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Paediatric Congenital Heart Disease Joint Cardiac Conference (JCC) Standard Operating Procedure

Date 12/05/2021

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1. Introduction

Patients with significant congenital heart disease being considered for a complex catheter intervention, surgery or an innovative procedure must be discussed at the regional Paediatric Cardiology Joint Cardiac Conference (JCC) to plan care. This multidisciplinary team (MDT) meeting is a weekly meeting that brings together clinicians with the necessary knowledge, skills and experience to ensure expert decisions are made for children diagnosed with congenital heart disease. This SOP outlines the process required to ensure that the meeting runs smoothly and efficiently and provides optimum patient centred care.

The JCC meeting is integral to the delivery of CHD care and follows national CHD standards (2016). Please refer to the Terms of Reference for further detail on MDT Members and quoracy.

2. Listing Patients for Discussion

The patients lead consultant will be responsible for identifying patients that require discussion at JCC. It is expected that the family will be made aware that their child's case is being discussed.

2.1 Alder Hey Children's Hospital (AH)

This will be done by adding the patient to the JCC database as 'in prep'. This will signal to the registrar/fellow team that the patient is to be prepared for discussion. It is good practice that trainees who have seen the patient in clinic, catheter lab or MR prepare the patients they have been involved with.

2.2 Royal Manchester Children's Hospital (RMCH)

Summary sheets are prepared by the cardiology team with secretarial support and emailed to the PCO team at Alder Hey (via secure nhs.net email) ahc-tr.cardiology@nhs.net. PCO team will add the summary sheet to the 'Manchester File' on the 'K' Drive and enter the patient on the JCC database.

2.3 Inpatients

It is likely that very few inpatients at AH/RMCH will need discussion. Those that do are usually:

- Pre-op NEW patient that meets the criteria below
- Pre/post op patient with SIGNIFICANT clinical change that meets the criteria below

- If cardiology advice is sought on general management, this should take the form of a mini-MDT, including the Consultant of the Week (COW) and other relevant colleagues
- All outcomes of discussions should be fully documented in the patient's clinical record

2.4 Paediatric Intensive Care Patients (PICU)

PICU patients should be discussed and then triaged at both PICU handover on the Wednesday and at the 0800 'walk-around'. Complex patients or those requiring decisions around catheter or surgery are typically discussed by the ICU consultant on call around 10.30am. This should not be a general handover of all cardiac patients on PICU.

Except in the case of urgent or inpatient cases patients requiring **routine presentation** will be identified and entered on the JCC List Management database no later than 4 pm on the preceding Tuesday for the Thursday meeting and Thursday for Monday meeting.

Patients should be added to the database as inpatient, urgent or outpatient
Examples of urgent patients would be:

- Severe valvar stenosis/coarctation requiring intervention
- Red flag arrhythmia symptoms/findings requiring device insertion
- Time critical lesions currently cared for as outpatient

3. Preparing a Case for MDT Discussion

The front page of the summary sheet (traditionally referred to as "the yellow sheet" because of the use of coloured paper to track the document in the notes) should be kept contemporaneous with up to date information. All fields must be completed with accurate diagnostic information (that should mirror the coding on the Alder Hey M6 record). For patients who have been discussed previously the word document should be amended (as previous versions will be saved as a 'pdf' in both the database and medisec patient record). When amending/ updating the sheet the records of all previous discussions should be kept on the second page.

The person preparing the case and producing the summary sheet should be well familiarised with the case and have reviewed all the relevant investigations (including ECHO, CT, MRI and cardiac catheter data). If vital investigations are missing this should be identified and resolved **BEFORE** the meeting.

4. Entering a Patient on the Database

Note many patients will already have records on the database and shouldn't be re-entered but re-listed for a discussion. For new patients all boxes should be completed. Please point the hyperlink at the relevant summary sheet.

- For a completely new patient use the "New Episode" button on the front page
- If the patient is already in the database, you can reduce transcription errors and save yourself time by using the new episode function from the Search page
- Select the New Episode option at the top right options list and find the patient
- There will be a screen which allows you to update any details you need to change in the existing entry (but does not change that entry)
- You can either link to a new yellow sheet or to the existing yellow sheet

5. How to Create a Summary Sheet

Following this simple process means that we can see:

1. when and how many times a patient is discussed
2. all the data relevant to that discussion (will be hyperlinked)
3. the resulting outcome data will act as a database for yellow sheets

5.1 Summary sheet naming convention

Please label the yellow sheet using the instructions below:

SURNAME_GIVENNAME_HOSPITAL NUMBER (OR NHS NUMBER)_YYMMDD

- Summary sheets should NEVER be renamed. The name convention manages all possible cases. The document is either appended to or a new document is created with a new date stamp. The system version control is predicated on a rational and structured approach to naming convention.
- YYMMDD is the date the sheet was created and is not the patients date of birth. For example, the date 12/05/2021 should be displayed as 210512
- Make sure that there are no spaces
- Make sure that the underscore _ is used precisely as described above. Do not confuse it with hyphen – or dash -. Hyphen's are part of normal names and can therefore be used within the name.
- Window's filenames do not allow the use of "/" . For example, a Hospital number of M02/1234 should be inputted as M021234
- It is very important that the name of the document remains consistent and doesn't change

5.2 Other Important Points

- The system uniquely identifies the summary sheet for that patient as the LATEST VERSION.
- Multiple yellow sheets for a given patient will sort in the correct order (so long as the same rule is followed every time and the child's demographic details do not change)

5.3 Creating a new summary sheet vs using an existing summary sheet

There are some ground rules to follow to help decide when and how to use an existing yellow sheet:

- It is the first time the child has been discussed – create a **NEW** sheet
- Patients who have been discussed previously should have their front sheet updated (on the word doc) to contemporaneous information with all boxes completed.
- Please leave the details of previous discussions on subsequent pages

6. Investigations

The specific investigations for presentation (echo/CT/catheter) will be identified both in the yellow sheet and in the JCC database. This is necessary to facilitate smooth running of the meeting and enable the radiology department to identify scans which need to be ready for review.

ECG images may be hyperlinked or inserted in the Diagrams section where appropriate. Report should be detailed in the relevant section.

Cross-sectional Imaging (MR/CT)

For Alder Hey scans the Alder Hey imaging consultants will prepare all cases flagged by entry of the relevant date in the CT/MRI field in the database. It is vital that individual's preparing cases enter this data as it is used to flag to the radiologists that they need to prepare cases. For non-urgent patients who have undergone **CT in Manchester** to be presented by a Manchester radiologist then the preparer should confirm the scan is available and enter the date in the database. The cardiac radiologists at Alder Hey should be given at least 48 hours warning so they can confirm they are or are not required to prepare.

Imaging should not be presented on an ad hoc basis and discussion will be suspended until the following week unless there is urgent clinical need.

Echo reports should be comprehensive detailing all the anatomy. Relevant structures should be measured, and z scored.

Cardiac Catheterisation All patients who have undergone cardiac catheterisation should have up to date data in diagram or table form on the summary sheet. Catheter data should be discussed with the relevant consultant prior to the meeting.

Planning cardiac surgery is a question of minimising the total risk of a procedure which may not be related just to the cardiac anatomy and technicalities of the procedure. It is important to consider other obstacles to safe surgery. Please consider other systems and the following points

- Neuro review + images available
- Infection type and time elapsed since potential illness
- Renal pathology with high risk of peri-operative failure should have discussion with renal team regarding post op renal support
- Evidence of potential metabolic illness without metabolic opinion

If you feel the cardiac lesion requires urgent attention prior to the availability of all opinions or results, please consider discussion with the mini-MDT group as in point 8.

7. Social History

It is vital that the important the social history is documented on the summary sheet. For example

1. Looked after children where parents may not have parental responsibility and consent will be needed from the local authority
2. Jehovah's witness families who may not be accepting of blood transfusion
3. Mental health concerns with parents or children who may require more support
4. Children or young people who have difficulties in the hospital environment who may benefit from play specialist input prior to their procedure
5. Patients >16yrs of age with learning disabilities where consent will need to be managed as per the Mental Capacity Act 2005

8. Patients Requiring Emergency Discussion

Some patients presenting will require emergency or urgent treatment that means full MDT is not possible. In this case an emergency mini MDT should be convened with a minimum of

- ✓ Congenital Cardiologist
- ✓ Congenital Surgeon
- ✓ Intensivist

These cases should be prepared where possible in the same way and outcomes of the discussion documented. Following emergency treatment these cases should be discussed and formally completed at the Thursday JCC (in line with CHD national standards).

9. Meeting Time and Location

Monday MDT

- inpatients and urgent outpatients will be discussed followed by the surgical list for the week
- 2B Cardiac Offices and via MS Teams
- 08.30am – 10.00am

Thursday JCC

- all other routine MDT discussions
- Tony Bell Boardroom, Institute in the Park and on MS Teams
- 08.30am – 11.30am

10. Meeting preparation

The agenda pdf will be outputted from the JCC database on Wednesday lunchtime and uploaded to Teams by the cardiac surgical PCO at Alder Hey.

The on-call cardiology SpR and/or cardiac surgical SpR are expected to arrive prior to the meeting to set up the computers to ensure a prompt start. The person logged on to the PC should run the computer throughout to minimise log on problems. Extra laptops should be taken to enable fetching of studies and maximise productivity.

Database should be checked for running order

- Alder Hey patients with older echo assessments should be fetched in preparation
- Manchester patients' images should be searched for on PACS (and then will be quickly accessible via the recent search list on the left)

11. Role of the Chair and Meeting Etiquette

(Please refer to the MDT Terms of Reference)

Please note that if the above process isn't followed or there is incomplete data or investigations you will not be able to present your patient. You will be asked to defer the discussion until all relevant information is available.

Attendance and quoracy is monitored using the attendance list taken from MS Teams. If you are not personally logged on please state your name and designation in the Teams chat. In addition, it is understood that all members will arrive on time for the MDT meeting, be prepared to present their patients for discussion and respect the speaker or lead.

11.1 Order of the Meeting

1. Inpatients
3. URGENT cases (to be listed as urgent prior to the meeting)
4. Outpatients (will be discussed in date order of adding to discussion list)

If AH/RMCH Consultant Of the Week (COW) is held up with an emergency, **short** routine cases can be presented prior to their arrival. Alder Hey ICU Patients requiring update or decision making are usually discussed by the ICU team at around 10.30 am

11.2 Presenting Patients at the Meeting

Cases should be presented by the producer of the summary sheet (SpR or fellow) or respective consultant. If this has been delegated to another individual, they should be familiar with the case and have reviewed all the relevant investigations prior to the meeting. Cases should under no circumstances be presented by an individual unfamiliar with case

All patient presentations should begin with a clear statement of intent:

"I am presenting this patient for Surgery"
"I am presenting this patient for Cardiac Catheter"
"I am presenting this patient for help in planning further investigation, specifically whether we should perform x/y/z to allow us to proceed to surgery/intervention/palliation"

If the patient pathway is not one of the above, the patient should be discussed within a 'mini-MDT' outside of the formal MDT meeting.

12. Documentation of the Case Discussion and Completing the Summary Sheet

As the summary sheet is effectively a clinical documentation of a management plan and considered a legal document, this should always be completed by the cardiac surgeons/ interventional team or a clinician at the MDT.

Outcome documentation should include

- ✓ Members of the MDT present during decision making
- ✓ Summary of the discussion had by the team where decision making is complex
- ✓ If further information is needed, clear description of what is required prior to re-presentation
- ✓ 'Surgery priority' should include the P code assigned
- ✓ Pre and post procedure imaging should be considered and detailed
- ✓ Team should consider whether case would be best performed in the hybrid theatre and this should be documented to assist planning

Patients are prioritised in according with the national Royal College of Surgery (RSC) classification P codes. Note these are rough guidance and are not entirely suited to CHD practice. Further detail around planned timing of surgery or intervention should be documented in the summary sheet by the consultant completing the form.

Table 1: Waiting List Priority according to Royal College of Surgeons (RCS) Classification

< 1 month	P2
< 3 months	P3
>3 months (delay 3 months possible)	P4
Patient wishes to postpone surgery because of COVID-19 concerns	P5
Patient wishes to postpone surgery due to non COVID-19 concerns	P6

13. Finalising the Outcome of the Discussion and Completing the Database

The chair will finalise the discussion and check the meeting participants agree (or consensus has been reached). The RCS P code should be agreed on. Where the discussion has been long or complex the outcome sheet documentation should be displayed to check participants agree.

Each database episode will be completed in the meeting with minimum outcome data to be included:

- > Always record the date discussed (this can be as simple as clicking the discussed today button)
- > Record the outcome

- When the outcome is *not* to be listed for a procedure then the reasoning should be briefly noted as Relevant Clinical Comments (this will be prompted for) e.g. plan is for CT and re-discuss
- If listed for surgery or catheter intervention, please tick the relevant box and complete the priority (P code). The database will complete the relevant listed dates automatically

14. Following the Meeting

A summary of the outcomes will be outputted from the database and uploaded to Teams each week. The PCO team at Alder Hey will email back a 'pdf' of summary sheet for each RMCH patient discussed (to be added to the Manchester clinical record). The interventional and surgical PCO team will add patients to the relevant waiting list (according to P code priority).

Inpatients in other hospitals around the Operational Delivery Network (ODN) will be added to the urgent whiteboard in the 2B offices with the plans for transfer to Alder Hey. The COW will be responsible for informing the 1C co-ordinator or ICU regarding plans for patients to be transferred.

Outpatients will be contacted by the cardiac specialist nursing team to make plans for pre assessment process to begin.

15. Monitoring MDT Meeting Productivity

Attendance and numbers of patients discussed and listed will be monitored. Note that backlog of patients waiting > 6 weeks for discussion at the MDT (NHSE Standard) is reported on a monthly basis to the North West CHD ODN.

16. Contingency

In the event that the electronic IT systems go down, the IT helpdesk should be contacted along with the Operational Service Manager. All issues with IT affecting the smooth running of the meeting should be reported as critical incidents.

17. References

1. Clinical Prioritisation Table adapted from Stephens EH, Dearani JA, Guleserian KJ, Overman DM, Tweddell JS, Backer CL, Romano JC, Bacha E. COVID-19: Crisis Management in Congenital Heart Surgery. Ann Thorac Surg. 2020 Aug;110(2):701-706. doi: 10.1016/j.athoracsur.2020.04.001. Epub 2020 Apr 14. PMID: 32302660; PMCID: PMC7194669.
2. NHS England: Congenital Heart Disease Standards and specifications: NHS England (2016) https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf

Appendix 1: CLINICAL PRIORITISATION FRAMEWORK FOR PAEDIATRIC CARDIAC SURGERY AND INTERVENTION

This table is a guide to priority listing for patients with CHD for surgery/ intervention. RCS code will be determined at the time of discussion on an individual case basis.

Neonatal (< 1mth)

	Emergency (<48hr) P1	Urgent (< 2wks)	Priority 2 (<4 wks)
Left heart obstructive lesions			
HLHS	restrictive or intact atrial septum	Norwood / Hybrid	
Critical aortic stenosis	unable to stabilise on prostin	case selection for valvuloplasty or valvotomy	
Coarctation of the aorta	unable to stabilise on prostin	case selection for approach and timing	
Right heart obstructive lesions			
PA / IVS	unable to stabilise on prostin	case selection RF perforation/ ductal stent / shunt	
PA VSD	unable to stabilise on prostin	case selection ductal stent / shunt	
Tetralogy of Fallot	unable to stabilise on prostin	case selection ductal or RVOT stent / shunt	
Critical pulmonary stenosis	unable to stabilise on prostin	balloon valvuloplasty	
Ebsteins anomaly		duct dependant pulmonary blood flow	
Mixing lesions			
TGA	hypoxaemia for BAS	intact IVS for ASO	VSD with mixing for ASO+ VSD
Common arterial trunk		excess pulmonary blood flow, truncal regurg unable to medically manage	case selection depending on symptoms
TAPVD	clinically obstructed	echo evidence of obstruction	
Other			
Shunt / stent	profound hypoxaemia thrombosis/ occlusion		
Arrhythmia	CHB unable to medically manage	CHB decision for pacing	
ALCAPA		optimise heart failure therapy	

Infant (< 1 year)

	Emergency (<48hr) P1	Urgent (< 2wks)	Priority 2 (<4 wks)
Left heart obstructive lesions			
LVOTO			impaired function, symptoms
Aortic stenosis			impaired function, symptoms
Coarctation of the aorta		impaired function	
Right heart obstructive lesions			
Tetralogy of Fallot	cyanotic spells unresponsive to medical management	cyanotic spells or cyanosis < 80%	
Shunt /stent dependant pulmonary blood flow (pre BCPC)	profound hypoxaemia thrombosis/ occlusion	increasing cyanosis, shunt / stent stenosis prioritise > 6mths	
Shunt /stent dependant pulmonary blood flow (pre biV repair)	profound hypoxaemia thrombosis/ occlusion	increasing cyanosis, shunt / stent stenosis prioritise > 9mths	
L – R shunt lesions			
VSD		FTT, heart failure on medical management prioritise > 6mths	
AVSD		FTT, heart failure on medical management, assessment of AVVR, prioritise > 6mths	
Regurgitant lesions			
Mitral regurgitation			heart failure on treatment, raised RVP
Aortic regurgitation	haemodynamically unstable		impaired function

Children

	Emergency (<48hr) P1	Urgent (< 2wks)	Priority 2 (<4 wks)
Left heart obstructive lesions			
LVOTO			impaired function, symptoms
Aortic stenosis			impaired function, symptoms
MV prosthesis	thrombosed prosthesis		increasing gradient, raised RVP

Right heart obstructive lesions			
RV – PA conduit			impaired function, >systemic RVP
Regurgitant lesions			
Mitral regurgitation			heart failure on treatment, raised RVP
Aortic regurgitation	haemodynamically unstable		impaired function, symptoms
Other			
Fontan candidate			increasing cyanosis, symptoms prioritise > 5yrs

Appendix 2

Summary Patient Pathway

Consultant decision that patient requires MDT discussion.
- ✓ Patient that requires cardiac surgery
- ✓ Patients requires complex* intervention
- ✓ Complex medical patient requiring discussion about medical management

Alder Hey
- ✓ Patient is added to the JCC MDT database ('in prep' for preparation by AH ST team)
- ✓ Summary 'yellow sheet' prepared by medical team

Royal Manchester Children's Hospital
- ✓ Summary 'yellow sheet' prepared by medical team
- ✓ Email to mailto:ahc-tr.cardiology@nhs.net
- ✓ Specify as inpatient, urgent or outpatient

Imaging
- ✓ Whoever is completing the summary sheet should review and ensure that all the relevant imaging is available

Cardiac PCO team at AH
- ✓ Check nhs.net email and save summary sheet to 'K' Drive enter patient on database
- ✓ Assign AH number (if not already done as part of image transfer)
- ✓ Add alert to medisec 'all letters to be copied to lead cons in RMCH'

Pre meeting prep
- ✓ Log in to computer and all systems
- ✓ Fetch any echo studies on ISCV
- ✓ Pre search for RMCH patients on PACS
- ✓ Identify chair for meeting

Imaging
- ✓ Medical team to arrange PACS transfer of images to Alder Hey as soon as possible (report to be included with CT)
- ✓ Dates of relevant CT/MRI and angiograms to be listed on the sheet
- ✓ Radiologist at RMCH to present Manchester CT
- ✓ Medical team to contact AH radiology in advance if they to need review Manchester imaging

Patient discussed
- ✓ Form completed by consultant
- ✓ Outcome and priority updated in database (patient will drop off discussion list)

- Listed surgery
- Listed intervention
- transfer Pt to AH for further assessment
- Intervention not required at this time watch + wait
- Requires further investigations and re-discuss
- Refer PH/ heart failure or second opinion

Cardiac PCO team at Alder Hey
- ✓ Form completed pdf – add to AH medisec record, completed form returned to RMCH
- ✓ Patient added to surgical, interventional or EP waiting list
- ✓ Summary of discussed patients circulated to group via SharePoint

OP

Patients not discussed will remain on the database for discussion at the next available MDT