this time period.

Figure 5.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into adult recipients, by transplant centre and financial year, 1 April 2012 to 31 March 2022



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 100% of transplants from 2013/2014 to 2019/2020. The OCS was not used in any DBD heart transplants in 2021/2022.

ADULT HEART TRANSPLANTATION Post-Transplant Survival

6. Post-Transplant Survival

This section presents survival post adult heart transplantation. Funnel plots are used to compare the <u>risk-adjusted</u> survival rate at each centre with the national rate. The <u>risk-adjusted</u> rates seek to compare centre performance after accounting for differences in <u>case mix</u> across centres. The <u>unadjusted survival rates</u> are also presented in the tables, showing the observed survival experience at that centre. The <u>risk factors</u> used to produce the <u>risk-adjusted survival rates</u> are listed in **Appendix A3.1**.

The survival analyses in **Section 6.1-6.3** include first time DBD heart only transplants. Thirty-day, 90-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2017 to 31 March 2021 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2013 to 31 March 2017. <u>Survival rates</u> are presented by transplant centre in **Tables 6.1-6.4** and **Figures 6.1-6.4**, by disease group in **Tables 6.5-6.6** and by VAD status at time of transplant in **Table 6.7**. Survival following DCD heart transplantation is provided separately in **Section 6.4** and survival outcomes following <u>multiorgan</u> heart transplantation are summarised in **Section 6.5**.

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 500 first adult <u>DBD</u> heart only transplants in the period 1 April 2017 to 31 March 2021. All of the centres' rates, except Manchester, were statistically consistent with the national rate of survival which was 91.4%. Manchester's rate lies between the 95% and 99.8% <u>confidence intervals</u> for the national rate providing some evidence of higher than expected survival.

	Table 6.1 30 day patient survival rates after first adult DBD heart transplant, by centre, 1 April 2017 to 31 March 2021 Centre Number of 94 30 day survival (95% CI)										
Centre	Number of transplants	/									
Birmingham Glasgow Harefield Manchester Newcastle Papworth	100 50 88 69 82 111	94.0 92.0 81.8 97.1 90.2 93.7	(87.1 - 97.3) (80.1 - 96.9) (72.0 - 88.4) (88.9 - 99.3) (81.4 - 95.0) (87.2 - 96.9)	93.3 89.5 88.9 96.9 92.5 87.6	(85.2 - 97.0) (72.1 - 96.1) (81.9 - 93.2) (87.6 - 99.2) (85.0 - 96.3) (74.0 - 94.1)						
UK	500	91.4	(88.6 - 93.5)								
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit											

Figure 6.1 Risk-adjusted 30 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2017 to 31 March 2021

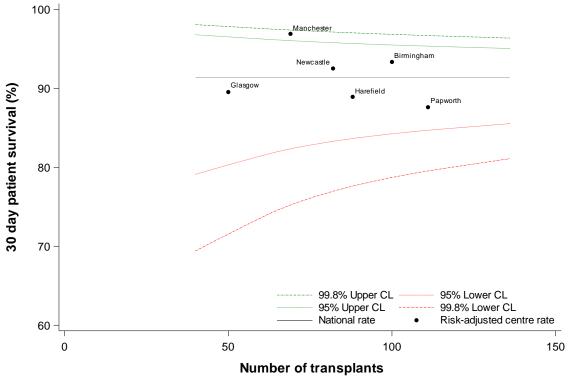


Table 6.2 and **Figure 6.2** show the 90-day post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 500 first adult <u>DBD</u> heart only transplants in the period 1 April 2017 to 31 March 2021. All of the centres' rates were statistically consistent with the national rate of survival which was 88.2%.

Table 6.2 90 day p	eatient survival aft 017 and 31 March		ult DBD heart tra	nsplant	, by centre,	
Centre	Number of		% 90 day survi	val (95%	CI)	
	transplants	Unadjusted Risk-adjuste				
Birmingham	100	92.0	(84.6 - 95.9)	90.0	(80.0 - 95.0)	
Glasgow	50	90.0	(77.6 - 95.7)	88.2	(71.6 - 95.1)	
Harefield	88	77.3	(67.0 - 84.7)	85.8	(77.9 - 90.8)	
Manchester	69	91.3	(81.7 - 96.0)	91.3	(80.6 - 96.1)	
Newcastle	82	86.6	(77.1 - 92.3)	89.6	(81.2 - 94.2)	
Papworth	111	91.9	(85.0 - 95.7)	85.5	(72.2 - 92.5)	
UK	500	88.2	(85.0 - 90.7)			
	Centre has reache	d the lower s	99.8% confidence li	mit		
	Centre has reache	d the lower s	95% confidence limi	t		
	Centre has reached	d the upper	95% confidence lim	it		
	Centre has reached	d the upper	99.8% confidence li	mit		

Figure 6.2 Risk-adjusted 90 day patient survival rates for adult DBD heart transplants, by centre, 1 April 2017 to 31 March 2021

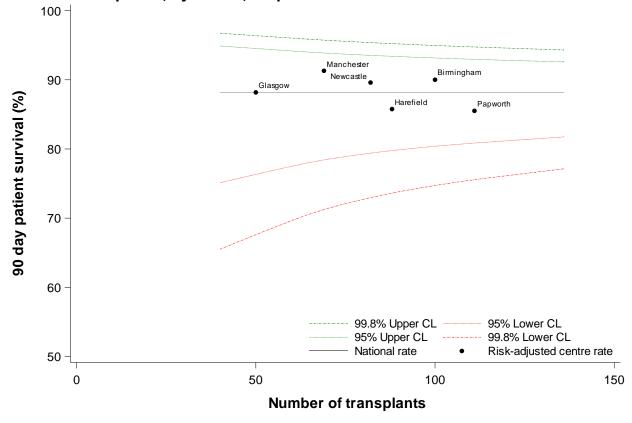


Table 6.3 and **Figure 6.3** show the 1-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 500 first adult <u>DBD</u> heart only transplants in the period 1 April 2017 to 31 March 2021. The national rate of survival was 84.5%. The centre specific rates were consistent with the national rate.

Table 6.3 1 year patient survival rates after first adult DBD heart transplant, by centre, 1 April 2017 to 31 March 2021									
Centre	Number of		% 1 year survi	val (95%	CI)				
	transplants	<u>Unadjusted</u> <u>Risk-adjuste</u>							
Birmingham	100	85.8	(77.2 - 91.3)	84.7	(74.1 - 90.9)				
Glasgow			(77.6 - 95.7)	86.3	(67.1 - 94.3)				
Harefield	88	,		81.4	(72.5 - 87.5)				
Manchester	69	91.3	(81.7 - 96.0)	90.3	(78.3 - 95.6)				
Newcastle	82	80.2	(69.7 - 87.4)	84.6	(74.9 - 90.6)				
Papworth	111	90.1	(82.8 - 94.4)	84.2	(71.4 - 91.2)				
UK	500	84.5	(81 - 87.4)						
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit									

Figure 6.3 Risk-adjusted one-year patient survival rates for adult DBD heart transplants, by centre, 1 April 2017 to 31 March 2021

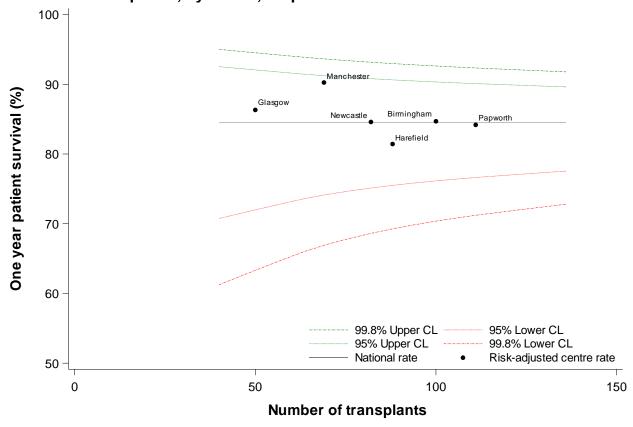
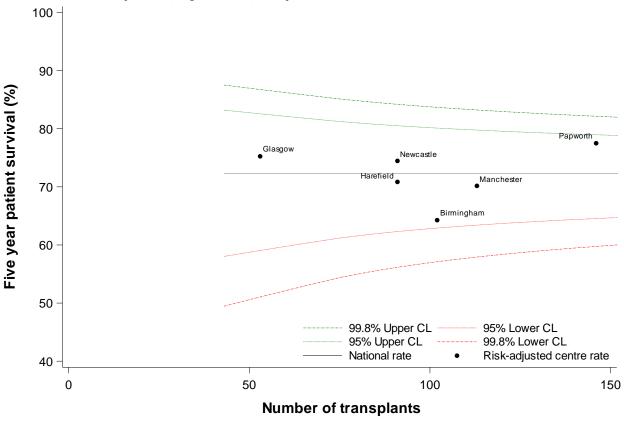


Table 6.4 and **Figure 6.4** show the 5-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 596 first adult <u>DBD</u> heart only transplants in the period 1 April 2013 to 31 March 2017. The national rate of survival was 72.3%. The centre specific rates were consistent with the national rate.

Table 6.4 5 year patient survival rates after first adult DBD heart transplant, by centre 1 April 2013 to 31 March 2017										
Centre	Number of		% 5 year survi	val (95%	CI)					
	transplants	<u>L</u>	<u>Inadjusted</u>	Ris	sk-adjusted					
Birmingham	102	67.1	(56.9 - 75.4)	64.3	(49.7 - 74.6)					
Glasgow	53	77.4	(63.6 - 86.5)	75.3	(56.3 - 85.9)					
Harefield	91	68.1	(57.5 - 76.6)	70.8	(58.1 - 79.7)					
Manchester	113	72.6	(63.3 - 79.8)	70.2	(57.6 - 79.0)					
Newcastle	91	71.0	(60.4 - 79.3)	74.5	(62.5 - 82.6)					
Papworth	146	77.3	(69.6 - 83.3)	77.5	(68.4 - 84.0)					
UK	596	72.3	(68.5 - 75.8)							
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit										

Figure 6.4 Risk-adjusted five year patient survival rates for adult DBD heart transplants, by centre, 1 April 2013 to 31 March 2017



6.2 Survival by disease group

Tables 6.5 and **6.6** 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 survival rates</u> are listed in <u>Appendix A3.1</u> (except centre was used in place of disease group). Recipients in the other/not reported group had a lower than average <u>risk-adjusted survival rate</u> at 1 year. Recipients with congenital heart disease had a lower than average <u>risk-adjusted survival rate</u> at 5 years.

Table 6.5 1 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2017 and 31 March 2021									
Disease group	Number of		% 1 year survival (95% CI)						
	transplants		<u>Inadjusted</u>	Risk-adjusted					
Cardiomyopathy	370	85.6	(81.6 - 88.8)	86.1	(81.9 - 89.4)				
Congenital heart disease	33	72.6	(53.9 - 84.7)	75.0	(51.9 - 87.0)				
Coronary heart disease	74	87.8	(77.9 - 93.5)	85.6	(72.3 - 92.5)				
Other/not reported	23	73.4	(50.1 - 87.1)	64.7	(21.4 - 84.1)				
ик	500	84.5	(81.0 - 87.4)						

Table 6.6 5 year patient survival rates after first adult DBD heart transplant, by disease group, 1 April 2013 and 31 March 2017									
Disease group	Number of		% 5 year survi	val (95%	CI)				
	transplants	<u>U</u>	<u>Unadjusted</u>		sk-adjusted				
Cardiomyopathy	430	74.0	(69.6 - 77.9)	73.7	(68.3 - 78.1)				
Congenital heart disease	39	63.9	(46.8 - 76.8)	49.7	(15.1 - 70.2)				
Coronary heart disease	99	66.6	(56.4 - 75.0)	70.7	(58.8 - 79.2)				
Other/Not reported	28	78.2	(57.8 - 89.6)	80.7	(57.0 - 91.3)				
ик	596	72.3	(68.5 - 75.8)						

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 implantable VADs for left, right and biventricular support 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 those not on support at time of transplant having superior survival.

Table 6.7 Unadjusted patient survival rates after first adult DBD heart transplant, by mechanical support status, 1 April 2017 and 31 March 2021									
Mechanical support status	Number of transplants	(day survival 95% CI) nadjusted	(9	day survival 95% CI) adjusted	(year survival 95% CI) nadjusted		
Short-term support Long-term support No support	86 75 339	90.7 77.3 94.7	(82.3 - 95.2) (66.1 - 85.2) (91.7 - 96.6)	88.4 70.7 92.0	(79.5 - 93.6) (59.0 - 79.6) (88.6 - 94.5)	82.5 67.9 88.7	(72.6 - 89.0) (56.1 - 77.2) (84.8 - 91.7)		
UK	500	91.4	(88.6 - 93.5)	88.2	(85.0 - 90.7)	84.5	(81.0 - 87.4)		

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 April 2013 to 31 March 2021 transplants were performed by five of the six adult centres, and there were 17 deaths within 1 year.

centre, 1 Apri	l 2013 and 31 March 2021				
Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (<u>unadjusted</u>)		
Glasgow¹	1	0	-	-	
Harefield	21	2	90.5	(67.0 - 97.5)	
Manchester ¹	9	0	-	-	
Newcastle ¹	4	0	-	-	
Papworth	89	2	97.8	(91.3 - 99.4)	
UK	124	4	96.8	(91.6 – 98.8)	

		t only transp	lant, by	
Number of patients	Number of deaths	% 90 day survival (95% CI) (<u>unadjusted</u>)		
1	0	-	-	
21	4	81.0	(56.9 - 92.4)	
9	2	-	-	
4	0	-	-	
89	5	94.4	(84.6 - 95.0)	
124	11	91.1	(84.6 – 95.0)	
	Number of patients 1 21 9 4 89	Number of Number of patients deaths 1 0 21 4 9 2 4 0 89 5	Number of Number of % 90 day patients deaths (ur) 1 0 - 21 4 81.0 9 2 - 4 0 - 89 5 94.4	

Table 6.10 1 year patient survival rates after first adult DCD heart only transplant, by centre, 1 April 2013 and 31 March 2021

Centre

Number of Number of % 1 year survival (95

Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (<u>unadjusted</u>)			
Glasgow ¹	1	0	-	-		
Harefield	21	6	71.4	(47.2 - 86.0)		
Manchester ¹	9	3	-	-		
Newcastle ¹	4	0	-	-		
Papworth	89	8	91.0	(82.8 - 95.4)		
UK	124	17	86.3	(78.9 – 91.2)		

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

6.5 Survival post multi-organ heart transplant

The survival outcomes of the small number of recipients of multi-organ heart transplants are reported in **Table 6.11**, at 90 days and 1 year post transplant. This includes all first-time multi-organ transplants involving the heart, from DBD or DCD donors, between 1 April 2013 and 31 March 2021. It does not include heart-lung transplants which are reported in <u>Section 12.4</u>.

Table 6.11 Survival outcomes following multi-organ heart transplants performed between 1 April 2013 and 31 March 2021								
Transplant type	Number of transplants	Number of patients alive at 90 days post- transplant N	Number of patients alive at 1 year post- transplant N					
Heart & kidney	4	4	4					
Heart & liver	5	4	4					

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 2010 and 31 December 2021. 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 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 and five year survival rates for Manchester both fell above the upper 99.8% confidence limits, indicating significantly high survival from listing at this centre. Newcastle's five year survival rate fell below the lower 99.8% confidence limits, 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. There is some evidence of higher survival at five years for Papworth.

Table 7.1	Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor heart transplant in patients registered between 1 January 2010 to 31 December 2021

			One year			Five year	
Contro	Number at	Survival		Number	Survival		Number
Centre	risk¹ at day 0	rate %	(95% CI)	at risk1	rate %	(95% CI)	at risk1
Birmingham	379	82.5	(77.7 - 86.2)	263	65.8	(58.8 - 71.6)	116
Glasgow	196	85.9	(80.3 - 90.0)	138	72.0	(63.5 - 78.6)	54
Harefield	428	86.9	(83.3 - 89.8)	312	69.8	(63.8 - 74.7)	122
Manchester	342	91.5	(87.7 - 94.1)	277	76.2	(70.3 - 81.0)	125
Newcastle	457	79.9	(75.1 - 83.8)	320	53.7	(45.7 - 60.5)	117
Papworth	532	86.9	(83.6 - 89.6)	417	72.3	(67.2 - 76.6)	194
1112	2224	05.0	(04.0 07.0)	4707	CO 0	(CE 7 70.0)	700
UK	2334	85.6	(84.0 - 87.0)	1727	68.0	(65.7 - 70.2)	728

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 2010 – 31 December 2021

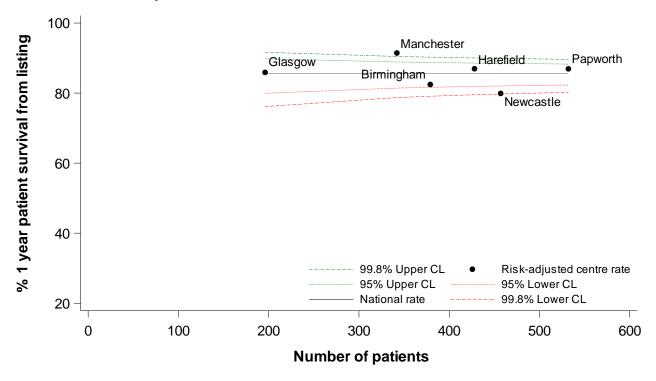
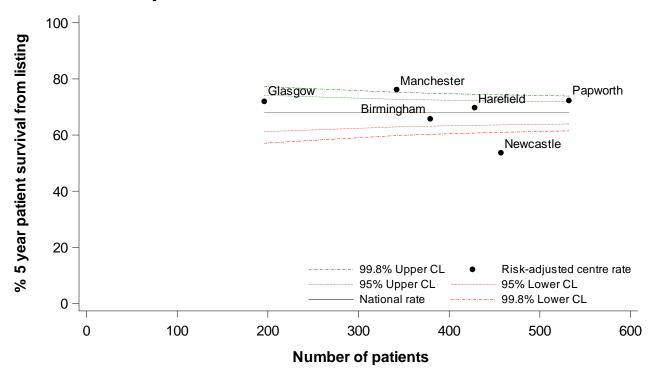


Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2010 – 31 December 2021



ADULT HEART TRANSPLANTATION Form Return Rates

8. Adult heart form return rates, 1 January 2021 – 31 December 2021

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 2021 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 94% or greater return rate for this period. Note that any skipped follow-up forms are counted as not returned.

Table 8.1 Form return rates for adult heart transplants, 1 January 2021 to 31 December 2021								
Centre	Transpla No. required	ant record % returned	3 month No. required	follow-up % returned	1 year f No. required	follow-up % returned	Lifetime No. required	follow-up % returned
Birmingham Queen Elizabeth Hospital	18	100	17	100	28	100	247	100
Royal Derby Hospital	-	-	-	-	-	-	1	0
Royal Devon And Exeter Hospital	-	-	-	-	-	-	1	0
Glasgow Golden Jubilee Hospital	27	100	26	100	15	100	148	98
Harefield Hospital	18	100	14	100	11	100	529	97
Manchester Wythenshawe Hospital	16	100	15	100	17	100	270	99
Newcastle Freeman Hospital	28	100	27	96	20	100	314	97
Oxford, John Radcliffe Hospital	-	-	-	-	-	-	1	0
Royal Papworth Hospital	29	100	32	100	34	100	632	94
Plymouth, Derriford Hospital	-	-	-	-	-	-	1	0
Sheffield Northern General Hospital	-	-	-	-	-	-	37	92
Truro, Royal Cornwall Hospital	-	-	-	-	-	-	1	100
Overall	136	100	131	99	125	100	2182	96

ADULT LUNG TRANSPLANTATION Transplant List

9.1 Adult lung and heart-lung transplant list on 31 March, 2013 – 2022

Figure 9.1 shows the number of adults on the lung and heart-lung transplant lists on 31 March each year between 2013 and 2022 split by urgency status. The number on the active non-urgent lung transplant list increased until 2017 when it remained relatively stable for a few years and then dropped significantly in 2021 and remained relatively low on 31 March 2022 at 239. The number on the heart-lung list has also reduced in the last few years. In May 2017, the super-urgent and urgent lung allocation schemes were introduced and on 31 March 2022, there were 9 adults on the urgent list and none on the super-urgent list. There has been a recent increase in the number suspended from the lung list.

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

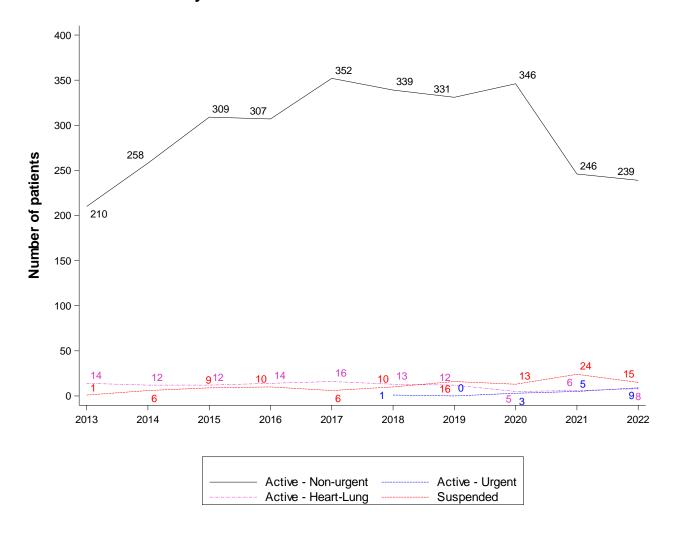


Figure 9.2 shows the number of adults on the <u>active lung and heart-lung transplant lists</u> on 31 March 2021, by centre and urgency. In total, there were 256 adults waiting, including 9 urgent across Newcastle and Papworth. Newcastle had the highest number of people registered on the transplant list while Manchester had the lowest.

Figure 9.2 Number of adults on the active lung and heart-lung transplant lists on 31 March 2022, by centre

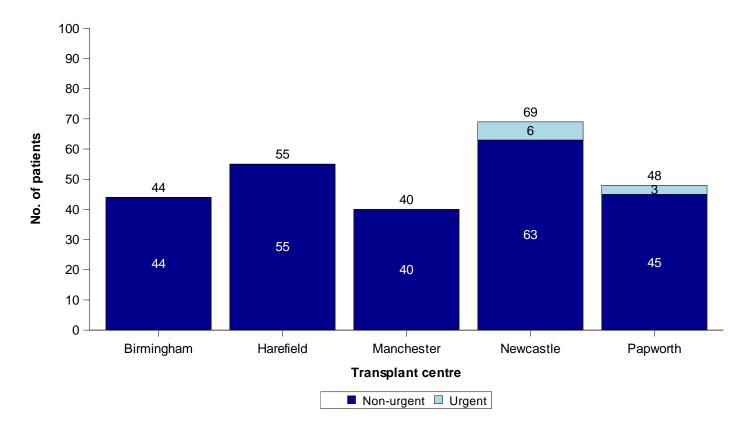
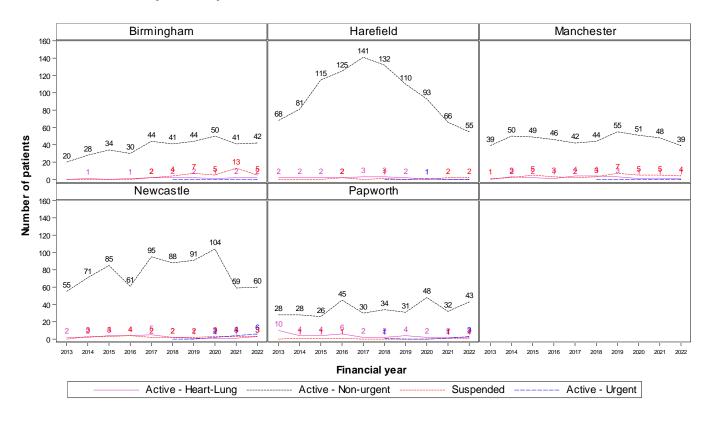


Figure 9.3 shows the trend over time in the number of adults on the lung transplant list on 31 March each year across centres. Harefield experienced a marked increase in their lung list between 2012 and 2017, but have since seen a significant decrease. Newcastle's list has recently decreased compared with 2020 and before. Birmingham have experienced a general increase over the decade in their active list and their suspended list, while the lists at Manchester and Papworth have remained relatively stable. There was no one waiting on the super-urgent list on 31 March in any year.

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



9.2 Demographic characteristics, 1 April 2021 – 31 March 2022

There were 191 adult registrations onto the lung or heart-lung transplant lists between 1 April 2021 and 31 March 2022. Demographic characteristics of these individuals are shown by centre and overall in **Table 9.1**. Nationally, 65% were male and the <u>median</u> age was 57 years. The most common primary disease group was fibrosing lung disease. For some characteristics, due to rounding, percentages may not add up to 100.

		Birmingham	Harefield	Manchester	Newcastle	Papworth	TOTAL
		N (%)					
Number of registrations		28 (100)	24 (100)	31 (100)	46 (100)	62 (100)	191 (100)
Highest urgency on the	Non-urgent	26 (93)	23 (96)	29 (94)	31 (67)	53 (85)	162 (85)
lung list during registration	Urgent	2 (7)	0 (0)	2 (6)	14 (30)	9 (15)	27 (14)
	Super-urgent	0 (0)	1 (4)	0 (0)	1 (2)	0 (0)	2 (1)
Recipient sex	Male	16 (57)	17 (71)	23 (74)	27 (59)	41 (66)	124 (65)
	Female	12 (43)	7 (29)	8 (26)	19 (41)	21 (34)	67 (35)
Recipient ethnicity	White	25 (89)	20 (83)	27 (87)	44 (96)	50 (81)	166 (87)
	Asian	3 (11)	4 (17)	3 (10)	0 (0)	8 (13)	18 (9)
	Black	0 (0)	0 (0)	0 (0)	0 (0)	4 (6)	4 (2)
	Missing	0 (0)	0 (0)	1 (3)	2 (4)	0 (0)	3 (2)
Recipient age (years)	Median (IQR)	57 (50, 61)	58 (51, 62)	57 (55, 61)	59 (52, 62)	56 (46, 60)	57 (50, 61)
	Missing	0	0	0	0	0	0
Primary disease	Cystic fibrosis and bronchiectasis	0 (0)	1 (4)	1 (3)	1 (2)	6 (10)	9 (5)
	Fibrosing lung disease	14 (50)	16 (67)	21 (68)	32 (70)	29 (47)	112 (59)
	COPD and emphysema	11 (39)	6 (25)	9 (29)	6 (13)	16 (26)	48 (25)
	Primary pulmonary hypertension	0 (0)	0 (0)	0 (0)	6 (13)	7 (11)	13 (7)
	Other heart/lung disease	3 (11)	1 (4)	0 (0)	1 (2)	3 (5)	8 (4)
	Not reported	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (1)

Table 9.1 Demogra	phic characteristics of a	dult patients registered	l onto the lung tra	nsplant list betwee	en 1 April 2021 and	d 31 March 2022, b	y centre
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Smoker	No Yes Missing	27 (96) 0 (0) 1 (4)	23 (96) 0 (0) 1 (4)	31 (100) 0 (0) 0 (0)	44 (96) 1 (2) 1 (2)	60 (97) 2 (3) 0 (0)	185 (97) 3 (2) 3 (2)
Lung function - FEV1 (litres)	Median (IQR) Missing	0.78 (0.54, 1.19) 2	1.59 (0.76, 1.93) 1	1.48 (0.68, 2.24) 1	1.57 (1.12, 2.07) 2	1.24 (0.71, 1.99) 0	1.31 (0.75, 1.93) 6
Lung function – FVC (litres)	Median (IQR) Missing	1.72 (1.12, 2.29) 2	2.20 (1.81, 2.52) 1	2.39 (1.73, 2.96) 1	2.36 (1.93, 2.70)	2.20 (1.59, 3.06)	2.20 (1.68, 2.79) 7

9.3 Post-registration outcomes, 1 April 2017 – 31 March 2019

The registration outcomes of adults listed for a lung only transplant between 1 April 2017 and 31 March 2019 are summarised in **Figures 9.4** – **9.6**, nationally and by centre, for non-urgent and urgent registrations respectively. The possible outcomes on the list include receiving a transplant, removal from the list, moving lists, dying on the list, or remaining on the list at a given time point post-registration. In these figures, the *first* outcome is used, so if an individual was transplanted then died their registration outcome would be "transplanted". If they 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, 25% of lung registrations resulted in transplant and 8% had died. Three years after listing, 45% has received a transplant and 18% had died. By centre (**Figure 9.5**), within 1 year of registration, the proportion transplanted ranged from 22% at Newcastle to 64% at Papworth and the proportion dying on the list ranged from 6% at Manchester to 20% at Newcastle. Removals from the non-urgent list were predominantly due to deteriorating condition.

6 months 3 years 1 vear 2 vears Time since listing ■ Transplanted □ Still waiting □ Became urgent ■ Became super-urgent □ Removed □ Died

Figure 9.4 Post-registration outcome for 519 non-urgent lung only registrations made in the UK, 1 April 2017 to 31 March 2019

Figure 9.5 1 year registration outcomes by centre, for non-urgent lung only registrations made in the UK, 1 April 2017 to 31 March 2019

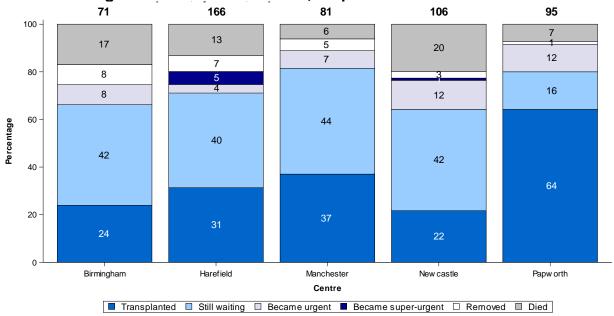
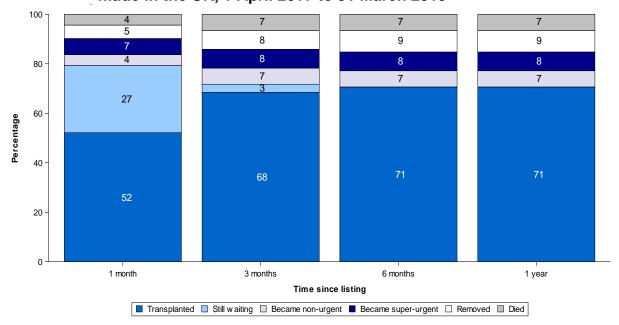


Figure 9.6 shows outcomes on the urgent lung list. The chance of transplant is much higher from the urgent list compared with the non-urgent list; within six months, 71% had received a transplant. A centre breakdown is not provided for urgent registrations, nor is a superurgent registration figure, due to small numbers.

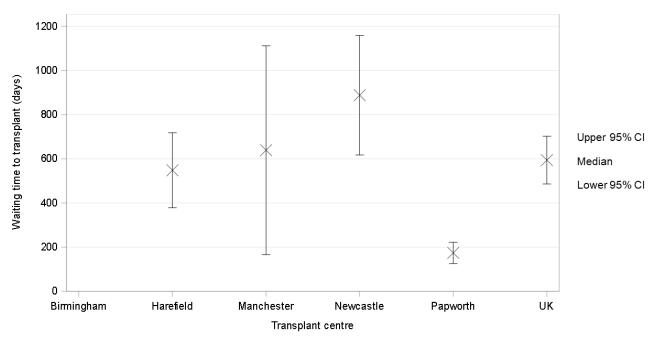
Figure 9.6 Post-registration outcome for 92 urgent lung only registrations made in the UK, 1 April 2017 to 31 March 2019



9.4 Median waiting time to transplant, 1 April 2018 - 31 March 2021

The median waiting time to non-urgent lung transplant from registration for adults is shown in Figure 9.7 and Table 9.2. This is estimated for individuals registered initially as non-urgent between 1 April 2018 and 31 March 2021 using the Kaplan Meier method. The national non-urgent median waiting time was 594 days and ranged from 174 days at Papworth to 888 days at Newcastle (log-rank p<0.0001), but could not be calculated for Birmingham due to low transplant rate. Median waiting time is not presented for urgent or super-urgent registrations, as only a small number 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 adults registered between 1 April 2018 and 31 March 2021, by centre



Note: Median waiting time could not be estimated for Birmingham due to low transplant rate

Table 9.2	Median active waiting time to lung transplant for adults registered on the non- urgent transplant list, by centre, 1 April 2018 to 31 March 2021								
Transplant centre	Number	Number	Wa	aiting time (days)					
·	registered	transplanted	Median	95% Confidence interval					
Birmingham ¹	93	25	-	-					
Harefield	165	83	548	378 - 718					
Manchester	94	44	639	166 - 1112					
Newcastle	135	48	888	617 - 1159					
Papworth	130	86	174	126 - 222					
UK	617	286	594	486 - 702					

The <u>median</u> waiting time to non-urgent lung transplant for adults is also considered by blood group. This is shown in **Figure 9.8** and **Table 9.3**. Blood group O had the longest average wait (1177 days) compared with the other blood groups (log-rank p<0.0001).

Figure 9.8 Median waiting time to non-urgent lung transplant for adults registered between 1 April 2018 and 31 March 2021, by blood group

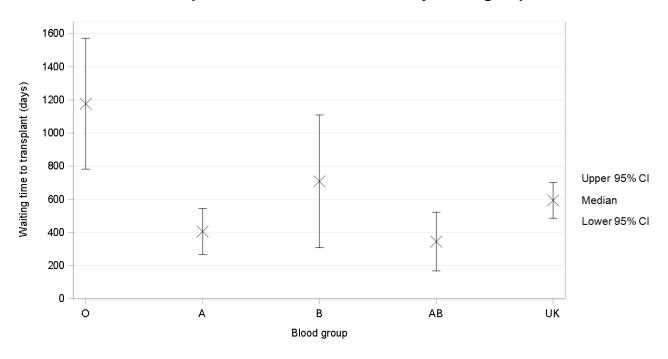


Table 9.3 Median active waiting time to lung transplant for adults registered on the non-urgent transplant list, by blood group, 1 April 2018 to 31 March 2021									
Blood Group	Number	Number	Waiting time (days)						
·	registered	transplanted	Median	95% Confidence interval					
0	277	104	1177	782 - 1572					
Α	271	148	406	267 - 545					
В	52	24	709	308 - 1110					
AB	17	10	345	168 - 522					
UK	617	286	594	486 - 702					

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 2019 and 31 March 2022 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 heart-lung block are considered, this includes cases where just the lungs were declined as well as cases where both the heart and lungs were declined. Superurgent, urgent and non-urgent offers are all considered. Offers to paediatric patients at Newcastle are excluded.

In 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 a <u>funnel</u> <u>plot</u>. The offer decline rate for Newcastle is above the higher 99.8% <u>confidence limit</u>, indicating a higher decline rate compared with the national rate. The offer decline rates for Harefield and Papworth are below the 95% <u>confidence limit</u>, providing some evidence of a lower than average decline 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 2019 to 31 March 2022

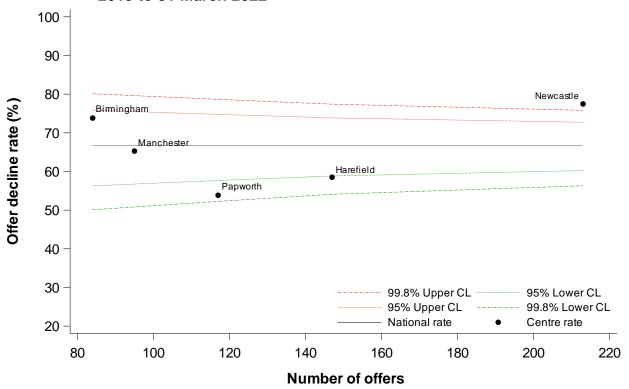


Table 10.1 shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the numbers of offers for lungs that were eventually transplanted were lower in 2020/2021 and 2021/2022 due to fewer transplants being performed.

	UK adult DBD donor bilateral lung offer decline rates by transplant centre and year, between 1 April 2019 and 31 March 2022								
Centre	201	19/20	202	20/21	202	21/22	O۱	/erall	
	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	No. offers	Decline rate (%)	
Birmingham	46	(67.4)	20	(75.0)	18	(88.9)	84	(73.8)	
Harefield	88	(72.7)	28	(35.7)	31	(38.7)	147	(58.5)	
Manchester	46	(63.0)	21	(57.1)	28	(75.0)	95	(65.3)	
Newcastle	69	(71.0)	68	(79.4)	76	(81.6)	213	(77.5)	
Papworth	46	(50.0)	26	(57.7)	45	(55.6)	117	(53.8)	
UK	295	(66.4)	163	(65.0)	198	(68.7)	656	(66.8)	
Centre has reached the upper 99.8% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the lower 99.8% confidence limit									

ADULT LUNG TRANSPLANTATION Transplants

11.1 Adult lung and heart-lung transplants, 1 April 2012 – 31 March 2022

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 remained mostly stable from 2012/2013 to 2017/2018, with peaks of 210 in 2013/2014 and 207 in 2017/2018. The number has since fallen, with only 87 transplants in 2020/2021 and 106 in the latest financial year. **Figure 11.2** shows that Birmingham, Manchester and Papworth performed more transplants in 2021/2022 compared with the previous year, whilst Newcastle and Harefield performed fewer. Last year DCD lung transplantation represented 23% 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 Papworth.

Figure 11.1 Number of adult lung transplants in the UK, by financial year and donor type, 1 April 2012 to 31 March 2022

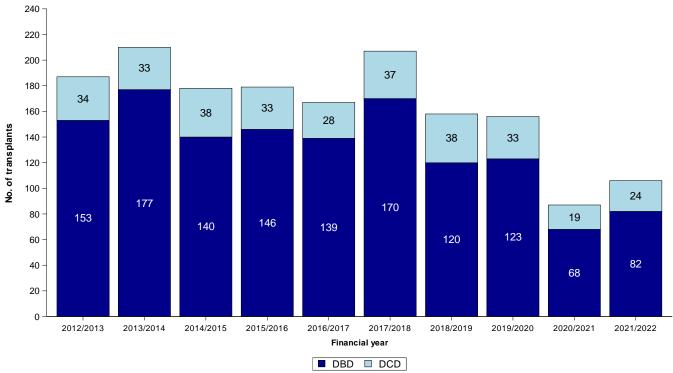


Figure 11.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2012 to 31 March 2022

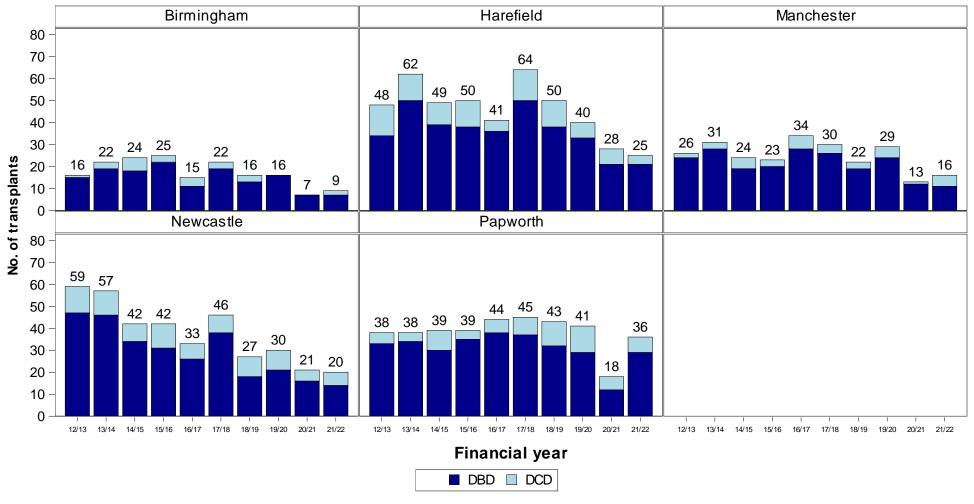


Figure 11.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2021 to 31 March 2022

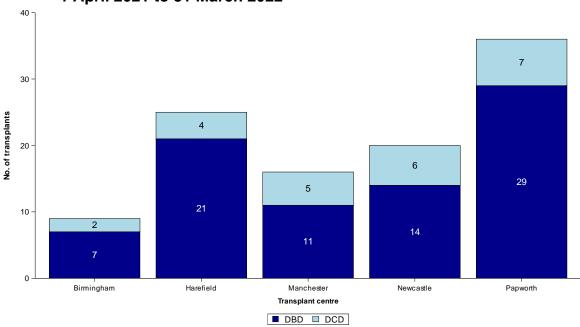


Figure 11.4 and **11.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. There was a total of 43 heart-lung block transplants, and no partial lung transplants, over the last ten years. The number of single lung transplants has decreased over the decade. 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 Papworth and Birmingham were the only centres that performed heart-lung block transplants (**Figure 11.6**).

Figure 11.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2012 to 31 March 2022

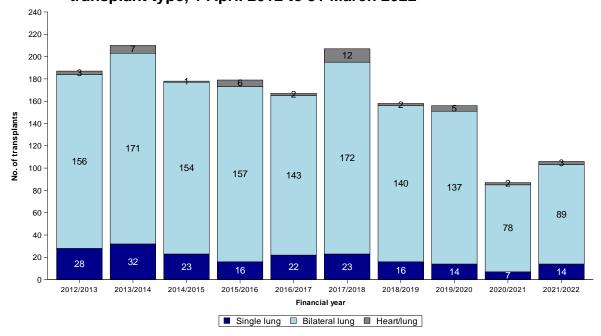


Figure 11.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2012 to 31 March 2022

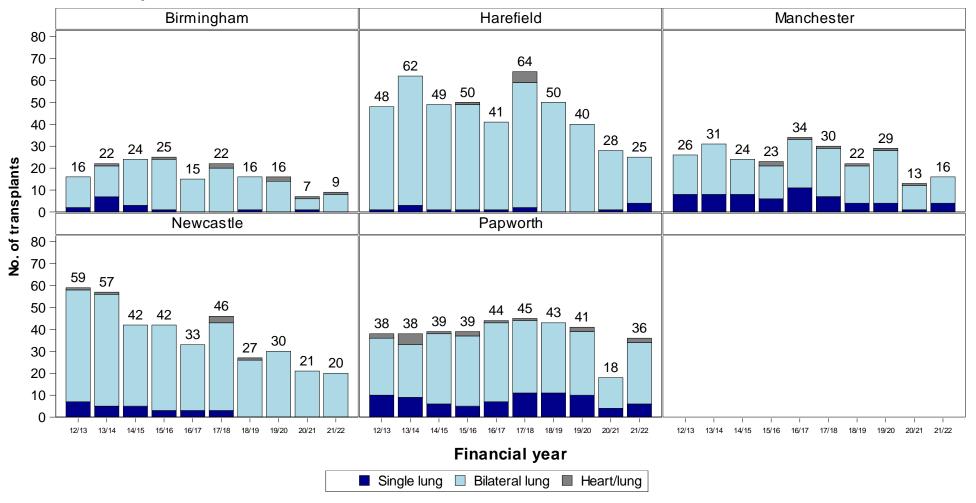
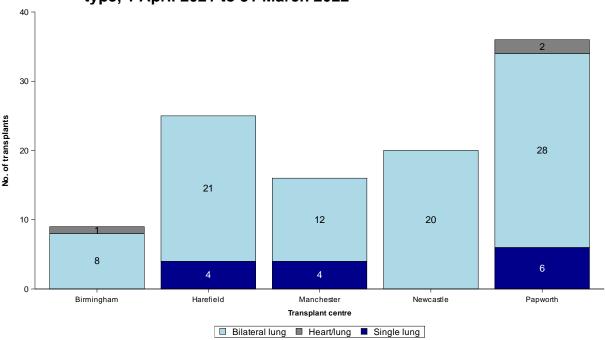


Figure 11.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2021 to 31 March 2022



In 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 30% in 2021/2022, the highest since these schemes were introduced.

Figure 11.7 Number of adult lung only transplants in the UK, by financial year and urgency status, 1 April 2012 to 31 March 2022

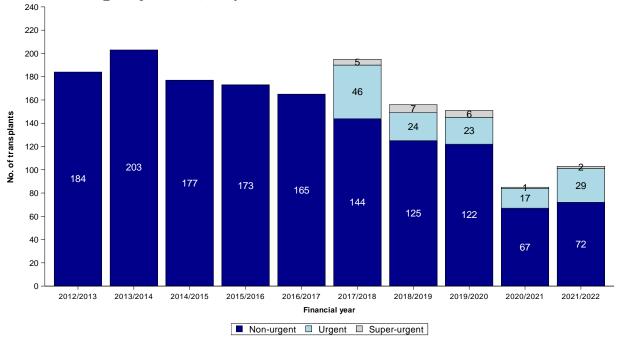
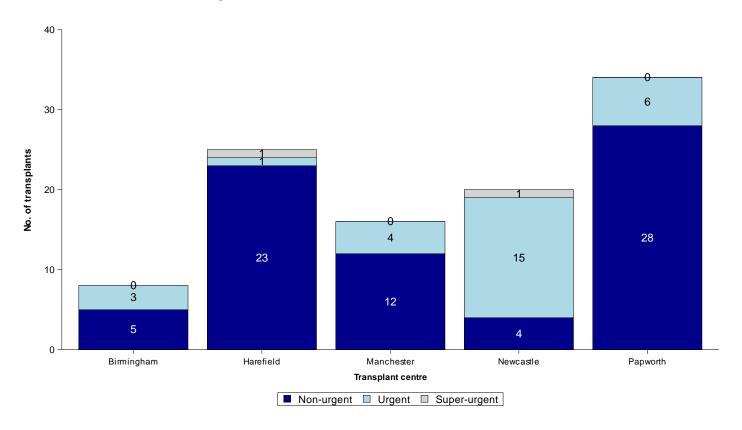


Figure 11.8 shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 29 urgent lung only transplants (ranging from 1 at Harefield to 15 at Newcastle) and 2 super-urgent lung only transplants, one performed at Harefield and one performed at Newcastle. Of the 3 adult heart-lung transplants in 2021/2022, all were non-urgent (not shown in the figure).

Figure 11.8 Number of adult lung only transplants in the UK, by centre and urgency status, 1 April 2021 to 31 March 2022



11.2 Demographic characteristics of transplants, 1 April 2021 – 31 March 2022

The demographic characteristics of the 106 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 11.1**. Nationally, 68% of lung recipients were male and the <u>median</u> age was 57 years while the median age of donors was 47 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 11.1	Demographic characteristics by centre	s of UK adult lu	ng transplants	s performed be	tween 1 April 2	2021 and 31 Ma	ırch 2022,
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		9 (100)	25 (100)	16 (100)	20 (100)	36 (100)	106 (100)
Urgency status at transplant	Non-urgent	6 (67)	23 (92)	12 (75)	4 (20)	30 (83)	75 (71)
	Urgent	3 (33)	1 (4)	4 (25)	15 (75)	6 (17)	29 (27)
	Super-urgent	0 (0)	1 (4)	0 (0)	1 (5)	0 (0)	2 (2)
Recipient sex	Male	4 (44)	18 (72)	13 (81)	15 (75)	22 (61)	72 (68)
	Female	5 (56)	7 (28)	3 (19)	5 (25)	14 (39)	34 (32)
Recipient ethnicity	White	8 (89)	22 (88)	15 (94)	19 (95)	31 (86)	95 (90)
	Asian	1 (11)	3 (12)	0 (0)	1 (5)	3 (8)	8 (8)
	Black	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
	Other	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
	Missing	0 (0)	0 (0)	1 (6)	0 (0)	0 (0)	1 (1)
Recipient age (years)	Median (IQR)	57 (49, 60)	54 (44, 59)	58 (55, 62)	60 (47, 64)	57 (47, 61)	57 (46, 61)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	68 (59, 72)	78 (64, 86)	81 (73, 88)	70 (59, 91)	74 (63, 81)	75 (64, 86)
	Missing	0	0	0	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	0 (0)	3 (12)	0 (0)	1 (5)	4 (11)	8 (8)
	Fibrosing lung disease	3 (33)	11 (44)	10 (63)	14 (70)	18 (50)	56 (53)
	COPD and emphysema	4 (44)	9 (36)	6 (38)	2 (10)	6 (17)	27 (26)
	Primary pulmonary hypertension	2 (22)	0 (0)	0 (0)	2 (10)	5 (14)	9 (9)
	Other heart/lung disease	0 (0)	2 (8)	0 (0)	1 (5)	3 (8)	6 (6)

Table 11.1	Demographic charact by centre	eristics of UK adult lu	ng transplants	s performed be	tween 1 April 2	2021 and 31 Ma	rch 2022,
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Recipient in hospital	No	5 (56)	23 (92)	14 (88)	15 (75)	31 (86)	88 (83)
	Yes	4 (44)	2 (8)	2 (13)	5 (25)	4 (11)	17 (16)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
In hospital, recipient on ventilator	No	3 (75)	2 (100)	2 (100)	5 (100)	3 (75)	15 (88)
	Yes	1 (25)	0 (0)	0 (0)	0 (0)	1 (25)	2 (12)
In hospital, recipient ECMO	No	4 (100)	1 (50)	2 (100)	4 (80)	4 (100)	15 (88)
	Yes	0 (0)	1 (50)	0 (0)	1 (20)	0 (0)	2 (12)
In hospital, recipient on inotropes	No	4 (100)	1 (50)	2 (100)	4 (80)	4 (100)	15 (88)
	Yes	0 (0)	1 (50)	0 (0)	1 (20)	0 (0)	2 (12)
Recipient CMV status	Negative	6 (67)	9 (36)	10 (63)	11 (55)	19 (53)	55 (52)
	Positive	3 (33)	16 (64)	6 (38)	9 (45)	17 (47)	51 (48)
Recipient HCV status	Negative	9 (100)	25 (100)	16 (100)	20 (100)	36 (100)	106 (100)
Recipient HBV status	Negative	9 (100)	25 (100)	16 (100)	20 (100)	36 (100)	106 (100)
Recipient HIV status	Negative	9 (100)	24 (96)	16 (100)	20 (100)	36 (100)	105 (99)
	Positive	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	1 (1)
Recipient Serum	Median (IQR)	60 (51, 90)	70 (54, 82)	73 (66, 80)	64 (48, 78)	69 (56, 86)	69 (54, 82)
Creatinine (umol/l)	Missing	0	0	0	0	2	2
Donor sex	Male	2 (22)	6 (24)	8 (50)	5 (25)	12 (33)	33 (31)
	Female	7 (78)	19 (76)	8 (50)	15 (75)	24 (67)	73 (69)
Donor ethnicity	White	9 (100)	23 (92)	15 (94)	17 (85)	33 (92)	97 (92)
	Asian	0 (0)	0 (0)	0 (0)	1 (5)	0 (0)	1 (1)
	Black	0 (0)	1 (4)	0 (0)	1 (5)	0 (0)	2 (2)
	Other	0 (0)	1 (4)	1 (6)	1 (5)	2 (6)	5 (5)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)

Table 11.1	Demographic characte by centre	eristics of UK adult lu	ng transplants	s performed be	tween 1 April :	2021 and 31 Ma	rch 2022,
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor age (years)	Median (IQR)	47 (38, 50)	49 (24, 61)	48 (38, 54)	42 (29, 49)	40 (26, 56)	47 (28, 55)
	Missing	0	0	0	0	0	0
Donor BMI	Median (IQR)	26 (23, 29)	24 (21, 27)	23 (22, 30)	26 (23, 30)	25 (21, 29)	25 (22, 29)
	Missing	0	0	0	0	0	0
Donor cause of death	CVA	9 (100)	20 (80)	12 (75)	17 (85)	30 (83)	88 (83)
	Trauma	0 (0)	3 (12)	4 (25)	0 (0)	2 (6)	9 (9)
	Others	0 (0)	2 (8)	0 (0)	3 (15)	4 (11)	9 (9)
Donor hypotension	No	9 (100)	17 (68)	13 (81)	6 (30)	29 (81)	74 (70)
	Yes	0 (0)	8 (32)	3 (19)	2 (10)	7 (19)	20 (19)
	Missing	0 (0)	0 (0)	0 (0)	12 (60)	0 (0)	12 (11)
Donor past cardio disease	No	8 (89)	22 (88)	15 (94)	20 (100)	34 (94)	99 (93)
	Yes	1 (11)	3 (12)	1 (6)	0 (0)	0 (0)	5 (5)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	2 (6)	2 (2)
Donor past hypertension	No	9 (100)	21 (84)	13 (81)	17 (85)	30 (83)	90 (85)
	Yes	0 (0)	4 (16)	3 (19)	3 (15)	6 (17)	16 (15)
Donor past tumour	No	9 (100)	24 (96)	13 (81)	20 (100)	35 (97)	101 (95)
	Yes	0 (0)	1 (4)	3 (19)	0 (0)	0 (0)	4 (4)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
Donor past smoker	No	4 (44)	15 (60)	9 (56)	13 (65)	19 (53)	60 (57)
	Yes	5 (56)	10 (40)	7 (44)	7 (35)	16 (44)	45 (43)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
Total ischaemia time (hours)	Median (IQR)	6.4 (5.9, 6.9)	6.9 (5.5, 8.1)	6.1 (5.4, 7.7)	6.1 (5.5, 7.2)	8.6 (7.4, 10.4)	7.0 (5.7, 8.5)
	Missing	1	0	1	0	1	3

Table 11.1	Demographic charac	teristics of UK adult lu	ng transplant	s performed be	tween 1 April :	2021 and 31 Ma	rch 2022,
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Transplant type	Single lung Bilateral lung Heart/lung	0 (0) 8 (89) 1 (11)	4 (16) 21 (84) 0 (0)	4 (25) 12 (75) 0 (0)	0 (0) 20 (100) 0 (0)	6 (17) 28 (78) 2 (6)	14 (13) 89 (84) 3 (3)

11.3 Total ischaemia time, 1 April 2012 – 31 March 2022

Figure 11.9 shows boxplots of the total ischaemia time for DBD donor lungs transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion (of second lung if applicable) and can be considered the out of body time. In cases where organ maintenance systems were used (3%), not all of this time duration is ischaemic, and no adjustment has been made for this. The national median total ischaemia time has increased from 5.9 hours to 6.8 hours over the last ten years.

Figure 11.9 Boxplots of total ischaemia time in adult DBD donor lung transplants, by financial year, 1 April 2012 to 31 March 2022

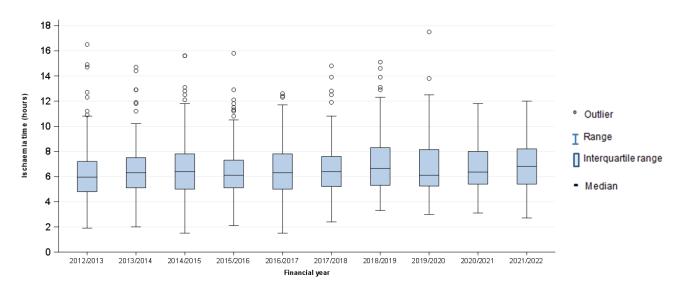


Figure 11.10 and **Figure 11.11** show boxplots of total ischaemia time by centre in the latest financial year and over the last 10 years, respectively. The median ischaemia time for lung transplants in 2021/2022 was longest for Papworth and shortest for Newcastle. Papworth and Birmingham have seen recent increases in median ischaemia time while Harefield has had a recent decrease.

Figure 11.10 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2021 to 31 March 2022

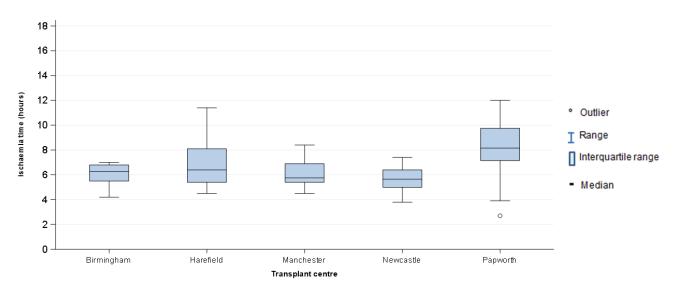
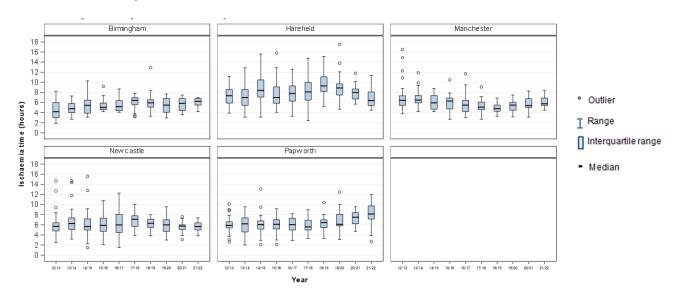


Figure 11.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2012 to 31 March 2022



ADULT LUNG TRANSPLANTATION Post-Transplant Survival

12. Post-Transplant Survival

This section presents survival post adult lung transplantation. Funnel plots are used to compare the <u>risk-adjusted</u> survival rate at each centre with the national rate. The <u>risk-adjusted</u> rates seek to compare centre performance after accounting for differences in <u>case mix</u> across centres. The <u>unadjusted survival rates</u> are also presented in the tables, showing the observed survival experience at that centre. The <u>risk factors</u> used to produce the <u>risk-adjusted survival rates</u> are listed in **Appendix A3.2**.

The survival analyses in **Section 12.1-12.3** include first time lung only transplants. Ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2017 to 31 March 2021 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2013 to 31 March 2017. 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**. Survival following heart-lung transplantation is provided separately in **Section 12.4** and survival outcomes following <u>multi-organ</u> lung transplantation are summarised in **Section 12.5**.

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 rates for each centre and nationally for the 580 first adult lung only transplants in the period 1 April 2017 to 31 March 2021. Manchester's survival rate at 90 days lies above the 95% upper <u>confidence limit</u>, providing some evidence 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 90.3%.

Table 12.1 90 day patient survival rates after first adult lung transplant, by centre, 1 April 2017 to 31 March 2021									
Centre	Number of transplants	,, ,, ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,							
Birmingham Harefield Manchester Newcastle Papworth	56 172 89 120 143	87.5 89.0 95.5 88.3 91.6	(75.6 - 93.8) (83.2 - 92.8) (88.5 - 98.3) (81.1 - 92.9) (85.7 - 95.1)	88.4 88.2 95.6 89.2 91.3	(75.6 - 94.5) (81.5 - 92.5) (88.3 - 98.4) (81.7 - 93.6) (84.8 - 95.1)				
UK	580	90.3	(87.6 - 92.5)						
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit									

Figure 12.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2017 to 31 March 2021

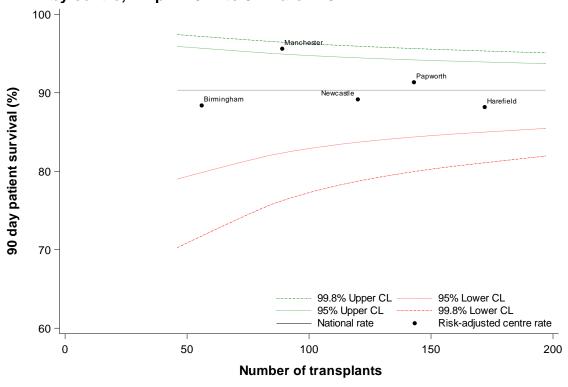


Table 12.2 and **Figure 12.2** show the 1-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 580 first adult lung only transplants in the period 1 April 2017 to 31 March 2021. The national rate of survival was 82.5%. The 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 2017 to 31 March 2021									
Centre	Number of transplants	75 7 9 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3							
Birmingham Harefield Manchester Newcastle Papworth	56 172 89 120 143	78.4 83.7 84.2 79.8 83.8	(61.2 - 87.5) (73.2 - 87.2) (74.3 - 91.0) (72.5 - 87.7) (76.8 - 89.8)						
UK	580	82.5	(79.1 - 85.4)						
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit									

Figure 12.2 Risk-adjusted one-year patient survival rates for adult lung transplants, by centre, 1 April 2017 to 31 March 2021

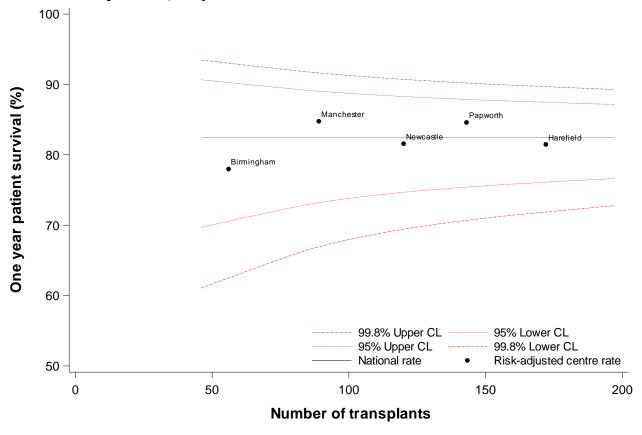


Table 12.3 and **Figure 12.3** show the 5-year post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient <u>survival rates</u> for each centre and nationally for the 706 first adult lung only transplants in the period 1 April 2013 to 31 March 2017. Birmingham's survival rate at 5 years falls below the 99.8% lower <u>confidence limit</u>, indicating lower than average survival at this time point, while Harefield's is above the 95% upper confidence limit, providing some evidence of a higher than average survival at this time point. All other centres were statistically consistent with the national rate of survival of 55.4%.

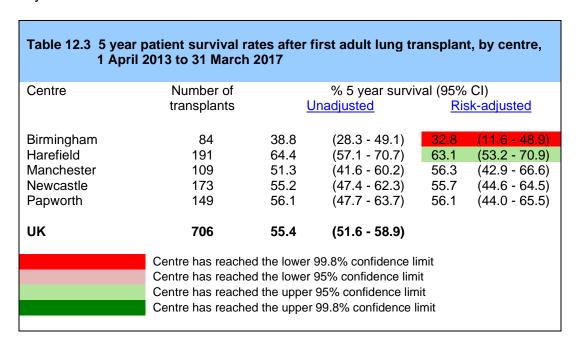
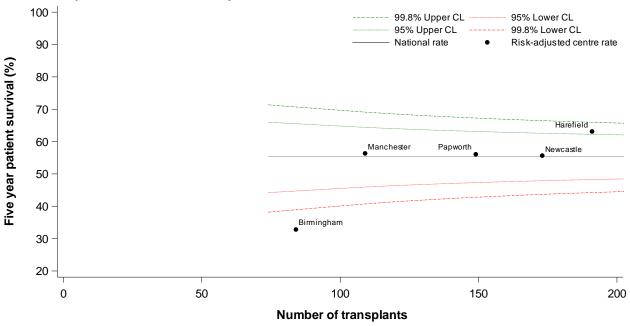


Figure 12.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2013 to 31 March 2017



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 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 2017 to 31 March 2021									
Disease group	Number of % 1 year survival (95% CI)								
	transplants	<u>L</u>	<u>Jnadjusted</u>	Ris	sk-adjusted				
Cystic fibrosis and bronchiectasis	161	86.9	(80.7 - 91.3)	83.6	(74.8 - 89.3)				
COPD and emphysema	192	83.2	(77.1 - 87.8)	83.3	(76.4 - 88.2)				
Fibrosing lung disease	172	78.3	(71.3 - 83.8)	81.7	(74.8 - 86.8)				
Other	55	80.0	(66.8 - 88.4)	80.2	(64.3 - 89.0)				
UK	580	82.5	(79.1 - 85.4)						

Table 12.5 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2013 to 31 March 2017										
Disease group	Number of % 5 year survival (95% CI)									
	transplants	ransplants <u>Unadjusted</u>		Ris	sk-adjusted					
Cystic fibrosis and bronchiectasis	209	59.2	(52.3 - 65.6)	58.6	(48.7 - 66.5)					
COPD and emphysema	235	57.8	(51.2 - 63.8)	53.2	(43.1 - 61.6)					
Fibrosing lung disease	208	49.5	(42.5 - 56.2)	57.5	(48.5 - 64.9)					
Other	54	51.9	(37.9 - 64.1)	37.8	(8.7 - 57.7)					
UK	706	55.4	(51.6 - 58.9)							

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 2017 and 31 March 2021 whereas the 5 year survival rates are for transplants performed between 1 April 2013 and 31 March 2017. 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=0.004).

1 April 2017 to 31 March 2021 (90 day and 1 year) and 1 April 2013 to 31 March 2017 (5 year)									
Transplant type	N*		day rival (95% CI) nadjusted	N*		ar vival (95% CI) <u>nadjusted</u>	N*		ear vival (95% CI) nadjusted
Single lung Bilateral lung	58 522	93.1 90.0	(82.7 - 97.4) (87.1 - 92.3)	58 522	79.2 82.9	(66.3 - 87.6) (79.3 - 85.8)	92 614	39.0 57.8	(29.0 - 48.8) (53.8 - 61.6)
UK	580	90.3	(87.6 - 92.5)	580	82.5	(79.1 - 85.4)	706	55.4	(51.6 - 58.9)

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 2013 to 31 March 2021, 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.

	tient survival after firs 13 and 31 March 2021	r addit ficare		mit, by contro,		
Centre	Number of transplants	Number of deaths	% 90 day survival (95% CI) (<u>unadjusted</u>)			
Birmingham ¹	7	1	-	-		
Harefield ¹	6	3	-	-		
Manchester ¹	7	0	-	-		
Newcastle ¹	5	1	-	-		
Papworth	12	2	83.3	(48.2 - 95.6)		
UK	37	7	81.1	(64.4 - 90.5)		

	ient survival after first 13 and 31 March 2021	addit neart-i	ung transpia	in, by centre,	
Centre	Number of transplants	Number of deaths	% 1 year survival (95% (unadjusted)		
Birmingham ¹	7	1	-	-	
Harefield ¹	6	5	-	-	
Manchester ¹	7	1	-	-	
Newcastle ¹	5	2	-	-	
Papworth	12	2	83.3	(48.2 - 95.6)	
UK	37	11	69.9	(52.2 - 82.1)	

12.5 Survival post multi-organ lung transplant

The survival outcomes of the small number of recipients of multi-organ lung transplants are reported in **Table 12.9**, at 90 days and 1 year post-transplant. This includes all first-time multi-organ transplants involving the lung, from DBD or DCD donors, between 1 April 2013 and 31 March 2021. It does not include heart-lung transplants which are shown in the previous section.

Table 12.9 Survival outcomes following multi-organ lung transplants performed between 1 April 2013 and 31 March 2021								
Transplant type	Number of transplants	Number of patients alive at 90 days post- transplant N	Number of patients alive at 1 year post- transplant N					
Lung & kidney	1	0	0					
Lung & liver	3 ¹	1	0					
¹ 1 transplant had missing survival data								

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 2010 and 31 December 2021. 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</u> <u>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 lung transplant listing are shown as <u>funnel plots</u> in **Figures 13.1** and **13.2** respectively. These rates are also shown in **Table 13.1**. Note that all rates 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 and five year rates for Birmingham fell outside the lower 99.8% confidence interval, indicating a significantly lower than average survival rates. The one year survival rate for Newcastle fell outside the lower 95% confidence limit, but within the 99.8% confidence limit, providing some evidence of a lower than average survival rate. The one year survival rate from listing for Harefield is above the 95% confidence limits, while the five year survival rate is above the 99.8% confidence interval, indicating a significantly higher than average survival at this centre. There was also evidence of significantly higher survival from listing at one year for Manchester but not five year.

Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor **Table 13.1** lung only transplant in patients registered between 1 January 2010 to 31 December 2021 One year Five year Number at risk Survival Number Survival Number Centre 1 at day 0 rate % (95% CI) at risk1 rate % (95% CI) at risk1 Birmingham 233 30.5 (20.0 - 39.6)59 359 (63.4 - 75.2)(78.7 - 85.0)Harefield 789 82.1 619 258 Manchester 416 311 52.7 (45.1 - 59.2)94 Newcastle 684 74.2 474 (40.3 - 52.1)178 (70.1 - 77.7)46.5 (74.9 - 82.4)Papworth 79.0 391 49.5 (42.7 - 55.5)139 569 UK 2817 78.4 (76.8 - 79.9)2028 49.3 (47.2 - 51.4)728 Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit ¹ Number of patients with reported follow-up beyond this time point

Figure 13.1 Risk-adjusted one year patient survival rates from listing by centre, 1 January 2010 – 31 December 2021

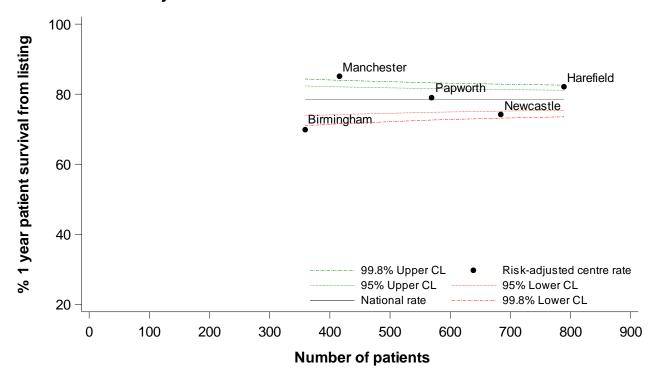
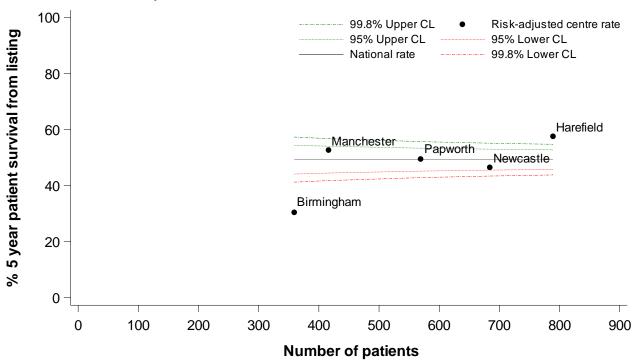


Figure 13.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2010 – 31 December 2021



ADULT LUNG TRANSPLANTATION Form Return Rates

14. Adult lung form return rates, 1 January – 31 December 2021

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 2021 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 97% 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 2021 to 31 December 2021										
Centre	Transpla No. required	nt record % returned	3 month No. required	follow-up % returned	1 year for No. required	ollow-up % returned	Lifetime No. required	follow-up % returned		
Birmingham Queen Elizabeth Hospital Harefield Hospital Manchester Wythenshawe Hospital Newcastle Freeman Hospital Royal Papworth Hospital Sheffield Northern General Hospital	10 22 16 17 36	100 100 100 100 100	9 21 15 24 32	100 100 100 100 100	8 27 12 21 20	100 100 100 100 100	99 455 183 325 331 3	100 98 100 100 97 100		
Overall	101	100	101	100	88	100	1396	99		

PAEDIATRIC HEART TRANSPLANTATION Transplant List

15.1 Paediatric heart only transplant list on 31 March, 2013 – 2022

Figure 15.1 shows the number of paediatric patients on the heart transplant list on 31 March each year between 2013 and 2022 split by urgency status. The number on the active non-urgent heart transplant list has generally increased over the decade, reaching 31 on 31 March 2022. There has also been an upward trend in the number on the urgent transplant list, with 13 urgent paediatric patients waiting on 31 March 2022. The paediatric super-urgent list was introduced in October 2020 and there was 1 paediatric patient waiting on this list on 31 March 2022.

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

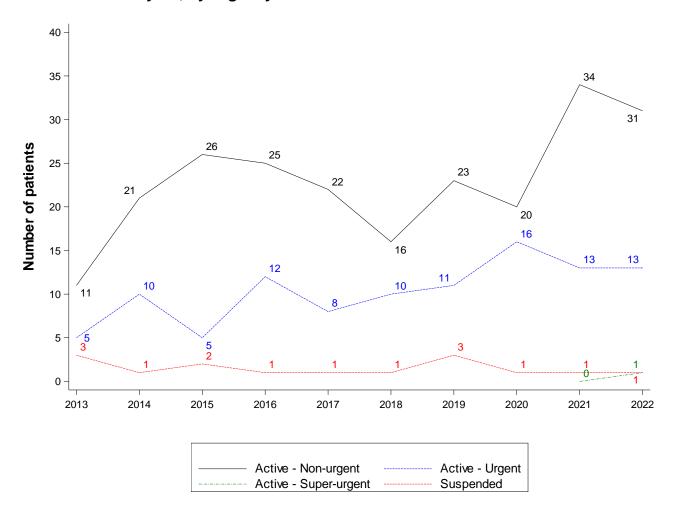


Figure 15.2 shows the number of paediatric patients on the <u>active heart transplant list</u> at 31 March 2022 by centre and urgency. In total, there were 45 paediatric patients waiting. Newcastle had the largest overall number of paediatric patients on the transplant list. **Figure 15.3** shows the number split by centre and mechanical circulatory support (MCS) status where MCS includes ventricular assist devices and extracorporeal membrane oxygenation. A total of 9 (20%) of the paediatric heart list were on MCS on 31 March 2022.

Figure 15.2 Number of paediatric patients on the active heart transplant list at 31 March 2022, by centre and urgency

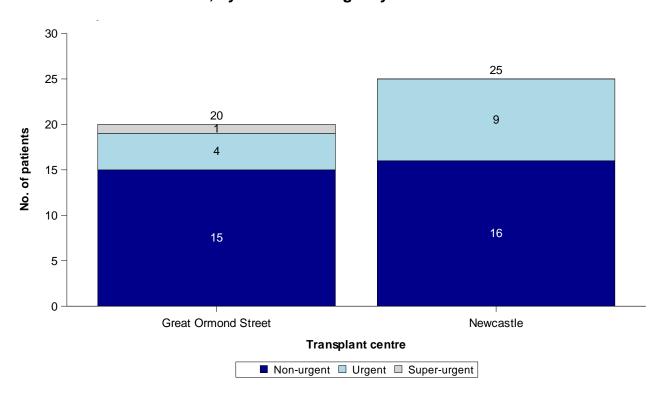


Figure 15.3 Number of paediatric patients on the active heart transplant list at 31 March 2022, by centre and mechanical circulatory support status

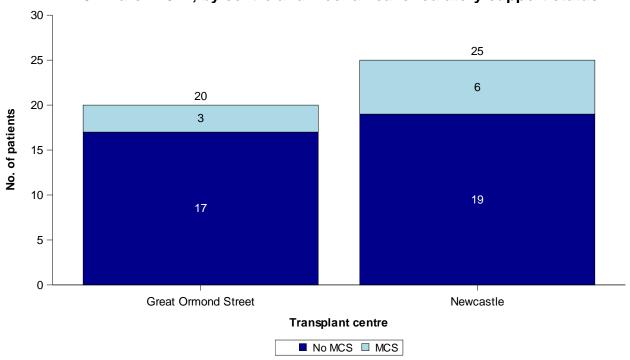
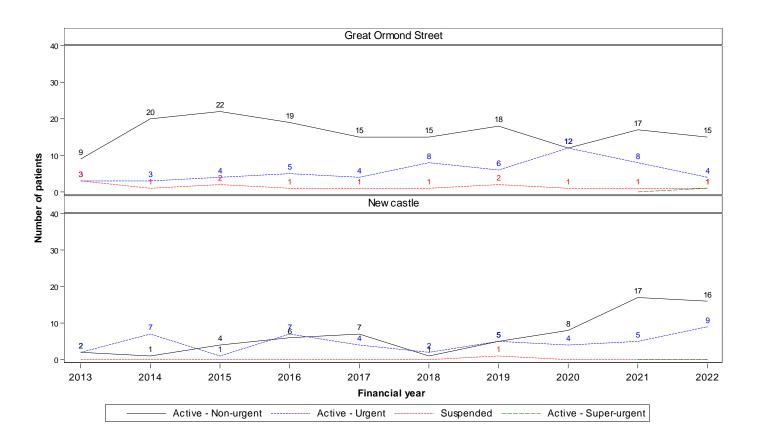


Figure 15.4 shows the trend over time in the number of paediatric patients on the heart transplant list on 31 March each year across each centre. Great Ormond Street Hospital's non-urgent list has decreased slightly over most of the decade and their urgent list has declined in the last two years from a peak of 12 in 2020, while Newcastle's non-urgent and urgent lists have both increased recently.

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



15.2 Demographic characteristics, 1 April 2021 – 31 March 2022

There were 50 paediatric registrations onto the heart transplant list between 1 April 2021 and 31 March 2022. Demographic characteristics of these individuals are shown by centre and overall, in **Table 15.1**. Nationally, 54% were male and the <u>median</u> age was 6 years. The most common primary disease group was cardiomyopathy. For some characteristics, due to rounding, percentages may not add up to 100.

	characteristics of paediatric il 2021 and 31 March 2022, b		s onto the heart	transplant list
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of registrations		23 (100)	27 (100)	50 (100)
Highest urgency during registration	Non-urgent	7 (30)	8 (30)	15 (30)
	Urgent	13 (57)	14 (52)	27 (54)
	Super-urgent	3 (13)	5 (19)	8 (16)
Recipient sex	Male	15 (65)	12 (44)	27 (54)
	Female	8 (35)	15 (56)	23 (46)
Recipient ethnicity	White	14 (61) 16 (59)		30 (60)
	Asian	6 (26) 8 (30)		14 (28)
	Black	2 (9) 1 (4)		3 (6)
	Other	1 (4) 1 (4)		2 (4)
	Missing	0 (0) 1 (4)		1 (2)
Recipient age (years)	Median (IQR)	7 (3, 9)	6 (1, 9)	6 (2, 9)
	Missing	0	0	0
Height (cm)	Median (IQR)	115 (92, 129)	110 (78, 137)	111 (90, 135)
	Missing	1	0	1
Weight (kg)	Median (IQR)	18 (13, 25)	20 (10, 27)	19 (11, 26)
	Missing	1	0	1
Primary disease	Coronary heart disease	3 (13)	0 (0)	3 (6)
	Cardiomyopathy	17 (74)	16 (59)	33 (66)
	Congenital heart disease	1 (4)	11 (41)	12 (24)
	Other/Not reported	2 (9)	0 (0)	2 (4)
Previous open-heart surgery	None	15 (65)	9 (33)	24 (48)
	One	4 (17)	6 (22)	10 (20)
	More than one	2 (9)	10 (37)	12 (24)
	Missing	2 (9)	2 (7)	4 (8)
Serum Bilirubin (umol/l)	Median (IQR)	15 (8, 26)	10 (6, 16)	12 (7, 26)
	Missing	1	3	4
Serum Creatinine (umol/l)	Median (IQR)	42 (28, 59)	32 (26, 44)	37 (27, 53)
	Missing	1	3	4

15.3 Post-registration outcomes, 1 April 2017 – 31 March 2019

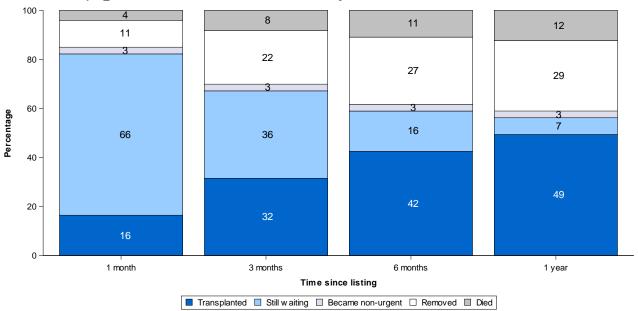
The registration outcomes of paediatric patients listed for a heart transplant between 1 April 2017 and 31 March 2019 are summarised in **Figure 15.5** and **Figure 15.6**, for non-urgent and urgent registrations, respectively (super-urgent registration outcomes are not presented due to small numbers). The possible outcomes on the non-urgent or urgent list include receiving a transplant, removal from the list, moving lists, dying on the list, or remaining on the list at a given time point post-registration. In these figures, the *first* outcome is used, so if an individual was transplanted then died their registration outcome would be "transplanted". If they 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 20% had received a transplant, 2% had died and 25% had been moved to the urgent list. At 3 years, 34% had been transplanted, however, now 43% of non-urgent recipients have been added to the urgent list. As can be seen in **Figure 15.6**, paediatric patients have a greater chance of transplant on the urgent heart list compared to the non-urgent list, with 42% receiving a transplant by 6 months. Removals from the urgent list were for a mixture of improved and deteriorating condition.

Percentage 6 months 1 vear 2 vears 3 years Time since listing ■ Transplanted ■ Still w aiting ■ Became urgent □ Removed ■ Died

Figure 15.5 Post-registration outcome for 44 new non-urgent heart only registrations made in the UK, 1 April 2017 to 31 March 2019

Figure 15.6 Post-registration outcome for 73 new urgent heart only registrations made in the UK, 1 April 2017 to 31 March 2019



15.4 Median waiting time to transplant, 1 April 2018 - 31 March 2021

Table 15.2 shows the <u>median</u> waiting time to heart transplant from listing for paediatric patients registered between 1 April 2018 and 31 March 2021. This is estimated using the <u>Kaplan Meier</u> method and is split by urgency at initial registration; non-urgent or urgent. All waiting time from initial registration is considered, regardless of any change in urgency. Any suspended time is discounted.

The national <u>median</u> waiting time to paediatric heart transplant was 762 days from non-urgent registration and 193 days from urgent registration. The median waiting time for non-urgent registrations could not be calculated for Newcastle due to low transplant rate. The <u>median</u> waiting time to heart transplant for paediatric patients is also considered by blood group in **Table 15.3**. Median waiting time to super-urgent transplant is not presented due to small numbers.

				atients registered on ril 2018 to 31 March 2021
Transplant centre	Number registered	Number transplanted	Wa Median	aiting time (days) 95% Confidence interval
Non-urgent at initial regis	stration			
Great Ormond Street Newcastle ¹	37 25	17 9	762 -	404 - 1120 -
UK	62	26	762	364 - 1160
Urgent at initial registrati	on			
Great Ormond Street Newcastle	27 47	18 24	276 191	42 - 510 84 - 298
UK	74	42	193	53 - 333
¹ Median and 95% confidence	intervals could not b	e calculated due to low	transplant rate	

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 2018 to 31 March 2021

Blood Group	Number	Number	ber Waiting time (days)				
	registered	transplanted	Median	95% Confidence interval			
Non-urgent at initial registe	ration						
0	34	13	975	632 - 1318			
A	21	10	510	148 - 872			
B ¹	6	3	-	-			
AB ¹	1	0	-	-			
UK	62	26	762	364 - 1160			
Urgent at initial registration	n						
0	26	12	406	242 - 570			
A	35	22	101	0 - 217			
B ¹	8 5	5	-	-			
AB ¹	5	3	-	-			
uĸ	74	42	193	53 - 333			

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

PAEDIATRIC HEART TRANSPLANTATION Response to Offers

16. Response to Offers

Table 16.1 compares individual centre paediatric heart offer decline rates over the three years between 1 April 2019 and 31 March 2022. This only considers offers of hearts from UK DBDs aged less than 16 that were eventually transplanted and excludes fast track offers. Hearts offered as part of a heart-lung block are included, which may be cases where just the heart is declined or where both the heart and lungs are declined. Non-urgent, urgent and super-urgent offers are all considered. Offers to adults at Newcastle are excluded.

In 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 2021/2022, there was an overall decline rate for paediatric offers of 69.0%.

Table 16.1 UK paediatric DBD donor heart offer decline rates by transplant centre and year, 1 April 2019 to 31 March 2022									
Centre	20	2019/20		20/21	202	21/22	Overall		
	No. offers	Decline rate (%)							
GOSH	14	(78.6)	15	(53.5)	15	(60.0)	44	(63.6)	
Newcastle	15	(46.7)	7	(85.7)	14	(78.6)	36	(66.7)	
UK	29	(62.1)	22	(63.6)	29	(69.0)	80	(65.0)	

PAEDIATRIC HEART TRANSPLANTATION Transplants

17.1 Paediatric heart transplants, 1 April 2012 – 31 March 2022

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 2019/2020. Last year's activity is shown by centre in **Figure 17.3**. The 30 transplants carried out in 2021/2022 comprised 19 at Great Ormond Street Hospital and 11 at Newcastle, and there was a total of 6 DCD transplants.

Figure 17.1 Number of paediatric heart transplants in the UK, by financial year and donor type, 1 April 2012 to 31 March 2022

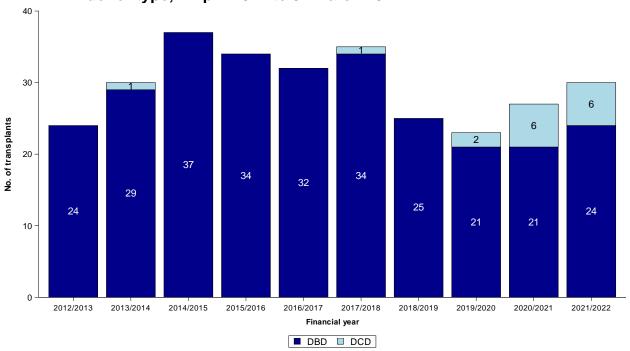


Figure 17.2 Number of paediatric heart transplants in the UK, by financial year, centre and donor type, 1 April 2012 to 31 March 2022

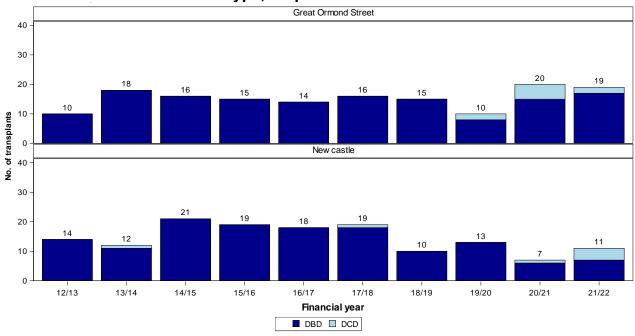


Figure 17.3 Number of paediatric heart transplants in the UK, by centre and donor type, 1 April 2021 to 31 March 2022

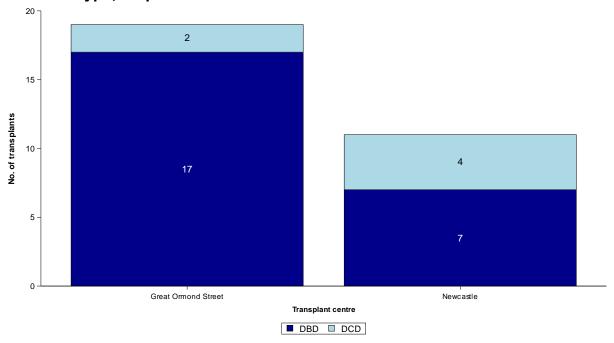


Figure 17.4 and **17.5** show the number of paediatric heart transplants performed in the last ten years, by urgency status of recipient, nationally and by centre, respectively. The majority of transplants were urgent, but in the last year, there were three super-urgent transplants. Last year's activity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

Figure 17.4 Number of paediatric heart transplants in the UK, by financial year and urgency status, 1 April 2012 to 31 March 2022

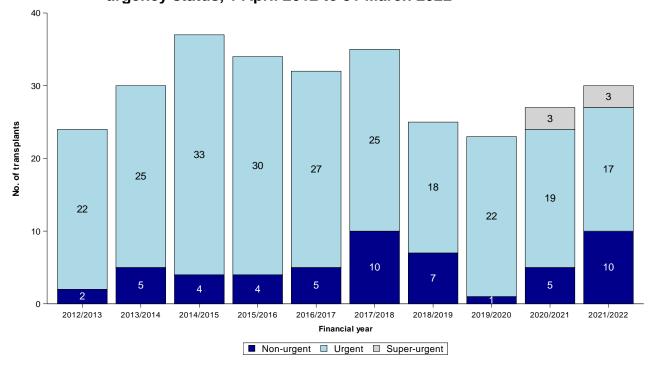


Figure 17.5 Number of paediatric heart transplants in the UK, by financial year, centre and urgency status, 1 April 2012 to 31 March 2022

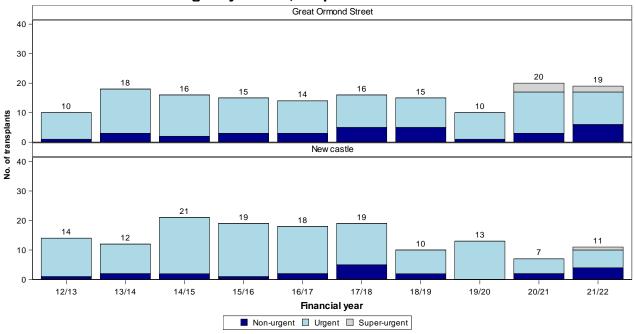
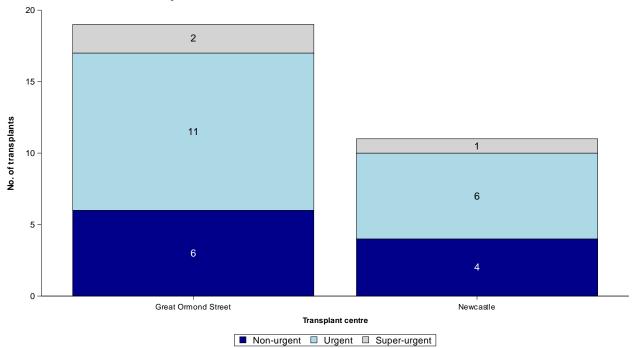


Figure 17.6 Number of paediatric heart transplants in the UK, by centre and urgency status, 1 April 2021 to 31 March 2022



17.2 Demographic characteristics of transplants, 1 April 2021 – 31 March 2022

The demographic characteristics of the 30 paediatric heart transplant recipients and donors in the latest year are shown by centre and overall in **Table 17.1**. Nationally, 57% of heart recipients were male and the <u>median</u> age was 11 years, while the median age of donors was 15 years. For some characteristics, due to rounding, percentages may not add up to 100.

		Great Ormond	Newcastle	TOTAL
		Street N (%)	N (%)	N (%)
Number of transplants		19 (100)	11 (100)	30 (100)
Urgency status at transplant	Non-urgent	6 (32)	4 (36)	10 (33)
	Urgent	11 (58)	6 (55)	17 (57)
	Super-urgent	2 (11)	1 (9)	3 (10)
Recipient sex	Male	9 (47)	8 (73)	17 (57)
	Female	10 (53)	3 (27)	13 (43)
Recipient ethnicity	White	15 (79)	7 (64)	22 (73)
	Asian	3 (16)	2 (18)	5 (17)
	Black	1 (5)	0 (0)	1 (3)
	Other	0 (0)	1 (9)	1 (3)
	Missing	0 (0)	1 (9)	1 (3)
Recipient age (years)	Median (IQR)	9 (4, 12)	11 (4, 13)	11 (4, 13)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	23 (17, 37)	26 (17, 41)	25 (17, 37)
	Missing	0	0	0
Recipient primary disease	Coronary heart disease	1 (5)	0 (0)	1 (3)
	Cardiomyopathy	14 (74)	7 (64)	21 (70)
	Congenital heart disease	2 (11)	4 (36)	6 (20)
	Other	2 (11)	0 (0)	2 (7)
NYHA class	III	6 (32)	4 (36)	10 (33)
	IV	11 (58)	7 (64)	18 (60)
	Missing	2 (11)	0 (0)	2 (7)
Recipient in hospital	No	10 (53)	4 (36)	14 (47)
	Yes	9 (47)	7 (64)	16 (53)
In hospital, recipient on ventilator	No	5 (56)	6 (86)	11 (69)
	Yes	4 (44)	1 (14)	5 (31)
In hospital, recipient VAD	None	4 (44)	6 (86)	10 (63)
	Left	4 (44)	1 (14)	5 (31)
	Both	1 (11)	0 (0)	1 (6)
In hospital, recipient TAH	No	9 (100)	7 (100)	16 (100)
In hospital, recipient ECMO	No	7 (78)	6 (86)	13 (81)
	Yes	2 (22)	1 (14)	3 (19)

Table 17.1 Demographic characteristics of UK paediatric heart transplants performed between 1 April 2021 and 31 March 2022, by centre **Great Ormond** Newcastle TOTAL Street N (%) N (%) N (%) In hospital, recipient on No 7 (44) 6 (67) 1 (14) Yes inotropes 3 (33) 6(86)9 (56) In hospital, recipient IABP No 9 (100) 6 (86) 15 (94) 1 (6) Yes 0(0)1 (14) Recipient CMV status Negative 16 (84) 8 (73) 24 (80) Positive 3 (16) 3 (27) 6 (20) Recipient HCV status Negative 19 (100) 11 (100) 30 (100) Recipient HBV status Negative 19 (100) 11 (100) 30 (100) Recipient HIV status Negative 19 (100) 11 (100) 30 (100) Recipient Serum Creatinine Median (IQR) 36 (29, 47) 51 (40, 67) 40 (32, 51) (umol/l) Missing 0 Donor sex Male 5 (26) 6 (55) 11 (37) Female 14 (74) 5 (45) 19 (63) Donor ethnicity White 16 (84) 6 (55) 22 (73) Asian 1 (5) 0(0)1 (3) Other 0(0)3(27)3 (10) 4 (13) Missing 2 (11) 2 (18) Donor age (years) Median (IQR) 19 (12, 39) 13 (10, 18) 15 (11, 33) Missing 0 0 0 Median (IQR) 19 (18, 22) Donor BMI 20 (16, 24) 20 (17, 24) Missing 0 Donor cause of death **CVA** 15 (79) 7 (64) 22 (73) Trauma 1 (5) 2 (18) 3 (10) Others 3 (16) 2 (18) 5 (17) Donor hypotension No 17 (89) 5 (45) 22 (73) Yes 2 (11) 0 (0) 2 (7) Missing 0 (0) 6 (55) 6 (20) Donor past diabetes No 19 (100) 11 (100) 30 (100) 27 (90) Donor past cardio disease No 17 (89) 10 (91) Missing 2 (11) 1 (9) 3 (10) No 30 (100) Donor past hypertension 19 (100) 11 (100) Donor past tumour Nο 18 (95) 11 (100) 29 (97) Yes 1 (5) 0 (0) 1 (3) Donor past smoker No 13 (68) 8 (73) 21 (70) Yes 6(32)3(27)9 (30)

Table 17.1 Demographic characteristics of UK paediatric heart transplants performed between 1 April 2021 and 31 March 2022, by centre								
		Great Ormond Street	Newcastle	TOTAL				
		N (%)	N (%)	N (%)				
Total ischaemia time (hours)	Median (IQR) Missing	3.8 (3.2, 4.6) 0	3.9 (3.4, 5.5) 0	3.9 (3.4, 4.9) 0				

17.3 Total ischaemia time, 1 April 2012 – 31 March 2022

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 17.7 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by financial year, 1 April 2012 to 31 March 2022

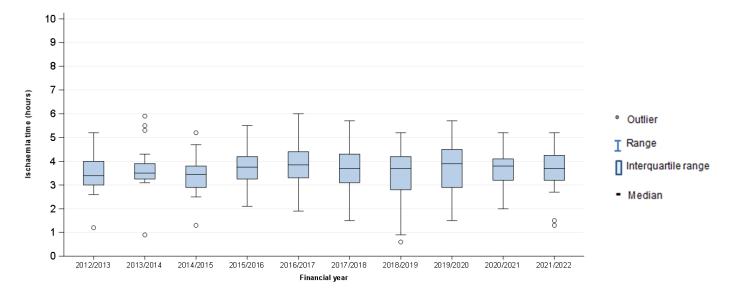
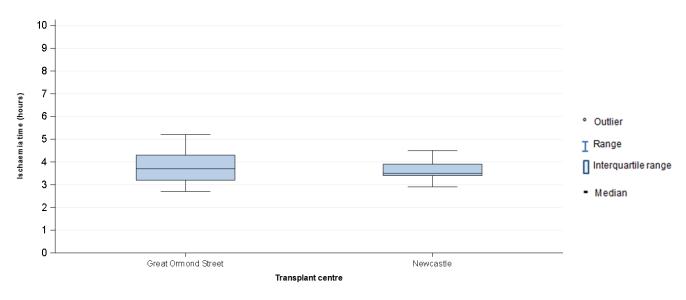


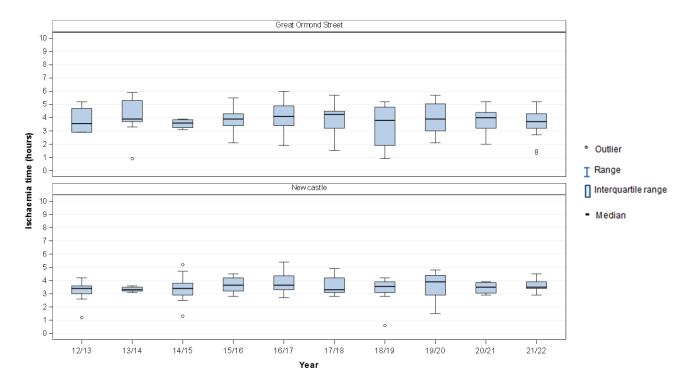
Figure 17.8 and **Figure 17.9** show <u>boxplots</u> of total ischaemia time by centre in the latest financial year (2020/2021) and over the last 10 years, respectively.

Figure 17.8 Boxplots of total ischaemia time for DBD donor hearts transplanted into paediatric recipients, by transplant centre, 1 April 2021 to 31 March 2022



The Organ Care System (OCS) was not used in any paediatric DBD heart transplants in 2021/2022

Figure 17.9 Boxplots of total ischaemia time in DBD donor hearts transplanted into paediatric recipients, by transplant centre and financial year, 1 April 2012 to 31 March 2022



Includes time on the Organ Care System (OCS) for one transplant performed at Newcastle in 2017/2018

PAEDIATRIC HEART TRANSPLANTATION Post-Transplant Survival

18. Post-Transplant Survival

The survival analyses presented in this section exclude <u>multi-organ transplants</u> and include first time transplants only. **Section 18.1** includes <u>DBD</u> heart transplants only where thirty-day, ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2017 to 31 March 2021 and 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2013 to 31 March 2017. **Section 18.2** summarises survival following <u>DCD</u> heart transplant for the small number of paediatric recipients of DCD hearts.

18.1 Survival post DBD heart transplant

The 30-day post-transplant <u>unadjusted</u> patient survival rates for each centre and nationally are shown in **Table 18.1** for the 97 first DBD paediatric heart only transplants in the period 1 April 2017 to 31 March 2021 (note that 1 transplant was excluded from this analysis due to missing survival information). There were no deaths within 30 days at Great Ormond Street Hospital. The 90 day <u>survival rates</u> are shown in **Table 18.2**.

Table 18.1 30 day patient survival rates after first DBD paediatric heart only transplant, by centre, 1 April 2017 to 31 March 2021								
Centre	Number of patients	Number of deaths	% 30 day survival (95% CI) (unadjusted)					
Great Ormond Street Hospital Newcastle	53 44	0 2	100.0 95.5	(-) (83.0 - 98.8)				
UK	97 ¹	2	97.9	(92.0 - 99.5)				
¹ 1 transplant was excluded due to missing survival data (at Newcastle)								

Table 18.2 90 day patient survival rates after first DBD paediatric heart only transplant, by centre, 1 April 2017 to 31 March 2021								
Centre	Number of patients	Number of deaths	% 90 day survival (95% CI) (unadjusted)					
Great Ormond Street Hospital Newcastle	53 44	1 3	98.1 93.2	(87.4 - 99.7) (80.3 - 97.7)				
UK	97 ¹	4	95.9	(89.4 - 98.4)				
¹ 1 transplant was excluded due to missing survival data (at Newcastle)								

The one year post-transplant <u>unadjusted</u> <u>survival rates</u> are shown in **Table 18.3**. There is evidence that Great Ormond Street Hospital's unadjusted survival rate is higher than Newcastle's (log-rank p=0.006).

Table 18.3 1 year patient survival after first DBD paediatric heart only transplant, by centre, 1 April 2017 to 31 March 2021								
Centre	Number of patients	Number of deaths	% 1 year survival (95% CI) (unadjusted)					
Great Ormond Street Hospital Newcastle	53 44	1 8	98.1 81.6	(87.4 - 99.7) (66.5 - 90.3)				
UK	97¹	9	90.7	(82.8 - 95.0)				
¹ 1 transplant was excluded due to missing	survival data (at Newo	astle)						

Five year <u>survival rates</u> were estimated from the 129 first DBD paediatric heart only transplants performed in the period 1 April 2013 to 31 March 2017. The <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 18.4**.

Table 18.4 5 year patient survival after first DBD paediatric heart only transplant, by centre, 1 April 2013 to 31 March 2017								
Centre	Number of patients	Number of deaths	% 5 year survival (95% CI) (unadjusted)					
Great Ormond Street Hospital Newcastle	63 66	8 15	87.1 76.8	(75.8 - 93.3) (64.5 - 85.4)				
UK	129	23	81.8	(73.8 - 87.5)				

18.2 Survival post DCD heart transplant

The survival outcomes of paediatric recipients of DCD heart only transplants in the period 1 April 2017 to 31 March 2021 are summarised in **Table 18.5**, at 30 days, 90 days and 1 year post-transplant.

Table 18.5 Survival outcomes after first DCD paediatric heart only transplant, by centre, 1 April 2017 to 31 March 2021								
Centre	Number of patients	Number of patients alive at 30 days post- transplant	Number of patients alive at 90 days post- transplant	Number of patients alive at 1 year post-transplant				
Great Ormond Street Hospital Newcastle	6 1	6 1	6 1	6 1				
UK	7	7	7	7				

PAEDIATRIC HEART TRANSPLANTATION Form Return Rates

19. Paediatric heart form return rates, 1 January – 31 December 2021

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 2021 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 rates for paediatric heart transplants, 1 January 2021 to 31 December 2021								
Centre	Transplar No. requested	nt record % returned	3 month to No. requested	follow-up % returned	1 year fo No. requested	ollow-up % returned	Lifetime to No. requested	follow-up % returned
Great Ormond Street Hospital Newcastle, Freeman Hospital Overall	20 10 30	100 100 100	13 8 21	100 100 100	24 4 28	100 100 100	106 205 311	100 97 98

PAEDIATRIC LUNG TRANSPLANTATION Transplant List

20.1 Paediatric lung and heart/lung transplant list on 31 March, 2013 – 2022

Figure 20.1 shows the number of paediatric patients on the lung transplant list on 31 March each year between 2013 and 2022 split by urgency status. The number 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 in 2020 (2 non-urgent, 1 urgent) and has risen to 11 (9 non-urgent, 1 heart-lung and 1 urgent) on 31 March 2022.

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

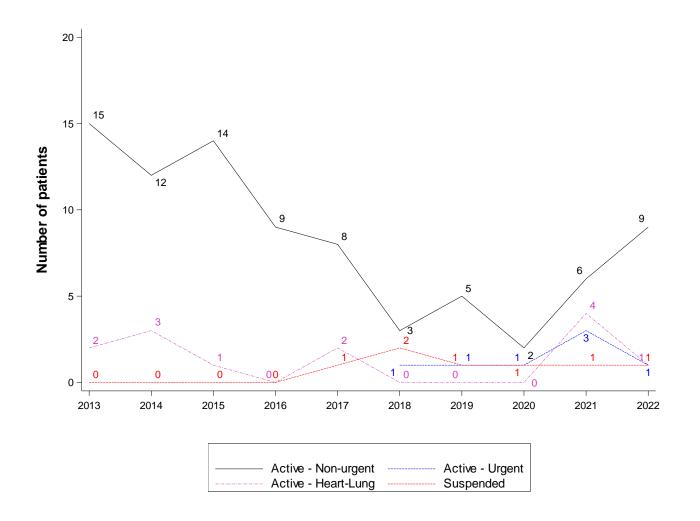


Figure 20.2 shows the number of paediatric patients on the <u>active lung transplant list</u> at 31 March 2022 by centre. In total, there were 11 paediatric patients waiting; 10 at Great Ormond Street Hospital and 1 at Newcastle. One patient at Great Ormond Street Hospital was on the urgent list, and no patients were on the super-urgent list (note that one of the non-urgent registrations at Great Ormond Street Hospital was an urgent heart-lung registration).

Figure 20.2 Number of paediatric patients on the active lung transplant list at 31 March 2022, by centre and urgency

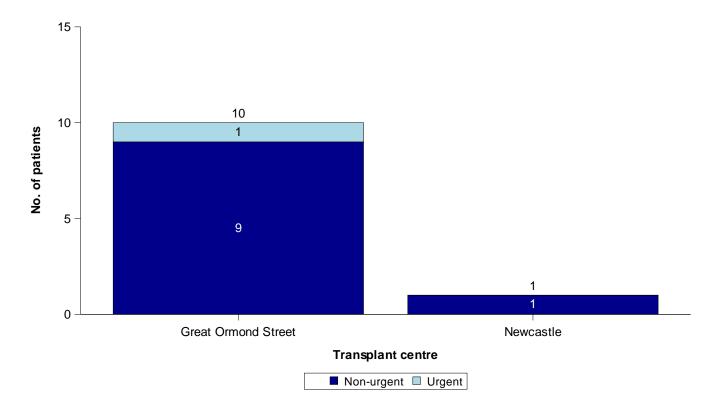
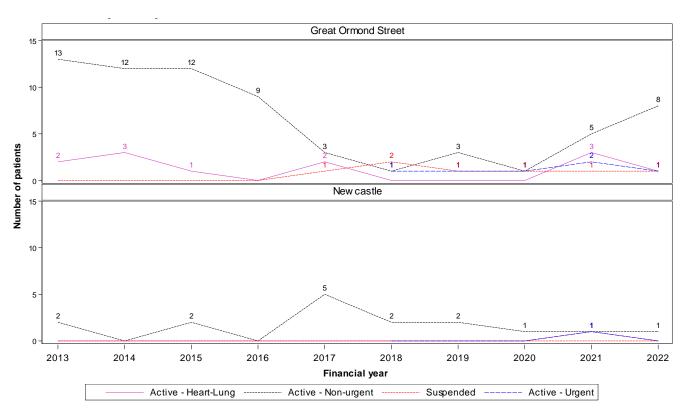


Figure 20.3 shows the trend over time in the number of paediatric patients on the lung transplant list at each centre on 31 March each year between 2013 and 2022. Great Ormond Street Hospital experienced a decrease in their list between 2015 and 2018 but after remaining low for several years it has now increased slightly to 10 active patients (8 non-urgent, 1 urgent, 1 heart-lung) on 31 March 2022. Newcastle had a peak of 5 on their list in 2017, but this has now decreased to 1 non-urgent listing.

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



20.2 Demographic characteristics, 1 April 2020 – 31 March 2022

There were 19 paediatric registrations onto the lung transplant list between 1 April 2020 and 31 March 2020 (two years analysed due to small numbers). Demographic characteristics are shown by centre and overall in **Table 20.1**. Nationally, 68% of the patients were female and the <u>median</u> age was 8 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 20.1 Demographic characteristics of paediatric registrations onto the lung transplant list between 1 April 2020 and 31 March 2022, by centre							
		Great Ormond	Newcastle	TOTAL			
		Street N (%)	N (%)	N (%)			
Number of registrations		15 (100)	4 (100)	19 (100)			
Year of registration	2020/2021	12 (80)	3 (75)	15 (79)			
	2021/2022	3 (20)	1 (25)	4 (21)			
Highest urgency during registration	Non-urgent	11 (73)	3 (75)	14 (74)			
	Urgent	4 (27)	1 (25)	5 (26)			
Recipient sex	Male	4 (27)	2 (50)	6 (32)			
	Female	11 (73)	2 (50)	13 (68)			
Recipient ethnicity	White	13 (87)	4 (100)	17 (90)			
	Asian	1 (7)	0 (0)	1 (5)			
	Other	1 (7)	0 (0)	1 (5)			
Recipient age (years)	Median (IQR) ¹	7 (3, 13)	-	8 (3, 14)			
	Missing	0	0	0			
Height (cm)	Median (IQR) ¹	117 (83, 166)	-	119 (88, 166)			
	Missing	0	0	0			
Weight (kg)	Median (IQR) ¹	19 (12, 54)	-	19 (13, 54)			
	Missing	0	0	0			
Primary Disease	Fibrosing lung disease	0 (0)	2 (50)	2 (11)			
	Primary pulmonary hypertension	10 (67)	1 (25)	11 (58)			
	Other heart/lung disease	5 (33)	1 (25)	6 (32)			
¹ Medians for groups with le	ss than 5 registrations are not presented	due to small numbers	S				

20.3 Post-registration outcomes, 1 April 2017 – 31 March 2019

The registration outcomes of paediatric patients listed for a non-urgent lung transplant between 1 April 2017 and 31 March 2019 are summarised in **Figure 20.4**. The possible outcomes on the list include receiving a transplant, removal from the list, dying on the list, or remaining on the list at a given time point post-registration. In these figures, the *first* outcome is used, so if an individual was transplanted then died their registration outcome would be "transplanted".

Within six months of listing, 40% were transplanted, 10% had died, 20% had been moved to the urgent list and the remaining 30% were still waiting. After three years, the transplant rate had increased to 60% and the percentage moved to the urgent list had increased slightly to 30%. Due to small numbers, outcomes on the urgent or super-urgent lists are not presented.

Percentage 6 months 1 year 2 years 3 years Time since listing ■ Transplanted ■ Still w aiting ■ Became urgent □ Removed ■ Died

Figure 20.4 Post-registration outcome for 10 non-urgent paediatric lung only registrations made in the UK, 1 April 2017 to 31 March 2019

20.4 Median waiting time to transplant, 1 April 2018 - 31 March 2021

The median waiting time to lung transplant from non-urgent registration for paediatric patients registered between 1 April 2018 and 31 March 2021 is shown in Table 20.2. This is estimated using the Kaplan Meier method. Any suspended time is discounted, but any time on the urgent list, which was introduced in May 2017, is included. The national median waiting time to paediatric lung transplant was 225 days.

Table 20.2 Median active waiting time to lung transplant for paediatric patients registered on the transplant list, by centre, 1 April 2018 to 31 March 2021							
Transplant centre	Number registered	Number transplanted	Waiting time (days) Median 95% Confidence interval				
Non-urgent at initial registration							
Great Ormond Stree Newcastle ¹	t 16 4	9 -	225 -	0 - 702 -			
UK	20	12	225	0 - 619			
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 2019 and 31 March 2022. This only considers offers of lungs from UK <u>DBDs</u> aged less than 16 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 heart-lung block are considered, this includes cases where just the lungs are declined as well as cases where both the heart and lungs are declined. Urgent and non-urgent offers are all considered. Offers to adults at Newcastle are excluded.

In 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 83.3% and was the same at both centres.

Table 21.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2019 to 31 March 2022					
Centre	Number of offers	Decline rate (%)			
Great Ormond Street Hospital Newcastle	6 6	(83.3) (83.3)			
UK	12	(83.3)			

PAEDIATRIC LUNG TRANSPLANTATION Transplants

22.1 Paediatric lung and heart-lung transplants, 1 April 2012 – 31 March 2022

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 2012/2013 and 2016/2017 but has since decreased to just two in 2021/2022. The majority of paediatric lung transplants over the decade were performed by Great Ormond Street Hospital. Newcastle have not performed any paediatric lung transplants since 2019/2020. The number of transplants in the latest financial year (2021/2022) is shown by donor type in **Figure 22.3**.

Figure 22.1 Number of paediatric lung transplants in the UK, by financial year and donor type, 1 April 2012 to 31 March 2022

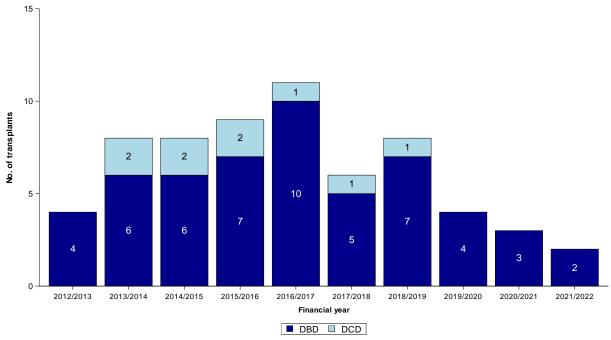


Figure 22.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2012 to 31 March 2022

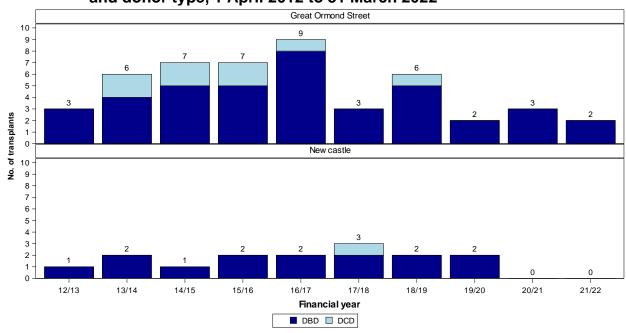


Figure 22.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2021 to 31 March 2022

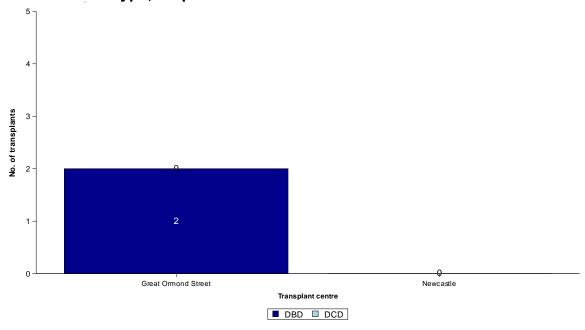


Figure 22.4 and **22.5** show the number of paediatric lung transplants performed in the last ten years, by transplant type, overall and by centre respectively. Over the time period there have been three paediatric heart-lung block transplants. Newcastle performed one partial lung transplant in 2012/2013.

Figure 22.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2012 to 31 March 2022

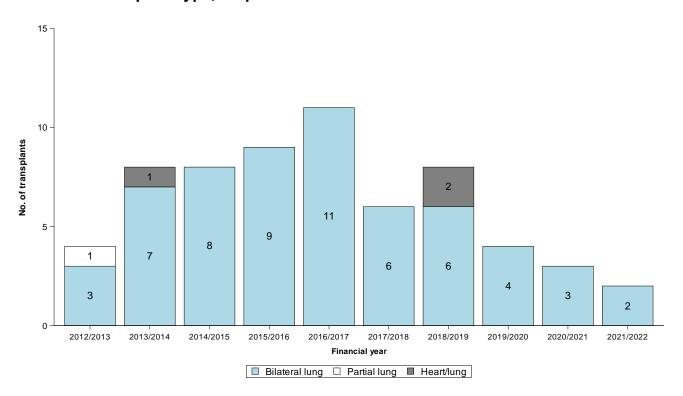
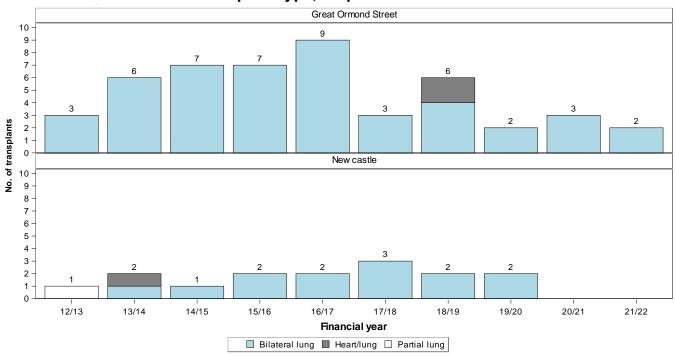


Figure 22.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2012 to 31 March 2022



In 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 is shown in **Figure 22.7**. There were 2 urgent lung only transplant last year and no super-urgent transplants.

Figure 22.6 Number of paediatric lung only transplants in the UK, by financial year and urgency, 1 April 2012 to 31 March 2022

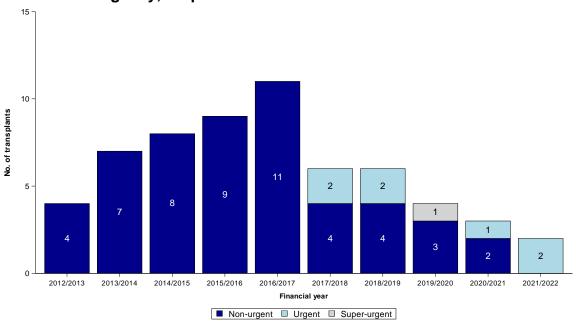
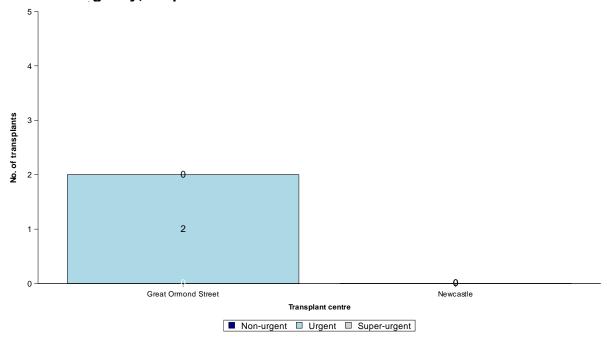


Figure 22.7 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2021 to 31 March 2022



22.2 Demographic characteristics of transplants, 1 April 2012 – 31 March 2022

The demographic characteristics of the 63 paediatric lung transplant recipients and donors in the last ten years are shown by centre and overall in **Table 22.1**. Nationally, 56% of lung recipients were female and the <u>median</u> age was 13 years, while the median age of donors was 14 years. For some characteristics, due to rounding, percentages may not add up to 100.

	characteristics of UK paedia arch 2022, by centre	tric lung transplant	s performed betv	veen 1 April
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		48 (100)	15 (100)	63 (100)
Urgency status at transplant	Non-urgent	43 (90)	11 (73)	54 (86)
	Urgent	5 (10)	3 (20)	8 (13)
	Super-urgent	0 (0)	1 (7)	1 (2)
Recipient sex	Male	18 (38)	10 (67)	28 (44)
	Female	30 (63)	5 (33)	35 (56)
Recipient ethnicity	White	43 (90)	14 (93)	57 (91)
	Asian	3 (6)	1 (7)	4 (6)
	Black	1 (2)	0 (0)	1 (2)
	Missing	1 (2)	0 (0)	1 (2)
Recipient age (years)	Median (IQR)	13 (9, 14)	13 (10, 15)	13 (9, 15)
	Missing	0	0	0
Recipient weight (kg)	Median (IQR)	35 (24, 46)	38 (27, 41)	36 (24, 43)
	Missing	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	19 (40)	11 (73)	30 (48)
	Fibrosing lung disease Primary pulmonary hypertension	1 (2) 18 (38)	1 (7) 2 (13)	2 (3) 20 (32)
	Other heart/lung disease	10 (21)	1 (7)	11 (18)
Recipient in hospital	No	37 (77)	6 (40)	43 (68)
	Yes	10 (21)	8 (53)	18 (29)
	Missing	1 (2)	1 (7)	2 (3)
In hospital, recipient on ventilator	No	9 (90)	6 (75)	15 (83)
	Yes	1 (10)	2 (25)	3 (17)
In hospital, recipient ECMO	No	10 (100)	6 (75)	16 (89)
	Yes	0 (0)	1 (13)	1 (6)
	Missing	0 (0)	1 (13)	1 (6)
In hospital, recipient on inotropes	No	8 (80)	5 (63)	13 (72)
	Yes	2 (20)	3 (38)	5 (28)
Recipient CMV status	Negative	35 (73)	12 (80)	47 (75)
	Positive	13 (27)	1 (7)	14 (22)
	Missing	0 (0)	2 (13)	2 (3)

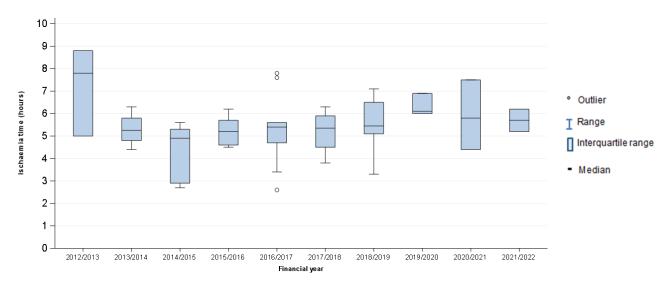
Table 22.1 Demographic characteristics of UK paediatric lung transplants performed between 1 April 2012 and 31 March 2022, by centre **Great Ormond** Newcastle **TOTAL** Street N (%) N (%) N (%) Negative Recipient HCV status 47 (98) 14 (93) 61 (97) Missing 1 (2) 1 (7) 2 (3) Recipient HBV status Negative 47 (98) 14 (93) 61 (97) Missing 2 (3) 1 (2) 1 (7) Recipient HIV status Negative 47 (98) 14 (93) 61 (97) Missing 1 (2) 1 (7) 2 (3) 39 (28, 50) Recipient serum creatinine Median (IQR) 39 (30, 50) 33 (26, 55) (umol/l) Missing 10 2 Donor sex Male 22 (46) 7 (47) 29 (46) Female 26 (54) 8 (53) 34 (54) Donor ethnicity White 39 (81) 51 (81) 12 (80) Asian 0 (0) 1 (2) 1 (2) Other 2 (4) 1 (7) 3 (5) Missing 6 (13) 8 (13) 2 (13) Donor age (years) Median (IQR) 15 (8, 41) 10 (7, 14) 14 (8, 31) Missing 0 0 0 Donor BMI Median (IQR) 19 (16, 24) 19 (15, 21) 19 (16, 23) Missing 0 0 Donor cause of death CVA 27 (56) 37 (59) 10 (67) Trauma 4 (8) 2 (13) 6 (10) Others 17 (35) 3(20)20 (32) Donor hypotension 37 (59) No 28 (58) 9 (60) Yes 13 (27) 4 (27) 17 (27) Missing 7 (15) 2 (13) 9 (14) Donor past cardio disease No 40 (83) 14 (93) 54 (86) Yes 1 (2) 0(0)1 (2) Missing 7 (15) 1 (7) 8 (13) Donor past hypertension No 40 (83) 12 (80) 52 (83) Yes 3 (5) 2 (4) 1 (7) Missing 6 (13) 2 (13) 8 (13) Donor past tumour No 39 (81) 13 (87) 52 (83) Yes 3 (6) 0(0)3 (5) Missing 6 (13) 2 (13) 8 (13) Donor past smoker No 35 (73) 14 (93) 49 (78) Yes 8 (17) 0 (0) 8 (13) 6 (10) Missing 5 (10) 1 (7) Total ischaemia time (hours) Median (IQR) 5.3 (4.6, 6.2) 5.5 (5.2, 6.0) 5.3 (4.7, 6.2) 2 Missing 6 8

Demographic characteristics of UK paediatric lung transplants performed between 1 April 2012 and 31 March 2022, by centre **Table 22.1 Great Ormond** Newcastle TOTAL Street N (%) N (%) N (%) Transplant type Bilateral lung 46 (96) 13 (87) 59 (94) Partial lung 0 (0) 1 (7) 1 (2) Heart/lung 2 (4) 1 (7) 3 (5)

22.3 Total ischaemia time, 1 April 2012 – 31 March 2022

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.

Figure 22.8 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2012 to 31 March 2022



PAEDIATRIC LUNG TRANSPLANTATION Post-Transplant Survival

23. Post-Transplant Survival

The survival analyses presented in this section exclude heart-lung transplants and other multi-organ transplants and include first time transplants only. Partial lung transplants are also excluded. Both DBD and DCD lung transplants are included. Ninety-day and 1-year survival rates are based on transplants performed in the period 1 April 2017 to 31 March 2021 while 5-year survival rates are based on transplants performed in the period 1 April 2013 to 31 March 2017.

The 90-day post-transplant <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 23.1** for the 18 first paediatric lung only transplants in the period 1 April 2017 to 31 March 2021. Only 6 of these transplants were performed at Newcastle so it was not possible to generate a robust survival rate, however there were no reported deaths within 90 days for these patients. Nationally, the 90-day survival rate following first paediatric lung transplant was 94.4%.

Table 23.1 90 day patient survival rates after first paediatric lung transplants, by centre, 1 April 2017 to 31 March 2021						
Centre	Number of patients	Number of deaths	•	survival (95% CI) adjusted)		
Great Ormond Street Hospital Newcastle ¹	12 6	1 0	91.7	(53.9 - 98.8) -		
ик	18	1	94.4	(66.6 - 99.2)		
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers						

There were 4 additional deaths between 90 days and 1 year for the 18 paediatric lung only transplants performed in the period 1 April 2017 to 31 March 2021; 1 from Great Ormond Street Hospital and 3 from Newcastle.

Table 23.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2017 to 31 March 2021					
Centre	Number of patients	Number of deaths	•	urvival (95% CI) adjusted)	
Great Ormond Street Hospital Newcastle ¹	12 6	2 3	83.3	(48.2 - 95.6) -	
UK	18	5	72.2	(45.6 - 87.4)	

Five year <u>survival rates</u> were estimated from the 35 first lung only transplants performed in the period 1 April 2013 to 31 March 2017. 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 2013 to 31 March 2017						
Centre	Number of patients	Number of deaths	•	urvival (95% CI) adjusted)		
Great Ormond Street Hospital Newcastle ¹	29 6	7 3	75.6 -	(55.4 - 87.5) -		
UK	35	10	68.3	(48.9 - 81.6)		
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers						

PAEDIATRIC LUNG TRANSPLANTATION Form Return Rates

24. Paediatric lung form return rates, 1 January – 31 December 2021

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 2021 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 2021 to 31 December 2021								
Centre	Transplar No. requested	nt record % returned	3 month f No. requested	follow-up % returned	1 year fo No. requested	ollow-up % returned	Lifetime t No. requested	follow-up % returned
Great Ormond Street Hospital Newcastle, Freeman Hospital	4	100	3 -	100	1 -	100	18 15	100 100
Overall	4	100	3	100	1	100	33	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 transpla	nts analysed			
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2012 – 31 March 2022	• Introduction	None	1515	1640
1 April 2012 – 31 March 2022	• Transplants	Multi-organ transplants	1499	1635
1 April 2017 – 31 March 2021	Post-transplant survival – • 30/90-day • 1-year survival	 Multi-organ transplants DCD heart transplants excluded from main analysis Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants 	500	580
1 April 2013 – 31 March 2017	Post-transplant survival – • 5-year survival	 Multi-organ transplants DCD heart transplants excluded from main analysis Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants 	596	706

Table A1.2 Paediatric tran	splants analysed			
Time period	Report Section	Exclusion criteria	No. heart transplants	No. lung (+ heart-lung) transplants
1 April 2012 – 31 March 2022	• Introduction	None	297	63
1 April 2012 – 31 March 2022	• Transplants	Multi-organ transplants	296	63
1 April 2017 – 31 March 2021	Post-transplant survival – • 30/90-day • 1-year survival	 Multi-organ transplants Heart-lung transplants Partial lung transplants Second (or more) transplants DCD heart transplants 	97	18
1 April 2013 – 31 March 2017	Post-transplant survival – • 5-year survival	 Multi-organ transplants (including heart-lung transplants) Partial lung transplants Second (or more) transplants DCD heart transplants 	129	35

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 2021 and 31 March 2022 were extracted from the UK Transplant Registry (numerator). Patients registered for a heart-lung block were 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-2020 population estimates based on the Office for National Statistics (ONS) 2011 Census figures (denominator). No NHS regionage- or sex-specific standardisation of rates was performed.

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

Transplant rates

Transplant rates pmp were obtained as the number of heart transplants on NHS group 1 recipients between 1 April 2021 and 31 March 2022 (numerator), divided by the mid-2020 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 2021 and 31 March 2022 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

<u>Kaplan-Meier</u> 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 Cox Proportional Hazards model was used to determine the probability of survival for each patient based on their individual risk factor values. The sum of these probabilities for all patients at a centre gives the number, E, of patients or grafts expected to survive at least one year or five years after transplant at that centre. The number of patients who actually survive the given time period is given by O. The risk-adjusted estimate is then calculated by multiplying the ratio O/E by the overall unadjusted survival rate across all centres. The risk-adjustment models used were developed in consultation with clinicians and were based on statistical significance as well as previous studies of factors affecting the survival rates of interest. The factors included in the models are shown in A3.

Missing values for <u>risk factors</u> were imputed using simple imputation of the median or most common group for the adult heart model (where missing values represented <10% of the cohort). Missing ischaemia time (3% of cohort) was imputed with a centre and year specific median. For the adult lung model, multiple imputation was used where data were missing in <12% of the cohort. 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 ≥ 18 years registered for the first time for a heart or lung transplant between 1 January 2010 and 31 December 2021. 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 on 10 June 2022 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 Risk factors and categories used in and 5-year survival models	n the adult heart risk adjusted 30-day, 90-day, 1-year
Donor age	(modelled as continuous variable)
Recipient age 60 or over	Yes No
Recipient CMV status	Positive Negative
Recipient bilirubin at registration VAD at transplant	(continuous, logged) Short-term (including ECMO) Long-term (including total artificial hearts) None
Recipient IABP at transplant	Yes No
Primary disease group	Cardiomyopathy Coronary heart disease Congenital heart disease Other
Recipient eGFR group at transplant	44 ml/min or below 45-59 ml/min 60-89 ml/min 90 or above 44 ml/min or below 45-59 ml/min
Recipient diabetes at registration	Yes No
Recipient hypertension at registration	Yes No
Recipient blood group	O A B AB
Ischaemia time (hours) OCS used on heart	(modelled as continuous variable) Yes No
Interaction between ischaemia time and OCS	

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

Cox Proportional Hazards model

A statistical model that relates the instantaneous risk (hazard) of an event occurring at a given time point to the <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 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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