

## ANNUAL REPORT ON LUNG TRANSPLANTATION

REPORT FOR 2023/2024 (1 APRIL 2014 – 31 MARCH 2024)

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PRODUCED IN COLLABORATION WITH NHS ENGLAND

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### **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 2014 to 31 March 2024. 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 15 July 2024.

#### **Key findings**

#### ADULT LUNG TRANSPLANTATION

- On 31 March 2024 there were 262 adults waiting for a lung transplant: 251 non-urgent,5 urgent and 6 heart-lung. In comparison to 31 March 2023, this number has decreased by 8%.
- One year mortality was 18% on the non-urgent waiting list and 19% on the urgent waiting list (including removals due to deteriorating condition).
- Median waiting time to lung transplant was 530 days from non-urgent registration and 22 days from urgent registration.
- During 2023/2024 there were 135 adult lung transplants including 4 heart-lung transplants. This was 35% higher than the previous year but remained lower than pre COVID-19 pandemic. Of the 135 transplants, 18% were urgent or super-urgent.
- The national rate of patient survival following adult lung transplant was 88.7% at 90 days, 80.7% at 1 year and 56.2% at 5 years.

#### PAEDIATRIC LUNG TRANSPLANTATION

- On 31 March 2024 there were 13 paediatric patients waiting for a lung or heart-lung transplant: 9 non-urgent, 2 urgent and 2 heart-lung. Median waiting time to transplant was 1,044 days from non-urgent registration.
- During 2023/2024, there were 4 paediatric lung transplants, 3 more than the previous year. These transplants were performed at Great Ormond Street Hospital, with 2 being non-urgent and the other 2 urgent.
- The national rate of patient survival following paediatric lung transplant was 100% at 90 days, 80.0% at 1 year and 58.4% at 5 years.

Use of the contents of this report should be acknowledged as follows: *Annual Report on Lung Transplantation* 2023/2024, NHS Blood and Transplant

### INTRODUCTION

#### 2. Introduction

This report presents data on activity and outcomes of lung transplant candidates and recipients between 1 April 2014 and 31 March 2024, 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 cardiothoracic organ 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 and post-transplant survival is considered in <u>Section 6.4</u>. Other <u>multi-organ transplants</u> are presented separately in <u>Section 6.5</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.

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 lists</u> at financial year end between 2015 and 2024. The number of people waiting for a lung transplant decreased substantially in 2021, down to 271 from 358, and on 31 March 2024 was similar at 275.

Figure 2.1 Number of people on the national active lung and heart-lung transplant lists on 31 March each year, 2015 to 2024

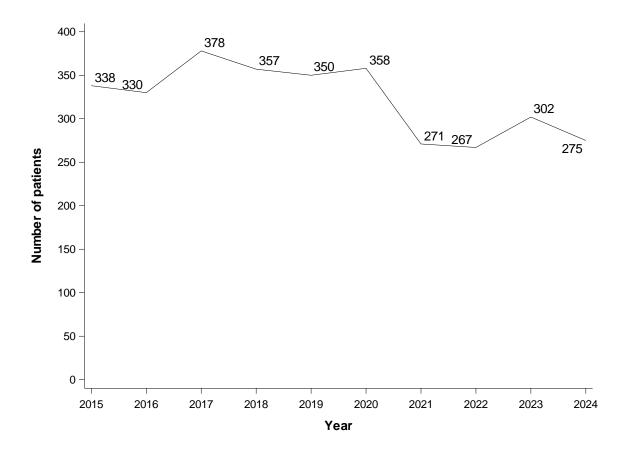
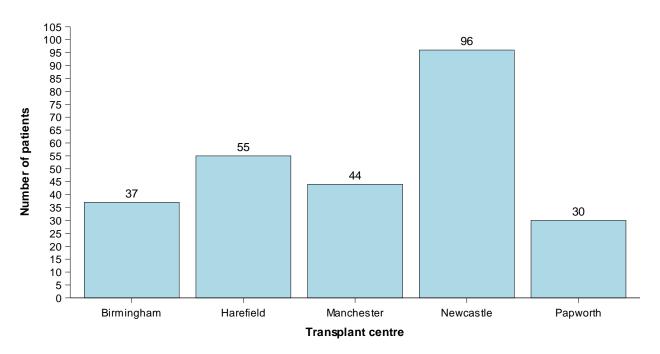


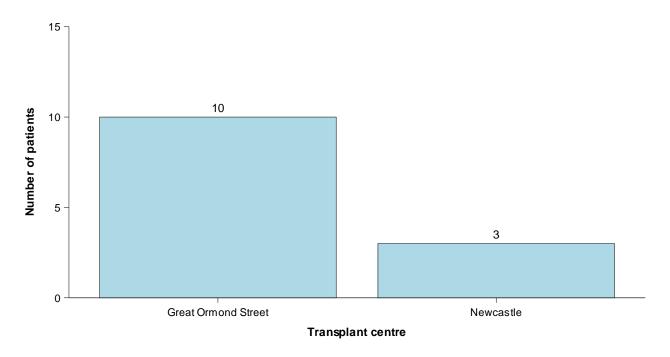
Figure 2.2 and Figure 2.3 show the number of adult and paediatric patients on the active transplant lists on 31 March 2024 at each centre. In total, there were 262 adults and 13 paediatric patients waiting for a lung transplant. Newcastle had the highest number of adults on the lung transplant list, however this number is not reflective of their local list on 31 March 2024 as many patients had died or been removed from the list without appropriate updates being made to the UK Transplant Registry. Great Ormond Street Hospital had the highest number of paediatric patients on the lung transplant list.

Figure 2.2 Number of adults on the active lung transplant list on 31 March 2024, by centre



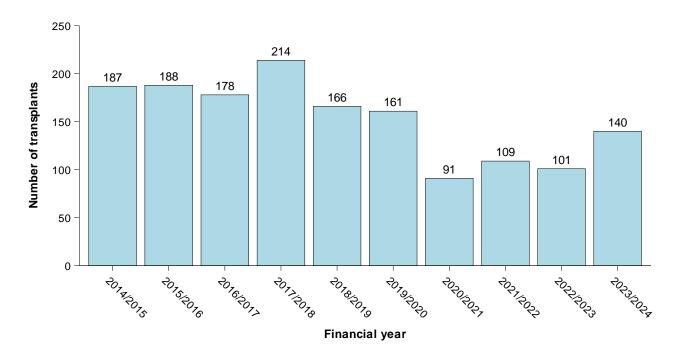
Note: Waiting list figures for Newcastle are not reflective of their local list on 31 March 2024 due to patients having died or been removed from the list without appropriate updates being made to the UK Transplant Registry

Figure 2.3 Number of paediatric patients on the active lung transplant transplant list on 31 March 2024, by centre



**Figure 2.4** shows the total number of transplants performed in each of the last ten financial years. The number of lung transplants last year increased by 39% to 140 but remained lower than pre COVID-19 pandemic.

Figure 2.4 Number of lung transplants in the UK, by financial year, 1 April 2014 to 31 March 2024



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

Figure 2.5 Number of adult lung transplants in the UK, by centre, 1 April 2023 to 31 March 2024

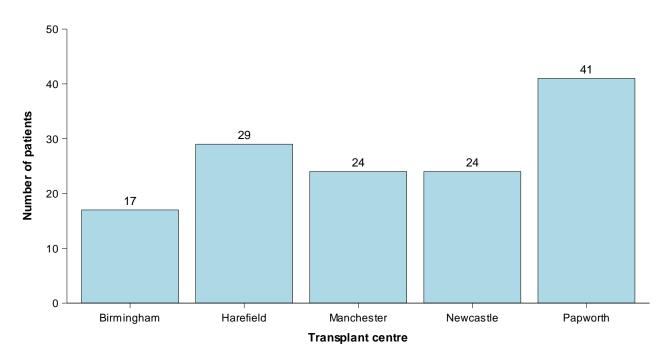
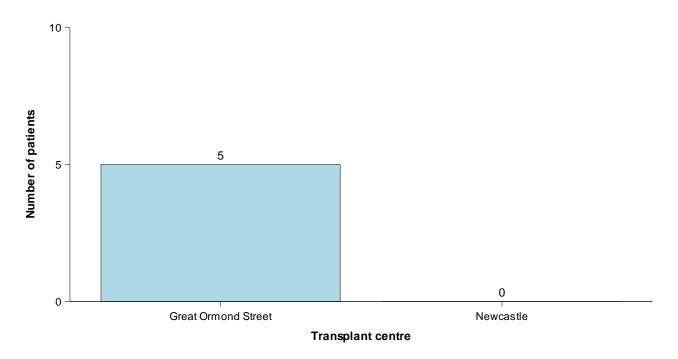
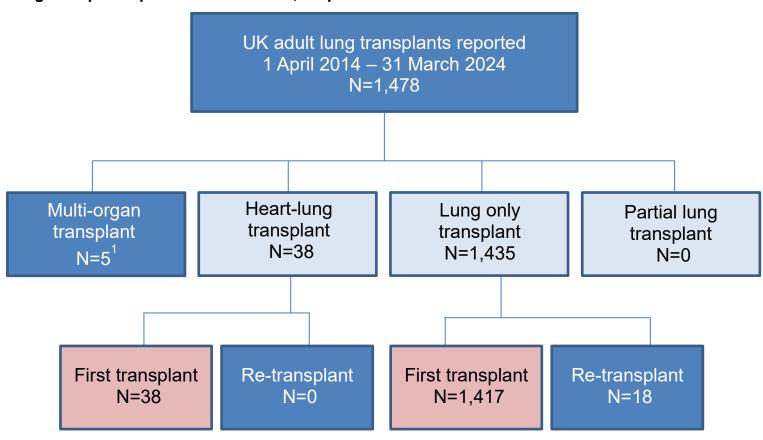


Figure 2.6 Number of paediatric lung transplants in the UK, by centre, 1 April 2023 to 31 March 2024



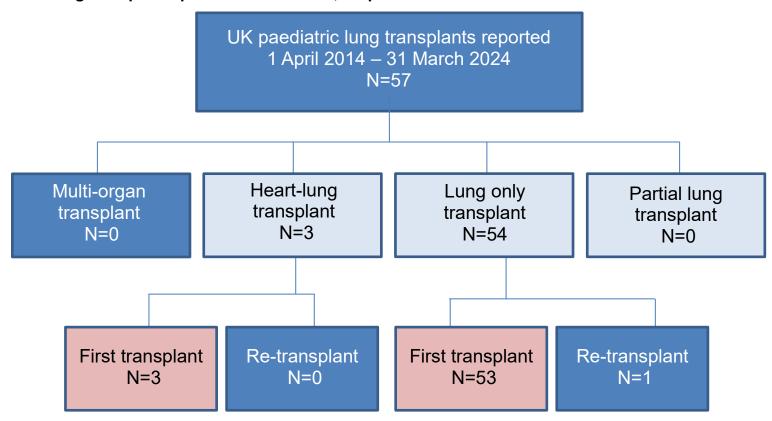
**Figure 2.7** shows a breakdown of the 1,478 adult lung transplants performed in the UK in the ten-year period while **Figure 2.8** shows a similar breakdown for the 57 paediatric transplants performed during the same period. Re-transplants are included in the transplant activity sections of this report 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 section (Sections 6.5).

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



<sup>&</sup>lt;sup>1</sup> Includes 4 lung and liver and 1 lung and kidney transplant

Figure 2.8 Paediatric lung transplants performed in the UK, 1 April 2014 to 31 March 2024

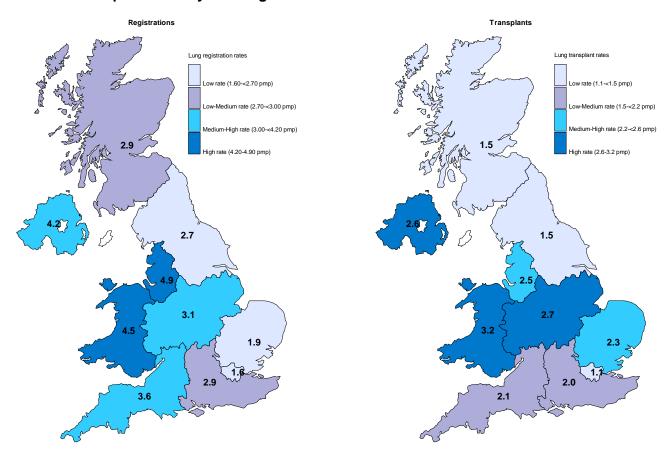


#### 2.2 Geographical variation in registration and transplant rates

**Figure 2.9** shows rates of registration to the lung transplant list per million population (pmp) between 1 April 2023 and 31 March 2024 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 3.0 pmp and 2.1 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 0.0818 (p-value = 0.003) and 0.0052 (p-value = 0.279), 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 indicates that there is significant evidence of systematic variation in registration rates between areas but not in transplant rates. 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

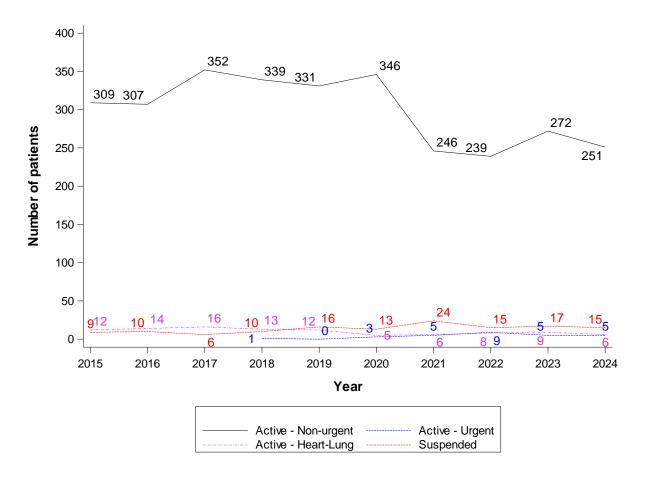


Lung registration and transplant rates per million population (pmp) in the UK, Table 2.1 1 April 2023 - 31 March 2024, by Country/NHS region Country/ Registrations (pmp) Transplants (pmp) **NHS** region North East and Yorkshire 22 (2.7)12 (1.5)North West 37 (4.9)19 (2.5)Midlands 34 (3.1)30 (2.7)East of England 12 (1.9)15 (2.3)London 10 (1.1)14 (1.6)South East (2.0)27 (2.9)19 South West 21 (3.6)12 (2.1)**England** 167 (2.9)117 (2.0)Isle of Man (0.0)(0.0)0 0 **Channel Islands** (0.0)0 (0.0)0 Wales 14 (4.5)10 (3.2)**Scotland** (2.9)8 16 (1.5)**Northern Ireland** 8 (4.2)5 (2.6)**TOTAL** 205 (3.0)140 (2.1)

# ADULT LUNG TRANSPLANTATION Transplant List

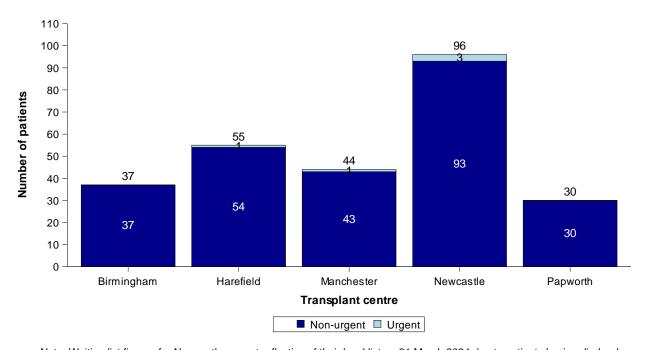
**Figure 3.1** shows the number of adults on the lung and heart-lung transplant lists on 31 March each year between 2015 and 2024 split by urgency status. The number on the active non-urgent lung transplant list increased until 2017 when it remained relatively stable for a few years and then dropped significantly in 2021 and remained relatively low on 31 March 2024 at 251. 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 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 heart and heart-lung transplant lists on 31 March each year, by urgency status



**Figure 3.2** shows the number of adults on the <u>active lung and heart-lung transplant lists</u> on 31 March 2024, by centre and urgency. In total, there were 262 adults waiting, including 5 on the urgent list across Harefield, Manchester and Newcastle. Newcastle had the highest number of people registered on the transplant list, however this number is not reflective of their local list on 31 March 2024 as many patients had died or been removed from the list without appropriate updates being made to the UK Transplant Registry.

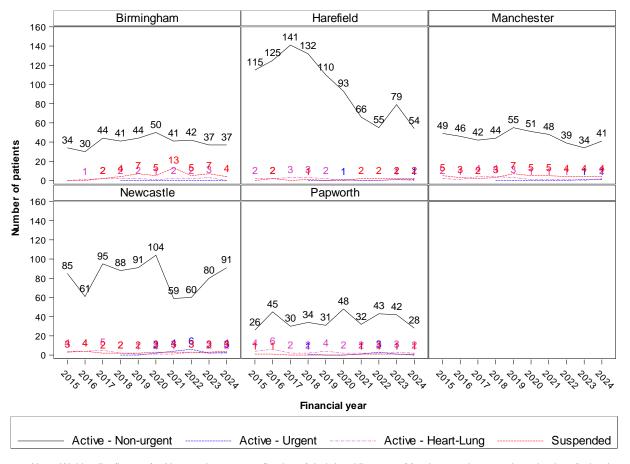
Figure 3.2 Number of adults on the active lung and heart-lung transplant lists on 31 March 2024, by centre and urgency



Note: Waiting list figures for Newcastle are not reflective of their local list on 31 March 2024 due to patients having died or been removed from the list without appropriate updates being made to the UK Transplant Registry

**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 have experienced a substantial decreased in their lung list since 2017, whilst other centres haven't experienced this trend. 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 and heart-lung transplant lists on 31 March each year, for the last 10 years, by centre



Note: Waiting list figures for Newcastle are not reflective of their local list on 31 March 2024 due to patients having died or been removed from the list without appropriate updates being made to the UK Transplant Registry

#### 3.2 Demographic characteristics, 1 April 2023 – 31 March 2024

There were 201 adult registrations onto the lung or heart-lung transplant lists between 1 April 2023 and 31 March 2024. Demographic characteristics of these individuals are shown by centre and overall in Table 3.1. Nationally, 67% were male and the median age was 56 years. The most common primary disease group was fibrosing lung disease. For some characteristics, due to rounding, percentages may not add up to 100.

Demographic characteristics of adult patient registrations onto the lung and heart-lung transplant lists between Table 3.1 1 April 2023 and 31 March 2024, by centre TOTAL Birmingham Harefield **Papworth** Manchester Newcastle N (%) N (%) N (%) N (%) N (%) N (%) Number of registrations 32 (100) 41 (100) 45 (100) 43 (100) 40 (100) 201 (100) Non-urgent 30 (94) 39 (87) 35 (81) 177 (88) Highest urgency during 38 (93) 35 (88) 2 (6) 2 (5) 4 (10) 19 (10) registration Urgent 5 (11) 6 (14) 1 (2) 1 (2) 2 (5) 5 (3) Super-urgent 0(0)1 (3) Recipient sex 26 (58) Male 19 (59) 31 (76) 30 (70) 28 (70) 134 (67) 10 (24) 19 (42) 12 (30) 67 (33) Female 13 (41) 13 (30) Recipient ethnicity White 28 (88) 35 (85) 40 (89) 41 (95) 36 (90) 180 (90) 3 (9) 2 (5) 2 (4) 1 (2) 2 (5) 10 (5) Asian 2 (5) 3 (8) 1 (2) 7 (4) Black 1 (3) 0(0)1 (2) 0 (0) 0(0)0 (0) Other 0(0)1 (1) Missing 0(0)0(0)2 (4) 1 (2) 0(0)3 (2) Recipient age (years) Median (IQR) 59 (52, 62) 52 (36, 57) 54 (49, 60) 58 (54, 60) 58 (51, 61) 56 (49, 60) Missing

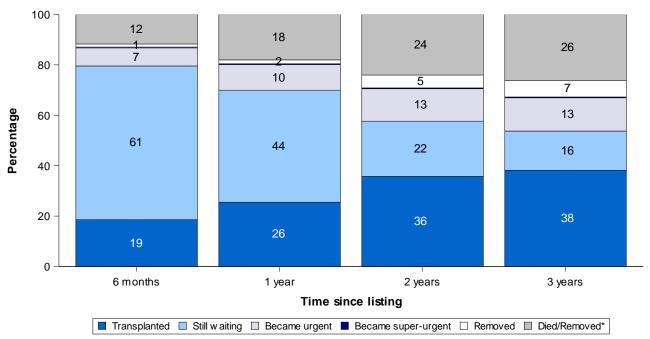
Table 3.1 Demographic characteristics of adult patient registrations onto the lung and heart-lung transplant lists between 1 April 2023 and 31 March 2024, by centre Birmingham Harefield Manchester Newcastle Papworth **TOTAL** N (%) N (%) N (%) N (%) N (%) N (%) **Primary Disease** Cystic fibrosis and 2 (5) 2 (5) 18 (9) 1 (3) 10 (24) 3 (7) bronchiectasis Fibrosing lung disease 19 (59) 22 (49) 26 (60) 28 (70) 111 (55) 16 (39) COPD and emphysema 9 (28) 11 (24) 12 (28) 46 (23) 11 (27) 3 (8) Primary pulmonary 3 (9) 9 (20) 3 (7) 7 (18) 26 (13) 4 (10) hypertension and other lung diseases Smoker No 31 (97) 41 (100) 45 (100) 42 (98) 40 (100) 199 (99) Yes 0(0)0(0)0(0)1 (2) 0(0)1 (1) Missing 1 (3) 0 (0) 0 (0) 0 (0) 0 (0) 1 (1) Lung function - FEV1 Median (IQR) 1.21 (0.70, 1.75) 0.95 (0.70, 1.85) 1.23 (0.80, 1.67) 1.44 (0.69, 1.69) 1.69 (1.27, 2.10) 1.40 (0.77, 1.86) Missing (litres) 13 Lung function - FVC Median (IQR) 1.82 (1.36, 2.74) 2.49 (1.85, 2.96) 2.06 (1.42, 2.94) 2.20 (1.69, 3.04) 2.24 (1.68, 2.85) 2.17 (1.57, 2.96) (litres) Missing 4 14

#### 3.3 Post-registration outcomes, 1 April 2019 – 31 March 2021

The registration outcomes of adults listed for a lung only transplant between 1 April 2019 and 31 March 2021 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. Removals from the list due to deteriorating condition are grouped with deaths in this analysis. 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.

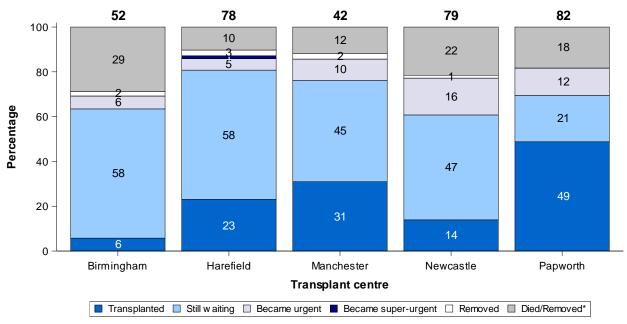
Nationally, within six months of non-urgent registration, 19% of lung registrations resulted in transplant and 12% had died. Three years after listing, 38% has received a transplant and 26% had died. By centre (**Figure 3.5**), within 1 year of registration, the proportion transplanted ranged from 6% at Birmingham to 49% at Papworth and the proportion dying on the list ranged from 10% at Harefield to 29% at Birmingham. Removals from the non-urgent list were predominantly due to deteriorating condition.

Figure 3.4 Post-registration outcome for 333 non-urgent lung only registrations made in the UK, 1 April 2019 to 31 March 2021



<sup>\*</sup>Removals due to condition deteriorating

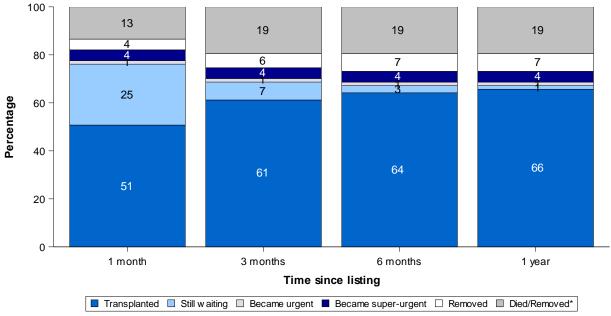
Figure 3.5 1 year post-registration outcomes for 333 non-urgent lung only registrations made in the UK, by centre,
1 April 2019 to 31 March 2021



\*Removals due to condition deteriorating

**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, 64% 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 67 urgent lung only registrations made in the UK, 1 April 2019 to 31 March 2021



\*Removals due to condition deteriorating

#### 3.4 Median waiting time to transplant, 1 April 2020 - 31 March 2023

The <u>median</u> 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 2020 and 31 March 2023 using the <u>Kaplan Meier</u> method. The national non-urgent <u>median</u> waiting time was 530 days and ranged from 267 days at Papworth to 809 days at Birmingham (log-rank p<0.0001). The national urgent <u>median</u> waiting time was 22 days. Median waiting time is not presented for super-urgent registrations, due to low frequency of patients initially registered as super-urgent.

Figure 3.7 Median active waiting time to non-urgent lung transplant for adults registered between 1 April 2020 and 31 March 2023, by centre

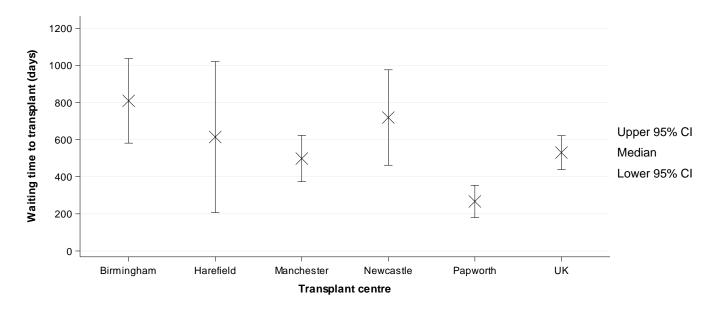


Table 3.2 Median active waiting time to lung transplant for adult patients registered on the transplant list, by urgency at registration and centre,  1 April 2020 to 31 March 2023								
Transplant centre	Number of patients registered	Number transplanted	Waiting time (days) 95% Confidence Median interval					
Non-urgent at initial r	Non-urgent at initial registration							
Birmingham	70	22	809	581 - 1037				
Harefield	93	42	614	207 - 1021				
Manchester	76	37	498	373 - 623				
Newcastle	101	45	719	462 - 976				
Papworth	132	88	267	180 - 354				
UK	472	234	530	439 - 621				
Urgent at initial registration								
ик	25	18	22	11 - 33				

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 (719 days) compared with the other blood groups (log-rank p=0.002).

Figure 3.8 Median active waiting time to non-urgent lung transplant for adults registered between 1 April 2020 to 31 March 2023, by blood group

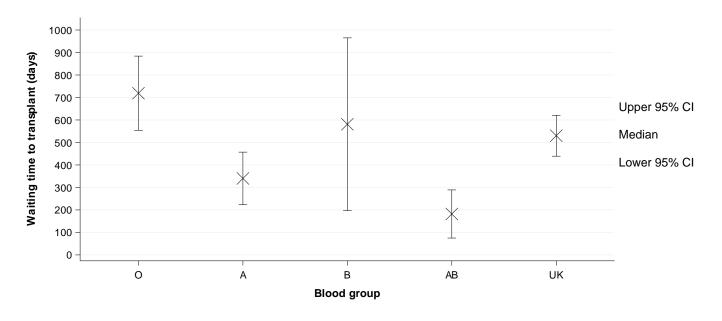


Table 3.3 Median active waiting time to lung transplant for adult patients registered on the transplant list, by urgency at registration and blood group, 1 April 2020 to 31 March 2023

Blood Group	Number of patients registered	Number transplanted	Waiting Median	ng time (days) 95% Confidence interval				
Non-urgent at initial registration								
0	215	96	719	554 - 884				
Α	194	104	340	223 - 457				
В	47	22	581	197 - 965				
AB	16	12	182	75 - 289				
UK	472	234	530	439 - 621				
Urgent at initial registration								
UK	25	18	22	11 - 33				

# ADULT LUNG TRANSPLANTATION Response to Offers

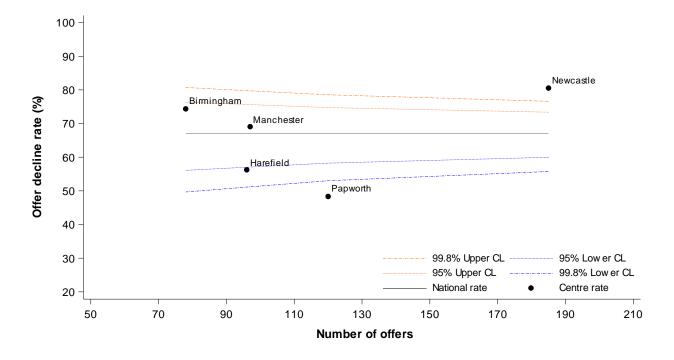
#### 4. Response to Offers

This section presents an analysis of adult DBD donor lung offer decline rates. This only considers offers of bilateral lungs between 1 April 2021 and 31 March 2024 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 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 Papworth 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 Harefield is below the 95% <u>confidence limit</u>, providing some evidence of a lower decline rate.

Figure 4.1 UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2021 to 31 March 2024



**Table 4.1** shows a breakdown of each centre's bilateral lung decline rate across the three years analysed. Nationally, the decline rate for offers of lungs that were eventually transplanted was lowest in 2023/2024.

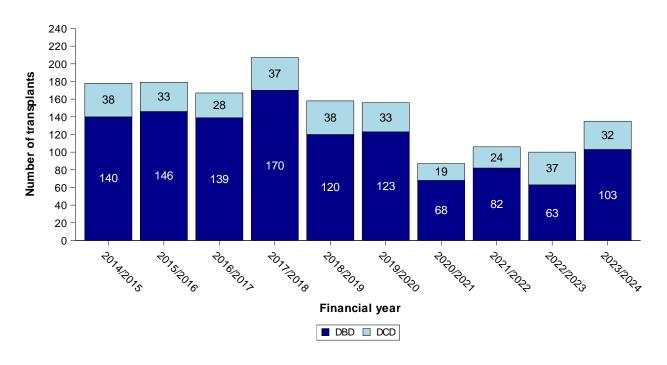
Table 4.1 Adult Bilateral Lung/Cardiac Block/ offer results by transplant centre, between 1 April 2021 and 31 March 2024								
Centre	2021/22		2022/23		2023/24		Overall	
	No. offers	Decline rate (%)						
Birmingham	19	(89.5)	24	(66.7)	35	(71.4)	78	(74.4)
Harefield	32	(40.6)	26	(69.2)	38	(60.5)	96	(56.3)
Manchester	28	(75.0)	31	(77.4)	38	(57.9)	97	(69.1)
Newcastle	77	(81.8)	41	(80.5)	67	(79.1)	185	(80.5)
Papworth	47	(55.3)	33	(60.6)	40	(30.0)	120	(48.3)
UK	203	(69.0)	155	(71.6)	218	(61.9)	576	(67.0)
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 2014 – 31 March 2024

**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 fell in 2020/2021, to 87, coinciding with the COVID-19 pandemic. Before then, annual numbers were over 150, with a peak of 207 in 2017/2018. In the latest financial year, numbers have risen slightly to 135. **Figure 5.2** shows that, in general, all centres performed more transplants in 2023/2024 compared to the previous year, except for Newcastle, which performed one fewer. Last year DCD lungs represented 24% of the total transplants. 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 2014 to 31 March 2024



32

Figure 5.2 Number of adult lung transplants in the UK, by financial year, centre and donor type, 1 April 2014 to 31 March 2024

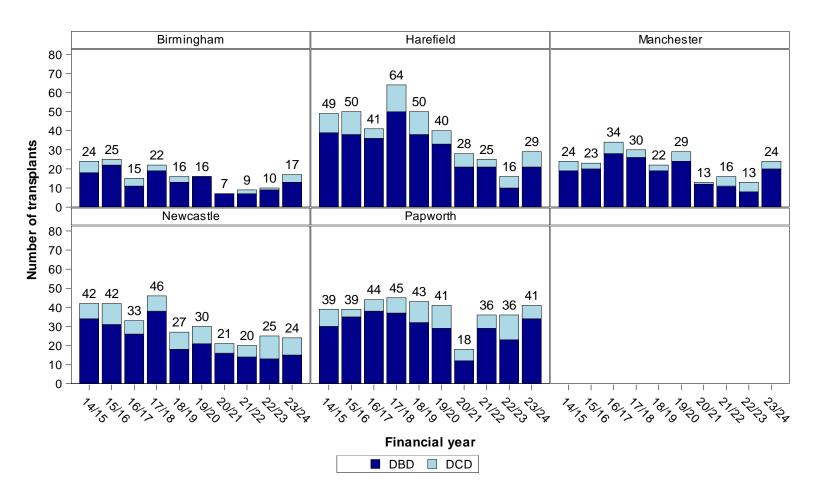
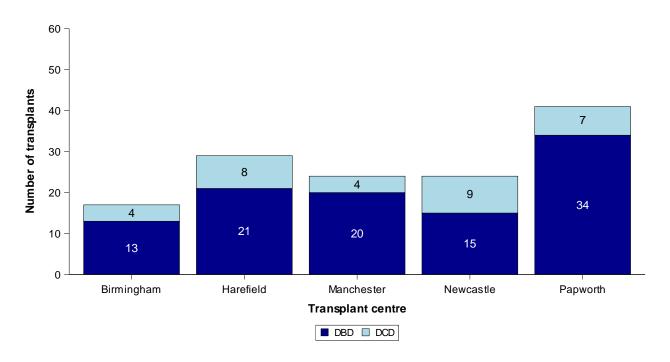


Figure 5.3 Number of adult lung transplants in the UK, by centre and donor type, 1 April 2023 to 31 March 2024



**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 was a total of 38 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, with just 5 in the most recent year. When broken down by centre, all centres have reduced their use of single lungs. In the last financial year, Papworth was the highest user of single lungs and heart-lung blocks (**Figure 5.6**).

Figure 5.4 Number of adult lung transplants in the UK, by financial year and transplant type, 1 April 2014 to 31 March 2024

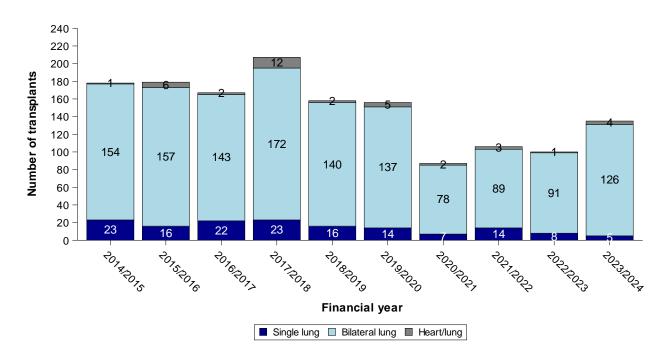


Figure 5.5 Number of adult lung transplants in the UK, by financial year, centre and transplant type, 1 April 2014 to 31 March 2024

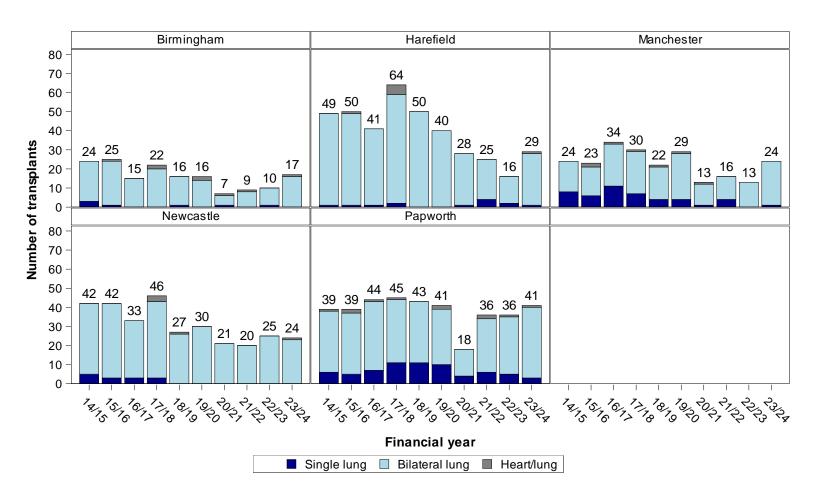
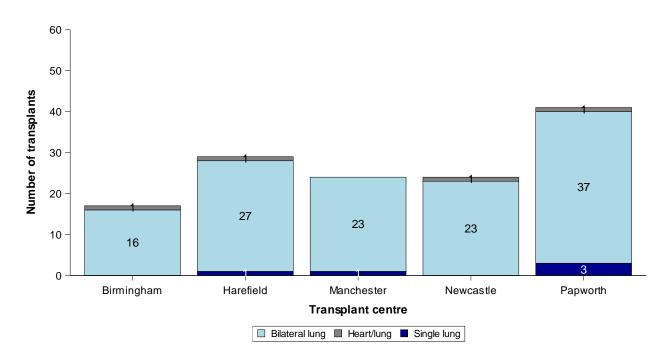
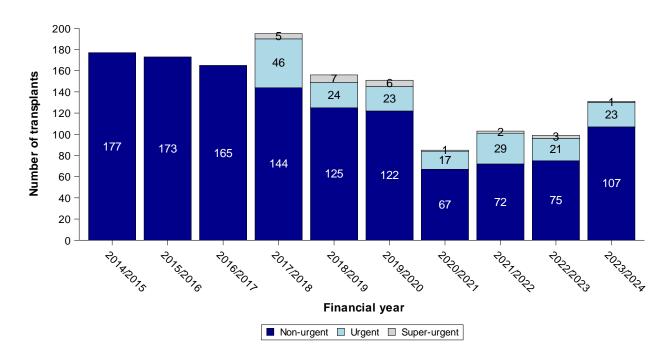


Figure 5.6 Number of adult lung transplants in the UK, by centre and transplant type, 1 April 2023 to 31 March 2024



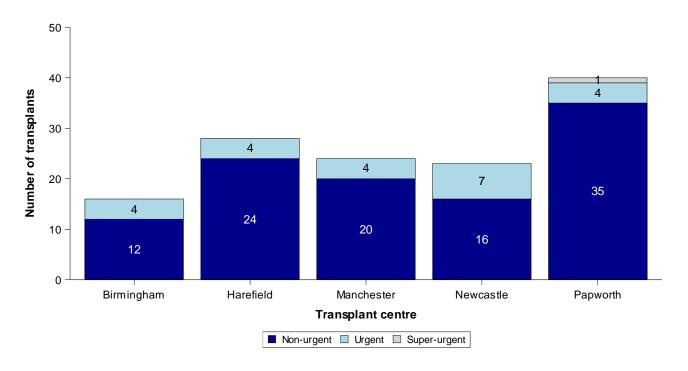
In May 2017, the super-urgent and urgent lung allocation schemes were introduced, allowing for prioritisation of the sickest patients awaiting a lung transplant. Prior to this, lung only patients had no access to a national priority list. The number of lung only transplants per year by urgency status is shown in **Figure 5.7**; the proportion of urgent or super-urgent lung transplants was 18% in 2023/2024.

Figure 5.7 Number of adult lung only transplants in the UK, by financial year and urgency status, 1 April 2014 to 31 March 2024



**Figure 5.8** shows the number of lung only transplants in the latest financial year, by urgency and centre, which shows that there were 23 urgent lung only transplants (4 at each centre apart from Newcastle which had 7) and 1 super-urgent lung only transplant at Papworth. Four adult heart-lung transplant took place in 2023/2024, and they were all urgent (not shown in the figure).

Figure 5.8 Number of adult lung only transplants in the UK, by centre and urgency status, 1 April 2023 to 31 March 2024



# 5.2 Demographic characteristics of transplants, 1 April 2023 – 31 March 2024

The demographic characteristics of the 135 adult lung and heart-lung transplant recipients and donors in the latest year are shown by centre and overall in **Table 5.1**. Nationally, 72% of lung recipients were male and the <u>median</u> age was 57 years while the median age of donors was 43 years. For some characteristics, due to rounding, percentages may not add up to 100.

		Dimesia als sas	l lava <b>t</b> ialal	Manakasta	Marrianetta	Dammenth	TOTA!
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Number of transplants		17 (100)	29 (100)	24 (100)	24 (100)	41 (100)	135 (100)
Urgency status at	Non-urgent	12 (71)	24 (83)	20 (83)	16 (67)	35 (85)	107 (79)
transplant	Urgent	5 (29)	5 (17)	4 (17)	8 (33)	5 (12)	27 (20)
•	Super-urgent	0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	1 (1)
Recipient sex	Male	12 (71)	20 (69)	21 (88)	13 (54)	31 (76)	97 (72)
·	Female	5 (29)	9 (31)	3 (13)	11 (46)	10 (24)	38 (28)
Recipient ethnicity	White	16 (94)	23 (79)	23 (96)	23 (96)	34 (83)	119 (88)
	Asian	1 (6)	1 (3)	1 (4)	0 (0)	4 (10)	7 (5)
	Black	0 (0)	5 (17)	0 (0)	0 (0)	3 (7)	8 (6)
	Missing	0 (0)	0 (0)	0 (0)	1 (4)	0 (0)	1 (1)
Recipient age (years)	Median (IQR)	58 (54, 62)	53 (37, 58)	58 (50, 63)	58 (55, 62)	57 (51, 62)	57 (49, 62)
	Missing	0	0	0	0	0	0
Recipient weight (kg)	Median (IQR)	80 (62, 84)	69 (57, 84)	76 (66, 87)	68 (60, 79)	78 (67, 91)	76 (64, 84)
	Missing	0	0	0	0	0	0
Recipient primary	Cystic fibrosis and bronchiectasis	1 (6)	8 (28)	1 (4)	1 (4)	2 (5)	13 (10)
	Fibrosing lung disease	6 (35)	11 (38)	14 (58)	7 (29)	22 (54)	60 (44)
	COPD and emphysema	9 (53)	8 (28)	7 (29)	11 (46)	9 (22)	44 (33)
	Primary pulmonary hypertension	1 (6)	2 (7)	2 (8)	5 (21)	8 (20)	18 (13

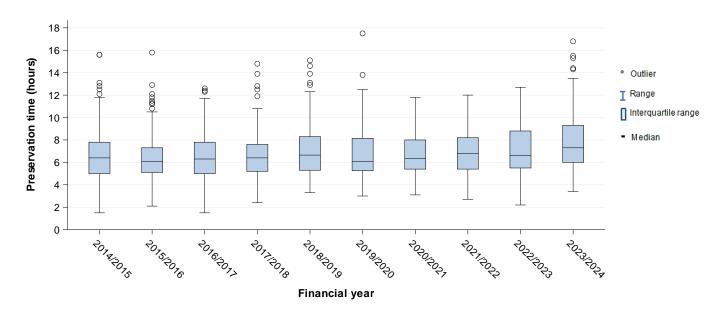
		Birmingham N (%)	Harefield N (%)	Manchester N (%)	Newcastle N (%)	Papworth N (%)	TOTAL N (%)
Recipient in hospital	No	15 (88)	26 (90)	23 (96)	19 (79)	36 (88)	119 (88
	Yes	2 (12)	3 (10)	1 (4)	5 (21)	5 (12)	16 (12
n hospital, recipient n ventilator	No	2 (100)	3 (100)	1 (100)	5 (100)	5 (100)	16 (100
n hospital, recipient	No	2 (100)	2 (67)	1 (100)	5 (100)	4 (80)	14 (88
СМО	Yes	0 (0)	1 (33)	0 (0)	0 (0)	1 (20)	2 (13
n hospital, recipient	No	2 (100)	2 (67)	1 (100)	4 (80)	3 (60)	12 (7
n inotropes	Yes	0 (0)	1 (33)	0 (0)	1 (20)	2 (40)	4 (2
ecipient CMV status	Negative	11 (65)	11 (38)	20 (83)	15 (63)	24 (59)	81 (6
·	Positive	6 (35)	18 (62)	4 (17)	9 (38)	17 (41)	54 (4
ecipient HCV status	Negative	17 (100)	28 (97)	24 (100)	24 (100)	41 (100)	134 (9
	Positive	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)	1 (
ecipient HBV status	Negative	17 (100)	27 (93)	24 (100)	24 (100)	41 (100)	133 (9
	Positive	0 (0)	2 (7)	0 (0)	0 (0)	0 (0)	2 (
ecipient HIV status	Negative	17 (100)	29 (100)	24 (100)	24 (100)	41 (100)	135 (10
ecipient serum	Median (IQR)	59 (49, 79)	69 (55, 83)	75 (61, 91)	67 (51, 96)	68 (55, 80)	69 (55, 8
reatinine (umol/l)	Missing	1	0	0	0	0	
onor sex	Male	8 (47)	10 (34)	10 (42)	13 (54)	13 (32)	54 (4
	Female	9 (53)	19 (66)	14 (58)	11 (46)	28 (68)	81 (6
onor ethnicity	White	15 (88)	27 (93)	22 (92)	18 (75)	34 (83)	116 (8
	Asian	0 (0)	2 (7)	0 (0)	3 (13)	2 (5)	7
	Black Other	0 (0) 0 (0)	0 (0) 0 (0)	2 (8) 0 (0)	0 (0) 1 (4)	0 (0) 2 (5)	2 3
	Missing	2 (12)	0 (0)	0 (0)	2 (8)	3 (7)	7

Table 5.1 Demographic characteristics of UK adult lung transplants performed between 1 April 2023 and 31 March 2024, by centre Birmingham Harefield **Papworth** TOTAL Manchester Newcastle N (%) N (%) N (%) N (%) N (%) N (%) Donor age (years) Median (IQR) 43 (33, 54) 46 (37, 54) 49 (27, 54) 37 (25, 56) 41 (25, 52) 43 (28, 54) Missing 0 Donor BMI (kg/m<sup>2</sup>) 25 (23, 28) Median (IQR) 24 (23, 27) 25 (22, 28) 25 (23, 28) 26 (24, 29) 25 (22, 28) Missing Donor cause of death Intracranial/CVA 16 (94) 27 (93) 23 (96) 21 (88) 34 (83) 121 (90) Trauma 0(0)0 (0) 1 (4) 0(0)2(5)3 (2) Others 1 (6) 2 (7) 0(0)5 (12) 3 (13) 11 (8) 98 (73) Donor hypotension No 14 (82) 21 (72) 16 (67) 15 (63) 32 (78) 7 (29) 5 (21) Yes 3 (18) 8 (28) 9 (22) 32 (24) 0(0)0 (0) 1 (4) 4 (17) 0(0)5 (3) Missing Donor history of No 28 (97) 24 (100) 39 (95) 128 (95) 15 (88) 22 (92) 2 (5) cardiac disease Yes 0 (0) 3 (2) 1 (6) 0(0)0(0)1 (6) 1 (3) 0(0)2 (8) 0(0)Missing 4 (3) Donor history of No 14 (82) 22 (76) 24 (100) 19 (79) 37 (90) 116 (86) hypertension 7 (24) Yes 3 (18) 0(0)5 (21) 4 (10) 19 (14) Donor history of No 16 (94) 29 (100) 24 (100) 23 (96) 40 (98) 132 (98) cancer/malignancy Yes 1 (6) 0 (0) 0(0)1 (4) 1 (2) 3 (2) 13 (54) Donor past/current No 11 (65) 13 (45) 16 (67) 17 (41) 70 (52) 16 (55) 11 (46) 8 (33) 24 (59) 65 (48) smoker Yes 6 (35) 6.6 (6.2, 7.2) 6.3 (5.3, 8.0) 7.3 (5.7, 8.8) 7.8 (6.2, 9.9) Total preservation Median (IQR) 11.4 (7.4, 14.3) 8.2 (7.1, 10.1) time<sup>1</sup> (hours) Missing 1 (3) 1 (4) 0 (0) 3(7)5 (4) Transplant type Single lung 0(0)Bilateral lung 16 (94) 27 (93) 23 (96) 23 (96) 126 (93) 37 (90) Heart/lung 1 (3) 0(0)1 (2) 4 (3) 1 (6) 1 (4) <sup>1</sup> Time from cross clamp in the donor to reperfusion in the recipient

### 5.3 Total preservation time, 1 April 2014 – 31 March 2024

**Figure 5.9** shows <u>boxplots</u> of the total preservation time for <u>DBD</u> donor lungs transplanted into adult recipients over the last 10 years. The total preservation 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 (5%), not all of this time duration is ischaemic, and no adjustment has been made for this. The national <u>median</u> total preservation time has increased from 6.8 hours to 7.3 hours over the last ten years.

Figure 5.9 Boxplots of total preservation time for DBD donor lungs transplanted into adult recipients, by financial year, 1 April 2014 to 31 March 2024



**Figure 5.10** and **Figure 5.11** show <u>boxplots</u> of total preservation time by centre in the latest financial year and over the last 10 years, respectively. The median total preservation time for lung transplants in 2023/2024 was longest for Harefield and shortest for Birmingham and Manchester. Papworth and Harefield, in particular, have seen recent increases in median total preservation time.

Figure 5.10 Boxplots of total preservation time for DBD donor lungs transplanted into adult recipients, by transplant centre, 1 April 2023 to 31 March 2024

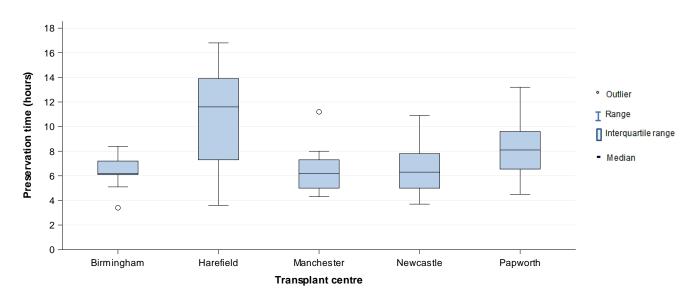
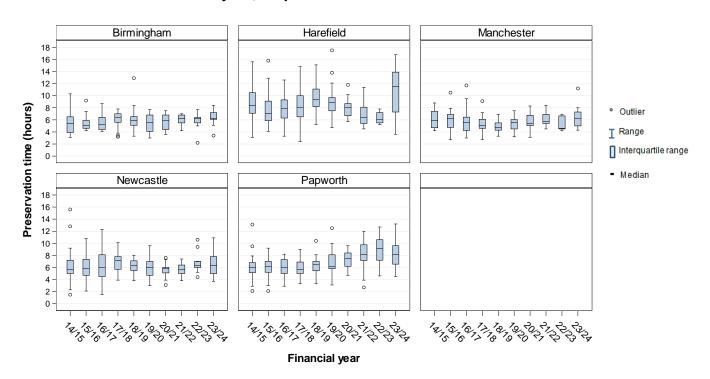


Figure 5.11 Boxplots of total preservation time for DBD donor lungs transplanted into adult recipients, by transplant centre and financial year, 1 April 2014 to 31 March 2024



# ADULT LUNG TRANSPLANTATION Post-Transplant Survival

### 6. 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**.

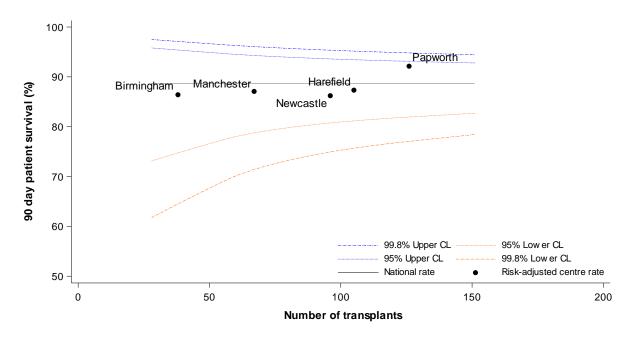
The survival analyses in **Section 6.1-6.3** include first time lung only transplants. Ninety-day and 1-year <u>survival rates</u> are based on transplants performed in the period 1 April 2019 to 31 March 2023 while 5-year <u>survival rates</u> are based on transplants performed in the period 1 April 2015 to 31 March 2019. 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 433 first adult lung only transplants in the period 1 April 2019 to 31 March 2023. All centres were statistically consistent with the national rate of survival which was 88.7%.

Table 6.1 90 day p	patient survival rate 2019 and 31 March		st adult lung tra	nsplant,	by centre,
Centre	Number of transplants	<u>Ur</u>	% 90 day survi adjusted	•	CI) k-adjusted
Birmingham Harefield Manchester Newcastle Papworth	38 105 68 96 126	89.7	(74.3 - 95.9) (76.3 - 90.4) (79.6 - 95.0) (79.0 - 92.7) (85.8 - 95.6)		(63.8 - 94.9) (79.3 - 92.2) (72.9 - 93.8) (75.7 - 92.2) (85.4 - 95.8)
UK	433	88.7	(85.3 - 91.3)		
	Centre has reache Centre has reache Centre has reache Centre has reache	ed the lowe ed the uppe	r 95% confidence er 95% confidence	e limit e limit	

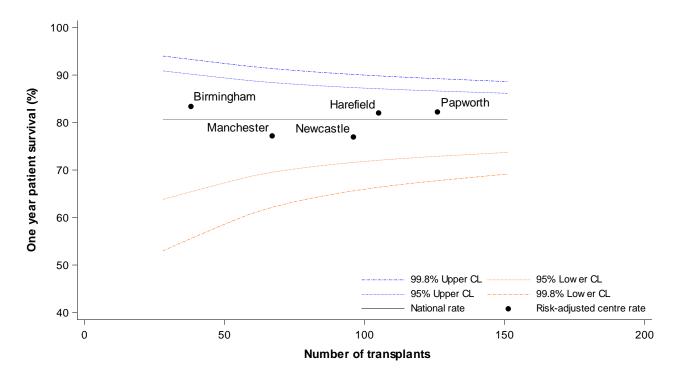
Figure 6.1 Risk-adjusted 90 day patient survival rates for adult lung transplants, by centre, 1 April 2019 to 31 March 2023



**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 433 first adult lung only transplants in the period 1 April 2019 to 31 March 2023. The national rate of survival was 80.7%. The rates for all centres were statistically consistent with the national rate.

	atient survival rate 2019 to 31 March 2		t adult lung tran	splant, l	oy centre,
Centre	Number of transplants	<u>Ur</u>	% 1 year surviv nadjusted	`	CI) k-adjusted
Birmingham Harefield Manchester Newcastle Papworth	38 105 68 96 126		(70.2 - 94.1) (70.9 - 86.4) (70.8 - 89.5) (66.6 - 84.0) (73.8 - 87.5)	83.4 82.0 77.2 77.0 82.2	(60.1 - 93.1) (72.4 - 88.3) (59.8 - 87.0) (65.0 - 84.8) (73.3 - 88.2)
UK	433	80.7	(76.6 - 84.1)		
	Centre has reached Centre has reached Centre has reached Centre has reached	the lower 95 the upper 9	5% confidence limit 5% confidence limit	t	

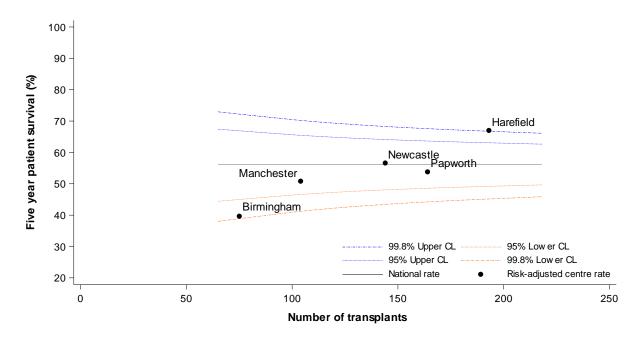
Figure 6.2 Risk-adjusted one year patient survival rates for adult lung transplants, by centre, 1 April 2019 to 31 March 2023



**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 680 first adult lung only transplants in the period 1 April 2015 to 31 March 2019. Birmingham's survival rate at 5 years falls below the 95% lower <u>confidence limit</u>, indicating somewhat lower survival at this time point, while Harefield's is above the 99.8% upper confidence limit, providing evidence of a higher survival at this time point. All other centres were statistically consistent with the national rate of survival of 56.2%.

	patient survival afte 2015 and 31 March		ult lung transpla	ant, by co	entre,
Centre	Number of transplants	<u>L</u>	% 5 year surv <u>Inadjusted</u>	•	cl) sk-adjusted
Birmingham Harefield Manchester Newcastle Papworth	75 193 104 144 164	45.3 67.6 51.0 52.4 54.7	( /	39.7 67.0 50.8 56.6 53.8	(18.0 - 55.6) (57.7 - 74.3) (35.3 - 62.6) (45.0 - 65.8) (42.0 - 63.2)
UK	680	56.2	(52.4 - 59.9)		
	Centre has reach Centre has reach Centre has reach Centre has reach	ed the low ed the up	ver 95% confiden oer 95% confider	ice limit nce limit	

Figure 6.3 Risk-adjusted five year patient survival rates for adult lung transplants, by centre, 1 April 2015 to 31 March 2019



# 6.2 Survival by disease group

**Tables 6.4** and **6.5** present <u>unadjusted</u> and <u>risk-adjusted survival rates</u> by primary disease group, at 1 year and 5 years post-transplant, respectively. The <u>risk factors</u> used to produce the <u>risk-adjusted survival rates</u> are listed in <u>Appendix A3</u>. There were no statistically significant differences in <u>survival rates</u> across disease groups at 1 year. There was some evidence of lower survival for patients with primary pulmonary hypertension or other diseases at 5 years.

	Table 6.4 1 year patient survival rates after first adult lung transplant, by disease group, 1 April 2019 to 31 March 2023									
Disease group	Number of transplants	<u>L</u>	% 1 year surviv <u>Inadjusted</u>	`	CI) sk-adjusted					
Cystic fibrosis and bronchiectasis COPD and emphysema Fibrosing lung disease Primary pulmonary hypertension and other diseases	63 157 167 46	82.5 82.6 78.3 80.4	(70.6 - 89.9) (75.6 - 87.7) (71.2 - 83.8) (65.8 - 89.3)	82.1 80.9 79.2 81.3	(67.8 - 90.1) (72.2 - 86.9) (71.2 - 85.0) (64.1 - 90.3)					
UK	433	80.7	(76.6 - 84.1)							

Table 6.5 5 year patient survival rates after first adult lung transplant, by disease group, 1 April 2015 to 31 March 2019									
Disease group	Number of		% 5 year survi	val (95%	CI)				
	transplants	<u>U</u>	<u>Inadjusted</u>	Ris	sk-adjusted				
Cystic fibrosis and bronchiectasis	213	62.2	(55.3 - 68.4)	59.9	(50.0 - 67.8)				
COPD and emphysema	205	58.4	(51.3 - 64.8)	55.4	(44.8 - 63.9)				
Fibrosing lung disease	205	49.4	(42.4 - 56.1)	55.4	(46.0 - 63.3)				
Primary pulmonary hypertension and other diseases	57	50.9	(37.3 - 62.9)	49.6	(27.0 - 65.2)				
ик	680	56.2	(52.4 - 59.9)						

### 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 2019 and 31 March 2023 whereas the 5 year survival rates are for transplants performed between 1 April 2015 and 31 March 2019. Survival rates across transplant types were comparable at 90 days and 1 year, however a borderline significant difference was found at 5 years (log-rank p=0.06).

1 Apri	I 2019 to	o 31 Mai	rch 2023 (90 day	and 1 ye	ar) and	1 April 2015 to 3	1 March	2019 (5	year)
Transplant type	N*		day rival (95% CI) nadjusted	N*		<b>ar</b> vival (95% CI) nadjusted	N*		ear vival (95% CI) nadjusted
Single lung Bilateral lung	42 391	90.5 88.5	(76.6 - 96.3) (84.9 - 91.3)	42 391	76.2 81.2	(60.3 - 86.4) (76.9 - 84.7)	75 605	42.6 57.9	(31.3 - 53.4) (53.9 - 61.8)
UK	433	88.7	(85.3 - 91.3)	433	80.7	(76.6 - 84.1)	680	56.2	(52.4 - 59.9)

# 6.4 Survival post heart-lung transplant

**Table 6.7** and **Table 6.8** present short-term patient <u>survival rates</u> following combined heart-lung transplant, by centre and nationally. During the time period 1 April 2015 and 1 April 2023, a small number of transplants were performed, with the highest number being performed at Papworth, however as no centre performed at least 10 transplants no centre-specific rates are presented. The national rates of survival were 84.8% at 90 days and 72.3% at one year.

Table 6.7 90 day pation 1 April 201	ent survival after first  5 and 1 April 2023	adult heart-lu	ıng transplar	nt, by centre,
Centre	Number of transplants	Number of deaths	•	survival (95% CI) adjusted)
Birmingham <sup>1</sup>	7	1	-	-
Harefield <sup>1</sup>	6	3	-	-
Manchester <sup>1</sup>	7	0	-	-
Newcastle <sup>1</sup>	4	0	-	-
Papworth <sup>1</sup>	9	1	-	-
UK	33	5	84.8	(67.4 - 93.4)
<sup>1</sup> Survival rates for groups	s with less than 10 patient	s are not preser	nted due to sma	all numbers

	ent survival after first and 1 April 2023	addit Heart-Id	ilg transplan	i, by centre,
Centre	Number of transplants	Number of deaths	•	urvival (95% CI) adjusted)
Birmingham <sup>1</sup>	7	1	-	-
Harefield <sup>1</sup>	6	5	-	-
Manchester <sup>1</sup>	7	1	-	-
Newcastle <sup>1</sup>	4	1	-	-
Papworth <sup>1</sup>	9	1	-	-
UK	33	9	72.3	(53.5 - 84.5)

# 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 2015 and 31 March 2023. It does not include or heart-lung transplants which are shown in the previous section.

		ving multi-organ lung tr ril 2015 and 31 March 2	
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 & liver	4	3	2

# 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 April 2015 to 31 March 2023. 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. transplant type. Survival time was censored 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, or at date of removal from the list for patients not receiving a transplant (unless removed due to deteriorating condition, in which case this was classed as an event).. A review of the <u>risk factors</u> included in the survival-from-listing model was conducted in 2024 and the factors 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** and **7.2**, respectively, along with the unadjusted rates. Note that the rates for one year and five-year survival are calculated from disjoint cohorts of patients, to allow for the full one- and five-year follow-up periods to elapse.

The one year survival rate from listing for Birmingham is below the 95% <u>confidence limit</u>, while the five year survival rate is below the 99.8% confidence interval, indicating a significantly lower survival at this centre. There was also evidence of significantly higher survival from listing at five years for Papworth.

Table 7.1	1 year patient surv between 1 April 20			s registere	ed
			1 year Survival R	ate % (95%	% CI)
Centre	Number of registrations	Un	adjusted	Risk	c-adjusted
Birmingham Harefield Manchester Newcastle Papworth	98 124 98 172 179	63.2 83.8 75.4 73.1 76.3	(52.9 - 71.9) (76.0 - 89.2) (65.6 - 82.8) (65.7 - 79.1) (69.3 - 81.9)	61.8 77.8 75.8 77.8 76.2	(47.0 - 72.4) (65.5 - 85.6) (63.9 - 83.8) (70.4 - 83.4) (67.8 - 82.4)
UK	671	74.8	(71.3 - 77.9)		
	Centre has reached to	the lower 95 the upper 95	% confidence limit % confidence limit		

Figure 7.1 Risk-adjusted one year patient survival rates from listing, by centre, 1 April 2019 to 31 March 2023

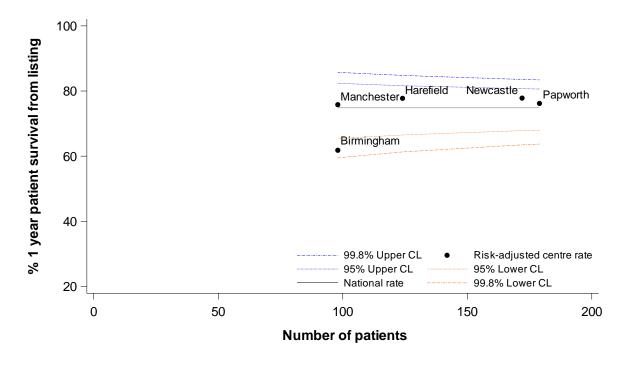
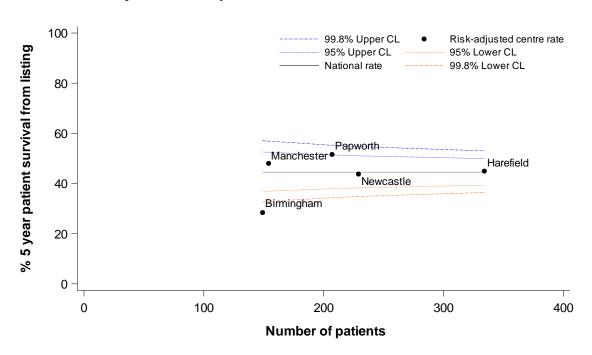


Table 7.2 5 year patient survival from listing for patients registered between 1 April 2015 to 31 March 2019						
			5 year Survival F	Rate % (95%	% CI)	
Centre	Number of registrations	Unadjusted		Risk-adjusted		
Birmingham Harefield Manchester Newcastle Papworth	149 334 154 229 207	36.9 50.7 43.2 39.9 46.6	(29.1 - 44.8) (45.1 - 56.1) (35.1 - 50.9) (33.4 - 46.3) (39.7 - 53.3)	28.4 45.0 48.0 43.8 51.6	(12.2 - 41.6) (35.7 - 52.9) (35.8 - 57.9) (33.4 - 52.5) (41.6 - 59.9)	
UK	1073	44.6	(41.5 - 47.6)			
Centre has reached the lower 99.8% confidence limit Centre has reached the lower 95% confidence limit Centre has reached the upper 95% confidence limit Centre has reached the upper 99.8% confidence limit						

Figure 7.2 Risk-adjusted five year patient survival rates from listing, by centre, 1 April 2015 to 31 March 2019



# ADULT LUNG TRANSPLANTATION Form Return Rates

# 8. Adult lung form return rates, 1 January – 31 December 2023

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 2023 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 95% or greater for this period. Note that any skipped follow-up forms are counted as not returned.

Table 8.1 Form return rates for ac	dult lung t	ransplants	s, 1 Janua	ry 2023 to	31 Decem	ber 2023		
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
Aberdeen, Aberdeen Royal Infirmary Belfast, Belfast City Hospital	-	-	-	-	-	-	1 1	0 0
Birmingham, Queen Elizabeth Hospital	16	100	15	100	9	89	95	97
Harefield, Harefield Hospital	29	100	28	100	16	100	438	99
Manchester, Wythenshawe Hospital	24	100	23	100	15	100	162	100
Newcastle, Freeman Hospital	27	100	24	100	18	100	287	97
Papworth, Papworth Hospital	42	100	41	100	27	100	299	97
Sheffield, Northern General Hospital	-	-	-	-	-	-	2	100
Overall	138	100	131	100	85	99	1285	97

# PAEDIATRIC LUNG TRANSPLANTATION Transplant List

### 9.1 Paediatric lung and heart/lung transplant list on 31 March, 2015 - 2024

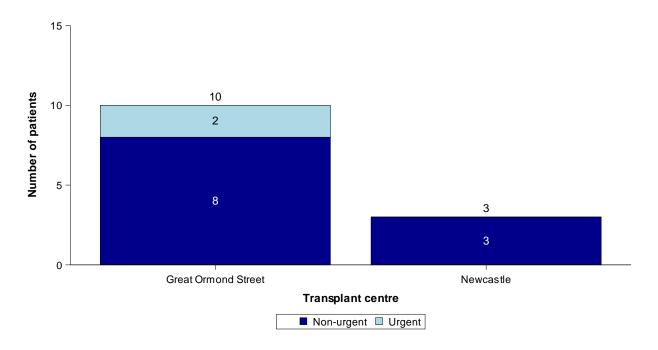
**Figure 9.1** shows the number of paediatric patients on the lung transplant list on 31 March each year between 2015 and 2024 split by urgency status. The number on the active lung transplant list was high in 2015, with 14 on the non-urgent list and 1 active for a heart-lung transplant. It then decreased to 3 in 2020 (2 non-urgent, 1 urgent) and has since risen to 15 (9 non-urgent, 2 heart-lung and 2 urgent) on 31 March 2024.

Number of patients Year Active - Urgent Active - Non-urgent Active - Heart-Lung Suspended

Figure 9.1 Number of paediatric patients on the lung transplant list on 31 March each year, by urgency status

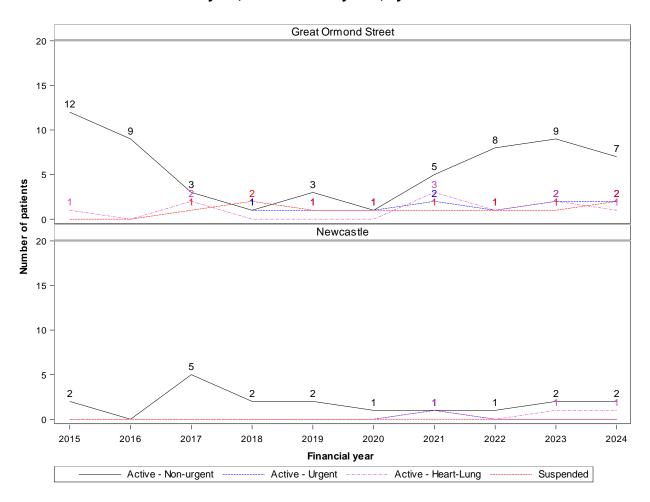
**Figure 9.2** shows the number of paediatric patients on the <u>active lung transplant list</u> on 31 March 2024 by centre. In total, there were 13 paediatric patients waiting; 10 at Great Ormond Street Hospital and 3 at Newcastle. Two patients at Great Ormond Street Hospital were on the urgent list, and none 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 9.2 Number of paediatric patients on the active lung transplant list on 31 March 2024, by centre and urgency



**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 2015 and 2024. 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 8 active patients (7 non-urgent, 1 heart-lung) on 31 March 2024. Newcastle had a peak of 5 on their list in 2017, but this has now decreased to 2 non-urgent patients and 1 heart-lung.

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



# 9.2 Demographic characteristics, 1 April 2022 – 31 March 2024

There were 11 paediatric registrations onto the lung transplant list between 1 April 2022 and 31 March 2024 (two years analysed due to small numbers). Demographic characteristics are shown by centre and overall in **Table 9.1**. Nationally, 55% of the patients were male and the median age was 13 years. For some characteristics, due to rounding, percentages may not add up to 100.

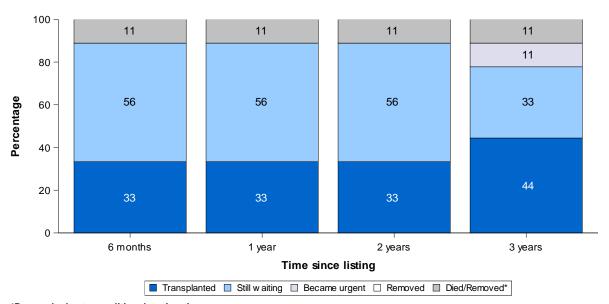
		Great Ormond	Newcastle	TOTAL
		Street N (%)	N (%)	N (%)
Number of registrations		9 (100)	2 (100)	11 (100)
Year of registration	2022/2023	5 (56)	2 (100)	7 (64)
	2023/2024	4 (44)	0 (0)	4 (36)
Highest urgency during registration	Non-urgent	4 (44)	2 (100)	6 (55)
	Urgent	5 (56)	0 (0)	5 (46)
Recipient sex	Male	6 (67)	0 (0)	6 (55)
	Female	3 (33)	2 (100)	5 (46)
Recipient ethnicity	White	8 (89)	1 (50)	9 (82)
	Asian	0 (0)	1 (50)	1 (9)
	Other	1 (11)	0 (0)	1 (9)
Recipient age (years)	Median (IQR) <sup>1</sup>	13 (5, 14)	-	13 (5, 14)
	Missing	0	0	0
Height (cm)	Median (IQR) <sup>1</sup>	149 (111, 161)	-	146 (111, 161)
	Missing	0	0	0
Weight (kg)	Median (IQR) <sup>1</sup>	45 (16, 52)	-	33 (16, 52)
	Missing	0	0	0
Primary Disease	Cystic fibrosis and bronchiectasis	1 (11)	1 (50)	2 (18)
	Fibrosing lung disease Primary pulmonary hypertension and other diseases	1 (11) 7 (78)	0 (0) 1 (50)	1 (9) 8 (73)

### 9.3 Post-registration outcomes, 1 April 2019 – 31 March 2021

The registration outcomes of paediatric patients listed for a non-urgent lung transplant between 1 April 2019 and 31 March 2021 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. Removals from the list due to deteriorating condition are grouped with deaths in this analysis. 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, 33% were transplanted, 56% were still waiting and 11% died. After three years, the transplant rate had increased to 44% and the percentage moved to the urgent list was 11%. Due to small numbers, outcomes on the urgent or super-urgent lists are not presented.

Figure 9.4 Post-registration outcome for 9 non-urgent paediatric lung only registrations made in the UK,
1 April 2019 to 31 March 2021



\*Removals due to condition deteriorating

# 9.4 Median waiting time to transplant, 1 April 2020 - 31 March 2023

The <u>median</u> waiting time to lung transplant from non-urgent registration for paediatric patients registered between 1 April 2020 to 31 March 2023 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 on the transplant list, by centre, 1 April 2020 to 31 March 2023						
Transplant centre	Number registered	Number transplanted	W Median	aiting time (days) 95% Confidence interval		
Non-urgent at initial regis	tration					
Great Ormond Street Newcastle <sup>1</sup>	12 3	6 1	1044 -	373 - 1715 -		
UK	15	7	1044	659 - 1429		

<sup>&</sup>lt;sup>1</sup> 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 2021 to 31 March 2024. 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.

**Table 10.1** shows the number of offers and decline rates, with Newcastle having a 100% decline rate, Great Ormond Street having an 87.5% decline rate.

Table 10.1 UK paediatric DBD donor bilateral lung offer decline rates by transplant centre, 1 April 2021 and 31 March 2024					
Centre	Number of offers	Decline rate (%)			
Newcastle Great Ormond Street	6 8	(100.0) ( 87.5)			
UK	14	( 92.9)			

# PAEDIATRIC LUNG TRANSPLANTATION Transplants

# 11.1 Paediatric lung and heart-lung transplants, 1 April 2014 – 31 March 2024

**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 has decreased since 2016/2017 when there were 11 transplants, down to just 1 performed in 2022/2023. There has been a recent increase to 5 in 2023/2024. 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 (2023/2024) is shown by donor type in **Figure 11.3**.

Figure 11.1 Number of paediatric lung transplants in the UK, by financial year and donor type, 1 April 2014 to 31 March 2024

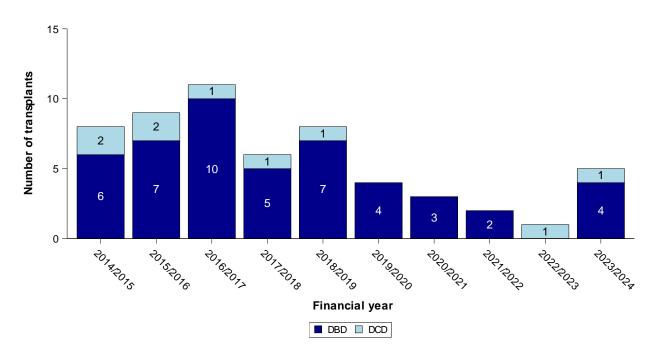


Figure 11.2 Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2014 to 31 March 2024

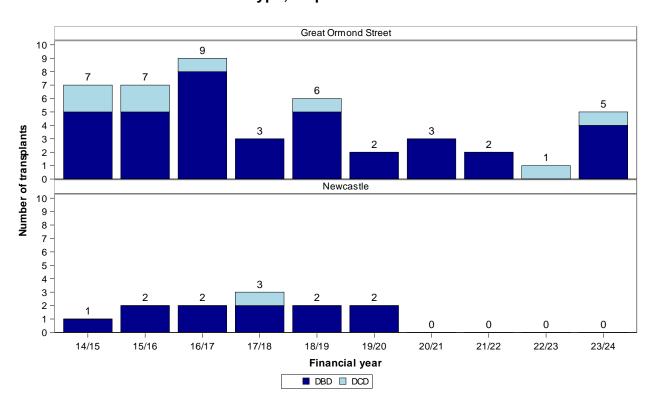
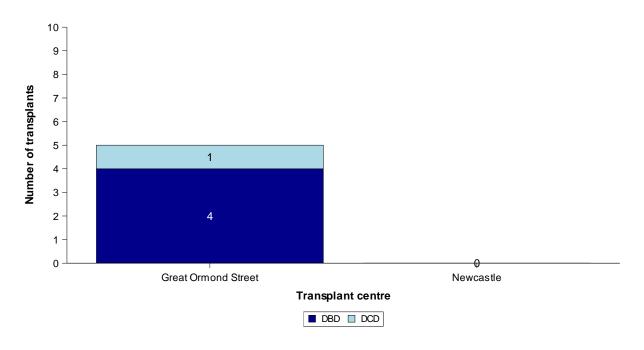


Figure 11.3 Number of paediatric lung transplants in the UK, by centre and donor type, 1 April 2023 to 31 March 2024



**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 11.4 Number of paediatric lung transplants in the UK, by financial year and transplant type, 1 April 2014 to 31 March 2024

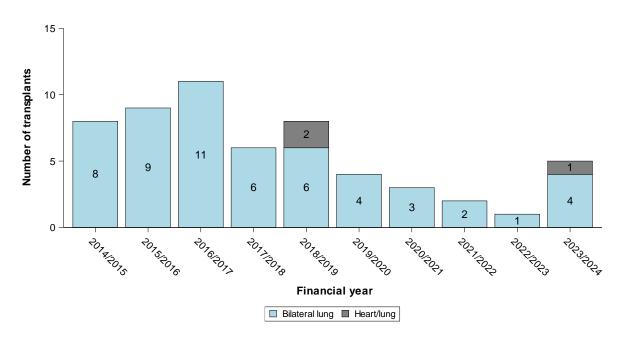
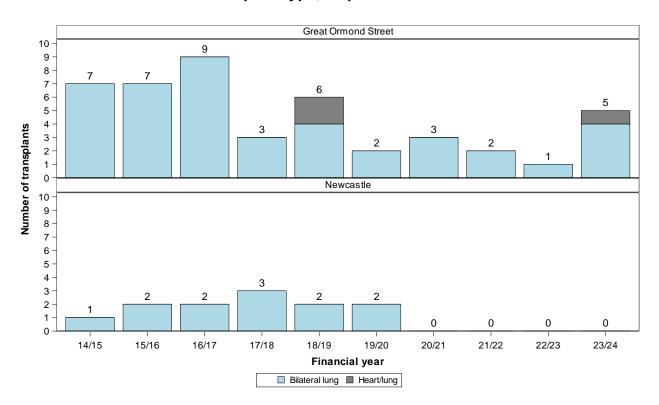


Figure 11.5 Number of paediatric lung transplants in the UK, by financial year, centre and transplant type, 1 April 2014 to 31 March 2024



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**. Of the four lung only transplants in 2023/2024, two were urgent and two were non-urgent.

Figure 11.6 Number of paediatric lung only transplants in the UK, by financial year and urgency status, 1 April 2014 to 31 March 2024

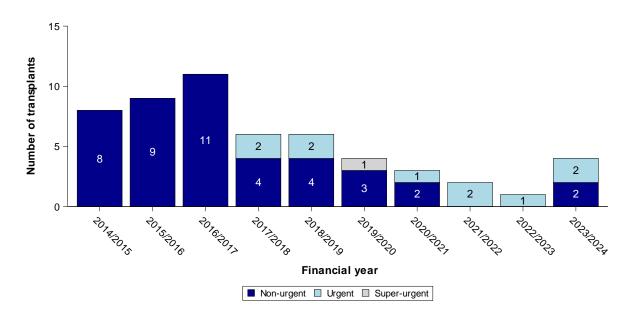
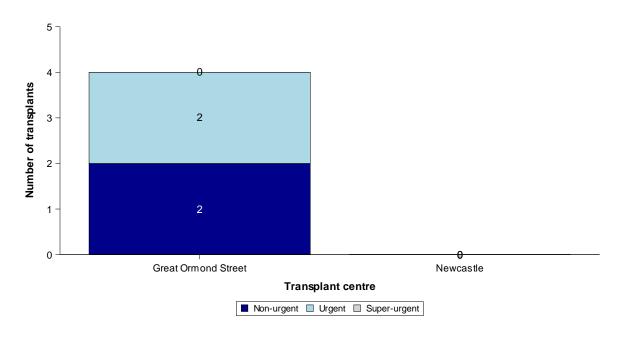


Figure 11.7 Number of paediatric lung only transplants in the UK, by centre and urgency status, 1 April 2023 to 31 March 2024



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# 11.2 Demographic characteristics of transplants, 1 April 2014 – 31 March 2024

The demographic characteristics of the 57 paediatric lung transplant recipients and donors in the last ten years are shown by centre and overall in **Table 11.1**. Nationally, 58% of lung recipients were female and the <u>median</u> age was 12 years, while the median age of donors was 14 years. For some characteristics, due to rounding, percentages may not add up to 100.

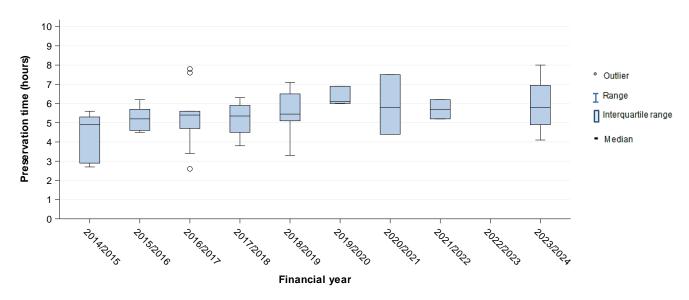
	c characteristics of UK paediatric I h 2024, by centre	ung transplants p	erformed betwe	en 1 April 2014
		Great Ormond Street	Newcastle	TOTAL
		N (%)	N (%)	N (%)
Number of transplants		45 (100)	12 (100)	57 (100)
Urgency status at	Non-urgent	36 (80)	8 (67)	44 (77)
transplant	Urgent Super-urgent	9 (20)	3 (25) 1 (8)	12 (21)
	Super-urgent	0 (0)	1 (6)	1 (2)
Recipient sex	Male	16 (36)	8 (67)	24 (42)
	Female	29 (64)	4 (33)	33 (58)
Recipient ethnicity	White	40 (89)	12 (100)	52 (91)
-	Asian	2 (4)	0 (0)	2 (4)
	Black	1 (2)	0 (0)	1 (2)
	Other	1 (2)	0 (0)	1 (2)
Recipient age (years)	Median (IQR)	12 (9, 14)	13 (10, 15)	12 (10, 15)
7 3 0 7	Missing	0	`o´ ´	`o´ ´
Recipient weight (kg)	Median (IQR) Missing	36 (24, 49) 0	39 (24, 41) 0	37 (24, 45) 0
Recipient primary disease	Cystic fibrosis and bronchiectasis	15 (33)	9 (75)	24 (42)
,,	Fibrosing lung disease	2 (4)	1 (8)	3 (5)
	Primary pulmonary hypertension and other diseases	28 (62)	2 (17)	30 (53)
Recipient in hospital	No	35 (78)	6 (50)	41 (72)
	Yes	9 (20)	5 (42)	14 (25)
	Missing	1 (2)	1 (8)	2 (4)
In hospital, recipient on	No	8 (89)	4 (80)	12 (86)
ventilator	Yes	1 (11)	1 (20)	2 (14)
In hospital, recipient ECMO	No	9 (100)	3 (60)	12 (86)
in neophal, recipient Lewie	Yes	0 (0)	1 (20)	1 (7)
	Missing	0 (0)	1 (20)	1 (7)
In hospital, recipient on	No	6 (67)	3 (60)	9 (64)
inotropes	Yes	3 (33)	2 (40)	5 (36)
Recipient CMV status	Negative	34 (76)	10 (83)	44 (77)
•	Positive	11 (24)	1 (8)	12 (21)
	Missing	0 (0)	1 (8)	1 (2)
Recipient HCV status	Negative	44 (98)	11 (92)	55 (97)
,	Missing	1 (2)	1 (8)	2 (4)

**Table 11.1** Demographic characteristics of UK paediatric lung transplants performed between 1 April 2014 and 31 March 2024, by centre **Great Ormond** Newcastle **TOTAL** Street N (%) N (%) N (%) 55 (97) Recipient HBV status Negative 44 (98) 11 (92) Missing 1 (2) 1 (8) 2 (4) Recipient HIV status Negative 44 (98) 11 (92) 55 (97) Missing 2 (4) 1 (2) 1 (8) Recipient serum creatinine Median (IQR) 41 (30, 51) 40 (26, 55) 41 (28, 52) (umol/l) Missing 5 2 Donor sex Male 25 (44) 19 (42) 6(50)Female 6 (50) 32 (56) 26 (58) Donor ethnicity White 37 (82) 9 (75) 46 (81) Asian 1 (2) 0(0)1 (2) Other 2 (4) 1 (8) 3 (5) Missing 5 (11) 2 (17) 7 (12) Donor age (years) Median (IQR) 17 (8, 39) 10 (8, 14) 14 (8, 31) Missing Donor BMI (kg/m<sup>2</sup>) Median (IQR) 21 (16, 24) 18 (14, 21) 20 (16, 23) Missing 0 0 0 Donor cause of death Intracranial/CVA 27 (60) 7 (58) 34 (60) Trauma 4 (9) 2(17)6 (11) Others 14 (31) 3 (25) 17 (30) Donor hypotension Nο 27 (60) 6 (50) 33 (58) 13 (29) 4 (33) 17 (30) Yes 7 (12) 5 (11) Missing 2 (17) Donor history of cardiac No 39 (87) 11 (92) 50 (88) disease Yes 1 (2) 0(0)1 (2) Missing 5 (11) 1 (8) 6 (11) Donor history of No 40 (89) 9 (75) 49 (86) hypertension Yes 0 (0) 1 (8) 1 (2) Missing 5 (11) 2 (17) 7 (12) Donor history of No 38 (84) 10 (83) 48 (84) cancer/malignancy Yes 2 (4) 0 (0) 2 (4) Missing 5 (11) 2 (17) 7 (12) Donor past/current smoker No 32 (71) 11 (92) 43 (75) Yes 9 (20) 0(0)9 (16) 1 (8) Missing 4 (9) 5 (9) Total preservation time<sup>1</sup> Median (IQR) 5.6 (4.6, 6.3) 5.5 (5.2, 5.6) 5.5 (4.7, 6.2) (hours) Missing 2 4 6 Transplant type Bilateral lung 42 (93) 12 (100) 54 (95) Heart/lung 3(7)0(0)3 (5) <sup>1</sup> Time from cross clamp in the donor to reperfusion in the recipient, regardless of donor type

#### 11.3 Total preservation time, 1 April 2014 – 31 March 2024

**Figure 11.8** shows <u>boxplots</u> of total preservation time for <u>DBD</u> donor lungs transplanted into paediatric recipients over the last 10 years. The total preservation 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 preservation time varied substantially over the decade, however these are based on a very small number of transplants per year. 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 preservation time for DBD donor lungs transplanted into paediatric recipients, by financial year, 1 April 2014 to 31 March 2024



# PAEDIATRIC LUNG TRANSPLANTATION Post-Transplant Survival

#### 12. 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 2019 and 31 March 2023 while 5-year survival rates are based on transplants performed in the period 1 April 2015 and 31 March 2019.

The 90-day post-transplant <u>unadjusted</u> patient <u>survival rates</u> are shown in **Table 12.1** for the 10 first paediatric lung only transplants in the period 1 April 2019 and 31 March 2023. 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 2019 and 31 March 2023				
Centre	Number of patients	Number of deaths	-	vival (95% CI) j <u>usted</u> )
Great Ormond Street Hospital <sup>1</sup> Newcastle <sup>1</sup>	8 2	0 0	- -	-
UK	10	0	100.0	-
<sup>1</sup> Survival rates for groups with less than 10 patients are not presented due to small numbers				

There were 2 deaths between 90 days and 1 year for the 10 paediatric lung only transplants performed in the period 1 April 2019 and 31 March 2023; 1 from Great Ormond Street Hospital and 1 from Newcastle, generating a national survival rate of 80%.

Table 12.2 1 year patient survival rates after first paediatric lung transplants, by centre, 1 April 2019 and 31 March 2023				
Centre	Number of patients	Number of deaths	•	survival (95% CI) <u>adjusted</u> )
Great Ormond Street Hospital Newcastle <sup>1</sup>	8 2	1 1	-	- -
UK	10	2	80.0	(40.9 - 94.6)
<sup>1</sup> 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 31 first lung only transplants performed in the period 1 April 2015 and 31 March 2019. 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 2015 to 31 March 2019				
Centre	Number of patients	Number of deaths	•	urvival (95% CI) adjusted)
Great Ormond Street Hospital Newcastle <sup>1</sup>	23 8	8 4	65.2 -	(42.3 - 80.8) -
UK	31	12	58.4	(38.3 - 74)
<sup>1</sup> Survival rates for groups with less than 10 patients are not presented due to small numbers				

# PAEDIATRIC LUNG TRANSPLANTATION Form Return Rates

### 13. Paediatric lung form return rates, 1 January – 31 December 2023

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 2023 for the transplant record, and all follow up forms issued in this time period. All forms have been returned.

Table 13.1 Form return rates for paediatric lung transplants, 1 January 2023 to 31 December 2023								
Centre	Transplai	nt record	3 month f	follow-up	1 year fo	ollow-up	Lifetime f	follow-up
	No.	%	No.	%	No.	%	No.	%
	requested	returned	requested	returned	requested	returned	requested	returned
Great Ormond Street Hospital	5	100	4 -	100	1	100	12	100
Newcastle, Freeman Hospital	-	-		-	-	-	12	100
Overall	5	100		100	1	100	24	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. lung (+ heart-lung) transplants
1 April 2014 – 31 March 2024	• Introduction	None	1478
1 April 2014 – 31 March 2024	• Transplants	Multi-organ transplants	1473
1 April 2019 – 31 March 2023	Post-transplant survival – • 90-day • 1-year survival	<ul> <li>Multi-organ transplants</li> <li>Heart-lung transplants         excluded from main analysis</li> <li>Partial lung transplants</li> <li>Second (or more) transplants</li> <li>Group 2 transplants</li> </ul>	433
1 April 2015 – 31 March 2019	Post-transplant survival – • 5-year survival	<ul> <li>Multi-organ transplants</li> <li>Heart-lung transplants         excluded from main analysis</li> <li>Partial lung transplants</li> <li>Second (or more) transplants</li> <li>Group 2 transplants</li> </ul>	680

Table A1.2 Paediatric transplants analysed					
Time period	Report Section	Report Section Exclusion criteria			
1 April 2014 – 31 March 2024	• Introduction	None	<b>transplants</b> 57		
1 April 2014 – 31 March 2024	• Transplants	Multi-organ transplants	57		
1 April 2019 – 31 March 2023	Post-transplant survival – • 90-day • 1-year survival	<ul> <li>Multi-organ transplants</li> <li>Heart-lung transplants</li> <li>Partial lung transplants</li> <li>Second (or more) transplants</li> <li>Group 2 transplants</li> </ul>	10		
1 April 2015 – 31 March 2019	Post-transplant survival – • 5-year survival	<ul> <li>Multi-organ transplants         (including heart-lung transplants)</li> <li>Partial lung transplants</li> <li>Second (or more) transplants</li> <li>Group 2 transplants</li> </ul>	31		

#### 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 2023 and 31 March 2024 were extracted from the UK Transplant Registry on 21 July 2024 (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-2022 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, 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 lung transplants on NHS group 1 recipients between 1 April 2023 and 31 March 2024 (numerator), divided by the mid-2022 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 2023 and 31 March 2024 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**

<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 <a href="Cox Proportional Hazards model">Cox Proportional Hazards model</a> 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 <a href="survival rates">survival rates</a> of interest. The factors included in the model are shown in <a href="A3">A3</a>.

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 total preservation 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  $\sigma^2$ . If the factor is one for all areas, then area differences are fully explained by the area-specific Poisson rate. If the factor varies with a nonzero variance,  $\sigma^2$ , then we conclude that there are unexplained area differences.

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

#### Survival from listing

Data were obtained for all patients ≥ 18 years registered for the first time for a heart or lung transplant between 1 April 2015 to 31 March 2023. 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 21 July 2024 if the patient was on the transplant list at time of analysis.

Exclusions from the analysis:

- patient registered for a heart-lung block or other <u>multi-organ transplant</u>
- patients who were not listed prior to transplant
- patients first registered on another transplant list (e.g. kidney list)
- patients registered outside the UK or not entitled to NHS treatment
- adult patients registered at paediatric centres

Patients registered for a lung transplant who were non-urgent and then urgently listed on the same day (or vice-versa) were recorded as urgent at 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. Missing data for these risk factors have been imputed using the median or modal value to ensure that cases with missing data are not excluded from the risk-adjusted analysis.

Table A2.1	Factors used in risk-adjusted model for patient survival from listing
Lung	Age, bilirubin (logarithm), ethnicity, weight, urgency status (non- urgent vs urgent/super-urgent), primary disease, in hospital at registration, daily dose of prednisolone

<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 fixed effect.

## A3: Risk models

Table A3.1 Risk factors and categories us 5-year survival model	sed in the adult lung risk adjusted 90-day. 1- year and
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
Total preservation 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 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.

#### 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 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.

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