

NHS BLOOD AND TRANSPLANT**CARDIOTHORACIC ADVISORY GROUP****ACCESS TO HEART TRANSPLANTATION FOR PAEDIATRIC PATIENTS****SUMMARY****INTRODUCTION**

1. At the Spring 2015 CTAG meeting, it was agreed that the allocation of donor hearts to paediatric patients should be analysed and reviewed.
2. This decision was initiated following discussion around the CTAG paper (CTAG(15) H18) which presented activity at Great Ormond Street Hospital (GOSH) in relation to a size matching rule which was imposed in April 2010.
3. It was agreed that the following outcomes would be compared, separately, between GOSH and the Newcastle paediatric unit and between paediatrics and adult patients:
 - a. Time to transplant
 - b. Time to death on the listThe number of organs declined by GOSH, the Newcastle paediatric unit and adult centres would also be considered.
4. This paper examines whether there are differences in post registration outcomes between GOSH, Newcastle paediatrics and adult centres whilst taking into account urgent status and case mix. The number of declined organs are also considered.

DATA AND RESULTS

5. **Table A** shows that the proportion of paediatric patients registered urgently at Newcastle between 1 January 2010 and 31 December 2014 was higher than the proportion of patients urgently registered at both GOSH and at adult centres. The proportion of urgent patients transplanted within six months was consistent across the three groups. The proportion of non-urgent patients transplanted at Newcastle is higher, but this is due to small number of non-urgent registrations at Newcastle (n=8). Thus, 7% of Newcastle paediatric patients registered were classified as non-urgent compared with 31% of GOSH patients ($p<0.001$).
6. The overall median waiting time to transplant for GOSH patients was longer than the median waiting time for Newcastle paediatric patients. However, the median waiting time for urgent paediatrics patients at Newcastle was similar to that for adult patients.
7. Three year patient survival post-transplant for paediatric patients was higher than the estimates for adult patients.

Table 1 Overview of paediatric heart only transplant activity between 1 January 2010 and 31 December 2014				
		GOSH patients	Newcastle paediatric patients	Adult patients
Patients registered	Urgent	88 (68%)	104 (93%)	577 (55%)
	Non-urgent	41 (32%)	8 (7%)	464 (45%)
	Total	129 (100%)	112 (100%)	1041 (100%)
% transplanted within 6 months	Urgent	59%	63%	59%
	Non-urgent	20%	63%	24%
	Total	47%	63%	43%
Median time to transplant (95% confidence interval)	Urgent	105 (67, 143)	63 (48, 78)	53 (41, 65)
	Non-urgent	558 (-)*	122 (0, 306)	1349 (-)*
	Total	150 (110, 190)	63 (39, 87)	199 (152, 246)
Three year patient survival after transplant (95% confidence interval)	Urgent	88% (75, 94)	92% (82, 97)	78% (73, 83)
	Non-urgent	93% (59, 99)	90% (47, 99)	69% (61, 76)
	Total	92% (83, 96)	89% (78, 95)	75% (71, 79)

* Not estimated due to small numbers of events or patients

CONCLUSIONS

8. Between 2010 and 2014, there were 129 registrations at GOSH and 112 paediatric registrations at Newcastle. The proportion of patients urgently registered at GOSH was lower than the proportion at Newcastle. There was strong statistical evidence of a difference in the proportion of patients transplanted within six months of registration at the two paediatric centres.
9. There were significant unadjusted differences between the two centres in the time to transplant curves by urgency status and transplant centre. However, given the different case mix at the two centres, risk adjusted models should be built to account for the differences between the two centres.
10. There were no significant differences between the two centres in terms of patient survival following transplantation.
11. Members are asked to consider whether the results reflect equitable access to paediatric heart transplantation.
12. Members are also asked to consider whether risk-adjustment should be performed for any of the time to event analyses in this paper.

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September 2015

NHS BLOOD AND TRANSPLANT

CARDIOTHORACIC ADVISORY GROUP

ACCESS TO HEART TRANSPLANTATION FOR PAEDIATRIC PATIENTS

INTRODUCTION

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2. This decision was initiated following discussion around the CTAG paper (CTAG(15) H18) which presented activity at Great Ormond Street Hospital (GOSH) in relation to a size matching rule which was imposed in April 2010.
3. It was agreed that the following outcomes would be compared, separately, between GOSH and the Newcastle paediatric unit and between paediatric and adult centres:
 - a. Time to transplant
 - b. Time to death on the list

The number of organs declined by GOSH, the Newcastle paediatric unit and adult centres would also be considered.
4. This paper examines whether there are differences in post registration outcomes between GOSH, the Newcastle paediatric unit and adult centres (including the Newcastle adult unit) whilst taking into account urgent status and case mix. The number of declined organs are also considered.

BACKGROUND

5. Great Ormond Street Hospital (GOSH) appears top of the non-urgent, non-zonal offering rota for adult donor hearts and lungs. This is a historical arrangement which makes allowance for the fact that Great Ormond Street does not have its own retrieval zone. However, clinicians at adult heart transplant centres expressed concern regarding the number of adult donor hearts that were accepted and transplanted by GOSH.
6. The appropriateness of this arrangement was discussed at the 2009 CTAG meetings and as a result, the following size matching rule was implemented in April 2010 for non-urgent paediatric patients at GOSH:
 - Heart offers from adult donors less than or equal to 1.5m tall could be accepted by GOSH at the top of the non-zonal rota for any non-urgent paediatric patients
 - Heart offers from adult donors taller than 1.5m should only be accepted at the top of the non-zonal rota by GOSH for paediatric patients within a 20cm height difference of the donor. Offers for other paediatric patients at GOSH (for whom the donor-recipient height difference is greater than 20cm) should only be accepted after the heart has been declined by all adult centres.
 - GOSH remains at liberty to place potential recipients within the Urgent Heart Allocation Scheme (UHAS) provided the entry criteria are satisfied. For the UHAS scheme, the restriction of height matching does not apply for any centre.
7. The size-matching rule was not applied to the Newcastle paediatric unit as the centre decided at the September 2009 meeting that, for paediatric patients, they would continue to access adult hearts through their zone rather than the national pool.

8. This size-matching rule has been in place for five years, during which time the number of adult donor non-urgent heart transplants performed at GOSH has decreased to 2 transplants between 1 May 2012 and 31 December 2014 (**CTAG(15)H8**). This paper initiated discussion as to whether or not there is equity of access across the two centres and between the adult and paediatric centres.

DATA

9. Outcome data on all 1282 UK NHS Group 1 registrations on the heart only transplant list between 1 January 2010 and 31 December 2014 were extracted from the UK Transplant Registry (UKTR) on 9 July 2015. Adult patients were defined as patients aged 16 years or over at time of registration. Paediatric patients registered at adult only centres were included in the adult group whilst adult patients registered at GOSH were included in the paediatric group.
10. The Kaplan-Meier estimation method was used to compare the time to transplant and time to death on the list separately for adult and paediatric registrations. Registrations were censored at point of removal from the list in both analyses along with patients who were still waiting on the list as at 9 July 2015. Time non-urgently and urgently registered on the transplant list were combined for registrations.
11. To examine the current active transplant list, demographic and registration data for 43 paediatric patients active on the heart transplant list on 31 July 2015 were also extracted from UKTR on 1 August 2015.
12. To explore the impact of the rule on post-transplant patient survival, data on first deceased donor after brain death (DBD) heart only transplants performed in the UK between 1 January 2010 and 31 December 2014 were also extracted from the UK Transplant Registry. The Kaplan-Meier estimation method was used to compare the post-transplant patient survival for adult and paediatric transplants.
13. Offering data for all UK DBD aged less than 50 years where the heart was offered for paediatric patients at GOSH and Newcastle were also extracted from the UK Transplant Registry.

RESULTS

REGISTRATION OUTCOME

14. There were 129 registrations at GOSH between 1 January 2010 and 31 December 2014, of which 88 (68%) were urgently registered during their registration. In comparison, 104 (93%) of the 112 paediatric patients registered at Newcastle were urgently registered during their registration on the transplant list (**Table 1**).

Table 1 Urgency status by centre for first UK NHS group 1 registrations, 1 January 2010 to 31 December 2014			
	GOSH	Newcastle paediatrics	Adult centres
Non-urgent	41 (32%)	8 (7%)	464 (45%)
Urgent	88 (68%)	104 (93%)	577 (55%)
Total	129 (100%)	112 (100%)	1041 (100%)

15. **Figure 1** shows the number of paediatric registrations by registration year, centre and urgency status. The number of non-urgent registrations at the Newcastle paediatric unit has been consistently lower than at GOSH. **Figure 2** shows equivalent information for paediatric transplants performed during the same period.

Figure 1 UK first NHS Group 1 paediatric heart only registrations, 1 January 2010 to 31 December 2014, by registration year, centre and urgency status

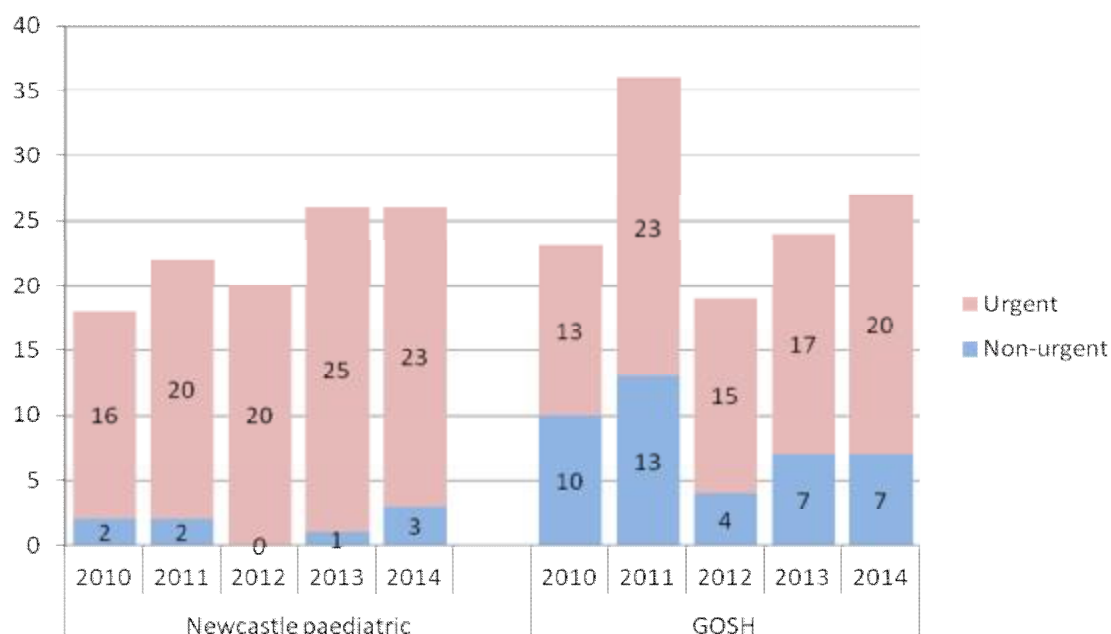
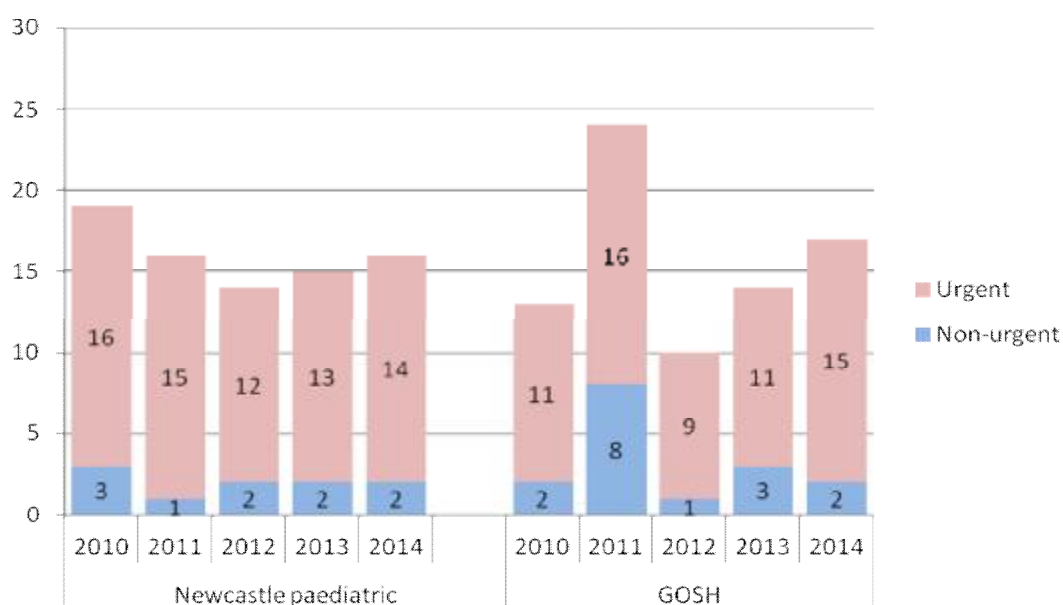


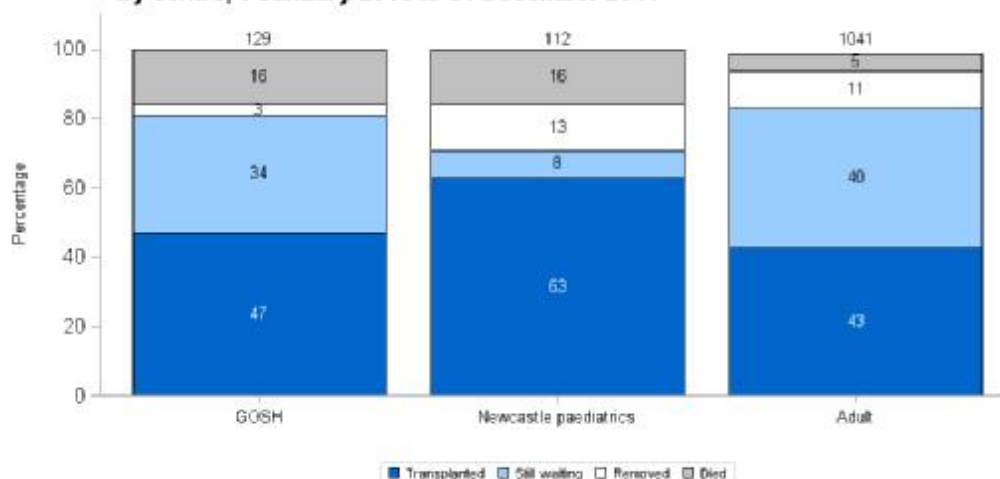
Figure 2 UK first NHS Group 1 paediatric heart only transplants, 1 January 2010 to 31 December 2014, by transplant year, centre and urgency status



16. Registration outcomes (death, transplant, removal, still waiting) within six months of registration are shown in **Figure 3** by centre. There is no evidence of a statistically significant difference between the two paediatric centres in the proportion of patients at

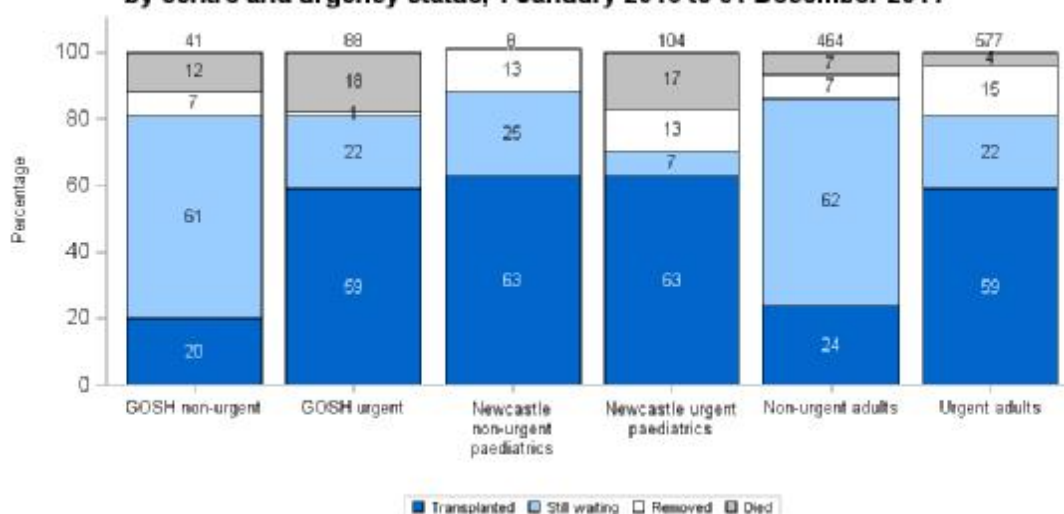
that died within six months of registration (Fisher's exact test $p>0.99$). However, there is strong evidence of a difference between paediatric centres in the proportion of patients transplanted at six months post-registration (Fisher's exact test $p=0.01$).

Figure 3 Six month post-registration outcome for new UK first heart only registrations, by centre, 1 January 2010 to 31 December 2014



17. Registration outcomes (death, transplant, removal, still waiting) within six months of registration are shown in **Figure 4** by centre and urgency status during registration. The proportion of urgent patients transplanted within six months of registration is very similar at GOSH, the Newcastle paediatric unit and for adult centres (59%, 63% and 59% respectively). The proportion of non-urgent patients transplanted within six months at GOSH and adult centres is also similar (20% and 24% respectively). The proportion of non-urgent patients transplanted at Newcastle is higher (63%), but this is due to the small number of non-urgent registrations at Newcastle ($n=8$). Thus, 7% of Newcastle paediatric patients registered were classified as non-urgent compared with 31% of GOSH patients ($p<0.001$).

Figure 4 Six month post-registration outcome for new UK first heart only registrations, by centre and urgency status, 1 January 2010 to 31 December 2014



18. **Table A1** in the **Appendix** shows the demographics for patients registered at GOSH and paediatric patients at Newcastle by urgency status during the registration. Overall, there were significant differences between the two centres in patient age ($p\text{-value}=0.0001$),

weight (p -value=0.0003), primary disease (0.002), VAD at registration (p <0.0001) and ECMO at registration (p =0.001). There were no significant differences between the two centres in patient blood group and registration year (p >0.1).

19. **Table 2** shows the Urgent Heart categories for all 192 patients registered on to the UHAS between 1 January 2010 and 31 December 2014. The most common category for paediatric patients at Newcastle was the 'Other' category (35%) while the common category for GOSH was '>15kg on high dose inotrope' (24%).

Table 2 Urgent criteria for paediatric patients urgently registered on UK heart only transplant list, 1 January 2010 to 31 December 2014			
	GOSH (n=88)	Newcastle (n=104)	Overall (n=192)
Short-term MCSD	8 (9%)	10 (10%)	18 (9%)
MCSD with device complications	0 (0%)	1 (1%)	1 (1%)
IABP	0 (0%)	2 (2%)	2 (1%)
ECMO	4 (5%)	7 (7%)	11 (6%)
>15kg on high dose inotrope	21 (24%)	13 (12%)	34 (18%)
≤ 15 kg on ventilation and inotropes	19 (22%)	8 (8%)	27 (14%)
Other	18 (20%)	36 (35%)	54 (28%)
Not reported	18 (20%)	27 (26%)	45 ()

20. **Figure 5a** shows unadjusted Kaplan-Meier curves for time to transplant by urgency status and registration age group. **Figure 5b** shows similar time to death on the list curves. There were significant differences between the four groups for both time to transplant and time to death on the list, which is expected as patients who are urgently registered have priority when a heart is offered for transplantation.
21. There were no significant differences in the time to transplant curves between non-urgent adult and non-urgent paediatrics (log-rank p -value=0.17) or between urgent adult and urgent paediatrics (log-rank p -value=0.8). There were also no significant differences in the time to death on the list curves between non-urgent adult and non-urgent paediatrics (log-rank p -value=0.4). However, there was a significant difference in the time to death on the list between urgent adult and urgent paediatrics (log-rank p -value<0.0001).

Figure 5 Time to a) transplant and b) death on the list for patients registered for a first heart only transplant, 1 January 2010 to 31 December 2014, by urgency and age group

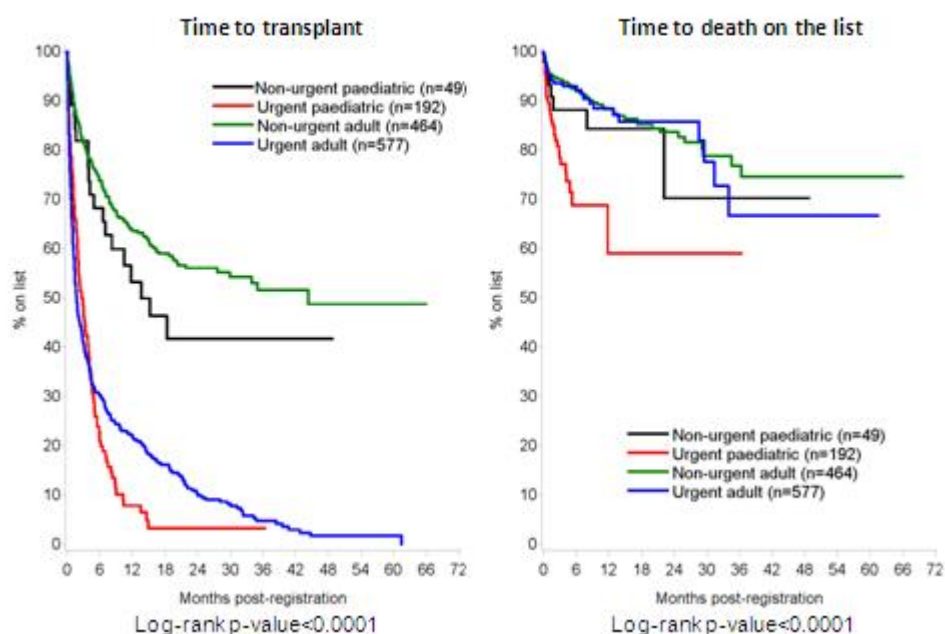


Table 2 Unadjusted median waiting time for patients registered for a first heart only transplant in the UK, 1 January 2010 to 31 December 2014

	No. at risk	Median waiting time to transplant (days, 95% CI)
Non-urgent paediatric	49	414 (150, 678)
Non-urgent adult	464	1349 (-)
Urgent paediatric	192	83 (59, 107)
Urgent adult	577	53 (41, 65)
Log-rank p-value		<0.0001
Adult overall	241	199 (152, 246)
Paediatric overall	1041	116 (95, 137)
Log-rank p-value		<0.001

22. **Figure 6a** shows unadjusted Kaplan-Meier curves for time to transplant for paediatric patients by urgency status and transplant centre. **Figure 6b** shows similar curves for time to death on the list. There were significant differences between the four groups for time to transplant. However, there were no significant differences in the time to death on the list for paediatric patients.

Figure 6 Time to a) transplant and b) death on the list for patients registered for a first paediatric heart only transplant, 1 January 2010 to 31 December 2014, by urgency and transplant centre

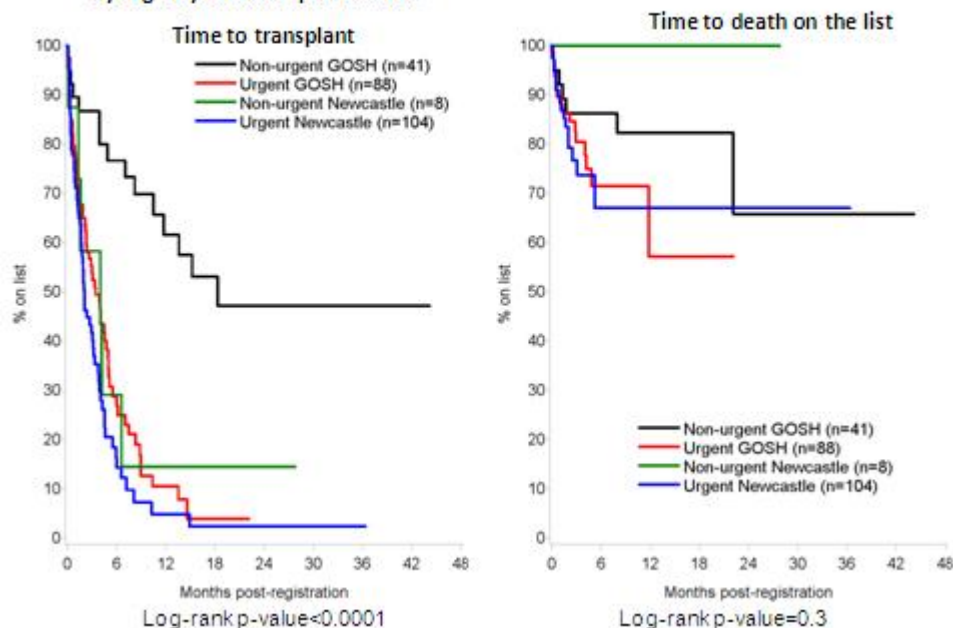


Table 3 Unadjusted median waiting time for paediatric patients registered for a first heart only transplant in the UK, 1 January 2010 to 31 December 2014

	No. at risk	Median waiting time to transplant (days, 95% CI)
Non-urgent GOSH	41	558 (-)
Non-urgent Newcastle	8	122 (0, 306)
Urgent GOSH	88	105 (67, 143)
Urgent Newcastle	104	63 (48, 78)
Log-rank p-value		<0.0001
GOSH overall	129	150 (110, 190)
Newcastle overall	112	63 (39, 87)
Log-rank p-value		<0.0001

TRANSPLANT LIST AS AT 31 JULY 2015

23. There were 273 patients active on the heart only transplant list on 31 July 2015. Of these patients, 12 were paediatrics at Newcastle and 31 were registered at GOSH. **Table A2** shows the demographics for paediatric patients by transplant centre and urgency status. Overall, there were significant differences at a 10% level between the two centres in patient age ($p=0.03$), weight at registration ($p=0.07$), blood group ($p=0.09$), time on the transplant list ($p=0.09$), VAD at registration ($p=0.05$) and primary disease at registration ($p=0.07$).

POST-TRANSPLANT SURVIVAL

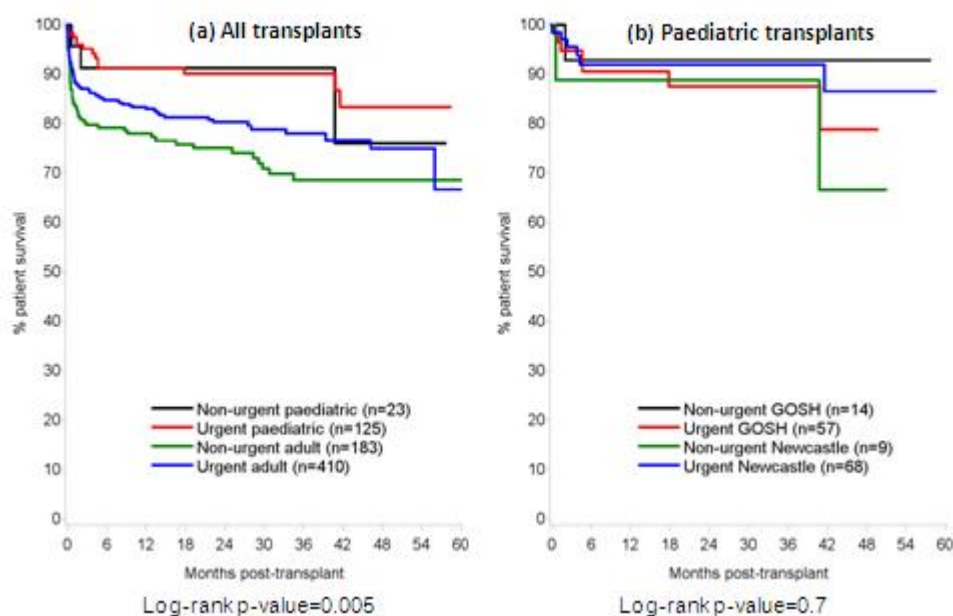
24. There were 754 first deceased donor after brain death (DBD) heart only transplants performed in the UK between 1 January 2010 and 31 December 2014. Of these transplants, 78 were performed at GOSH and 80 were received by paediatrics at Newcastle (**Table 5**). There was no significant difference in the proportion of urgent transplants performed at both centres (p-value=0.2).

Table 5 Urgency status by transplant centre for first UK DBD heart only transplants, 1 January 2010 to 31 December 2014

	GOSH	Newcastle paediatrics	Adult centres
Non-urgent	16 (21%)	10 (13%)	184 (31%)
Urgent	62 (79%)	70 (87%)	412 (69%)
Total	78 (100%)	80 (100%)	596 (100%)

25. **Figure 7a** shows the Kaplan-Meier post-transplant patient survival curves by age group and urgency status whilst **Figure 7b** shows similar curves by transplant centre and urgency status for paediatric patients. Paediatric patients had a higher post-transplant survival compared with adult patients and there was a significant difference between the four survival curves (log-rank p-value=0.006). However, there was no significant difference between the two transplant centres for paediatric patients (log-rank p-value=0.7)

Figure 7 Patient survival following first UK DBD heart only transplants, (a) by age group and urgency status, (b) by transplant centre and urgency status for paediatric patients, 1 January 2010 to 31 December 2014



HEARTS OFFERED TO PAEDIATRIC CENTRES

26. 394 offers of 241 hearts transplanted from UK DBD donors aged less than 50 were recorded as offered to paediatric patients at Newcastle and GOSH for transplantation between 1 January 2010 and 31 December 2014. However, there are likely to be more hearts offered to Newcastle that may have been considered for paediatric patients which are not recorded on the UK Transplant Registry. This is because hearts offered non-urgently to Newcastle can be considered for both adult and paediatric patients.
27. **Table 5** shows the offering outcome by transplant centre. 77% of the offers to GOSH patients were declined compared with 66% of the offers at Newcastle paediatric unit. 23% of the offers to GOSH patients resulted in a transplant compared with 33% at Newcastle.

Table 5 Offering outcome for hearts offered to paediatric patients from UK DBD donors aged less than 50 years, 1 January 2010 to 31 December 2014				
	Declined	Accepted but not used	Transplanted	Total
GOSH	182 (77%)	0 (0%)	53 (23%)	235 (100%)
Newcastle	105 (66%)	2 (1%)	52 (33%)	159 (100%)
Overall	287 (73%)	2 (1%)	105 (26%)	394

28. **Table A3** shows the primary reasons given by the paediatric centres for declining an offer. The main reasons were donor size (59%), poor function (16%), donor past history (6%) and no suitable recipient (5%).

CONCLUSIONS

29. Between 2010 and 2014, there were 129 registrations at GOSH and 112 paediatric registrations at Newcastle. The proportion of patients urgently registered at GOSH was lower than the proportion at Newcastle. There was strong statistical evidence of a difference in the proportion of patients transplanted within six months of registration at the two paediatric centres.
30. Paediatric patients at Newcastle were significantly younger and weighed less than patients registered at GOSH ($p < 0.001$). Nearly 50% of the patients at Newcastle with known VAD status at registration were on a VAD at registration compared with 10% at GOSH. There were more patients with congenital heart disease registered at Newcastle than at GOSH. There were no significant differences between the two centres in terms of patient blood group and registration year ($p > 0.1$).
31. There were significant unadjusted differences between the two centres in the time to transplant curves by urgency status and transplant centre. However, given the different case mix at the two centres, risk adjusted models should be built to account for the differences between the two centres.

32. 273 patients were active on the heart only transplant list on 31 July 2015, 43 of whom were either paediatrics at Newcastle or registered at GOSH. Paediatric patients actively registered at Newcastle were younger than GOSH and were on the list for a shorter period of time. There was a higher proportion of blood group B patients registered at GOSH than at Newcastle. 60% of the patients at Newcastle with known VAD status at registration were on a VAD at registration compared with 7% at GOSH.
33. There were no significant differences between the two centres in terms of patient survival following transplantation.
34. Members are asked to consider whether the results reflect equitable access to paediatric heart transplantation.
35. Members are also asked to consider whether any risk-adjustment should be performed for any time to event analyses.

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Appendix

Table A1		Demographics for paediatric patients registered on UK heart only transplant list, 1 January 2010 to 31 December 2014						
Variable	Level	GOSH		Newcastle		Overall		p-value
		Non-urgent (n=41)	Urgent (n=88)	Non-urgent (n=8)	Urgent (n=104)	GOSH (n=129)	Newcastle (n=112)	
Patient age	< 1 year	4 (10%)	25 (28%)	0 (0%)	45 (43%)	29 (23%)	45 (40%)	0.0015
	1 – 3 years	9 (22%)	20 (23%)	1 (13%)	23 (22%)	29 (22%)	24 (21%)	
	4 – 9 years	15 (36%)	16 (18%)	5 (62%)	24 (23%)	31 (24%)	29 (26%)	
	≥ 10 years	13 (32%)	27 (31%)	2 (25%)	12 (12%)	40 (31%)	14 (13%)	
	Median (IQR)	6 (2, 12)	2.5 (0, 12)	5 (4.5, 8)	1 (0, 6)	5 (1, 12)	1 (0, 6)	0.0001
Weight	<10kg	7 (17%)	33 (38%)	0 (0%)	57 (55%)	40 (31%)	57 (51%)	0.005
	10-15 kg	7 (17%)	16 (18%)	2 (25%)	19 (18%)	23 (18%)	21 (19%)	
	16-32 kg	16 (39%)	16 (18%)	4 (50%)	16 (15%)	32 (25%)	20 (18%)	
	≥ 33 kg	11 (27%)	23 (26%)	2 (25%)	12 (12%)	34 (26%)	14 (12%)	
	Median (IQR)	19 (13.4, 33.6)	13.1 (7.3, 35.8)	18.7 (16.1, 30.2)	8.4 (6.1, 17.4)	16.1 (8.6, 34.5)	9.5 (6.5, 19)	0.0003
Blood group	O	20 (49%)	39 (44%)	4 (50%)	49 (47%)	59 (46%)	53 (47%)	0.7
	A	11 (27%)	28 (32%)	4 (50%)	30 (29%)	39 (30%)	34 (31%)	
	B	9 (22%)	17 (19%)	0 (0%)	18 (17%)	26 (20%)	18 (16%)	
	AB	1 (2%)	4 (5%)	0 (0%)	7 (7%)	5 (4%)	7 (6%)	
Registration year	2010	10 (24%)	13 (15%)	2 (25%)	16 (15%)	23 (18%)	18 (16%)	0.6
	2011	13 (32%)	23 (26%)	2 (25%)	20 (19%)	36 (28%)	22 (20%)	
	2012	4 (10%)	15 (17%)	0 (0%)	20 (19%)	19 (15%)	20 (18%)	
	2013	7 (17%)	17 (19%)	1 (13%)	25 (24%)	24 (18%)	26 (23%)	
	2014	7 (17%)	20 (23%)	3 (37%)	23 (22%)	27 (21%)	26 (23%)	
VAD at registration	Yes	0 (0%)	10 (14%)	0 (0%)	51 (52%)	10 (10%)	51 (48%)	<0.0001
	No	32 (100%)	63 (86%)	7 (100%)	48 (48%)	95 (90%)	55 (52%)	
	Unknown	9 (-)	15 (-)	1 (-)	5 (-)	24 (-)	6 (-)	
ECMO at registration	Yes	0 (0%)	5 (7%)	0 (0%)	17 (18%)	5 (5%)	17 (17%)	0.0013
	No	32 (100%)	68 (93%)	7 (100%)	79 (82%)	100 (95%)	86 (83%)	
	Unknown	9 (-)	15 (-)	1 (-)	8 (-)	24 (-)	9 (-)	
Primary disease at registration	Congenital heart disease	18 (44%)	14 (16%)	7 (88%)	44 (42%)	32 (25%)	51 (46%)	0.0024
	Dilated cardiomyopathy	9 (22%)	60 (68%)	1 (12%)	46 (44%)	69 (53%)	47 (42%)	
	Other	14 (34%)	14 (16%)	0 (0%)	14 (14%)	28 (22%)	14 (12%)	

Table A2 Demographics for paediatric patients active on UK heart only transplant list on 31 st July 2015								
Variable	Level	GOSH		Newcastle		Overall		p-value
		Non-urgent (n=21)	Urgent (n=10)	Non-urgent (n=3)	Urgent (n=9)	GOSH (n=31)	Newcastle (n=12)	
Patient age	< 1 year	1 (5%)	1 (10%)	0 (0%)	3 (33%)	2 (7%)	3 (25%)	0.2
	1 – 3 years	4 (19%)	5 (50%)	1 (33%)	3 (33%)	9 (29%)	4 (33%)	
	4 – 9 years	7 (33%)	3 (30%)	2 (67%)	2 (22%)	10 (32%)	4 (33%)	
	≥ 10 years	9 (43%)	1 (10%)	0 (0%)	1 (11%)	10 (32%)	1 (8%)	
	Median (IQR)	9 (7, 14)	2 (1, 4)	4 (3, 6)	1 (0, 4)	8 (1, 11)	2 (0.5, 4.5)	0.03
Weight	<10kg	5 (24%)	5 (50%)	0 (0%)	3 (33%)	10 (32%)	3 (25%)	0.07
	10-15 kg	2 (10%)	4 (40%)	2 (67%)	4 (44%)	6 (19%)	6 (50%)	
	16-32 kg	7 (33%)	1 (10%)	1 (33%)	1 (11%)	8 (26%)	2 (17%)	
	≥ 33 kg	7 (33%)	0 (0%)	0 (0%)	0 (0%)	7 (23%)	0 (0%)	
	Unknown	0 (0%)	0 (0%)	0 (0%)	1 (11%)	0 (0%)	1 (8%)	0.14
	Median (IQR)	21 (12.8, 36.6)	10.3 (7.4, 13)	15 (12, 20)	10.3 (4.5, 14.2)	15.8 (8.8, 30)	12 (5, 15)	
Blood group	O	13 (62%)	5 (50%)	2 (67%)	3 (33%)	18 (58%)	5 (42%)	0.09
	A	4 (19%)	1 (10%)	1 (33%)	5 (56%)	5 (16%)	6 (50%)	
	B	4 (19%)	4 (40%)	0 (0%)	1 (11%)	8 (26%)	1 (8%)	
	AB	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
Active waiting time (days)	< 30 days	3 (14%)	4 (40%)	0 (0%)	2 (22%)	7 (23%)	2 (17%)	0.09
	30 – 89 days	2 (10%)	3 (30%)	1 (33%)	6 (67%)	5 (16%)	7 (58%)	
	90 – 179 days	1 (5%)	2 (20%)	0 (0%)	1 (11%)	3 (10%)	1 (8%)	
	180 - < 1 year	2 (10%)	1 (10%)	1 (33%)	0 (0%)	3 (10%)	1 (8%)	
	1 - < 2 year	8 (38%)	0 (0%)	0 (0%)	0 (0%)	8 (26%)	0 (0%)	
	≥ 2 years	5 (24%)	0 (0%)	1 (33%)	0 (0%)	5 (16%)	1 (8%)	
VAD at registration	Yes	0 (0%)	1 (25%)	2 (100%)	1 (33%)	1 (7%)	3 (60%)	0.05
	No	11 (100%)	3 (75%)	0 (0%)	2 (67%)	14 (93%)	2 (40%)	
	Unknown	10 (-)	6 (-)	1 (-)	6 (-)	16 (-)	7 (-)	
ECMO at registration	Yes	0 (0%)	1 (25%)	1 (50%)	0 (0%)	1 (7%)	1 (20%)	0.6
	No	11 (100%)	3 (75%)	1 (50%)	3 (100%)	14 (93%)	4 (80%)	
	Unknown	10 (-)	6 (-)	1 (-)	6 (-)	16 (-)	7 (-)	
Primary disease at registration	Congenital heart disease	8 (38%)	2 (20%)	2 (67%)	6 (67%)	10 (32%)	8 (67%)	0.07
	Dilated cardiomyopathy	4 (19%)	5 (50%)	1 (33%)	2 (22%)	9 (29%)	3 (25%)	
	Other	9 (43%)	3 (30%)	0 (0%)	1 (11%)	12 (39%)	1 (8%)	

Table A3 Primary reason given by paediatric centres for declining an offer of a heart from UK DBD donors aged less than 50 years, 1 January 2010 to 31 December 2014			
	GOSH (n=182)	Newcastle (n=105)	Total (n=287)
Donor size	90 (49.5%)	79 (75.2%)	169 (58.9%)
No suitable recipients	40 (22.0%)	6 (5.7%)	46 (16.0%)
Poor function	16 (8.8%)	1 (1.0%)	17 (5.9%)
Donor past history	11 (6.0%)	2 (1.9%)	13 (4.5%)
HLA/ABO type	5 (2.7%)	5 (4.8%)	10 (3.5%)
Donor age	7 (3.8%)	2 (1.9%)	9 (3.1%)
Positive x-match	3 (1.6%)	2 (1.9%)	5 (1.7%)
Centre already retrieving/ transplanting	0 (0%)	2 (1.9%)	2 (0.7%)
Donor cause of death	0 (0%)	2 (1.9%)	2 (0.7%)
Centre criteria not achieved	1 (0.5%)	0 (0%)	1 (0.3%)
Donor virology	1 (0.5%)	0 (0%)	1 (0.3%)
No beds	0 (0%)	1 (1.0%)	1 (0.3%)
No staff	1 (0.5%)	0 (0%)	1 (0.3%)
Organ used elsewhere	0 (0%)	1 (1.0%)	1 (0.3%)
Recipient unfit	1 (0.5%)	0 (0%)	1 (0.3%)
Tumour	1 (0.5%)	0 (0%)	1 (0.3%)
Other	3 (1.6%)	2 (1.9%)	5 (1.7%)
Unknown	2 (1.1%)	0 (0%)	2 (0.7%)