NHS BLOOD AND TRANSPLANT

CARDIOTHORACIC ADVISORY GROUP

CLINICAL CHARACTERISTICS OF URGENT PATIENTS

SUMMARY

BACKGROUND

1 This paper summarises the clinical data provided in the initial registration form for urgent heart registrations between 1 April 2014 and 31 March 2015.

DATA ANALYSIS

2 Data on 223 urgent heart registrations for 213 patients registered between 1 April 2014 and 31 March 2015 were obtained. The urgent heart category was not reported for 9% of adult registrations and 13% paediatric registrations In addition 7% of adult registrations and 23% of paediatric registrations were made under the 'Other' category.

ACTIONS

3 Members are encouraged to ensure that all information on the initial Urgent Heart Recipient Registration form is provided both accurately and in a timely manner.

4 Basic validation, as agreed by CTAG in April 2014, will be performed on the data provided in these forms at the time of listing when IT resource becomes available.

5 A number of changes to the form are to be made in order to clarify the registration process and to support validation.

Jenny Lannon and Esther Wong
Statistics and Clinical Studies **September 2015**

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BACKGROUND

1 The current urgent heart registration forms were introduced in May 2008 to collect more comprehensive data on the clinical condition of urgent patients. Inclusion criterion for adult urgent patients were also introduced and audited on the forms.

2 Each new registration onto the urgent heart allocation scheme (UHAS) should be accompanied by an initial Urgent Heart Recipient Registration form. For patients who remain on the urgent list for more than 7 days, Urgent Heart Recipient Weekly Update forms should be submitted each week.

3 It was agreed by CTAG in April 2014 that basic validation should be performed on the data provided in the initial registration form before a patient is listed on to the UHAS. This will be implemented when IT resource becomes available.

4 In the meantime, this paper summarises the clinical data provided in the initial registration form for urgent heart registrations between 1 April 2014 and 31 March 2015. Data provided in the weekly updates are not presented.

DATA

5 Data on 223 urgent heart registrations for 213 patients registered between 1 April 2014 and 31 March 2015 were obtained from the manual records kept by the Organ Donation and Transplantation (ODT) Duty Office. Initial registration forms could not be located for six of these registrations. Data for these registrations have been classed under the 'Not reported' categories in this paper.

RESULTS

6 A total of 176 adult urgent heart registrations and 47 paediatric urgent heart registrations were made between 1 April 2014 and 31 March 2015.

7 **Table 1** shows the urgent heart registration category and key criteria for urgent listing. The most common category for adult patients to be listed under was 'high dose inotropes' and for paediatric patients, 'Other'. 7% of adult patients were registered under the 'Other' category while 23% of paediatric patients were registered under this category. The urgent category was not reported for 7% of adult patients and 13% of paediatric patients.

Table 1 Urgent heart registration category, Level 2 Critical Care status and Cardiac Index criterion status for all adult and paediatric urgent patients, 1 April 2014 – 31 March 2015

	Adult		Paediatric	
	N	%	N	%
Category				
Short-term MCSD	28	16	9	19
MCSD with device-related complications	24	14	2	4
IABP	8	5	0	0
ECMO	2	1	3	6
High-dose inotropes	74	42	8	17
Combination of inotropes	18	10	0	0
Non-invasive ventilation	0	0	-	-
Paediatric≤15kg on ventilation and inotropes	-	-	8	17
Other	13	7	11	23
Not reported	9	9	6	13
Inpatient in Level 2 Critical Care				
Yes	153	87	43	91
No	18	10	1	2
Not reported	5	3	3	6
Cardiac Index (CI)<2l/min/m^2				
VAD or ECMO	28	16	6	13
Not on VAD or ECMO and CI<2	119	68	15	32
Not on VAD or ECMO and CI=>2	20	11	3	6
Not reported	9	5	23	49

9 A table of reasons (from 18 September 2015 onwards) for listing under the 'Other' category is recorded in the **Appendix** based on the information discussed and agreed with the UHAS adjudication panel. This information was available for 8 of 13 adult patients registered under the "Other " category and none of the 11 paediatric patients.

10 **Table 2** shows the VAD, ECMO, IABP and inotrope status of all urgent patients registered. 30% of adult patients were on a VAD at time of listing, 2% were on ECMO and 5% were on IABP. The corresponding figures for paediatric patients were 17%, 6% and 9%, respectively. 62% of adult patients and 60% of paediatric patients were on inotropes at the time of listing. It should be noted that the classification of high dose inotropes in Table 2 does not account for milrinone as the current categorisation for urgent listing under high does inotropes states ' milrinone >0.375µg/kg/min or adjusted to achieve therapeutic milrinone levels of 100-300 ng/ml (which may correspond to a lower dose in patients with impaired renal function)'.

Table 2 VAD, ECMO, IABP and Inotrope status for all adult and paediatric urgent patients, 1 April 2014 – 31 March 2014

	Adult		Paediatric	
	N	%	N	%
VAD				
None	119	68	35	74
Left	25	14	3	6
Right	3	2	0	0
Both	24	14	5	11
Not reported	5	4	4	9
ECMO				
No	166	94	41	87
Yes	3	2	3	6
Not reported	7	4	3	6
IABP				
No	161	91	40	85
Yes	9	5	4	9
Not reported	6	4	3	6
Inotropes				
Yes – high dose*	30	17	5	11
Yes – low dose	57	32	22	47
Yes – unknown dose	22	13	1	2
No inotropes	62	35	14	30
Not reported	5	3	5	11

* The following are defined as 'high dose' inotropes: dopamine>5µg/kg/min, dobutamine>7.5µg/kg/min, epinephrine>0.05µg/kg/min, enoximone>5µg/kg/min, levosimandan - any dose.

11 **Table 3** shows the laboratory results for patients at time of urgent listing. Laboratory investigations were not reported on all initial registration forms.

Table 3 Laboratory investigations data for adult and paediatric urgent patients, 1 April 2014 – 31 March 2014

	Hb (g/dl)	WCC ($x10^9$/l)	Serum creatinine (µmol/l)	Serum bilirubin (µmol/l)	CRP (mg/dl)
Adults					
N	148	165	165	165	148
Mean	11.9	9.1	113.6	28.2	30.1
Standard deviation	2.8	7.6	50.8	28.4	41.3
N (high*)	-	24	8	19	48
Paediatrics					
N	37	37	38	30	27
Mean	11.1	13.4	47.3	18.4	48.8
Standard deviation	2.3	12.3	42.8	14.0	58.7
N (high*)	-	18	1	2	13

* 'High' here means:
- WCC >12 $x10^9$/l
- Serum creatinine >200 µmol/l
- Serum bilirubin >50 µmol/l
- CRP >25 mg/dl

CONCLUSION

12 The clinical characteristics of patients registered on the urgent list, 1 April 2014 – 31 March 2015, indicates that the urgent heart category was not reported for 9% of adult registrations and 13% for paediatric registrations. In addition 7% of adult registrations and 23% of paediatric registrations were made under the 'Other' category.

ACTION

14 Members are encouraged to ensure that all information on the initial Urgent Heart Recipient Registration form is provided both accurately and in a timely manner.

15 Basic validation, as agreed by CTAG in April 2014, will be performed on the data provided in these forms at the time of listing when IT resource becomes available.

.16 A number of changes to the form are to be made in order to clarify the registration process and to support validation. These are specifically;

- To make the descriptions of Categories 59 and 9 ('registering as 'Other' for adult and paediatric, respectively) consistent and include the request for documentation of approval by the Adjudication Panel and the Chairman of the Cardiothoracic Advisory Group (or deputy) .
- A description of the registration process for registering a patient under Category 59 or 9 including an NHSBT audit email address (as agreed by CTAG in April 2014).
- To amend the description of Category 5 (high dose inotropes category) to separate patients on milrinone >0.375µg/kg/min from those patients on milrinone levels 'adjusted to achieve therapeutic milrinone levels of 100-300 ng/ml'.

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Appendix

Table A1 Reasons for urgent listing under the 'Other' Category (Categories 9 and 59) as discussed by the UHAS Adjudication Panel, registrations between 18 September 2014 and 25 August 2015

Patient	Adult/Paed	Month	Reason
1	Adult	October 2014	IHD, previous MI, severe LVSD, CRTD, been in hospital over 4 weeks on CCU Main problem is recurrent VT despite 2 "successful VT ablations" Multiple different morphologies, only stable on high dose iv lidocaine (continuous) aswell as high dose fish oils, oral mexilitene, oral amiodarone (Iv increases QTc) - was in slow VT all weekend until dose of lidocaine was increased
2	Adult	January 2015	No more EP can do Diagnosis: Ischaemic heart failure- severe LV systolic dysfunction • Large anterior STEMI: occluded LAD –failed attempts to open artery. • LV thrombus • ICD Sept 2013 – Medtronic Evera VR • Was on elective Tx waiting list Recently, multiple hospital admissions for AF/VT with multiple ICD firing. Had EP intervention including pulmonary vein isolation. Continues on IV Amiodarone but has required repeat DC shock for further episodes of polymorphic VT. Patient in great anxiety/distress
3	Adult	February 2015	Patient has chronic heart failure with severe LVSD due to a dilated cardiomyopathy. Had a relatively uneventful period of mechanical circulatory support. Renal function is normal. Two major problems encountered in the last month. 1. Ventricular arrhythmias. Two episodes of fast ventricular tachycardia, ultimately degrading into ventricular fibrillation, which were treated with a total of six ICD shocks. In one episode, the first 4 ICD shocks were unsuccessful, raising concerns about defibrillation threshold and safety margin. 2. Aortic regurgitation. Patient has developed moderate to severe aortic regurgitation which is new. A recent right heart catheter showed elevated left-sided filling pressures (mean PCWP 18) despite LVAD flow of 3.3L/min (usual) despite excellent systemic blood pressure control with LVAD set at 2700 RPM.
4	Adult	February 2015	Hospitalised following readmission with recurrent VT. The most recent episode required manual cardioversion (the ICD is end of life and the VT was not within the detection zone) and resulted in significant renal and hepatic dysfunction due to the effects on the right ventricle which has now resolved. Patient continues to get VT several times a day ranging from a few minutes up to 45 minutes and has developed right heart dysfunction requiring iv furosemide. Detection zone altered to avoid shocks as was previously being shocked as many as 3-4 times per day despite beta blockade and amiodarone (unable to use ATP algorithms due to EOL). Patient had an episode of sepsis in due to Streptococcus Bovis and a

5	Adult	March 2015	caecal benign adenoma was identified as the likely cause and successfully resected endoscopically. Received 6 weeks of iv antibiotics and subsequent cultures have remained negative. Patient suffers of Restrictive Cardiomyopathy secondary to Amyloid and without infiltration of any other organ. Referred via the National Amyloid Centre and following assessment by our hematologists this patient is a suitable candidate for autologous Bone Marrow Transplant. Renal function is drifting in the wrong direction and has had some symptomatic deterioration. Due to the nature of the underlying disease it is very difficult to support him much further than with what has been done so far. Patient is not candidate for MCS and due to the restrictive nature of Cardiomyopathy, unlikely to respond much to inotropes and unlikely to ever meet the standard criteria for urgent listing.
6	Adult	March 2015	Patient has chronic heart failure with extreme RV systolic dysfunction and mild LV systolic dysfunction due to Arrhythmogenic Cardiomyopathy. Exists in a virtual Fontan state with no increase in mean pressure from right atrium through to pulmonary artery. On the routine waiting list for heart transplantation for 5 years. Encountered two problems: 1. Worsening renal function. There has been a progressive deterioration in renal function despite filling pressures that are as optimal as possible for the pathophysiology. Serum Creatinine is around 140-160umol/L (estimated GFR of around 45-50 ml/min). 2. Recurrent ventricular arrhythmias. Admitted to local hospital with symptomatic slow VT. The morphology of the VT on a 12-lead ECG suggests a large circuit in the RV outflow tract. VT may be terminated by ATP through ICD, but is recurring on multiple occasions on every subsequent day despite long programmed ICD detection periods, acceptable electrolytes, the maximum tolerated dose of beta-blocker and Amiodarone (on for many years). VT is unlikely to amenable to catheter ablation and that attempting catheter ablation would confer a risk of complications (pulmonary thromboembolism) that might increase pulmonary vascular resistance and lead to serious haemodynamic consequences. Inotropic support would likely exacerbate the ventricular arrhythmias and mechanical circulatory support would not be helpful in the current clinical situation.
7	Adult	April 2015	Diagnoses: 1. Ebstein's anomaly of the tricuspid valve with severe regurgitation 2.Tricuspid valve replacement with a 29mm Mosaic valve, longitudinal plication of the atrialised portion of the right ventricle and right atrial plication 3. Percutaneous tricuspid valve replacement with implantation of a Melody valve into the tricuspid valve prosthesis after pre-stenting with a 34mm CP stent 4. Redo emergency transcatheter tricuspid valve replacement for early failure of the melody valve with thickening of the valve leaflets and severe tricuspid stenosis 5. Emergency redo transcatheter procedure with balloon dilatation of the again stenosed Melody valve using a 22mm x 2cm Atlas Gold balloon with improvement of tricuspid valve function Inpatient with very limited exercise capacity. Likely to need yet another "palliative" tricuspid valve ballooning soon.
8	Adult	June 2015	Anterior MI one year previous with chronic heart failure and underwent heart transplantation earlier this year. Came off

	cardiopulmonary bypass on relatively high doses of inotropes and eventually needed a Centrimag RVAD. On RVAD support patient was extubated,renal and liver function returned to normal as did filling pressures. The RVAD was removed after which point patient was re-established on support with Dopamine, Adrenalin and Enoximone at this time. Gradually weaned off inotropic support. However, centre could not maintain stability and were forced to rapidly escalate inotropic support. Patient is now on Dopamine, Adrenaline and Enoximone again. Self-ventilating, eating well, passing 2500 ml of urine a day. No anti-microbial therapy.