NHS BLOOD AND GROUP TRANSPLANT

CARDIOTHORACIC ADVISORY– HEART

PAEDIATRIC SURVIVAL FROM LISTING

INTRODUCTION

1 Survival from listing is analysed and presented in the Annual Report on Heart Transplantation for adult patients only, however there is interest in examining survival from listing for paediatric patients. This report presents a preliminary analysis of survival from listing for heart transplantation, at one year and five years, for paediatric patients, by centre and overall.

DATA AND METHODS

2 Survival from listing is defined as time from joining the transplant list, to death, which may occur while waiting on the transplant list, or post-transplant, thus survival from listing includes both time on the list and post-transplant survival time, if applicable to that patient. Survival times are censored at either the date of removal from the list, or at the last known follow up date post-transplant, or on 25 February 2025 if the patient was on the transplant list at time of analysis. Removals due to deteriorating condition were classed as events.

3 Patients were included in the analysis if they were registered at either Great Ormond Street Hospital (GOSH) or at Newcastle and were aged less than 16 at time of listing AND their final listing/follow-up centre was either GOSH or Newcastle. Therefore, paediatric patients who were transferred to an adult only centre during listing or for follow-up, or were transferred out of the UK, were excluded. Also, a patient who was initially listed at GOSH but later transferred to Newcastle was assigned to Newcastle and vice versa. See **Appendix 1** for numbers of cases affected.

4 For one-year survival from listing analysis, patients first registered between 1 April 2020 and 31 March 2024 were included, and for five-year survival from listing analysis, patients first registered between 1 April 2016 and 31 March 2020 were included. All urgency groups were included together. Multi-organ registrations were excluded, as were patients who were first registered on another organ transplant list.

5 The analysis is not risk-adjusted, however, the centre cohorts are compared according to baseline characteristics; p-values were calculated using the chi-squared test for categorical variables and the Mann-Whitney U test for continuous variables. Any differences in unadjusted survival should therefore consider differences in patient groups, which may explain these differences. Another limitation of the analysis is the small cohorts of patients.

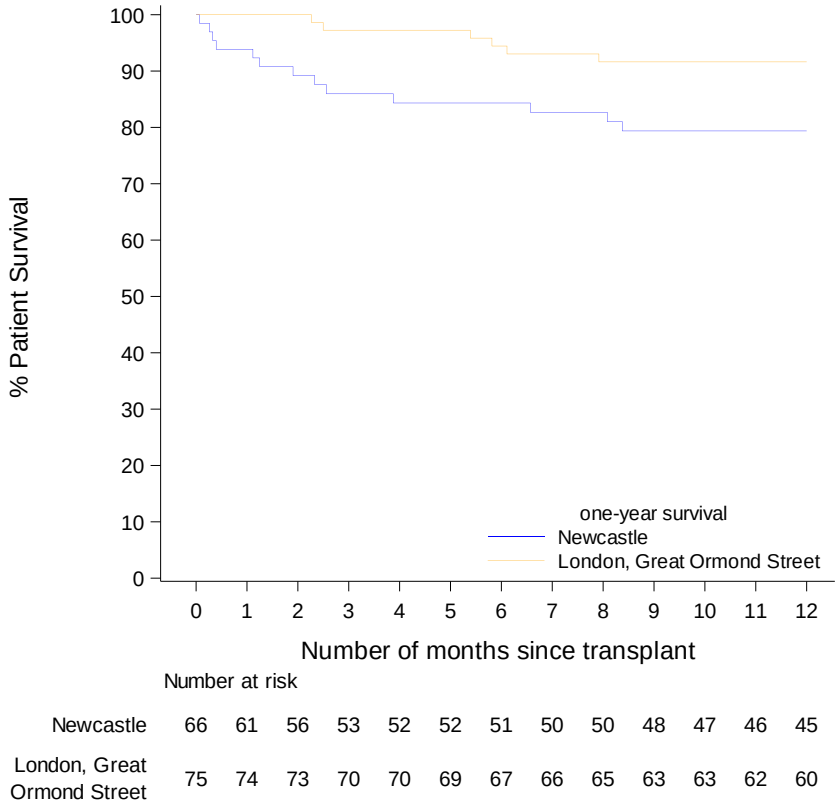
RESULTS

6 **Table 1** and **Figure 1** present one-year survival from listing. The national rate is 85.9% and the centre specific rates are 91.6% for GOSH and 79.4% for Newcastle. As the rate for GOSH lies above the upper 95% confidence limit for the national rate, this indicates a significantly higher unadjusted rate at this centre. Similarly, the log-rank p-value indicates a significant difference in unadjusted one-year survival between the two centres, as shown in **Figure 1** (p=0.03).

Table 1 One-year patient survival from listing for paediatric patients registered between 1 April 2020 to 31 March 2024

Centre	Number of registrations	Number of deaths	1 year survival rate % (95% CI) (unadjusted)	
Great Ormond Street	75	6	91.6	(82.3 - 96.1)
Newcastle	66	13	79.4	(67.1 - 87.5)
UK	**141**	**19**	**85.9**	**(78.8 - 90.8)**

Figure 1 One-year patient survival from listing, for registrations 1 April 2020 – 31 March 2024, by centre (log-rank p-value = 0.03)

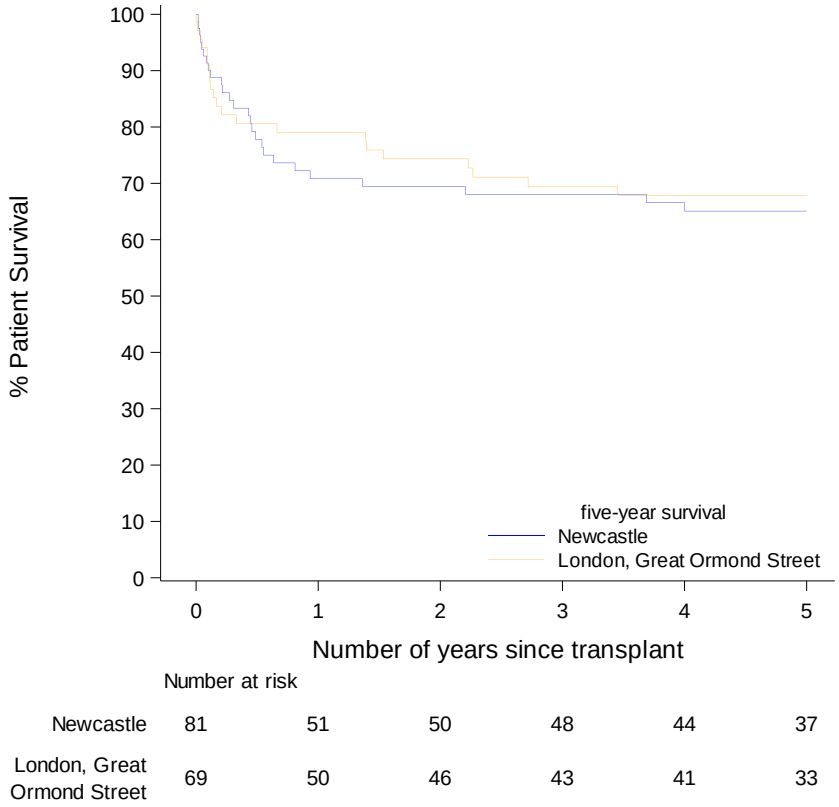


7 **Table 2** and **Figure 2** present five-year survival from listing. The national rate is 66.5% and the centre specific rates are 67.9% for GOSH and 65.1% for Newcastle. There was no significant difference between five-year unadjusted survival at the two centres (log-rank p=0.74), with both centres' survival rates falling within the national rate confidence interval.

Table 2 Five-year patient survival from listing for paediatric patients registered between 1 April 2016 to 31 March 2020

Centre	Number of registrations	Number of deaths	5 year survival rate % (95% CI) (unadjusted)	
Great Ormond Street	69	21	67.9	(55.0 - 77.8)
Newcastle	81	26	65.1	(53.0 - 74.8)
UK	**150**	**47**	**66.5**	**(58.0 - 73.7)**

Figure 2 Five-year patient survival from listing, for registrations 1 April 2016 – 31 March 2020, by centre (log-rank p-value = 0.74)



8 **Tables 3** and **4** show baseline demographics for the one-year and five-year survival analysis cohorts, respectively. In the one-year analysis cohort, the only statistically significant difference across centres was observed in the disease group distribution, with Newcastle having more congenital heart disease cases and GOSH more cardiomyopathy cases. In the five-year analysis cohort, statistically significant differences were found in the urgency status at registration, with Newcastle having more urgent cases and GOSH more non-urgent cases. There was also some evidence of a difference in disease group distribution, similar to the one-year cohort.

Table 3 Baseline characteristics of patients in one-year survival from listing analysis

	Newcastle	Great Ormond Street	p-value
Number of patients N	66	75	
Age Median (IQR)	5 (1-12)	7 (1-12)	0.59
Disease group			0.02
Cardiomyopathy N (%)	39 (59%)	52 (69%)	
Congenital heart disease N (%)	27 (41%)	17 (23%)	
Coronary heart disease N (%)	-	2 (3%)	
Other N (%)	-	4 (5%)	
Urgency status at registration			0.71
Non-urgent N (%)	23 (35%)	28 (37%)	
Urgent N (%)	35 (53%)	41 (55%)	
Super-urgent N (%)	8 (12%)	6 (8%)	
Highest urgency in registration			0.45
Non-urgent N (%)	16 (24%)	20 (27%)	
Urgent N (%)	37 (56%)	46 (61%)	
Super-Urgent N (%)	13 (20%)	9 (12%)	
Blood Group			0.23
O N (%)	33 (50%)	37 (49%)	
A N (%)	16 (24%)	25 (33%)	
B N (%)	12 (18%)	12 (16%)	
AB N (%)	5 (8%)	1 (1%)	
MCS			0.87
No N (%)	53 (80%)	61 (81%)	
Yes N (%)	13 (20%)	14 (19%)	
Height (cm) Median (IQR)	109 (80-149)	115 (78-146)	0.60
Missing N	*0*	*0*	
Weight (kg) Median (IQR)	18 (9-36)	21 (12-39)	0.47
Missing N	*0*	*0*	

Table 4 Baseline characteristics of patients in five-year survival from listing analysis

		Newcastle	Great Ormond Street	p-value
Number of patients N		81	69	
Age Median (IQR)		3 (1-8)	3 (1-5)	0.59
Disease group				0.08
Cardiomyopathy N (%)		45 (56%)	52 (75%)	
Congenital heart disease N (%)		33 (41%)	16 (23%)	
Coronary heart disease N (%)		2 (2%)	1 (1%)	
Other N (%)		1 (1%)	-	
Urgency status at registration				0.03
Non-urgent N (%)		22 (27%)	36 (52%)	
Urgent N (%)		59 (73%)	32 (46%)	
Super-urgent N (%)		-	1 (1%)	
Highest urgency in registration				0.89
Non-urgent N (%)		13 (16%)	13 (19%)	
Urgent N (%)		67 (83%)	55 (80%)	
Super-urgent N (%)		1 (1%)	1 (1%)	
Blood Group				0.64
O N (%)		35 (43%)	35 (51%)	
A N (%)		30 (37%)	25 (36%)	
B N (%)		13 (16%)	8 (12%)	
AB N (%)		3 (4%)	1 (1%)	
MCS				0.25
No N (%)		58 (72%)	55 (80%)	
Yes N (%)		23 (28%)	14 (20%)	
Height (cm)	Median (IQR)	93 (74-128)	89 (74-110)	0.44
	Missing N	*2*	*0*	
Weight (kg)	Median (IQR)	13 (9-22)	13 (9-19)	0.48
	Missing N	*0*	*0*	

ACTION

9 This analysis was requested by CTAG. Members should consider the methodology and results and suggest any further work or action.

Miguel Reyes, Sally Rushton
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Appendix 1 – Cross tabulation of initial listing centre with final listing/follow-up centre

1 year survival dataset

	Initial listing centre		
Final listing/follow-up centre	Newcastle	GOSH	Total
Adult only/non-UK centre	1	5	6
GOSH	3	72	75
Newcastle	64	2	66
Total	68	79	147

5 year survival dataset

	Initial listing centre		
Final listing/follow-up centre	Newcastle	GOSH	Total
Adult only/non-UK centre	6	17	23
GOSH	1	68	69
Newcastle	80	1	81
Total	87	86	173

Rows highlighted in grey are those patients retained in the analysis