

**NHS BLOOD AND TRANSPLANT  
CARDIOTHORACIC ADVISORY GROUP – HEART**

**PAEDIATRIC ACCESS TO ADULT DONOR HEARTS – REMOVAL OF 20CM  
RULE FOR GREAT ORMOND STREET HOSPITAL**

**SUMMARY**

**BACKGROUND**

1. The 20cm rule was removed entirely in December 2023, meaning that Great Ormond Street Hospital are now able to accept adult donor hearts in second position in the non-urgent sequence from anywhere in the country, regardless of the height difference between the recipient and donor. This report reviews the impact of this change in allocation policy, examining 9 months' worth of offering data and waiting list data.

**DATA ANALYSIS AND KEY FINDINGS**

1. Data were extracted from the UK Transplant Registry on all DBD and DCD hearts offered from UK donors to UK centres between 11 December 2023 and 10 September 2024, and all paediatric patients on the transplant list during this period.
2. During the 9 month period, there were 435 adult donor hearts offered; 139 were only offered to the super-urgent and urgent tiers, resulting in 5 paediatric transplants, and 296 were offered to the non-urgent tiers, resulting in 4 paediatric transplants. This resulted in a total of 9 paediatric transplants using adult donor hearts, an average of 1 per month. In only one case the height difference exceeded 20cm, where the rule would have previously applied (a non-urgent transplant at GOSH).
3. The median donor height of those adult hearts that were offered was 172cm, while the median donor weight was 78kg. In comparison, of the 21 paediatric patients who were on the non-urgent heart transplant list at GOSH during the period, the median height was 93cm and the median weight was 15kg. The median height and weight of the 17 paediatric patients at Newcastle were 103cm and 18kg respectively.
4. While paediatric patients make up 12% of the heart transplant list, paediatric donor heart offers only represent 4% of all hearts offered.
5. Median waiting time to transplant for both non-urgent and urgent paediatric patients is longer than for adults, with a median of 204 days for urgent paediatric patients. This appears to be driven by longer waiting times for small children who require paediatric donors, as opposed to those aged 7-15. Removal of the 20cm rule will not impact access to hearts for urgent paediatric patients.

**ACTION**

6. CTAG-Heart should consider the results in this report and discuss whether more is needed to improve access to adult donor hearts for paediatric recipients.

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**September 2024**

## NHS BLOOD AND TRANSPLANT CARDIOTHORACIC ADVISORY GROUP – HEART

### PAEDIATRIC ACCESS TO ADULT DONOR HEARTS – REMOVAL OF 20CM RULE FOR GREAT ORMOND STREET HOSPITAL

#### BACKGROUND

7. Historically there has been a rule in place which meant an adult donor heart could only be accepted by Great Ormond Street Hospital (GOSH) for a non-urgent paediatric recipient, after the zonal centre had declined, if the height difference between the donor and recipient was less than 20cm (known as “the 20cm rule”). On 4 May 2023, this rule was relaxed so that for donors in the Harefield zone only, GOSH could accept for any recipient after Harefield had declined.
8. This change was reviewed at CTAG-Heart in October 2023, and it was found that no non-urgent heart transplants had been performed by GOSH with a height difference of more than 20cm, indicating that the change had not increased access to the adult donor pool for non-urgent paediatric patients at GOSH. Therefore, the decision was made to remove the rule entirely, meaning that GOSH could accept a heart in second position from anywhere in the country regardless of the height difference. This change was made on 11 December 2023.
9. The **Appendix I** shows the adult donor offering sequences for DBD and DCD, highlighting the section where the 20cm rule previously applied. The 20cm rule did not apply to super-urgent or urgent offers, nor did it apply to Newcastle who could accept for either paediatric or adult recipients on receipt of a non-urgent centre offer (either zonally or lower in sequence). Note that for DCD donors, the offering sequence in the Appendix now shows the super-urgent tiers, however this was only introduced in August 2024, prior to this offers were made on a centre basis where centres could choose an urgent or super-urgent recipient if suitable.
10. This paper reviews the impact of the removal of the 20cm rule entirely, examining data between 11 December 2023 and 10 September 2024 (9 months). It also looks at paediatric access to adult donor hearts for Newcastle.

#### DATA

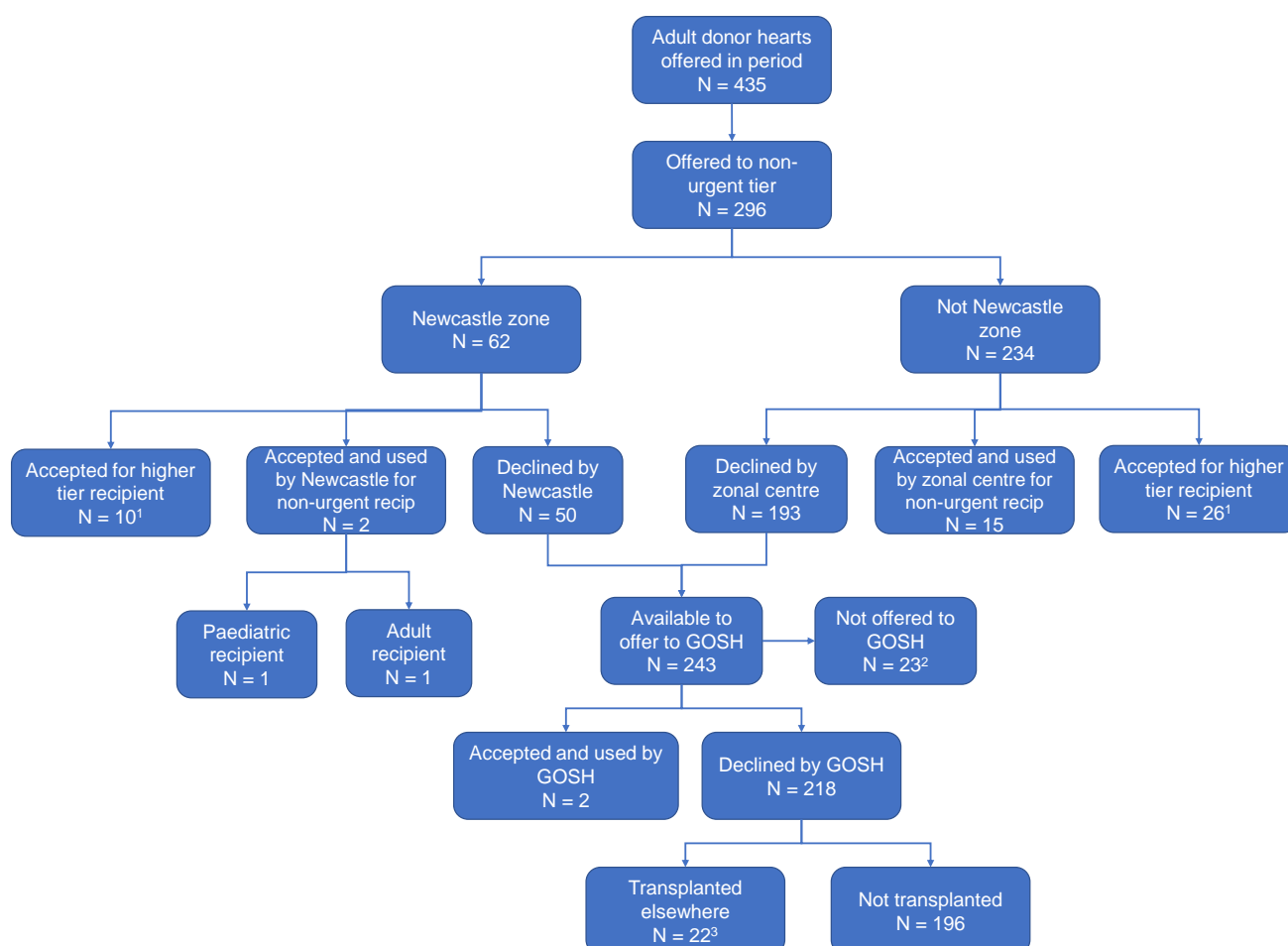
11. Data were extracted from the UK Transplant Registry on all DBD and DCD hearts offered from UK adult donors ( $\geq 16$ ) to UK centres between 11 December 2023 and 10 September 2024. This included donors that did not proceed to donation. Data were also extracted on paediatric donor offers and paediatric patients on the transplant list at GOSH or Newcastle during this period.

#### RESULTS

12. **Figure 1** shows the offering pathway of the 435 adult donor hearts offered from potential DBD and DCDs in the 9 months, of which 296 were offered to the non-urgent tier. In total there were 4 paediatric recipients; 2 at GOSH and 2 at Newcastle, 1 of which was an urgent recipient from a non-zonal donor which was offered to the non-urgent tier as a back-up only.

13. In addition to this, there were a further 5 paediatric heart transplants performed in the period from adult donors that weren't offered to the non-urgent tier; 4 at GOSH (2 super-urgent, 2 urgent) and 1 at Newcastle (super-urgent). This resulted in a total of 9 paediatric transplants using adult donor hearts, an average of 1 per month. In comparison, there were 147 adult transplants using adult donor hearts, and during the same time period there were 16 paediatric donor hearts offered resulting in 10 paediatric transplants and 3 adult transplants.

**Figure 1** Offering pathway of adult DBD and DCD hearts offered to the non-urgent tier, 11 December 2023 – 10 September 2024



<sup>1</sup> In these cases, the heart was accepted for a higher tier recipient even though it had been offered to the non-urgent tier for a variety of reasons (e.g. only being offered to the non-urgent tier as a back-up, because of the super-urgent liver pathway, or because they are DCD hearts); this included one urgent paediatric transplant by Newcastle from a non-zonal donor.

<sup>2</sup> Mainly cases where the heart was deemed untransplantable before offering to GOSH.

<sup>3</sup> None transplanted into paediatric recipients at Newcastle.

14. **Table 1** shows the details of the 3 non-urgent paediatric transplants from adult donors. In 2 cases the height difference was more than 20cm, including one case at Newcastle where the 20cm rule would never have applied. Therefore, just 1 transplant in the period was achieved by the removal of the 20cm rule.

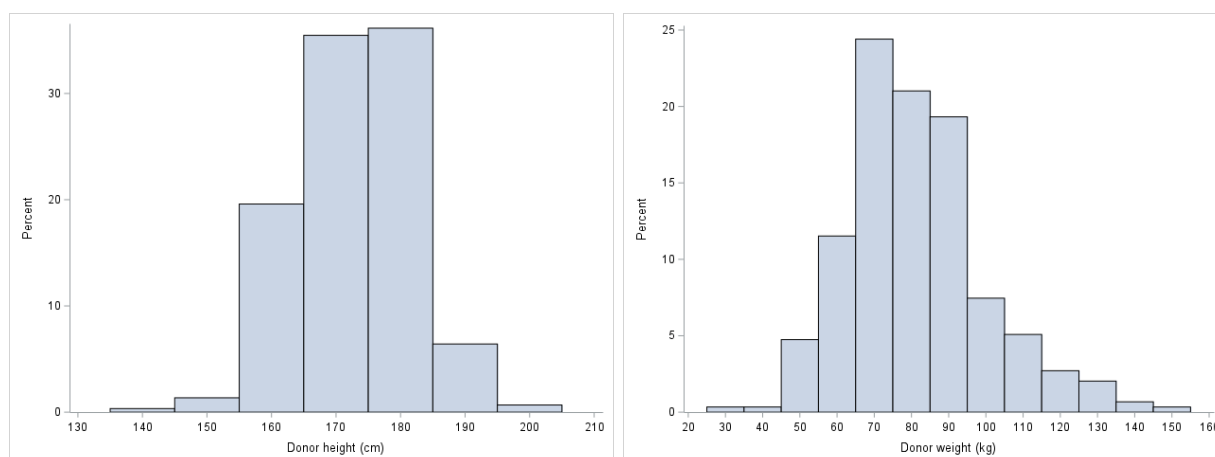
<b>Table 1      Non-urgent paediatric heart transplants from adult donors, 11 December 2023 – 10 September 2024</b>							
Centre	Donor type	Donor age	Donor height (cm)	Donor weight (kg)	Recipient age	Recipient height (cm)	Recipient weight (kg)
GOSH	DBD	22	162	70	8	111	23.6
GOSH	DCD	20	172	60	14	166	42
Newcastle	DCD	21	161	53.5	6	78	13.1

15. **Table 2** presents the decline reasons for the 218 adult donor hearts declined by GOSH.

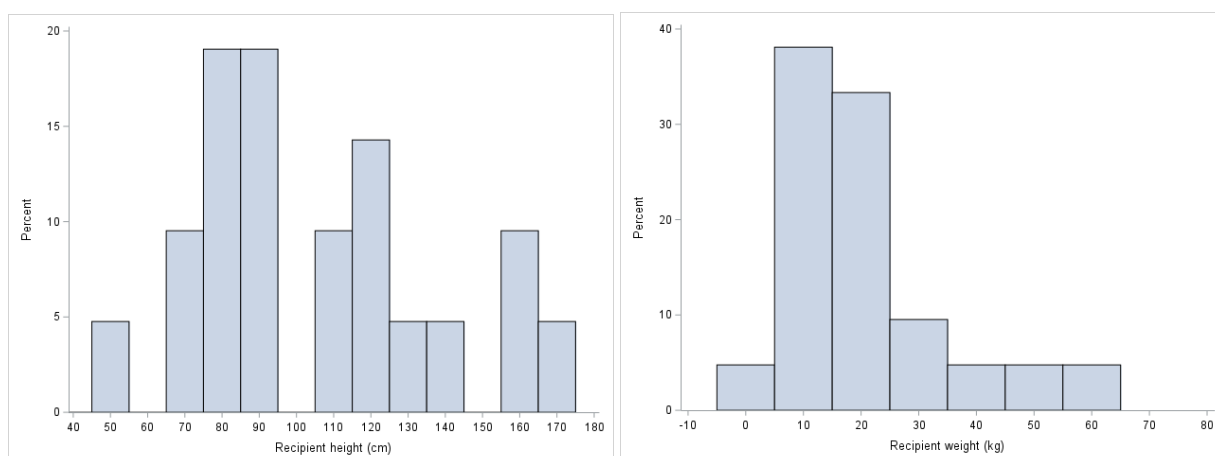
<b>Table 2      Decline reasons for adult donor hearts offered to GOSH in the non-urgent tier and declined, 11 December 2023 – 10 September 2024</b>	
Decline reason	Number of declines
No suitable recipients	56 (26%)
No response to fast track/group offer	43 (20%)
Donor unsuitable - age	40 (18%)
Donor unsuitable - past history	20 (9%)
Donor unsuitable - size	13 (6%)
Poor function - initial assessment	12 (6%)
ABO mismatch	10 (5%)
HLA mismatch	5 (2%)
HLA/ABO type	3 (1%)
Donor unsuitable - virology	3 (1%)
Size mismatch	3 (1%)
Other, please specify - donor unsuitable	3 (1%)
Other, please specify - logistic issues	3 (1%)
Poor function	2 (1%)
Other, please specify	1 (0%)
Other, please specify - organ unsuitable	1 (0%)
<b>Total</b>	<b>218</b>

16. **Figure 2** shows the distribution of heights and weights of the 296 adult donors offered to the non-urgent tier in the time period. **Figure 3** shows the distribution of heights and weights of the 21 paediatric patients who were on the non-urgent heart transplant list at any point in the period at GOSH, and **Figure 4** shows the same for the 17 paediatric patients at Newcastle.

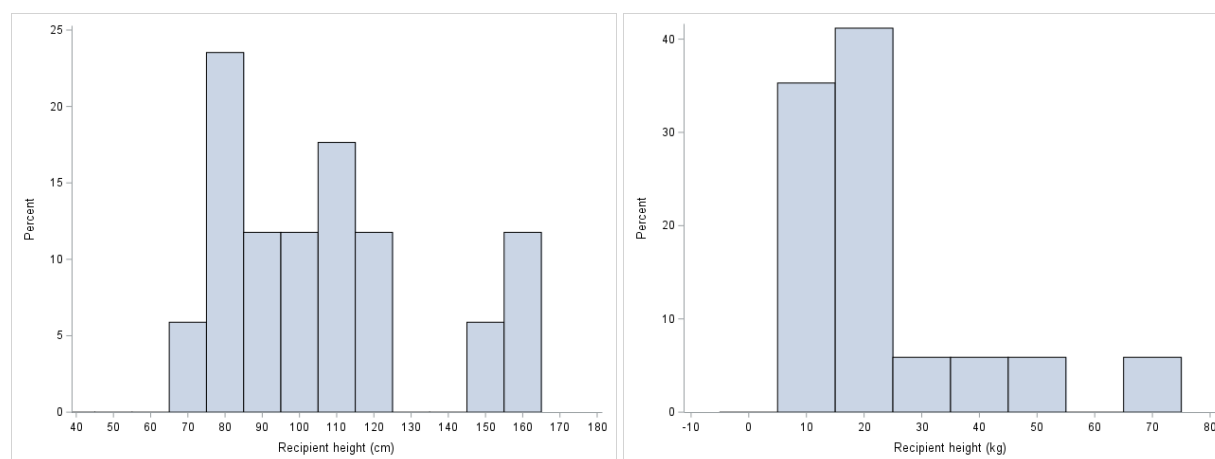
**Figure 2** Distribution of heights and weights of adult donors offered to the non-urgent tier, 11 December 2023 – 10 September 2024



**Figure 3** Distribution of height and weights of paediatric patients on the non-urgent heart transplant list at GOSH (N=21), 11 December 2023 – 10 September 2024



**Figure 4** Distribution of height and weights of paediatric patients on the non-urgent heart transplant list at Newcastle (N=17), 11 December 2023 – 10 September 2024



17. **Table 3** shows the median waiting times to heart transplant for paediatric and adult patients as reported in the Annual Report on Heart Transplantation<sup>1</sup>. This report also shows that paediatric patients represent 12% of the national heart transplant list. The median waiting times for paediatric patients are longer than for adults, in particular the urgent paediatric waiting time is considerably longer than for urgent adults. A further breakdown of this data suggests that this is driven by longer waiting times in the under 7s as opposed to the larger paediatric patients (see **Appendix II**).

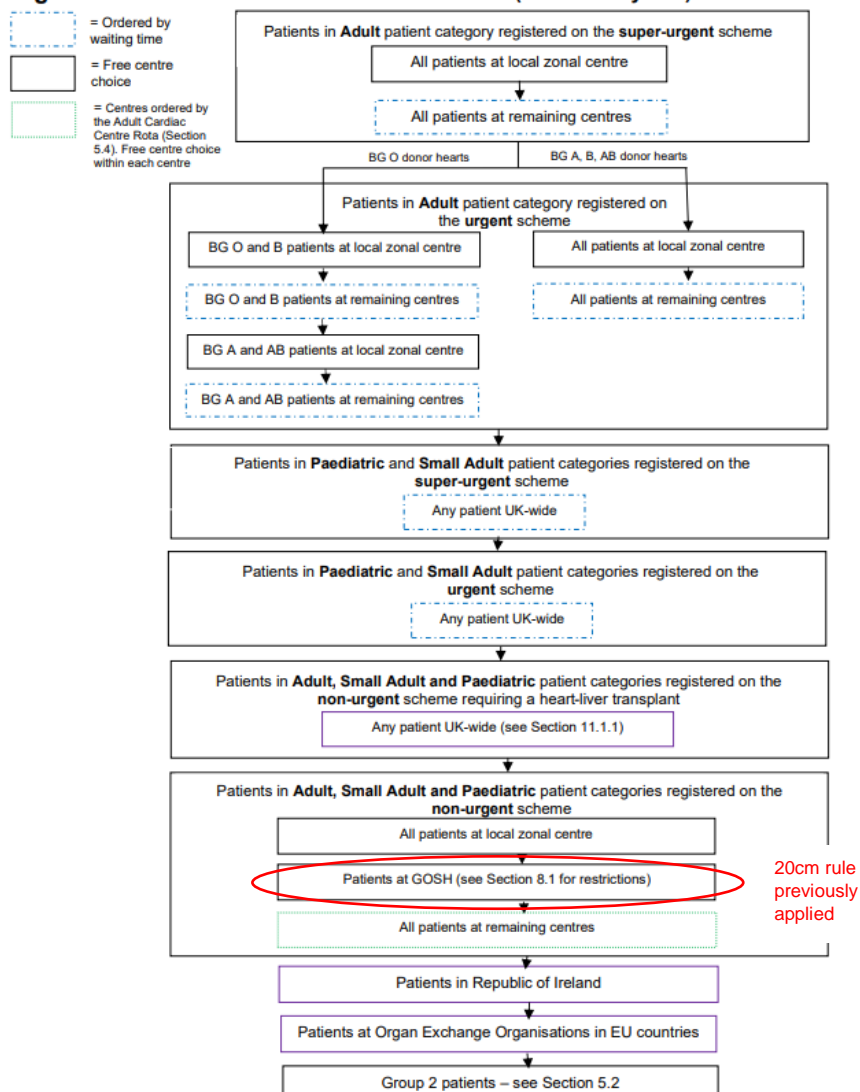
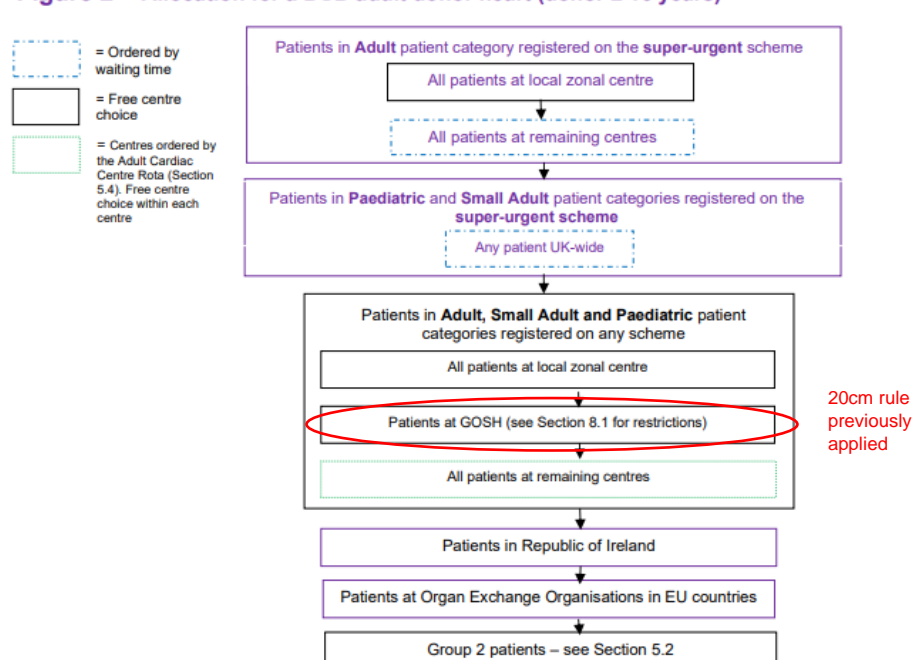
<b>Table 3                      Median waiting time results from Annual Report on Heart Transplantation 2023/2024</b>		
<b>Age group</b>	<b>Initial urgency</b>	<b>Median waiting time (days)</b>
Paediatric	Non-urgent	917
	Urgent	204
Adult	Non-urgent	867
	Urgent	43

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**September 2024**

<sup>1</sup> <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/34293/nhsbt-heart-transplantation-report-2324.pdf>

## Appendix I – Current adult donor heart offering sequences from POL228 Heart Allocation Policy

**Figure 1 Allocation for a DBD adult donor heart (donor ≥ 16 years)****Figure 2 Allocation for a DCD adult donor heart (donor ≥ 16 years)**

<b>Appendix II      Median waiting time to heart transplant by centre and age group, for paediatric patients registered on the urgent list April 2020 – March 2023</b>			
<b>Centre</b>	<b>Age group</b>	<b>Number of patients</b>	<b>Median waiting time (days) (95% CI)</b>
GOSH	<7 years	21	239 (177 – 301)
	7-15 years	14	62 (26 – 98)
Newcastle	<7 years	23	277 (188 – 366)
	7-15 years	13	51 (30 – 72)
Total		71	204 (119 – 289)