NHS BLOOD AND TRANSPLANT

CARDIOTHORACIC ADVISORY GROUP - HEART

REVIEW OF HEART TRANSPLANT ALLOCATION DATA

SUMMARY

INTRODUCTION

 The super-urgent heart allocation was introduced on 26 October 2016 alongside several changes to the urgent heart allocation policy. This report presents outcomes of patients on the heart transplant waiting list, considering urgency group, centre and disease group. It also presents post-transplant outcomes by urgency group.

DATA ANALYSIS

2. The cohort of registrations covers 6.8 years, from 26 October 2016 and 31 July 2023. The cohort of transplants covers 6.4 years from 26 October 2016 and 31 March 2023, to allow for follow-up submission. The analysis considers adult patients only (age≥16) and includes heart-lung block registrations/transplants. For the post-transplant survival analysis, only first-time transplants were considered.

RESULTS

- 3. There were 975 non-urgent registrations, 928 urgent registrations and 309 super-urgent registrations in the time period. Super-urgent registrations represented 14% of all registrations. At time of analysis, 74% of super-urgent registrations ended in transplant, compared with 66% for urgent registrations and 21% for non-urgent registrations. Four percent of super-urgent patients died on the list, compared with 3% for urgent registration and 7% for non-urgent registrations.
- 4. The most common primary disease in the super-urgent group was cardiomyopathy followed by coronary heart disease. Those patients in the 'Other' disease group had the highest mortality rate in each urgency group (8% in the super-urgent group, 4% in the urgent group and 12% in the non-urgent group).
- 5. The median waiting times to transplant were 14 days for super-urgent and 59 days for urgent. The median could not be estimated for non-urgent due to the low transplant rate. The 2 year rate of patient survival from first heart listing was lower for super-urgent patients (76%) than both urgent (82%) and non-urgent patients (85%), this difference was statistically significant (p<0.0001).
- 6. In the transplant cohort, the 90 day patient survival rate post-transplant was 89% for super-urgent patients, compared with 88% for urgent patients and 93% for non-urgent patients. At 1 year the survival rates were 85% for super-urgent, 83% for urgent, and 88% for non-urgent. At 2 years the survival rates were 81% for super-urgent, 80% for urgent, and 85% for non-urgent.
- 7. The proportion of patients requiring renal support in the first 30 days post-transplant was 49% in the super-urgent group, 53% in the urgent group and 49% in the non-urgent group. The proportion of patients requiring VA-ECMO support in the first 30 days post-transplant was 27% in the super-urgent group, 21% in the urgent group and 18% in the non-urgent group. There was borderline evidence of a difference in VA-ECMO rates between the urgency groups.

ACTION

8. This information is provided for monitoring purposes and no specific action is required.

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September 2023

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INTRODUCTION

9. The super-urgent heart allocation was introduced on 26 October 2016 alongside several changes to the urgent heart allocation policy. This report presents outcomes of patients on the heart transplant waiting list, considering urgency group, centre and disease group. It also presents post-transplant outcomes by urgency group.

DATA AND METHODS

- 10. Data were extracted from the UK Transplant Registry on 25 August 2023 for all adult (age≥16) patients registered for a heart or heart-lung block transplant between 26 October 2016 and 31 July 2023. Registrations for heart-lung transplant were included, and multiple registrations for the same patient were allowed (so the same patient may appear in different urgency categories if they changed urgency within the time period).
- 11. Registration outcomes were analysed across urgency groups, by centre and primary disease group. Median age at registration was analysed across primary disease groups and urgency as well as median waiting time to transplant.
- 12. Patient survival from time of first heart listing was analysed across urgency groups. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list or whether a transplant was performed. If a patient was registered more than once or changed urgency, they were classed by their first registration/urgency.
- 13. The number of adult heart transplants performed in each urgency category was analysed as well as short-term survival outcomes, where survival data were extracted on 1 September 2023. Heart-lung transplants were included.

RESULTS

Registration data

14. **Table 1** shows a breakdown of the non-urgent, urgent and super-urgent heart registrations in the analysis period, by centre and whether the patient was listed for a heart-only transplant or a heart-lung block. There were a total of 71 heart-lung block registrations made, 3% of all heart registrations in the period.

| Table 1 | _ | | y urgency, 2016 – 31 . | • | whether lu | ngs were als | SO |
|------------|----------------|----------------|---------------------------|----------------|----------------|----------------|-----------|
| Centre | Non- | urgent | Urg | jent | Super | -urgent | Total |
| | Heart- only | Heart- lung | Heart- only | Heart- lung | Heart- only | Heart- lung | |
| Birmingham | 119 | 12 | 160 | 5 | 50 | 1 | 347 |
| Glasgow | 73 | 0 | 91 | 0 | 38 | 0 | 202 |
| Harefield | 182 | 6 | 193 | 5 | 71 | 2 | 459 |
| Manchester | 120 | 11 | 111 | 4 | 38 | 0 | 284 |
| Newcastle | 202 | 5 | 201 | 4 | 36 | 1 | 449 |
| Papworth | 235 | 10 | 151 | 3 | 70 | 2 | 471 |
| Total | 931 | 44 | 907 | 21 | 303 | 6 | 2212 |

15. **Tables 2-4** present the outcomes of non-urgent, urgent and super-urgent registrations during the analysis period, by centre. Note that those patients registered towards the end of the time period are more likely to be "still waiting". There were 975 non-urgent registrations (for 955 patients), 928 urgent registrations (for 889 patients), and 309 super-urgent registrations (for 291 patients). Super-urgent registrations represented 14% of all registrations in the period. Twenty-one percent of non-urgent registrations ended in transplant compared with 66% for urgent registrations and 74% for super-urgent registrations.

| Table 2 | Outcom 25 Augu | | | | | rt reg | istrati | ons, | 26 Octob | oer 201 | 6 – 31 J | luly 202 | 3, as at |
|------------|-------------------|-------|----|----|------|--------|------------|------|----------|---------|----------|----------|----------|
| Centre | Still wa | iting | Di | ed | Remo | oved | Beca S- | | Transp | lanted | Becar | me U | Total |
| | N | % | N | % | N | % | N | % | N | % | N | % | N |
| Birmingham | 35 | 27 | 9 | 7 | 32 | 24 | 3 | 2 | 25 | 19 | 27 | 21 | 131 |
| Glasgow | 14 | 19 | 0 | - | 14 | 19 | 1 | 1 | 30 | 41 | 14 | 19 | 73 |
| Harefield | 48 | 26 | 12 | 6 | 61 | 32 | 6 | 3 | 22 | 12 | 39 | 21 | 188 |
| Manchester | 51 | 39 | 10 | 8 | 20 | 15 | 2 | 2 | 18 | 14 | 30 | 23 | 131 |
| Newcastle | 71 | 34 | 31 | 15 | 15 | 7 | 6 | 3 | 20 | 10 | 64 | 31 | 207 |
| Papworth | 38 | 16 | 11 | 4 | 18 | 7 | 13 | 5 | 91 | 37 | 74 | 30 | 245 |
| Total | 257 | 26 | 73 | 7 | 160 | 16 | 31 | 3 | 206 | 21 | 248 | 25 | 975 |

| Table 3 | | | | GENT by cen | | regist | rations, | , 26 Oc | tober 2 | 2016 – | 31 July 20 |)23, as | at |
|------------|----|--------------|----|----------------|----------|-----------|----------|---------|---------|-----------|------------|---------|-------|
| Centre | | till ting | Di | ed | Bec N | ame -U | Rem | oved | | ame -U | Transpl | anted | Total |
| | N | % | N | % | N | % | N | % | N | % | N | % | N |
| Birmingham | 2 | 1 | 6 | 4 | 0 | - | 31 | 19 | 19 | 12 | 107 | 65 | 165 |
| Glasgow | 2 | 2 | 2 | 2 | 0 | - | 6 | 7 | 13 | 14 | 68 | 75 | 91 |
| Harefield | 7 | 4 | 5 | 3 | 0 | - | 46 | 23 | 17 | 9 | 123 | 62 | 198 |
| Manchester | 2 | 2 | 0 | - | 0 | - | 30 | 26 | 5 | 4 | 78 | 68 | 115 |
| Newcastle | 9 | 4 | 11 | 5 | 0 | - | 47 | 23 | 15 | 7 | 123 | 60 | 205 |
| Papworth | 3 | 2 | 2 | 1 | 0 | - | 24 | 16 | 10 | 6 | 115 | 75 | 154 |
| Total | 25 | 3 | 26 | 3 | 0 | - | 184 | 20 | 79 | 9 | 614 | 66 | 928 |

| Table 4 | | | | PER-U 3, by c | | T heai | t regist | trations | s, 26 O | ctober | [·] 2016 – 3 [·] | l July 2 | 023, a |
|------------|-----------|---|----|------------------|-----------|-----------|----------|----------|---------|----------|------------------------------------|----------|--------|
| Centre | St wai | | Di | ed | Bec N- | ame -U | Remo | oved | Bec | ame J | Transpl | anted | Tota |
| | N | % | N | % | N | % | N | % | N | % | N | % | N |
| Birmingham | 0 | _ | 2 | 4 | 0 | _ | 5 | 10 | 1 | 2 | 43 | 84 | 51 |
| Glasgow | 0 | - | 2 | 5 | 0 | - | 4 | 11 | 0 | - | 32 | 84 | 38 |
| Harefield | 0 | - | 4 | 5 | 0 | - | 27 | 37 | 0 | - | 42 | 58 | 73 |
| Manchester | 0 | - | 0 | - | 0 | - | 7 | 18 | 0 | - | 31 | 82 | 38 |
| Newcastle | 0 | - | 3 | 8 | 0 | - | 11 | 30 | 0 | - | 23 | 62 | 37 |
| Papworth | 1 | 1 | 2 | 3 | 0 | - | 10 | 14 | 0 | - | 59 | 82 | 72 |
| Total | 1 | 1 | 13 | 4 | 0 | _ | 64 | 21 | 1 | 1 | 230 | 74 | 309 |

16. **Tables 5-7** present the outcomes of non-urgent, urgent and super-urgent registrations during the analysis period, by disease group. In this time period, cardiomyopathy represented 62% of non-urgent registrations, 67% of urgent registrations and 72% of super-urgent registrations. The 'Other' disease group had the highest mortality in non-urgent, urgent and super-urgent patients.

Outcomes of NON-URGENT heart registrations, 26 October 2016 - 31 Jul 2023, as at 25 August Table 5 2023, by primary disease group Disease group Still Died Removed Became Transplanted **Became** Total waiting S-U % Ν % % % Ν Ν % Ν Ν % Coronary HD Cardiomyopathy Congenital HD Other Total HD=Heart Disease

| | mes of Ul gust 2023 | | | | _ | | | ctobe | er 2016 – | 31 Jul 2 | 023, as at |
|------------------|------------------------|---|-----|----|------|------|-----------|-----------|-----------|----------|------------|
| Disease group | Sti waiti | | Die | ed | Remo | oved | Bec S- | ame ·U | Transp | lanted | Total |
| | N | % | N | % | N | % | N | % | N | % | N |
| Coronary HD | 4 | 3 | 4 | 3 | 41 | 28 | 6 | 4 | 90 | 62 | 145 |
| Cardiomyopathy | 17 | 3 | 17 | 3 | 101 | 16 | 67 | 11 | 422 | 68 | 624 |
| Congenital HD | 2 | 2 | 2 | 2 | 16 | 18 | 4 | 4 | 66 | 73 | 90 |
| Other | 2 | 3 | 3 | 4 | 26 | 38 | 2 | 3 | 36 | 52 | 69 |
| Total | 25 | 3 | 26 | 3 | 184 | 20 | 79 | 9 | 614 | 66 | 928 |
| HD=Heart Disease | | | | | | | | | | | |

| | mes of SU as at 25 A | | | | | _ | | - | | er 2016 – | 31 Jul |
|------------------|-------------------------|--------------|----|----|------|------|------|---|--------|-----------|--------|
| Disease group | | till ting | Di | ed | Remo | oved | Beca | | Transp | lanted | Total |
| | N | % | N | % | N | % | N | % | N | % | N |
| Coronary HD | 0 | - | 3 | 6 | 5 | 10 | 0 | _ | 44 | 85 | 52 |
| Cardiomyopathy | 1 | 1 | 8 | 4 | 46 | 21 | 1 | 1 | 168 | 75 | 224 |
| Congenital HD | 0 | - | 0 | - | 4 | 57 | 0 | - | 3 | 43 | 7 |
| Other | 0 | - | 2 | 8 | 9 | 35 | 0 | - | 15 | 58 | 26 |
| Total | 1 | 1 | 13 | 4 | 64 | 21 | 1 | 1 | 230 | 74 | 309 |
| HD=Heart Disease | | | | | | | | | | | |

17. **Table 8** presents median age at registration and the inter quartile range (IQR), by disease group and urgency. Congenital HD patients were younger on average, with a median of 36-42 years. Patients registered on the super-urgent list in the 'Other' category were younger than other categories with a median age of 32 years. Coronary HD patients were older with a median age of 55-56 years. The overall median age of super-urgent patients was 45 years, compared with 49 for urgent and 52 for non-urgent.

| Disease group | | Non-urgei | nt | | Urgent | | ; | Super-urge | nt |
|----------------|-----|-----------|-------|-----|--------|-------|-----|------------|-------|
| | N | Median | IQR | N | Median | IQR | N | Median | IQR |
| Coronary HD | 216 | 56 | 50-60 | 145 | 56 | 49-59 | 52 | 55 | 49-60 |
| Cardiomyopathy | 607 | 51 | 40-59 | 624 | 49 | 37-57 | 224 | 40 | 30-51 |
| Congenital HD | 85 | 42 | 31-51 | 90 | 38 | 28-47 | 7 | 36 | 30-45 |
| Other | 67 | 46 | 33-58 | 69 | 51 | 39-59 | 26 | 32 | 22-53 |
| Total | 975 | 52 | 40-59 | 928 | 49 | 38-57 | 309 | 45 | 31-53 |

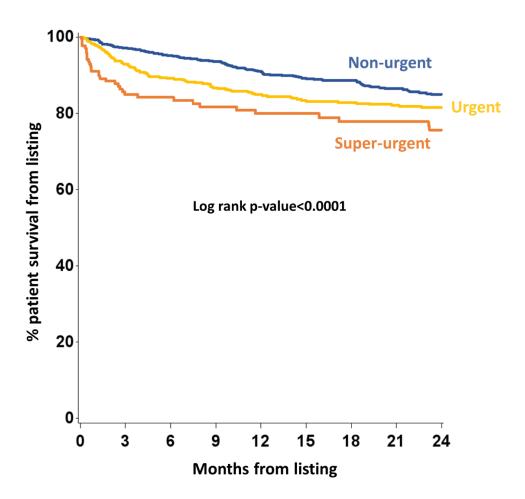
18. **Table 9** presents median waiting time to transplant across urgency groups, including 95% confidence intervals (CI). The median waiting time to transplant from non-urgent registration could not be calculated due to low transplant rate.

| Table 9 Median waiting time to transplant by urgency | | | | | | | | |
|--|-------------------------|---------------------------------------|-----------|------------|--|--|--|--|
| Urgency | Number of registrations | Number transplanted as at 01 Sep 2023 | Waiting t | ime (days) | | | | |
| | . og.o aoo | uo u. v. eop 2020 | Median | 95% CI | | | | |
| Non-urgent ¹ | 975 | 206 (21%) | - | - | | | | |
| Urgent | 928 | 614 (64%) | 59 | 52 - 66 | | | | |
| Super-urgent | 309 | 230 (74%) | 14 | 11 - 17 | | | | |
| Overall | 2212 | 1050 (47%) | 183 | 145 - 221 | | | | |

Survival from listing

19. **Figure 1** and **Table 10** present two year patient survival from first heart or heart-lung transplant listing curves by urgency. Survival time was defined as the time from joining the transplant list to death, regardless of the length of time on the transplant list, whether or not the patient was transplanted and any factors associated with such a transplant e.g. primary disease. There was a significant difference in the two year survival rates by urgency, with super-urgent patients having the lowest survival rate.

Figure 1 Two year Kaplan-Meier patient survival from listing curves for adult patients listed on the heart transplant list, 26 October 2016 – 31 July 2023, by urgency



| Table 10 | Patient survival July 2023 | l from heart listir | ng by urgend | y for adult | patients fire | st listed 26 | October 20 | 16 – 31 |
|------------------------------|-------------------------------|---|-----------------|-------------|-----------------|--------------|-----------------|---------|
| Urgency | Number at | Number of | 90 d | lays | 1 y | ear | 2 ye | ars |
| | risk on day 0 | deaths as at 1 Sep 2023 ¹ | Survival (%) | 95% CI | Survival (%) | 95% CI | Survival (%) | 95% CI |
| Non-urgent | 902 | 58 | 97 | 96 – 98 | 91 | 89 – 93 | 85 | 82 – 87 |
| Urgent | 617 | 71 | 93 | 91 – 95 | 85 | 81 – 88 | 82 | 78 – 85 |
| Super-urgent | 179 | 24 | 85 | 78 – 90 | 80 | 72 – 86 | 76 | 67 – 82 |
| Overall | 1698 | 153 | 94 | 93 – 95 | 88 | 86 – 89 | 83 | 81 – 85 |
| ¹ Deaths within 2 | -years of first listing | | | | | | | |

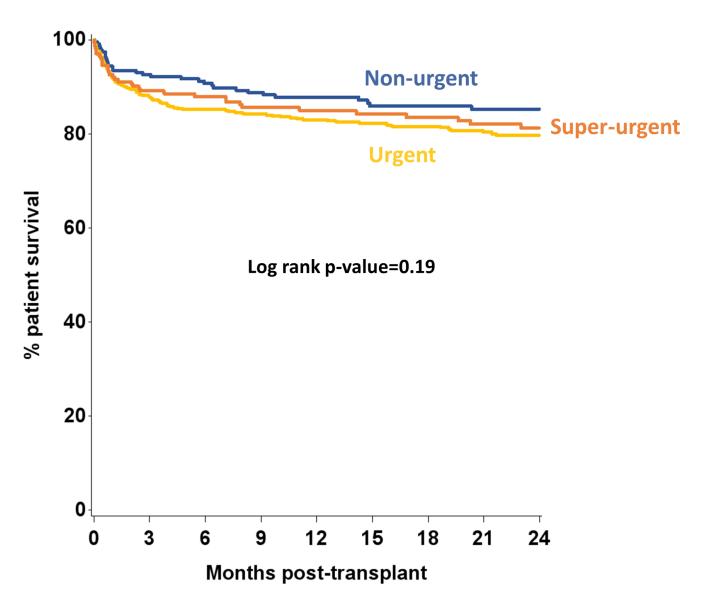
Transplant data

20. **Table 11** presents the number of transplants performed by each centre in each urgency category between 26 October 2016 and 31 March 2023. Note that these numbers will not match those transplanted in the previous section due to the different time period restriction and the fact that some of the non-urgent and urgent patients would have been registered prior to 26 October 2016.

| Table 11 | Adult heart centre and | • | s performed i | n the UK, 20 | 6 October 20 | 16 – 31 Mar | ch 2023, b |
|------------|------------------------|--------|---------------|--------------|--------------|-------------|------------|
| Centre | Non-u | ırgent | Urg | ent | Super- | urgent | Total |
| | N | % | N | % | N | % | N |
| Birmingham | 19 | 12 | 104 | 64 | 40 | 25 | 163 |
| Glasgow | 30 | 25 | 63 | 52 | 29 | 24 | 122 |
| Harefield | 26 | 14 | 118 | 65 | 37 | 20 | 181 |
| Manchester | 22 | 17 | 77 | 61 | 27 | 21 | 126 |
| Newcastle | 28 | 17 | 121 | 72 | 20 | 12 | 169 |
| Papworth | 108 | 39 | 111 | 41 | 55 | 20 | 274 |
| Total | 233 | 23 | 594 | 57 | 208 | 20 | 1035 |

21. **Figure 2** and **Table 12** present two year patient survival curves by urgency, where re-grafts (N=11) and patients with missing survival data were excluded (8 urgent transplant and 2 super-urgent transplants). Of the 203 super-urgent transplants considered, there were 34 deaths recorded up to 2 years post-transplant.

Figure 2 Two year Kaplan-Meier patient survival curves for adult patients transplanted 26 October 2016 – 31 March 2023, by urgency



| Table 12 | Patient surviv 2016 – 31 Mar | al post-heart tra ch 2023 | nsplant by ເ | irgency for | adult patier | nts first trai | nsplanted 20 | 6 October |
|--------------|---------------------------------|---|-----------------|-------------|-----------------|----------------|-----------------|-----------|
| Urgency | Number of | Number of | 90 d | ays | 1 ye | ear | 2 ye | ars |
| | transplants | deaths as at 1 Sep 2023 ¹ | Survival (%) | 95% CI | Survival (%) | 95% CI | Survival (%) | 95% CI |
| Non-urgent | 232 | 31 | 93 | 88 – 95 | 88 | 83 – 91 | 85 | 80 – 89 |
| Urgent | 579 | 109 | 88 | 85 - 90 | 83 | 80 - 86 | 80 | 76 – 83 |
| Super-urgent | 203 | 34 | 89 | 84 – 93 | 85 | 79 – 89 | 81 | 75 – 86 |
| Overall | 1014 | 174 | 89 | 87 – 91 | 85 | 82 – 87 | 81 | 79 – 84 |

22. **Table 13** shows the numbers of patients requiring renal support within 30 days post-first heart transplant, by urgency. There was no significant difference in the proportion of transplants requiring renal support between the different urgency groups.

| Table 13 | Requirement for renal s for adult patients first to | | | |
|--------------|---|-------------------|----|--------------------|
| Urgency | Number of transplants ¹ | Haemofiltration/F | • | Chi-square p-value |
| | | Number | % | |
| Non-urgent | 225 | 110 | 49 | 0.47 |
| Urgent | 576 | 305 | 53 | |
| Super-urgent | 201 | 99 | 49 | |
| Overall | 1002 | 514 | 51 | |

23. **Table 14** shows the numbers of patients requiring VA-ECMO support within 30 days postfirst heart transplant, by urgency, as reported on the VAD database. There was borderline evidence of a difference in the proportion of transplants requiring VA-ECMO support between the different urgency groups.

| Table 13 Urgency | Requirement for VA-ECMO support within 30 days post-heart transplant by urgency for adult patients first transplanted 26 October 2016 – 31 March 2023 | | | |
|------------------|---|------------------------|--------------------|--------------------|
| | Number of transplants ¹ | VA-ECMO supp Number | oort required % | Chi-square p-value |
| Non-urgent | 233 | 43 | 18 | 0.07 |
| Urgent | 594 | 126 | 21 | |
| Super-urgent | 208 | 57 | 27 | |
| Overall | 1035 | 226 | 22 | |

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