

ANNUAL REPORT ON LUNG TRANSPLANTATION

REPORT FOR 2022/2023 (1 APRIL 2013 – 31 MARCH 2023)

PUBLISHED AUGUST 2023

PRODUCED IN COLLABORATION WITH NHS ENGLAND



CONTENTS



Contents

1.	Ex	ecutive summary	5
2.	Int	roduction	7
2	2.1	Overview	9
2	2.2	Geographical variation in registration and transplant rates	16
AD	ULT	LUNG TRANSPLANTATION	19
3	3.	Transplant list	19
	3.1	Adult lung and heart-lung transplant list on 31 March, 2014 – 2023	20
	3.2	Demographic characteristics, 1 April 2022 – 31 March 2023	23
	3.3	Post-registration outcomes, 1 April 2018 – 31 March 2020	25
	3.4	Median waiting time to transplant, 1 April 2019 - 31 March 2022	27
4	1.	Response to offers	30
Ę	5.	Transplants	33
	5.1	Adult lung and heart-lung transplants, 1 April 2013 – 31 March 2023	34
	5.2	Demographic characteristics of transplants, 1 April 2022 – 31 March 2023	40
	5.3	Total ischaemia time, 1 April 2013 – 31 March 2023	43
6	5.	Post-transplant survival	45
	6.1	Survival by centre	47
	6.2	Survival by disease group	50
	6.3	Survival by transplant type	51
	6.4	Survival post heart-lung transplant	52
	6.5	Survival post multi-organ lung transplant	53
7	7.	Survival from listing	54
8	3.	Adult lung form return rates, 1 January – 31 December 2022	57
PA	EDI	ATRIC LUNG TRANSPLANTATION	59
Ç	9.	Transplant list	59
	9.1	Paediatric lung and heart/lung transplant list on 31 March, 2014 – 2023	60
	9.2	Demographic characteristics, 1 April 2021 – 31 March 2023	63
	9.3	Post-registration outcomes, 1 April 2018 – 31 March 2020	64
	9.4	Median waiting time to transplant, 1 April 2019 - 31 March 2022	65
	10.	Response to offers	66
	11.	Transplants	68
	11.	1 Paediatric lung and heart-lung transplants, 1 April 2013 – 31 March 2023	69
	11.	2 Demographic characteristics of transplants, 1 April 2013 – 31 March 2023	73
	11.	3 Total ischaemia time, 1 April 2013 – 31 March 2023	76
	12.	Post-transplant survival	77
	13.	Paediatric lung form return rates, 1 January – 31 December 2022	80

APPENDIX	82
A1: Number of patients analysed	
A2: Methods	85
A3: Risk models	
A4: Glossary of terms	

EXECUTIVE SUMMARY



1. Executive Summary

This report presents key data about lung transplantation in the UK. The period reported covers 10 years, from 1 April 2013 to 31 March 2023. The data include number of people listed for a transplant, number of transplants performed and <u>survival rates</u> following lung transplantation; both on a national and centre-specific basis. Data were extracted on 12 July 2023.

Key findings

ADULT LUNG TRANSPLANTATION

- On 31 March 2023 there were 286 adults waiting for a lung or heart-lung transplant: 281 non-urgent and 5 urgent. In comparison to 31 March 2022, this number increased by 11%. 1 year mortality was 15% on the non-urgent waiting list and 12% on the urgent waiting list. Median waiting time to transplant was 584 days from non-urgent registration and 22 days from urgent registration.
- During 2022/2023 there were 100 adult lung transplants including 1 heart-lung transplant. This was 6% lower than the previous year. 24% of transplants were urgent or super-urgent.
- The national rate of patient survival following adult lung transplant was 90.6% at 90 days, 81.7% at 1 year and 54.4% at 5 years.

PAEDIATRIC LUNG TRANSPLANTATION

- On 31 March 2023 there were 16 paediatric patients waiting for a lung or heart-lung transplant: 14 non-urgent and 2 urgent. Median waiting time to transplant was 1044 days from non-urgent registration.
- During 2022/2023 there was just 1 paediatric lung transplant, 1 less than the previous year; performed at Great Ormond Street Hospital, and was urgent.
- The national rate of patient survival following paediatric lung transplant was 100% at 90 days, 78.6% at 1 year and 61.7% at 5 years.

Use of the contents of this report should be acknowledged as follows: Annual Report on Lung Transplantation 2022/2023, NHS Blood and Transplant

INTRODUCTION



2. Introduction

This report presents data on activity and outcomes of lung transplant candidates and recipients between 1 April 2013 and 31 March 2023, for all centres performing 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 lung transplants performed in the UK.

Results are described separately for adults (aged 16 years or over) and paediatric patients (aged less than 16 years). There are six lung transplant centres in the UK. Four of the six 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> 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 (heart-lung block transplants are considered separately).

The time period of analysis covers 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 revised in July 2023 in consultation with the clinical community.

2.1 Overview

Figure 2.1 shows the number of transplant candidates on the <u>active transplant list</u> at financial year end between 2014 and 2023. 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 increased slightly again to 302.





Figure 2.2 and **Figure 2.3** show the number of adult and paediatric patients on the <u>active</u> <u>transplant list</u> on 31 March 2023 at each centre. In total, there were 286 adults and 16 paediatric patients waiting for a lung transplant. Newcastle had the highest number of adults on lung transplant list. Great Ormond Street Hospital had the highest number of paediatric patients on the lung transplant list.





Figure 2.3 Number of paediatric patients on the active lung transplant list on 31 March 2023, by centre



Figure 2.4 shows the total number of transplants performed in each of the last ten financial years. The number of transplants last year slightly decreased, by 7% to 101, and has remained significantly lower than pre COVID-19 pandemic.



Figure 2.4 Number of lung transplants in the UK, by financial year, 1 April 2013 to 31 March 2023

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 transplants. Great Ormond Street Hospital performed the highest number of paediatric transplants. For the third year running, Newcastle performed no paediatric lung transplants.



Figure 2.5 Number of adult lung transplants in the UK, by centre, 1 April 2022 to 31 March 2023





Figure 2.7 shows a breakdown of the 1,553 adult transplants performed in the UK in the ten-year period while **Figure 2.8** shows a similar breakdown for the 60 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. <u>Multi-organ transplants</u> are excluded from the rest of the report apart from the separate multi-organ outcome section (<u>Sections 6.5</u>).



Figure 2.7 Adult lung transplants performed in the UK, 1 April 2013 to 31 March 2023

¹ Includes 4 lung and liver and 1 lung and kidney transplant



Figure 2.8 Paediatric lung transplants performed in the UK, 1 April 2013 to 31 March 2023

2.2 Geographical variation in registration and transplant rates

Figure 2.9 shows rates of registration to the lung transplant list per million population (pmp) between 1 April 2022 and 31 March 2023 compared with lung transplant rates pmp for the same time period, by recipient country/NHS region of residence. **Table 2.1** shows the actual numbers as well as rates. If a patient has had more than one registration/transplant in the period, each registration/transplant is considered. Note that this analysis only considered NHS Group 1 patients. The UK lung registration and transplant rates are 3.1 pmp and 1.5 pmp respectively.

Since there will inevitable be some random variation in rates between areas, the systematic coefficient 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 this 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 (p-value = 0.999), 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 2.9 Comparison of lung registration rates (pmp) with transplant rates (pmp) by recipient country/NHS region of residence

·		-			
Country/ NHS region	Registrations	Registrations (pmp)		Transplants (pmp)	
North East and Yorkshire	27	(3.3)	16	(2.0)	
North West	19	(2.6)	9	(1.2)	
Midlands	38	(3.5)	13	(1.2)	
East of England	24	(3.8)	14	(2.2)	
London	32	(3.6)	10	(1.1)	
South East	20	(2.2)	12	(1.3)	
South West	18	(3.2)	11	(1.9)	
England	178	(3.1)	85	(1.5)	
Isle of Man	1	(12.5)	0	(0.0)	
Channel Islands	0	(0.0)	0	(0.0)	
Wales	9	(2.9)	6	(1.9)	
Scotland	12	(2.2)	7	(1.3)	
Northern Ireland	6	(3.2)	2	(1.1)	
TOTAL ^{1,2}	207	(3.1)	100	(1.5)	

Table 2.1 Lung registration and transplant rates per million population (pmp) in the UK,1 April 2022 - 31 March 2023, by Country/NHS region

¹ Registrations include 1 recipient whose postcode was unknown and exclude 1 recipient who resides in the Republic of Ireland.

² Transplants excludes 1 recipient who resides in the Republic of Ireland and 5 recipients who reside overseas

ADULT LUNG TRANSPLANTATION Transplant List



3.1 Adult lung and heart-lung transplant list on 31 March, 2014 – 2023

Figure 3.1 shows the number of adults on the lung and heart-lung transplant lists on 31 March each year between 2014 and 2023 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 2023 at 271. 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 2023, there were 5 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 3.1 Number of adults on the lung and heart-lung transplant lists on 31 March each year

Figure 3.2 shows the number of adults on the <u>active lung and heart-lung transplant lists</u> on 31 March 2023, by centre and urgency. In total, there were 286 adults waiting, including 5 urgent across Harefield, Manchester, Newcastle, and Papworth. Newcastle had the highest number of people registered on the transplant list while Manchester had the lowest.



Figure 3.2 Number of adults on the active lung and heart-lung transplant lists on 31 March 2023, by centre

Figure 3.3 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 and Papworth have experienced a general increase over the decade in their active lists, while the list at Manchester has generally decreased. There was no one waiting on the super-urgent list on 31 March in any year.



Figure 3.3 Number of adults on the lung transplant list on 31 March each year for the last 10 years, by centre

3.2 Demographic characteristics, 1 April 2022 – 31 March 2023

There were 201 adult registrations onto the lung or heart-lung transplant lists between 1 April 2022 and 31 March 2023. Demographic characteristics of these individuals are shown by centre and overall in **Table 3.1**. Nationally, 57% 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.

Table 3.1 Demographic Demograp	bhic characteristics of ad by centre	ult patient registrations o	onto the lung and	transplant list be	tween 1 April 202	2 and 31 March 20	023,
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of registrations		28 (100)	52 (100)	26 (100)	46 (100)	49 (100)	201 (100)
Highest urgency on the	Non-urgent	27 (96)	48 (92)	20 (77)	38 (83)	43 (88)	176 (88)
lung list during	Urgent	1 (4)	3 (6)	5 (19)	8 (17)	4 (8)	21 (10)
registration	Super-urgent	0 (0)	1 (2)	1 (4)	0 (0)	2 (4)	4 (2)
Recipient sex	Male	17 (61)	26 (50)	19 (73)	24 (52)	29 (59)	115 (57)
	Female	11 (39)	26 (50)	7 (27)	22 (48)	20 (41)	86 (43)
Recipient ethnicity	White	24 (86)	40 (77)	25 (96)	43 (93)	39 (80)	171 (85)
	Asian	3 (11)	7 (13)	1 (4)	1 (2)	7 (14)	19 (10)
	Black	0 (0)	5 (10)	0 (0)	0 (0)	1 (2)	6 (3)
	Other	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
	Missing	0 (0)	0 (0)	0 (0)	2 (4)	2 (4)	4 (2)
Recipient age (years)	Median (IQR)	60 (48, 64)	50 (41, 57)	58 (52, 61)	59 (53, 62)	57 (49, 60)	57 (47, 61)
	Missing	0	0	0	0	0	0

, · · · · · · · · · · · · · · · · · ·	.,						
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Primary Disease	Cystic fibrosis and bronchiectasis	1 (4)	11 (21)	0 (0)	5 (11)	2 (4)	19 (10)
	Fibrosing lung disease	14 (50)	18 (35)	23 (88)	28 (61)	18 (37)	101 (50)
	COPD and emphysema	8 (29)	15 (29)	1 (4)	11 (24)	16 (33)	51 (25)
	Primary pulmonary hypertension	1 (4)	0 (0)	0 (0)	1 (2)	7 (14)	9 (5)
	Other heart/lung disease	3 (11)	8 (15)	2 (8)	1 (2)	5 (10)	19 (10)
	Missing	1 (4)	0 (0)	0 (0)	0 (0)	1 (2)	2 (1)
Smoker	No	27 (96)	52 (100)	25 (100)	45 (98)	47 (100)	196 (98)
	Missing	1 (4)	0 (0)	1 (4)	1 (2)	2 (4)	5 (2)
Lung function - FEV1 (litres)	Median (IQR) Missing	1.35 (0.99, 1.90) 2	0.81 (0.60, 1.82) 2	1.75 (0.92, 2.00) 3	1.09 (0.71, 1.44) 4	1.14 (0.81, 1.78) 7	1.15 (0.74, 1.82) 18
Lung function – FVC (litres)	Median (IQR) Missing	1.93 (1.60, 2.66) 2	2.03 (1.62, 2.80) 2	2.10 (1.44, 2.62) 3	1.72 (1.42, 2.15) 4	2.09 (1.72, 3.21) 6	2.01 (1.56, 2.70) 17

Table 3.1 Demographic characteristics of adult patient registrations onto the lung and transplant list between 1 April 2022 and 31 March 2023, by centre, by centre

3.3 Post-registration outcomes, 1 April 2018 – 31 March 2020

The registration outcomes of adults listed for a lung only transplant between 1 April 2018 and 31 March 2020 are summarised in **Figures 3.4** – **3.6**, 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, 20% of lung registrations resulted in transplant and 10% had died. Three years after listing, 39% has received a transplant and 21% had died. By centre (**Figure 3.5**), within 1 year of registration, the proportion transplanted ranged from 14% at Birmingham to 53% at Papworth and the proportion dying on the list ranged from 4% at Manchester to 23% at Birmingham. Removals from the non-urgent list were predominantly due to deteriorating condition.

Figure 3.4 Post-registration outcome for 508 non-urgent lung only registrations made in the UK, 1 April 2018 to 31 March 2020





Figure 3.6 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, 59% had received a transplant. A centre breakdown is not provided for urgent registrations, nor is a super-urgent registration figure, due to small numbers.

Figure 3.6 Post-registration outcome for 74 urgent lung only registrations made in the UK, 1 April 2018 to 31 March 2020



3.4 Median waiting time to transplant, 1 April 2019 - 31 March 2022

The median waiting time to non-urgent lung transplant from registration for adults is shown in **Figure 3.7** and **Table 3.2**. This is estimated for individuals registered initially as non-urgent between 1 April 2019 and 31 March 2022 using the <u>Kaplan Meier</u> method. The national non-urgent <u>median</u> waiting time was 584 days and ranged from 280 days at Papworth to 584 days at Harefield (log-rank p<0.0001), but could not be calculated for Birmingham and Newcastle due to low transplant rate. The national urgent <u>median</u> waiting time is not presented for super-urgent registrations, as only a small number start off on this urgency scheme (most are initially on the non-urgent scheme) and this analysis is based on initial registration status.



Figure 3.7 Median waiting time to non-urgent lung transplant for adults registered between 1 April 2019 and 31 March 2022, by centre

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

Table 3.2	Median active waiting time to lung transplant for adult patients registered on
	the transplant list, by urgency at registration and centre, 1 April 2019 to 31 March 2022

Transplant centre	Number of patients registered	Number transplanted	Waitin Median	g time (days) 95% Confidence interval					
Non-urgent at initial registration									
Birmingham ¹ Harefield Manchester Newcastle ¹ Papworth	80 104 82 123 147	21 53 41 41 91	- 584 539 - 280	420 - 748 409 - 669 - 195 - 365					
UK	536	247	584	488 - 680					
Urgent at initial registration									
UK	30	20	22	11 - 33					
¹ Median and 95% confidence intervals could not be calculated due to low transplant rate									

The <u>median</u> waiting time to non-urgent lung transplant for adults is also considered by blood group. This is shown in **Figure 3.8** and **Table 3.3**. Blood group O had the longest average wait (874 days) compared with the other blood groups (log-rank p<0.0001).





Table 3.3Median active waiting time to lung transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2019 to 31 March 2022									
Blood Group	Number of patients registered	Number transplanted	Waitin Median	ng time (days) 95% Confidence interval					
Non-urgent a	t initial registration								
O A B AB	254 220 44 18	96 119 21 11	874 437 581 267	531 - 1217 324 - 550 73 - 1089 0 - 573					
UK	536	247	584	488 - 680					
Urgent at init	ial registration								
UK	30	20	22	11 - 33					

ADULT LUNG TRANSPLANTATION

Response to Offers



4. 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 2020 and 31 March 2023 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. 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 lung, even if they did not respond to the group offer, and any declines recorded for a centre ranked below the accepting centre were discounted.

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



Figure 4.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2020 to 31 March 2023

Number of offers

Table 4.1 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 2022/2023 due to fewer transplants being performed.

Table 4.1 Adult Bilateral Lung/Cardiac Block/ offer results by transplant centre,between 1 April 2020 and 31 March 2023									
Centre	202	20/21	2021/22		2022/23		Overall		
	No.	Decline	No.	Decline	No.	Decline	No.	Decline	
	offers	rate (%)	offers	rate (%)	offers	rate (%)	offers	rate (%)	
Birmingham	20	(75.0)	19	(89.5)	24	(66.7)	63	(76.2)	
Harefield	28	(35.7)	32	(40.6)	26	(69.2)	86	(47.7)	
Manchester	21	(57.1)	28	(75.0)	31	(77.4)	80	(71.3)	
Newcastle	68	(79.4)	77	(81.8)	41	(80.5)	186	(80.6)	
Papworth	26	(57.7)	47	(55.3)	33	(60.6)	106	(57.5)	
UK	163	(65.0)	203	(69.0)	155	(71.6)	521	(68.5)	
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



5.1 Adult lung and heart-lung transplants, 1 April 2013 – 31 March 2023

Figure 5.1 and **5.2** 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 2013/2014 to 2019/2020, with peaks of 210 in 2013/2014 and 207 in 2017/2018. The number has since fallen, with only 100 transplants in the latest financial year. **Figure 5.2** shows that Newcastle performed more transplants in 2022/2023 compared with the previous year, whilst Manchester and Harefield performed fewer. Last year DCD lung transplantation represented 37% of the total activity. Last year's activity is shown by centre and donor type in **Figure 5.3**. The highest number of transplants were performed by Papworth.



Figure 5.1 Number of adult lung transplants in the UK, by financial year and donor type, 1 April 2013 to 31 March 2023



Figure 5.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2013 to 31 March 2023



Figure 5.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2022 to 31 March 2023

Figure 5.4 and **5.5** show the number of adult lung transplants performed in the last ten years, by transplant type, nationally and by centre, respectively. There were a total of 41 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 was the only centre that performed a heart-lung block transplant (**Figure 5.6**).

Figure 5.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2013 to 31 March 2023




Figure 5.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2013 to 31 March 2023



Figure 5.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2022 to 31 March 2023

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 5.7**; the proportion of urgent or super-urgent lung transplants was 24% in 2022/2023.





Figure 5.8 shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 21 urgent lung only transplants (ranging from 1 at Birmingham to 8 at Newcastle) and 3 super-urgent lung only transplants, with Birmingham, Harefield, and Papworth performing one each. Only one adult heart-lung transplant took place in 2022/2023, and it was super-urgent (not shown in the figure).





5.2 Demographic characteristics of transplants, 1 April 2022 – 31 March 2023

The demographic characteristics of the 100 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 71% of lung recipients were male and the <u>median</u> age was 57 years while the median age of donors was 41 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 11.1 Demographic ch by centre	naracteristics of UK adult lung trans	splants perform	ed between 1 A	April 2022 and 3	1 March 2023,		
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		10 (100)	16 (100)	13 (100)	25 (100)	36 (100)	100 (100)
Urgency status at transplant	Non-urgent	8 (80)	13 (81)	9 (69)	17 (68)	28 (78)	75 (75)
	Urgent	1 (10)	2 (13)	4 (31)	8 (32)	6 (17)	21 (21)
	Super-urgent	1 (10)	1 (6)	0 (0)	0 (0)	2 (6)	4 (4)
Recipient sex	Male	9 (90)	10 (63)	10 (77)	18 (72)	24 (67)	71 (71)
	Female	1 (10)	6 (38)	3 (23)	7 (28)	12 (33)	29 (29)
Recipient ethnicity	White	8 (80)	14 (88)	11 (85)	25 (100)	32 (89)	90 (90)
	Asian	1 (10)	0 (0)	1 (8)	0 (0)	3 (8)	5 (5)
	Black	1 (10)	2 (13)	0 (0)	0 (0)	0 (0)	3 (3)
	Other	0 (0)	0 (0)	1 (8)	0 (0)	0 (0)	1 (1)
	Missing	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
Recipient age (years)	Median (IQR)	62 (53, 65)	53 (47, 61)	56 (48, 60)	60 (56, 61)	55 (49, 61)	57 (49, 61)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	71 (66, 81)	73 (60, 80)	76 (61, 79)	80 (73, 86)	76 (67, 85)	76 (65, 83)
	Missing	0	0	0	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	0 (0)	2 (13)	2 (15)	1 (4)	1 (3)	6 (6)
	Fibrosing lung disease	2 (20)	7 (44)	7 (54)	15 (60)	10 (28)	41 (41)
	COPD and emphysema	7 (70)	6 (38)	4 (31)	7 (28)	15 (42)	39 (39)
	Primary pulmonary hypertension	0 (0)	0 (0)	0 (0)	1 (4)	5 (14)	6 (6)
	Other heart/lung disease	1 (10)	1 (6)	0 (0)	1 (4)	5 (14)	8 (8)

Table 11.1 Demographic ch by centre	naracteristics of UK adult lung tra	nsplants perform	ed between 1 A	pril 2022 and 3	1 March 2023,		
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Recipient in hospital	No	7 (70)	12 (75)	12 (92)	21 (84)	30 (83)	82 (82)
	Yes	3 (30)	4 (25)	1 (8)	4 (16)	6 (17)	18 (18)
In hospital, recipient on ventilator	No	3 (100)	4 (100)	1 (100)	4 (100)	6 (100)	18 (100)
In hospital, recipient ECMO	No Yes Missing	2 (67) 1 (33) 0 (0)	2 (50) 1 (25) 1 (25)	1 (100) 0 (0) 0 (0)	3 (75) 1 (25) 0 (0)	5 (83) 1 (17) 0 (0)	13 (72) 4 (22) 1 (6)
In hospital, recipient on inotropes	No	2 (67)	3 (75)	1 (100)	4 (100)	6 (100)	16 (89)
	Yes	1 (33)	1 (25)	0 (0)	0 (0)	0 (0)	2 (11)
Recipient CMV status	Negative	2 (20)	3 (19)	8 (62)	14 (56)	19 (53)	46 (46)
	Positive	8 (80)	13 (81)	5 (38)	11 (44)	17 (47)	54 (54)
Recipient HCV status	Negative	10 (100)	16 (100)	13 (100)	25 (100)	36 (100)	100 (100)
Recipient HBV status	Negative	8 (80)	16 (100)	13 (100)	25 (100)	36 (100)	98 (98)
	Positive	2 (20)	0 (0)	0 (0)	0 (0)	0 (0)	2 (2)
Recipient HIV status	Negative	10 (100)	16 (100)	13 (100)	25 (100)	36 (100)	100 (100)
Recipient Serum Creatinine	Median (IQR)	62 (55, 69)	66 (59, 87)	82 (65, 86)	73 (65, 87)	69 (58, 83)	69 (59, 86)
(umol/l)	Missing	0	0	0	0	0	0
Donor sex	Male	7 (70)	9 (56)	7 (54)	8 (32)	16 (44)	47 (47)
	Female	3 (30)	7 (44)	6 (46)	17 (68)	20 (56)	53 (53)
Donor ethnicity	White	8 (80)	15 (94)	13 (100)	20 (80)	31 (86)	87 (87)
	Asian	0 (0)	0 (0)	0 (0)	4 (16)	3 (8)	7 (7)
	Black	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)
	Other	1 (10)	0 (0)	0 (0)	0 (0)	1 (3)	2 (2)
	Missing	1 (10)	1 (6)	0 (0)	1 (4)	0 (0)	3 (3)

Table 11.1 Demographic ch by centre	aracteristics of UK adult lung trans	plants perform	ed between 1 A	pril 2022 and 3	1 March 2023,		
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Donor age (years)	Median (IQR)	43 (36, 51)	54 (27, 59)	33 (24, 45)	39 (29, 58)	40 (29, 49)	41 (28, 53)
	Missing	0	0	0	0	0	0
Donor BMI (kg/m²)	Median (IQR)	23 (20, 26)	25 (23, 28)	25 (22, 28)	23 (22, 25)	24 (22, 30)	24 (22, 28)
	Missing	0	0	0	0	0	0
Donor cause of death	Intracranial/CVA	8 (80)	15 (94)	10 (77)	19 (76)	31 (86)	83 (83)
	Trauma	1 (10)	0 (0)	0 (0)	0 (0)	3 (8)	4 (4)
	Others	1 (10)	1 (6)	3 (23)	6 (24)	2 (6)	13 (13)
Donor hypotension	No	6 (60)	11 (69)	9 (69)	2 (8)	30 (83)	58 (58)
	Yes	2 (20)	4 (25)	4 (31)	3 (12)	6 (17)	19 (19)
	Missing	2 (20)	1 (6)	0 (0)	20 (80)	0 (0)	23 (23)
Donor past cardio disease	No	9 (90)	14 (88)	11 (85)	24 (96)	35 (97)	93 (93)
	Yes	0 (0)	1 (6)	1 (8)	0 (0)	0 (0)	2 (2)
	Missing	1 (10)	1 (6)	1 (8)	1 (4)	1 (3)	5 (5)
Donor past hypertension	No	8 (80)	14 (88)	11 (85)	22 (88)	33 (92)	88 (88)
	Yes	2 (20)	2 (13)	2 (15)	3 (12)	3 (8)	12 (12)
Donor past tumour	No	10 (100)	16 (100)	13 (100)	24 (96)	36 (100)	99 (99)
	Yes	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
Donor past smoker	No	3 (30)	7 (44)	3 (23)	14 (56)	21 (58)	48 (48)
	Yes	6 (60)	9 (56)	10 (77)	11 (44)	15 (42)	51 (51)
	Missing	1 (10)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
Total ischaemia time (hours)	Median (IQR)	6.3 (5.5, 7.4)	7.2 (5.5, 7.8)	6.7 (4.6, 7.2)	7.0 (6.4, 7.6)	9.3 (7.8, 10.9)	7.2 (6.3, 9.2)
	Missing	0	1	0	0	2	3
Transplant type	Single lung	1 (10)	2 (13)	0 (0)	0 (0)	5 (14)	8 (8)
	Bilateral lung	9 (90)	14 (88)	13 (100)	25 (100)	30 (83)	91 (91)
	Heart/lung	0 (0)	0 (0)	0 (0)	0 (0)	1 (3)	1 (1)

5.3 Total ischaemia time, 1 April 2013 – 31 March 2023

Figure 5.9 shows <u>boxplots</u> of the total ischaemia time for <u>DBD</u> donor lungs transplanted into adult recipients over the last 10 years. The total ischaemia time is the difference between donor cross-clamp and recipient reperfusion (of second lung if applicable) and can be considered the out of body time. In cases where organ maintenance systems were used (4%), not all of this time duration is ischaemic, and no adjustment has been made for this. The national <u>median</u> total ischaemia time has increased from 6.1 hours to 6.8 hours over the last ten years.





Figure 5.10 and **Figure 5.11** show <u>boxplots</u> 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 2022/2023 was longest for Papworth and shortest for Manchester. Papworth and Birmingham have seen recent increases in median ischaemia time while Harefield has had a recent decrease.





Figure 5.11 Boxplots of total ischaemia time in DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2013 to 31 March 2023



ADULT LUNG TRANSPLANTATION

Post-Transplant Survival



6. Post-Transplant Survival

This section presents survival post adult lung transplantation. <u>Funnel plots</u> are used to compare the <u>risk-adjusted</u> survival rate at each centre with the national rate. The <u>risk-adjusted</u> rates seek to compare centre performance after accounting for differences in <u>case</u> <u>mix</u> across centres. The <u>unadjusted</u> <u>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</u> <u>survival rates</u> are listed in <u>Appendix A3</u>.

The survival analyses in **Section 6.1-6.3** 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 2018 to 31 March 2022 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2014 to 31 March 2018. Both DBD and DCD lung transplants are included. <u>Survival rates</u> are presented by transplant centre in **Tables 6.1-6.3** and **Figures 6.1-6.3**, by disease group in **Tables 6.4-6.5**, and by transplant type (single or bilateral lungs) in **Table 6.6**. Survival following heart-lung transplantation is provided separately in **Section 6.4** and survival outcomes following <u>multi-organ</u> lung transplantation are summarised in **Section 6.5**.

6.1 Survival by centre

Table 6.1 and **Figure 6.1** show the 90-day post-transplant <u>unadjusted</u> and <u>risk-adjusted</u> patient survival rates for each centre and nationally for the 491 first adult lung only transplants in the period 1 April 2018 to 31 March 2022. All centres were statistically consistent with the national rate of survival which was 90.6%.

Table 6.1 90 day p 1 April 2	atient survival rat 2018 and 31 March	tes after fi n 2022	rst adult lung tra	nsplant	, by centre,
Centre	Number of transplants	L	% 90 day survi I <u>nadjusted</u>	val (95% <mark>Ris</mark>	sci) Sk-adjusted
Birmingham Harefield Manchester Newcastle Papworth	44 140 76 97 134	90.9 88.6 93.4 87.6 93.3	(77.6 - 96.5) (82.0 - 92.8) (84.9 - 97.2) (79.2 - 92.8) (87.5 - 96.4)	90.4 90.5 91.2 88.3 92.6	(74.4 - 96.4) (84.5 - 94.2) (78.9 - 96.3) (79.4 - 93.4) (85.7 - 96.1)
UK	491	90.6	(87.7 - 92.9)		
	Centre has reache Centre has reache Centre has reache Centre has reache	d the lower d the lower d the upper d the upper	99.8% confidence lin 95% confidence lim 95% confidence lim 99.8% confidence li	mit it it mit	

Figure 6.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2018 to 31 March 2022



Table 6.2 and **Figure 6.2** 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 491 first adult lung only transplants in the period 1 April 2018 to 31 March 2022. The national rate of survival was 81.7%. The rates for all centres were statistically consistent with the national rate.

Table 6.2 1 year p 1 April	atient survival rat 2018 to 31 March	es after fir 2022	st adult lung tra	nsplant,	by centre,
Centre	Number of		% 1 year survi	val (95%	CI)
	transplants	<u>L</u>	<u>Inadjusted</u>	<u>Ris</u>	sk-adjusted
Birmingham	44	86.0	(71.5 - 93.5)	85.8	(68.3 - 93.6)
Harefield	140	81.3	(73.8 - 86.9)	83.9	(76.4 - 89.1)
Manchester	76	82.7	(72.0 - 89.5)	76.2	(59.0 - 86.2)
Newcastle	97	78.0	(68.3 - 85.1)	79.5	(68.6 - 86.6)
Papworth	134	82.7	(75.1 - 88.1)	81.5	(72.2 - 87.7)
UK	491	81.7	(77.9 - 84.8)		
	Centre has reache	d the lower	99.8% confidence li	mit	
	Centre has reache	d the lower	95% confidence lim	it	
	Centre has reache	d the upper	95% confidence lim	it .	
	Centre has reache	d the upper	99.8% confidence li	mit	





Table 6.3 and **Figure 6.3** 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 698 first adult lung only transplants in the period 1 April 2014 to 31 March 2018. 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 99.8% upper confidence limit, providing evidence of a higher than average survival at this time point. All other centres were statistically consistent with the national rate of survival of 54.4%.

Table 6.3 5 year pa 1 April 20	atient survival aft 014 and 31 March	er first ad 2018	ult lung transpla	nt, by ce	entre,
Centre	Number of transplants	<u>L</u>	% 5 year survi Inadjusted	val (95% <u>Ris</u>	CI) sk-adjusted
Birmingham Harefield Manchester Newcastle Papworth	83 189 107 160 159	43.2 65.0 49.5 50.5 54.6	(32.4 - 53.6) (57.7 - 71.3) (39.8 - 58.6) (42.4 - 58.1) (46.6 - 62.0)	35.7 66.4 54.0 52.7 49.9	(14.4 - 51.7) (57.3 - 73.6) (40.0 - 64.8) (40.9 - 62.1) (36.9 - 60.2)
UK	698 Centre has reach Centre has reach Centre has reach Centre has reach	54.4 ned the low ned the low ned the upp ned the upp	(50.6 - 58.0) ver 99.8% confide ver 95% confidenc ber 95% confidenc ber 99.8% confide	nce limit e limit ce limit nce limit	

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



Number of transplants

6.2 Survival by disease group

Tables 6.4 and **6.5** 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</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 6.4 1 year patient survival rates after first adult lung transplant, by disease group,1 April 2018 to 31 March 2022

Disease group	Number of transplants	Number of % transplants <u>Unadju</u>		% 1 year survival (95% (adjusted <u>Risk</u>		
Cystic fibrosis and bronchiectasis COPD and emphysema Fibrosing lung disease Other	111 158 173 49	87.4 80.8 78.7 81.6	(79.6 - 92.3) (73.7 - 86.2) (71.7 - 84.2) (67.7 - 90.0)	86.4 80.0 80.2 82.3	(77.0 - 91.9) (71.4 - 86.0) (72.6 - 85.7) (66.0 - 90.8)	
UK	491	81.7	(77.9 - 84.8)			

Table 6.5 5 year patient survival rates after first adult lung transplant, by disease group,1 April 2014 and 31 March 2018	

Disease group	Number of	% 5 year survival (95% CI)			
	transplants	ants <u>Unadjus</u>		<u>justed</u> <u>Ris</u>	
Cystic fibrosis and bronchiectasis	209	59.7	(52.7 - 66.0)	55.8	(45.3 - 64.3)
COPD and emphysema	233	59.5	(52.9 - 65.5)	57.5	(48.0 - 65.3)
Fibrosing lung disease	202	44.4	(37.4 - 51.1)	51.6	(41.8 - 59.8)
Other	54	50.0	(36.1 - 62.4)	48.5	(24.9 - 64.7)
υκ	698	54.4	(50.6 - 58.0)		

6.3 Survival by transplant type

Table 6.6 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 2018 and 31 March 2022 whereas the 5 year survival rates are for transplants performed between 1 April 2014 and 31 March 2018. 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= 0.0151).

Table 6.6 Unadju	usted pa	atient su	rvival rates after	first adu	ılt lung	transplant, by tr	ansplan	t type,	i year)
1 April	2018 to	o 31 Mar	ch 2022 (90 day	and 1 ye	ar) and	1 April 2014 to 3	1 March	2018 (5	
Transplant type	N*	90 c % surv <u>Ur</u>	lay ival (95% CI) adjusted	N*	1 ye % sur\ <u>Ur</u>	ar /ival (95% CI) nadjusted	N*	5 y o % surv <u>U</u>	ear vival (95% CI) nadjusted
Single lung	51	96.1	(85.2 - 99.0)	51	81.8	(67.9 - 90.1)	81	38.2	(27.7 - 48.6)
Bilateral lung	440	90.0	(86.8 - 92.5)	440	81.6	(77.7 - 85.0)	617	56.6	(52.5 - 60.4)
UK * Number of trans	491 plants	90.6	(87.7 - 92.9)	491	81.7	(77.9 - 84.8)	698	54.4	(50.6 - 58.0)

6.4 Survival post heart-lung transplant

Table 6.7 and **Table 6.8** present short-term patient <u>survival rates</u> following combined heartlung transplant, by centre and nationally. During the time period 1 April 2014 to 31 March 2022, a small number of transplants were performed, with the highest number being performed at Papworth. The national rates of survival were 84.8% at 90 days and 72.0% at one year.

Table 6.7 90 day patient sur 1 April 2014 and	vival after first 31 March 2022	adult heart-lu	ung transplar	nt, by centre,
Centre	Number of transplants	Number of deaths	% 90 day s (<u>un</u> a	urvival (95% CI) adjusted)
Birmingham ¹	7	1	-	-
Harefield ¹	6	3	-	-
Manchester ¹	7	0	-	-
Newcastle ¹	4	0	-	-
Papworth ¹	9	1	-	-
UK	33	5	84.8	(67.4 - 93.4)
¹ Survival rates for groups with lea	ss than 10 patient	s are not preser	nted due to sma	all numbers

Table 6.8 1 year patient surv 1 April 2014 and 3	ival after first a 31 March 2022	adult heart-lu	ng transplant	, by centre,	
Centre	Number of transplants	Number of deaths	% 1 year sı (<u>una</u>	urvival (95% CI) adjusted)	
Birmingham ¹	7	1	-	-	
Harefield ¹	6	5	-	-	
Manchester ¹	7	1	-	-	
Newcastle ¹	4	1	-	-	
Papworth ¹	9	1	-	-	
UK	33	9	72.0	(53.0 - 84.4)	
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers					

6.5 Survival post multi-organ lung transplant

The survival outcomes of the small number of recipients of multi-organ lung transplants are reported in **Table 6.9**, 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 2014 and 31 March 2022. It does not include heart-lung transplants which are shown in the previous section.

Table 6.9Survival outcomes following multi-organ lung transplants performed between 1 April 2014 and 31 March 2022							
Transplant type		Number of transplants	Number of patients alive at 90 days post- transplant	Number of patients alive at 1 year post- transplant			
		Ν	Ń	Ň			
Lung & kidne	еу	1	0	0			
Lung & liver		4 ¹	1	0			
¹ 2 transplants had missing survival data							

ADULT LUNG 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 lung transplant between 1 January 2011 and 31 December 2022. 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</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 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 rates for Birmingham fell outside the lower 99.8% confidence interval, indicating a significantly lower than average survival rates. The one year survival rate from listing for Harefield is above the 95% <u>confidence limit</u>, 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.

Table 7.1Risk-adjusted 1 and 5 year patient survival from listing for first deceased donor lung only transplant in patients registered between 1 January 2011 and 31 December 2022							
Centre	Number at risk	Survival	One year	Number	Survival	Five year	Number
	¹ at day 0	rate %	(95% CI)	at risk ¹	rate %	(95% CI)	at risk ¹
Birmingham	366	69.0	(62.5 - 74.4)	238	28.2	(17.6 - 37.4)	64
Harefield	763	81.5	(78.0 - 84.5)	589	57.3	(52.0 - 62.1)	273
Manchester	414	83.8	(79.5 - 87.2)	317	52.1	(44.5 - 58.7)	104
Newcastle	683	75.3	(71.3 - 78.7)	470	49.6	(43.6 - 55.0)	188
Papworth	574	79.2	(75.2 - 82.6)	405	48.8	(42.0 - 54.8)	135
UK	2800	78.2	(76.6 - 79.7)	2019	49.4	(47.2 - 51.5)	764
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 2011 – 31 December 2022

Figure 7.2 Risk-adjusted five year patient survival rates from listing by centre, 1 January 2011 – 31 December 2022



ADULT LUNG TRANSPLANTATION Form Return Rates



8. Adult lung form return rates, 1 January – 31 December 2022

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 lung and heart-lung transplants between 1 January and 31 December 2022 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 8.1 Form return rates for a	idult lung t	ransplants	s, 1 Janua	ry 2022 to	31 Decem	ber 2022		
Centre	Transpla No. required	nt record % returned	3 month No. required	follow-up % returned	1 year f No. required	ollow-up % returned	Lifetime No. required	follow-up % returned
Birmingham Queen Elizabeth Hospital	8	100	9	100	10	100	102	98
Harefield Hospital	18	100	13	100	16	100	452	98
Manchester, Wythenshawe Hospital	16	100	14	100	13	100	160	100
Newcastle Freeman Hospital	22	100	15	100	16	100	305	97
Royal Papworth Hospital	31	100	27	100	33	100	317	97
Sheffield Northern General Hospital	-	-	-	-	-	-	2	50
Overall	95	100	78	100	88	100	1338	98

PAEDIATRIC LUNG TRANSPLANTATION

Transplant List



9.1 Paediatric lung and heart/lung transplant list on 31 March, 2014 – 2023

Figure 9.1 shows the number of paediatric patients on the lung transplant list on 31 March each year between 2014 and 2023 split by urgency status. The number on the active lung transplant list was high in 2014, with 12 on the non-urgent list and 3 active for a heart-lung transplant. It has since decreased to 3 in 2020 (2 non-urgent, 1 urgent) but has risen to 16 (11 non-urgent, 3 heart-lung and 2 urgent) on 31 March 2023.





Figure 9.2 shows the number of paediatric patients on the <u>active lung transplant list</u> at 31 March 2023 by centre. In total, there were 16 paediatric patients waiting; 13 at Great Ormond Street Hospital and 3 at Newcastle. Two patients at Great Ormond Street Hospital were 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 9.3 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 2014 and 2023. 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 12 active patients (9 non-urgent, 2 urgent, 1 heart-lung) on 31 March 2023. Newcastle had a peak of 5 on their list in 2017, but this has now decreased to 3 non-urgent patients.





9.2 Demographic characteristics, 1 April 2021 – 31 March 2023

There were 11 paediatric registrations onto the lung transplant list between 1 April 2021 and 31 March 2023 (two years analysed due to small numbers). Demographic characteristics are shown by centre and overall in **Table 9.1**. Nationally, 64% of the patients were female and the <u>median</u> age was 7 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 9.1Demographic characteristics of paediatric patient registrations onto the lung transplant list between 1 April 2021 and 31 March 2023, by centre, by centre					
		Great Ormond Street	Newcastle	TOTAL	
		N (%)	N (%)	N (%)	
Number of registrations		8 (100)	3 (100)	11 (100)	
Year of registration	2021/2022	3 (0)	1 (0)	4 (36)	
	2022/2023	5 (0)	2 (0)	7 (64)	
Highest urgency during registration	Non-urgent	5 (63)	3 (100)	8 (73)	
	Urgent	3 (38)	0 (0)	3 (27)	
Recipient sex	Male	4 (50)	0 (0)	4 (36)	
	Female	4 (50)	3 (100)	7 (64)	
Recipient ethnicity	White	7 (88)	2 (67)	9 (82)	
	Asian	0 (0)	1 (33)	1 (9)	
	Other	1 (13)	0 (0)	1 (9)	
Recipient age (years)	Median (IQR) ¹	6 (4, 13)	-	7 (2, 13)	
	Missing	0	0	0	
Height (cm)	Median (IQR) ¹	119 (90, 154)	-	126 (88, 149)	
	Missing	0	0	0	
Weight (kg)	Median (IQR) ¹	22 (12, 54)	-	22 (13, 53)	
	Missing	0	0	0	
Primary Disease	Cystic fibrosis and bronchiectasis	0 (0)	1 (33)	1 (9)	
	Fibrosing lung disease	1 (13)	1 (33)	2 (18)	
	Primary pulmonary hypertension	5 (63)	1 (33)	6 (55)	
	Other heart/lung disease	2 (25)	0 (0)	2 (18)	
¹ Medians for groups with	less than 5 registrations are not presented	d due to small numbers	3		

9.3 Post-registration outcomes, 1 April 2018 – 31 March 2020

The registration outcomes of paediatric patients listed for a non-urgent lung transplant between 1 April 2018 and 31 March 2020 are summarised in **Figure 9.4**. 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, 57% were transplanted, 14% became urgent, and 29% were still waiting. After three years, the transplant rate had increased to 86% and the percentage moved to the urgent list had remained at 14%. Due to small numbers, outcomes on the urgent or super-urgent lists are not presented.





9.4 Median waiting time to transplant, 1 April 2019 - 31 March 2022

The <u>median</u> waiting time to lung transplant from non-urgent registration for paediatric patients registered between 1 April 2019 to 31 March 2022 is shown in **Table 9.2**. This is estimated using the <u>Kaplan Meier</u> method. Any suspended time is discounted, but any time on the urgent list, which was introduced in May 2017, is included. The national median waiting time to paediatric lung transplant was 1,044 days.

Table 9.2 Median active waiting time to lung transplant for paediatric patients registered onthe transplant list, by centre, 1 April 2019 to 31 March 2022						
Transplant centre	Number registered	Number transplanted	W Median	aiting time (days) 95% Confidence interval		
Non-urgent at initial registration						
Great Ormond Street ¹	9	5	-	-		
Newcastle ¹	2	0	-	-		
ик	11	5	1044	38 - 1458		
¹ Median waiting time for groups with less than 10 patients are not presented due to small numbers						

PAEDIATRIC LUNG TRANSPLANTATION

Response to Offers



10. Response to Offers

Table 10.1 compares individual centre paediatric bilateral lung offer decline rates between 1 April 2020 to 31 March 2023. 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 lung, 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 100% and was the same at both centres.

Table 10.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2020 to 31 March 2023					
Centre	Number of offers	Decline rate (%)			
Great Ormond Street Hospital Newcastle	4 4	(100.0) (100.0)			
UK	8	(100.0)			

PAEDIATRIC LUNG TRANSPLANTATION

Transplants



11.1 Paediatric lung and heart-lung transplants, 1 April 2013 – 31 March 2023

Figure 11.1 and **11.2** show the number of paediatric lung and heart-lung transplants performed in the last ten years by donor type, nationally and by centre, respectively. The number of transplants increased between 2013/2014 and 2016/2017 but has since decreased to just one in 2022/2023. 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 (2022/2023) is shown by donor type in **Figure 11.3**.





Figure 11.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2013 to 31 March 2023





Figure 11.4 and 11.5 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.







Figure 11.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2013 to 31 March 2023

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 11.6** 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 11.7**. The only transplant last year was performed in an urgent recipient.





Figure 11.7 Number of paediatric lung only transplants in the UK, by centre and urgency, 1 April 2022 to 31 March 2023


11.2 Demographic characteristics of transplants, 1 April 2013 – 31 March 2023

The demographic characteristics of the 60 paediatric lung transplant recipients and donors in the last ten years are shown by centre and overall in **Table 11.1**. Nationally, 57% of lung recipients were female and the <u>median</u> age was 13 years, while the median age of donors was 13 years. For some characteristics, due to rounding, percentages may not add up to 100.

Table 11.1Demographic characteristics of UK paediatric lung transplants performed between 1 April 2013 and 31 March 2023, by centre				
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		46 (100)	14 (100)	60 (100)
Urgency status at transplant	Non-urgent	40 (87)	10 (71)	50 (83)
	Urgent Super-urgent	6 (13) 0 (0)	3 (21) 1 (7)	9 (15) 1 (2)
Recipient sex	Male	17 (37)	9 (64)	26 (43)
	Female	29 (63)	5 (36)	34 (57)
Recipient ethnicity	White	41 (89)	13 (93)	54 (90)
	Asian	3 (7)	1 (7)	4 (7)
	Black	1 (2)	0 (0)	1 (2)
	MISSING	Γ(Ζ)	0(0)	1 (2)
Recipient age (years)	Median (IQR) Missing	13 (9, 14) 0	14 (10, 15) 0	13 (9, 15) 0
Recipient weight (kg)	Median (IQR)	35 (23, 46)	39 (28, 41)	37 (24, 44)
	Wissing	0	0	0
Recipient primary disease	Cystic fibrosis and bronchiectasis	18 (39)	10 (71)	28 (47)
	Fibrosing lung disease	2 (4)	1 (7)	3 (5)
	Primary pulmonary	17 (37)	2 (14)	19 (32)
	Other heart/lung disease	9 (20)	1 (7)	10 (17)
Recipient in hospital	No	36 (78)	6 (43)	42 (70)
	Yes	9 (20)	7 (50)	16 (27)
	Missing	1 (2)	1 (7)	2 (3)
In hospital, recipient on	No	8 (89)	6 (86)	14 (88)
ventilator	Yes	1 (11)	1 (14)	2 (13)
In hospital, recipient ECMO	No	9 (100)	5 (71)	14 (88)
	Yes	0 (0)	1 (14)	1 (6)
	Missing	0 (0)	1 (14)	1 (6)
In hospital, recipient on	No	7 (78)	4 (57)	11 (69)
inotropes	Yes	2 (22)	3 (43)	5 (31)
Recipient CMV status	No	35 (76)	11 (79)	46 (77)
	Yes	11 (24)́	1 (7)	12 (20)
	Missing	0 (0)	2 (14)	2 (3)

Table 11.1Demographic characteristics of UK paediatric lung transplants performed between 1 April 2013 and 31 March 2023, by centre					
		Great Ormond Street	Newcastle	TOTAL	
		N (%)	N (%)	N (%)	
Recipient HCV status	No	45 (98)	13 (93)	58 (97)	
	Missing	1 (2)	1 (7)	2 (3)	
Recipient HBV status	No	45 (98)	13 (93)	58 (97)	
	Missing	1 (2)	1 (7)	2 (3)	
			()	(-)	
Recipient HIV status	No	45 (98)	13 (93)	58 (97)	
	Missing	1 (2)	1 (7)	2 (3)	
Desisiont Corum Creatining	Madian (IOD)	40 (00 50)	40 (07 55)	AO (00 EE)	
(umol/l)	Missing	40 (29, 50)	42 (27, 55)	40 (28, 55) 10	
	MISSING	0	2	10	
Donor sex	Male	21 (46)	6 (43)	27 (45)	
	Female	25 (54)	8 (57)	33 (55)	
Donor ethnicity	White	37 (80)	11 (79)	48 (80)	
	Asian	1 (2)	0 (0)	1 (2)	
	Other	2 (4)	1 (7)	3 (5)	
	Missing	6 (13)	2 (14)	8 (13)	
Dopor age (years)	Median (IOR)	15 (8 41)	10 (7 14)	13 (8 28)	
Donor age (years)	Missing	0	0(7, 14)	0	
	inicoling	0	Ũ	C C	
Donor BMI (kg/m ²)	Median (IQR)	19 (16, 23)	18 (15, 21)	19 (15, 23)	
	Missing	0	0	0	
Donor cause of death	Intracranial/CVA	25 (54)	9 (64)	34 (57)	
	Othere	4 (9 <i>)</i> 17 (27)	2 (14) 2 (21)	0(10)	
	Others	17 (37)	3 (21)	20 (33)	
Donor hypotension	No	27 (59)	8 (57)	35 (58)	
	Yes	12 (26)	4 (29)	16 (27)	
	Missing	7 (15)	2 (14)	9 (Ì5)	
		/			
Donor past cardio disease	No	38 (83)	13 (93)	51 (85)	
	Yes	1 (2)	0(0)	1 (2)	
	MISSING	7 (15)	1(7)	8 (13)	
Donor past hypertension	No	39 (85)	11 (79)	50 (83)	
2 oner paet hyperteneien	Yes	1 (2)	1 (7)	2 (3)	
	Missing	6 (13)	2 (14)	8 (13)	
	-				
Donor past tumour	No	38 (83)	12 (86)	50 (83)	
	Yes	2 (4)	0 (0)	2 (3)	
	Missing	6 (13)	2 (14)	8 (13)	
Donor past smoker	No	33 (70)	12 (02)	AG (77)	
	Yes	8 (17)	0 (0)	8 (13)	
	Missing	5 (11)	1 (7)	6 (10)	
			• \• /	- (- •)	
Total ischaemia time (hours)	Median (IQR)	5.3 (4.6, 6.2)	5.5 (5.2, 5.8)	5.3 (4.7, 6.1)	
	Missing	5	2	7	

Table 11.1	Demographic characteristics of UK paedia and 31 March 2023, by centre	atric lung transplants pe	rformed betweer	n 1 April 2013
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Transplant ty	be Bilateral lung	44 (96)	13 (93)	57 (95)
	Heart/lung	2 (4)	1 (7)	3 (5)

Г

11.3 Total ischaemia time, 1 April 2013 – 31 March 2023

Figure 11.8 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 (\leq 10). No further breakdown by centre is shown due to small numbers. In the financial year 2022/2023, there was only one transplant, so the boxplot for that year is not displayed.



Figure 11.8 Boxplots of total ischaemia time in DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2013 to 31 March 2023

PAEDIATRIC LUNG TRANSPLANTATION

Post-Transplant Survival



12. Post-Transplant Survival

Ē

The survival analyses presented in this section exclude heart-lung transplants and other <u>multi-organ transplants</u> and include first time transplants only. Partial lung transplants are also excluded. Both DBD and DCD lung transplants are included. Ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2018 and 31 March 2022 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2018 and 31 March 2014 and 31 March 2018.

The 90-day post-transplant <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 12.1** for the 14 first paediatric lung only transplants in the period 1 April 2018 and 31 March 2022. Only 3 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 100%.

Table 12.1 90 day patient survival rates after first paediatric lung transplants, by centre,1 April 2018 and 31 March 2022					
Centre	Number of patients	Number of deaths	% 90 day sur (<mark>unad</mark>	vival (95% CI) j <u>usted</u>)	
Great Ormond Street Hospital	11	0	100.0	-	
Newcastle ¹	3	0	-	-	
UK	14	0	100.0	-	
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers					

There were 3 deaths between 90 days and 1 year for the 14 paediatric lung only transplants performed in the period 1 April 2018 and 31 March 2022; 1 from Great Ormond Street Hospital and 2 from Newcastle.

Table 12.2 1 year patient survival rates after first paediatric lung transplants, by centre,1 April 2018 and 31 March 2022						
Centre	Number of patients	Number of deaths	% 1 year s (<u>un</u>	survival (95% CI) <u>adjusted</u>)		
Great Ormond Street Hospital Newcastle ¹	11 3	1 2	90.9 -	(50.8 - 98.7) -		
UK 14 3 78.6 (47.2 - 92.5)						
¹ Survival rates for groups with less than 10 patients are not presented due to small numbers						

Five year <u>survival rates</u> were estimated from the 34 first lung only transplants performed in the period 1 April 2014 and 31 March 2018. The unadjusted patient <u>survival rates</u> are shown in **Table 12.3**.

_

Table 12.3 5 year patient survival rates after first paediatric lung transplants, by centre,1 April 2014 and 31 March 2018						
Centre	Number of patients	Number of deaths	% 5 year s (<u>un</u>	survival (95% CI) <u>adjusted</u>)		
Great Ormond Street Hospital Newcastle ¹	26 8	8 4	68.8 -	(47.2 - 83.0) -		
UK	34	12	61.7	(42.3 - 76.3)		
¹ Survival rates for groups with less tha	in 10 patients are no	ot presented due	e to small num	pers		

PAEDIATRIC LUNG TRANSPLANTATION Form Return Rates



13. Paediatric lung form return rates, 1 January – 31 December 2022

Form return rates are reported in **Table 13.1** 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 2022 for the transplant record, and all follow up forms issued in this time period. There is 1 outstanding form for this period for Great Ormond Street Hospital.

Table 13.1 Form return rat	es for paed	iatric lung	transplants	s, 1 Januar	y 2022 to 31	l Decembo	er 2022	
Centre	Transplai No. requested	nt record % returned	3 month f No. requested	ollow-up % returned	1 year fo No. requested	ollow-up % returned	Lifetime f No. requested	ollow-up % returned
Great Ormond Street Hospital Newcastle, Freeman Hospital	1	100	1	100	3	100	11 13	91 100
Overall	1	100	1	100	3	100	24	96

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. lung (+ heart-lung) transplants
1 April 2013 – 31 March 2023	Introduction	None	1553
1 April 2013 – 31 March 2023	Transplants	<u>Multi-organ transplants</u>	1548
1 April 2018 – 31 March 2022	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ transplants</u> Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants Group 2 transplants 	491
1 April 2014 – 31 March 2018	Post-transplant survival – • 5-year survival	 <u>Multi-organ transplants</u> Heart-lung transplants excluded from main analysis Partial lung transplants Second (or more) transplants Group 2 transplants 	698

Table A1.2 Paediatric transplants analysed						
Time period	Report Section	Exclusion criteria	No. lung (+ heart-lung) transplants			
1 April 2012 – 31 March 2022	Introduction	None	60			
1 April 2012 – 31 March 2022	Transplants	<u>Multi-organ transplants</u>	60			
1 April 2018 – 31 March 2022	Post-transplant survival – • 30/90-day • 1-year survival	 <u>Multi-organ transplants</u> Heart-lung transplants Partial lung transplants Second (or more) transplants Group 2 transplants 	14			
1 April 2014 – 31 March 2018	Post-transplant survival – • 5-year survival	 <u>Multi-organ transplants</u> (including heart-lung transplants) Partial lung transplants Second (or more) transplants Group 2 transplants 	34			

Geographical variation analysis

Registration rates

All NHS group 1 patients who were registered onto the lung transplant list with an active status between 1 April 2022 and 31 March 2023 were extracted from the UK Transplant Registry on 29 June 2023 (numerator). Patients registered for a heart-lung block were included. 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-2021 population estimates based on the Office for National Statistics (ONS) 2021 Census figures (denominator). No NHS region age- or sex-specific standardisation of rates was performed.

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

Transplant rates

Transplant rates pmp were obtained as the number of lung transplants on NHS group 1 recipients between 1 April 2022 and 31 March 2023 (numerator), divided by the mid-2021 population estimates from the ONS (denominator). Patients who received a heart-lung block transplant were included. 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 2022 and 31 March 2023 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 lung transplant in the time period, only the first transplant was considered.

A2: Methods

Offer decline rates

The offer decline rate analysis was limited to lung offers from <u>DBD</u> donors who died at a UK hospital and the lung was eventually accepted and transplanted. Any offers from DCD donors were excluded.

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

Unadjusted post-transplant survival rates

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

Risk-adjusted post-transplant survival rates

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

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

Missing values for <u>risk factors</u> were imputed using simple imputation of the median or most common group for the adult lung model (where missing values represented <10% of the cohort). Missing ischaemia time (2% of cohort) was imputed with a centre and year specific median.

Funnel plots

The funnel plot is a graphical method to show how consistent the <u>survival rates</u> of the different transplant centres are compared to the national rate. The graph shows for each centre, a survival rate plotted against the number of transplants undertaken, with the national rate and <u>confidence limits</u> around this national rate superimposed. In this report,

95% and 99.8% <u>confidence limits</u> were used. Units that lie within the <u>confidence limits</u> have survival rates that are statistically consistent with the national rate. When a unit is close to or outside the limits, this is an indication that the centre may have a rate that is considerably different from the national rate.

Systematic component of variation

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

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

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

Survival from listing

Data were obtained for all patients \geq 18 years registered for the first time for a heart or lung transplant between 1 January 2011 and 31 December 2022. 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 3 July 2023 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

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 model for patient survival from listing 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 A3.1Risk factors5-year survival m	categories used in the adult lung risk adjusted 90-day. 1- year and odel
Donor type	DBD DCD
Donor age group	<30 30-<40 40-<50 >=50
Donor respiratory arrest	No Yes
Donor past smoker	No Yes
Recipient BMI group	<25 25-<30 >=30
Recipient ethnic group	White Ethnic minority group
Recipient bilirubin at registration (logged)) (modelled as continuous variable)
Recipient diabetes at registration	No Yes
Recipient eGFR group at transplant	>=90 <90
Recipient hospital status	Outpatient Inpatient
Ischaemia time (hours) Transplant type	Non-linear spline with knots at 2.9, 4.6, 5.8, 9.1 Single lung Bilateral lung
Donor/recipient blood group mismatch	Identical Compatible
Donor/recipient CMV mismatch	D-R- D+R+ D-R+ D+R-

A4: Glossary of terms

Active transplant list

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

Boxplots

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

Case mix

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

Confidence interval (CI)

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

Confidence limit

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

Cox Proportional Hazards model

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

Donor after brain death (DBD)

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

Donor after circulatory death (DCD)

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

Funnel plot

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

Inter-quartile range

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

Kaplan-Meier method

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

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 lung and kidney.

Patient survival rate

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

p value

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

Risk-adjusted survival rate

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

Risk factors

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

Unadjusted survival rate

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

Prepared by:

Statistics and Clinical Research, NHS Blood and Transplant

Miguel Reyes Lewis Simmonds Rachel Hogg

