



**NHS**

**East Midlands**  
Congenital Heart Network

The East Midlands Congenital Heart Network

# Joint referral and care guidance documents

December 2023



**East Midlands**  
Congenital Heart Centre

# Document Control and Governance

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## Contents

The East Midlands Congenital Heart Network .....	1
Document Control and Governance .....	2
1. Introduction .....	3
2. Care closer to home .....	4
3. Referral pathways .....	6
4. Antenatal diagnosis .....	7
5. Acute Paediatric / Neonatal presentation .....	10
6. Outpatient based (routine) referrals .....	13
7. Children with complex cardiac problems .....	15
8. Inpatient discharge arrangements .....	15

9. Cross-sectional imaging.....	16
10. 24-hour access to specialist advice .....	17
11. Centre to Centre referrals .....	17
12. Self-referral .....	21
13. Urgent dental assessment .....	23
14. Transition to adulthood .....	25
15. Adult congenital cardiac care.....	32
16. Palliative care .....	35
17. Communication.....	35
18. Working with other relevant networks .....	35
19. Clinical governance .....	45
20. Continuing professional development & validation of existing clinicians.....	46
21. Education and Training / CPD .....	47
22. East Midlands Congenital Heart Centre contact details.....	48
23. Abbreviations and definitions .....	49

## 1. Introduction

This document sets out an agreed model of care for the management of children and adults in the East Midlands with established and suspected congenital and paediatric heart disease, as part of the East Midlands Congenital Heart Network. It aims to document and regularise the existing and well established routes, for referral and communication, for the ‘client population’ currently served by the East Midlands Congenital Heart Centre (EMCHC) at Glenfield Hospital, University Hospitals of Leicester NHS Trust. It should also clarify expectations from the Network which EMCHC aspires to serve more fully.

## 2. Care closer to home

EMCHN patients live across a wide geographical region, from Leicestershire, Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire, Warwickshire and Cambridgeshire (Peterborough).

In order to ensure patients have as much of their care as close to home as possible, EMCHC has long standing outreach and referral links with a large number of hospitals across this region.

Patients are largely seen at EMCHC during initial (neonatal) care if required, and around the time of any invasive investigations or treatment including surgery. Otherwise it is the policy of the Network to ensure as many patients as possible are accommodated and managed in their local centres, both as inpatients and as outpatients.

Some hospitals in our region have dual relationships with other cardiac centres; for example Peterborough, the Coventry and Warwickshire Hospitals and Burton-on-Trent. Respect for these relationships is paramount, and EMCHC will continue to support these in whichever ways are possible.

Outreach services have been offered to all centres in the Network. To date, Burton, Coventry and Warwick, and Northampton remain without outreach clinics from our centre. Patients from these areas are generally seen either at EMCHC or in their closest available centre.

In order to ensure that as many East Midlands patients are seen as close to home as possible EMCHC currently provides a minimum of the following clinics annually;

### Paediatric

24 full day and 6 half day clinics at Derby

24 full day clinics at Queens Medical Centre, Nottingham and Kettering

12 full day clinics at Mansfield, Nuneaton, Grantham, Lincoln and Boston

12 half day clinics at Peterborough

## Adult

36 clinics at Derby

24 Clinics at Lincoln

18 clinics at Kettering

12 clinics at Nottingham City

10 clinics at King's Mill and Peterborough

We are also supportive of additional clinics within our network as and when required.

EMCHC is equipped to support and provide 24/7 medical advice. We have successfully been using a cloud based teleconferencing system (Zoom) for several years, allowing for both regular and ad hoc Multi-disciplinary team (MDT) discussion and information sharing from and with all our Network centres and clinicians. EMCHC has a long history of training Paediatricians with Expertise in Cardiology (PECs) and has a broad network of these now working in the region.

### **Paediatricians with expertise in cardiology (PEC) by clinic are:**

Derby - Dr G Joshi, Dr B Etuwewe, Dr B Subramanian and Dr C Nagaraj

Nottingham QMC - Dr S Balmuri, Dr M Fenner and Dr H Asgerally

Kettering - Dr P Pandey

Lincoln – Dr A Al Zaghal (link Consultant Paediatrician)

Mansfield (King's Mill) - Dr D Dave

Peterborough - Dr T Jones

Clinics are also currently provided at Boston, Grantham and Nuneaton Hospitals which do not currently have PEC input.

EMCHC also has a well-established ACHD clinic network supported by the following adult cardiologists with a specialist interest in adult congenital cardiology, in a similar manner to the PEC network.

Nottingham City - Dr W Smith, Dr M Sosin

Derby - Dr D Kelly, Dr A McCance

Lincoln - Dr R Andrews

Kettering- Dr S Hetherington

Peterborough – Dr R Schofield, Dr M Hughes

Mansfield – Dr N Ali

### 3. Referral pathways

This document sets out pathways for the following scenarios, involving a fetus, a neonate, a child or an adult with known or suspected cardiac disease.

- Antenatal diagnosis
- Acute Paediatric presentation
- Out-patient based (routine) referrals
- Complex cardiac problems
- Transition care to adult services
- Adults with CHD
- Palliative care
- Centre to centre referrals and second opinions
- Working with other Networks

The term “children” refers to those from birth to between their 16th and 19th birthdays according to need. Most children will transition towards the ACHD service from 14 years onwards and we would expect the majority to be managed in the ACHD service from

their 16th birthday. However, they may remain in the paediatric clinics up to their 19th birthday, especially when there are complex learning or social difficulties.

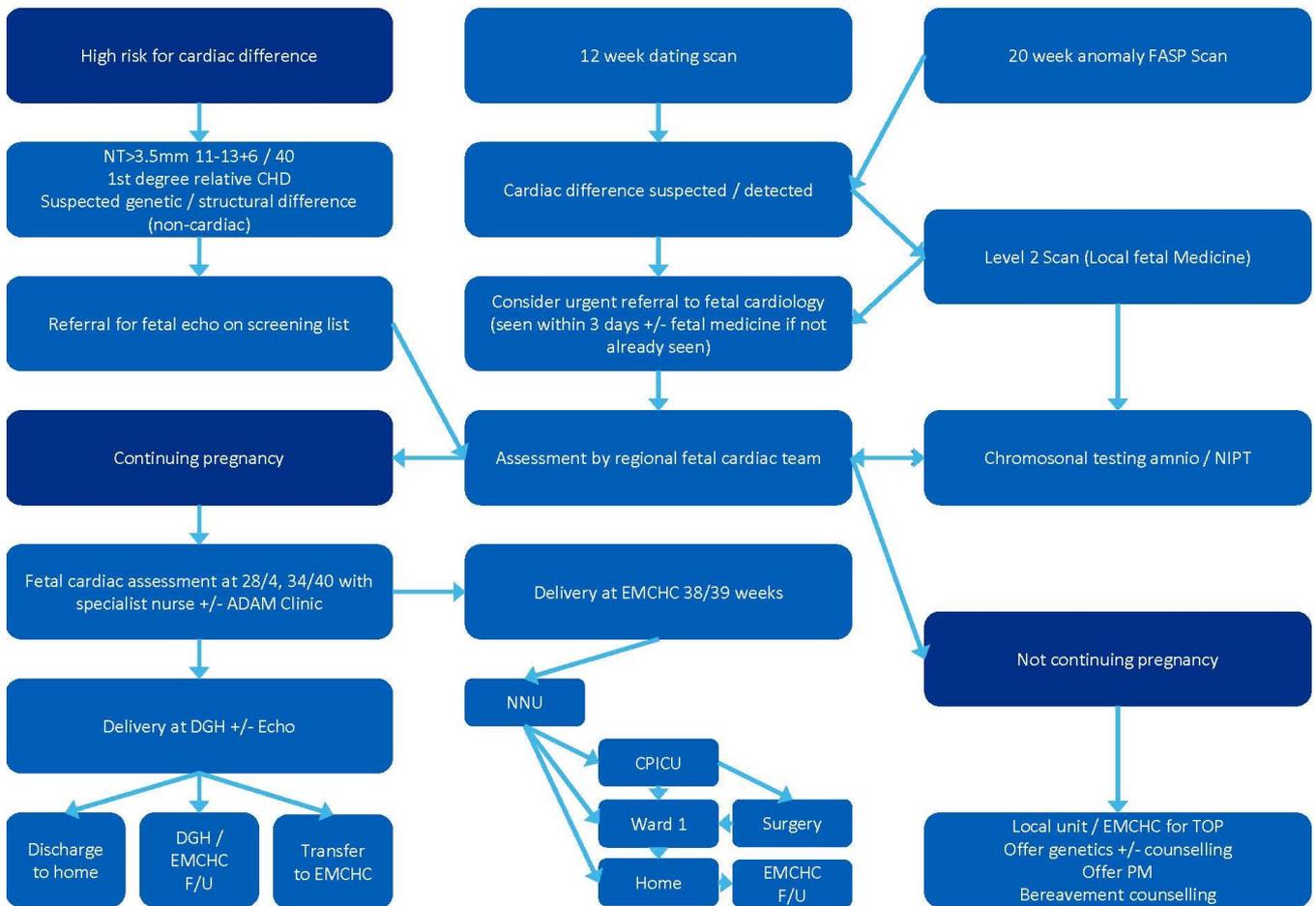
Patients with heart problems can present with varying manifestations and to a variety of healthcare workers; we have tried to address this by focussing on the clinical need of the child.

## 4. Antenatal diagnosis

Prospective parents will have been seen on a number of occasions, and counselled in conjunction with their local and tertiary obstetric, fetal medicine and neonatal teams and will have had the opportunity to visit EMCHC (and see a surgeon if wished) prior to delivery. Fetal referrals will be facilitated within 2 working days and the pathway and referral forms can be found below.

A clear plan of care will be agreed and documented prior to delivery with reference to location, timing, and preferred mode of delivery, as well as anticipated immediate postnatal management and transfer plans. All babies with antenatal diagnosed transposition of the great arteries will deliver in Leicester to enable prompt balloon Septostomy if required. Babies with other problems will be assessed according to needs, complexity, views of parents and health care professionals, as well as logistics, on an individual basis. The majority of babies are able to deliver in their local unit with ex-utero transfer supported as much as possible. All parents will have contact details for our cardiac nurse specialists as well as the fetal cardiac service.

## Prenatal Care & Referral Pathway



**EAST MIDLANDS CONGENITAL HEART CENTRE  
FETAL CARDIOLOGY REFERRAL FORM.**  
Email this completed form (along with the detailed scan report) to the ANNB screening team at UHL.  
E-mail: [uho-tr.fcadiac@nhs.net](mailto:uho-tr.fcadiac@nhs.net)  
Tel: 0116 258 4860/07814339627



*Caring at its best*

<p>NHS No: Surname: First Name: DOB: First Line of Address: Postcode: <b>Primary Contact Number:</b> <b>E-mail address:</b></p>	<p>Name of referrer:  Responsible Consultant  Name of Base Hospital: Date of referral: <b>E-mail address of referrer:</b> <b>Contact number of referrer:</b></p>
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**Please provide phone number & e-mail of the patient, as she will be contacted by us directly regarding the appointment.**

Parity:	Date of detailed scan:	EDD:	Gestation at referral:	Weight in kg:
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In order to provide appropriate information for the fetal cardiac scan, please see below for the type of referral required. Once you know which one is needed, please enter the number into the box below. **This information is critical to the planning and performance of the scan. Any additional information is to be added into the 'Further information' text box at the bottom of the page.**

**Referral type required. Please enter number from list below** →

1. Fetal malformation or anomaly identified or suspected. Specify anomalies in the box below.
2. Abnormal 4 or 5 chamber view / suspected structural heart defect on detailed scan. Specify anomalies in the box below.
  - For these first two indications, there is evidence of a structural anomaly and a **TIMELY** diagnostic scan is necessary. A referral form must be sent urgently to our Fetal Cardiac Referrals team, see above for email address.
  - For information regarding appointments & referrals, or if you would like confirmation that your referral has been received, you may wish to call the Antenatal and Newborn Screening team on 0116 258 4860 / 07814339627 Mon - Fri 8:30am and 4pm.
3. Previous child with structural cardiac defect. Using the box below, **indicate diagnosis, date of birth and name of child.**
  - NB:** -If previous child has ASD or PDA - subsequent pregnancy does not need antenatal fetal cardiac scan, but should be referred for postnatal cardiac assessment.
  - History of previous child with a murmur that resolved spontaneously does not require a cardiac referral investigation.
4. Pregnant woman or partner has a history of congenital heart disease. Using the box below, **indicate diagnosis, hospital of diagnosis, current status as well as name and DOB of partner if he is the affected individual.**
  - NB:** -If pregnant woman or partner has a history of ASD, PDA, an antenatal fetal cardiac scan is not indicated, **but** the baby should be referred for postnatal cardiac assessment.
  - History of cardiac murmur that resolved spontaneously in either parent does not require fetal or postnatal cardiac referral.
5. Other Indication: **Use box below to specify reason for referral.**

Further Information:

Will the patient require Fetal Medicine input?

SAFEGAURDING:    MENTAL HEALTH:    MEDICAL INFORMATION:    PLEASE PROVIDE DETAILS

Please send completed form to: [uho-tr.fcadiac@nhs.net](mailto:uho-tr.fcadiac@nhs.net)



## 5. Acute Paediatric / Neonatal presentation

For any child presenting acutely to a paediatric unit, the priority is, as always, to establish resuscitation and stabilisation based on the national guidelines (APLS) following which contact should be made with the local consultant on call, and if necessary the on-call paediatric cardiology team at EMCHC for additional advice.

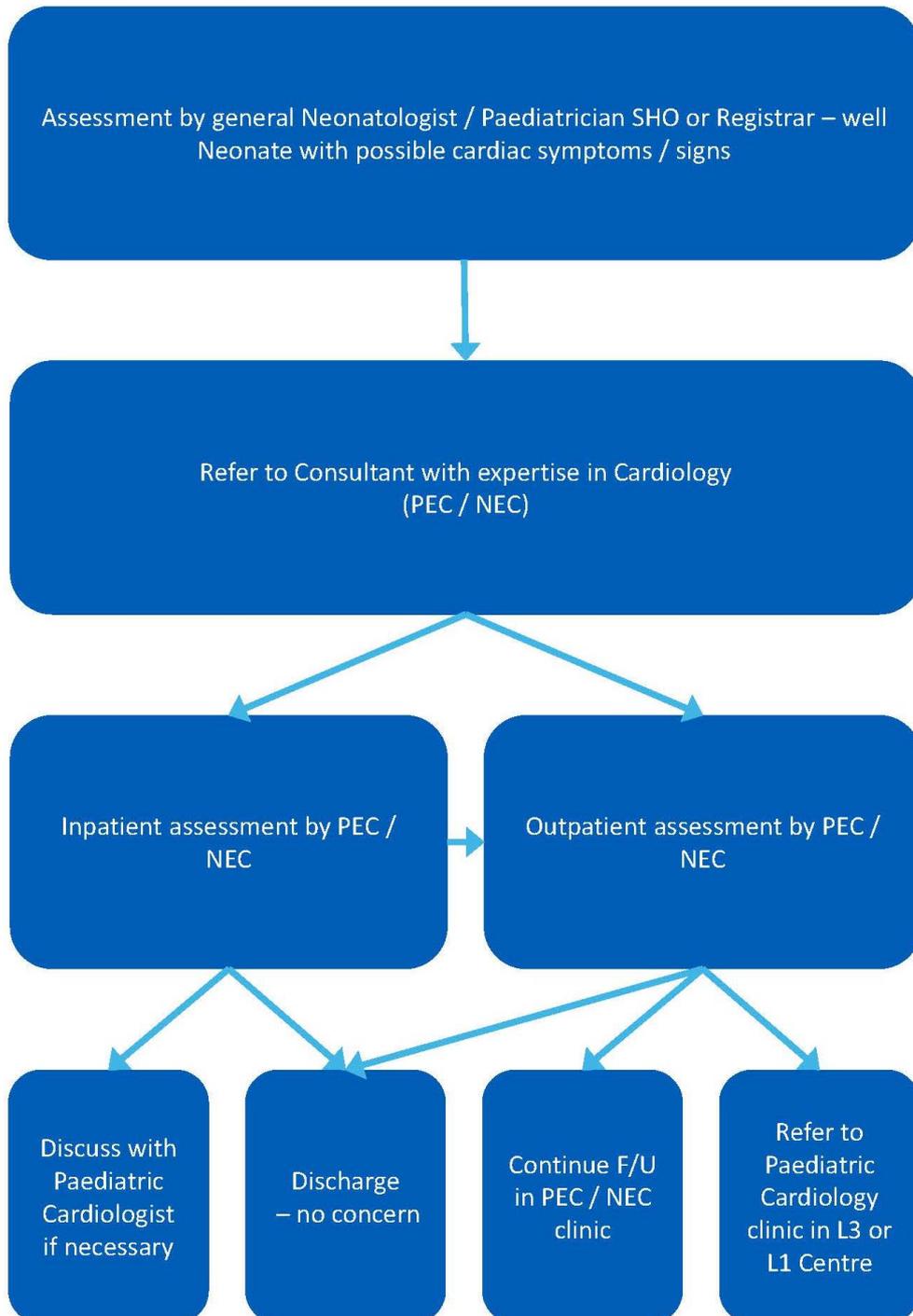
For any critically ill child contact should also be made with the COMET team. Comet is the dedicated critical care transport service for children in the East Midlands which works as a collaborative establishment between Leicester Children's Hospital and Nottingham Children's Hospital. Visit [comettransport.uk](http://comettransport.uk) or call 0300 300 0023. COMET team are able to coordinate referral conference calls with the duty PICU/Cardiology teams at EMCHC and offer advice, stabilisation and transport.

Telemedicine consultations (Zoom) are also available for all our network units and can readily be enabled for others, for MDT sharing of acute imaging as well as discussions. Based on this, the child then can be managed locally (e.g. some arrhythmias), and/or transferred to EMCHC depending on the clinical need.

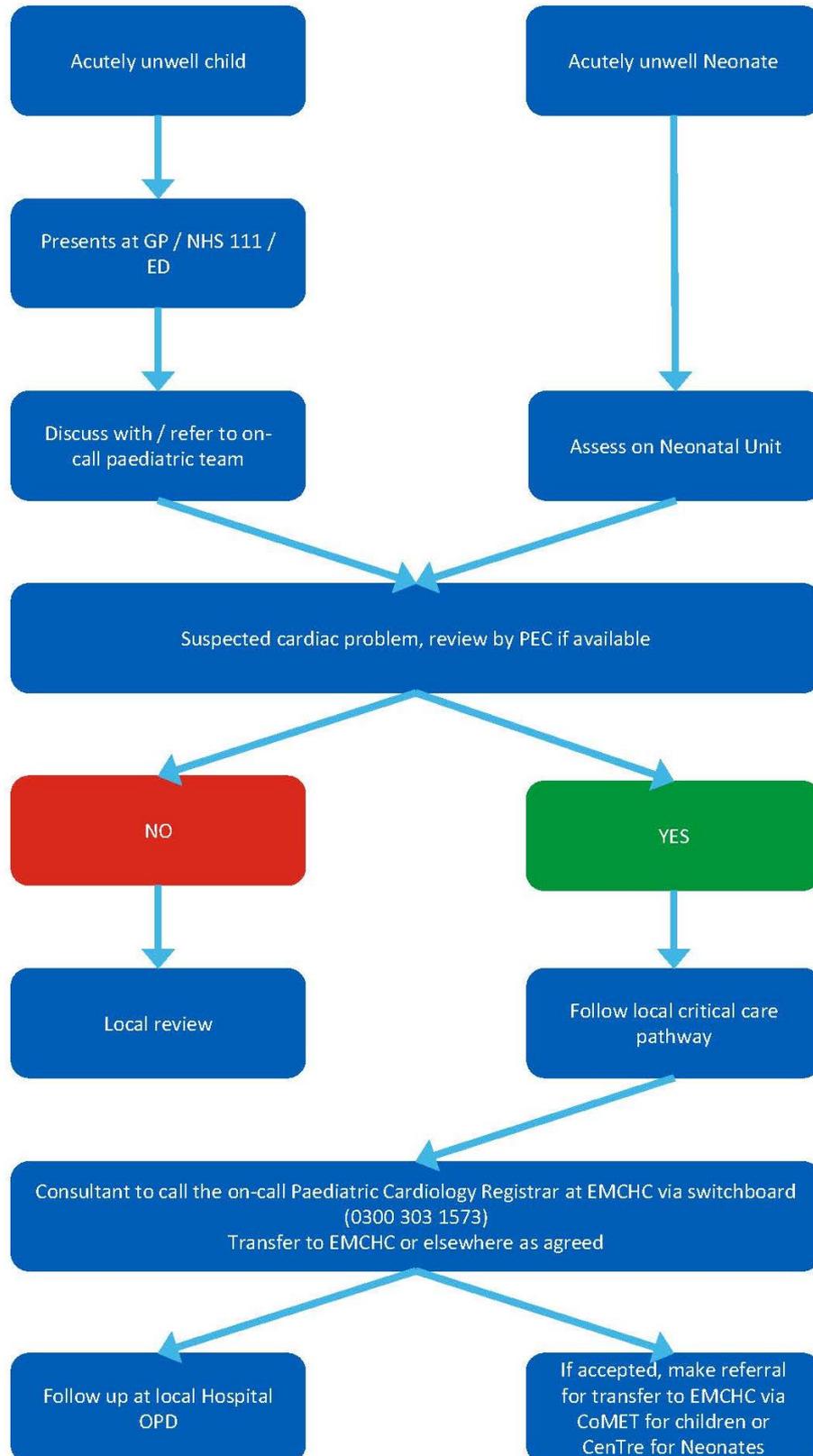
Preterm infants who, in the opinion of the local neonatologists require ligation of the arterial duct (PDA ligation) are referred according to the agreed [Neonatal network SOP](#) (to be found at the below link) via the Level 3 neonatal units in the East Midlands (Nottingham and Leicester).

[https://www.emnodn.nhs.uk/\\_files/ugd/143840\\_c4fa4066d06648bcac6ee83ddf2ebbd5.pdf](https://www.emnodn.nhs.uk/_files/ugd/143840_c4fa4066d06648bcac6ee83ddf2ebbd5.pdf)

## Referral Pathway for well newborns with cardiac query (post natal ward)



## Management of acutely unwell cardiac children



## 6. Outpatient based (routine) referrals

Many children are referred for cardiac assessments by GPs, A&E departments and the postnatal wards. Some will be referred from other specialties e.g. clinical genetics. Depending on the centre, these will initially be reviewed / triaged by general paediatricians, neonatologists, the local PEC and paediatric cardiologists.

Most centres in the East Midlands have now invested in experienced paediatricians with expertise in cardiology (PECs) and there are also some neonatologists with similar expertise, who maintain an on-going presence at, and training with EMCHC. The local PECs therefore generally now undertake triaging, initial clinical review and echocardiography as required for these referrals and take responsibility for prioritising and deciding which patients require tertiary cardiological review.

**As a guiding principle any patient with significant cardiac disease must have their case reviewed by (and usually see) a Cardiologist at least once.**

In practice this may mean an initial review of their case and investigations between the PEC and the cardiologist to provide advice and formulate a clear follow-up plan in either joint clinics, tertiary cardiac clinics or sometimes in the PEC's own review clinic.

In a small number of centres initial patient review may be undertaken by general paediatricians with access to technician-provided echocardiography, or they may be referred directly to the Network cardiology clinics according to local expertise.

Accordingly, the pathway for this group of children would be from:

- (a) Review and discharge when there is no pathology
- (b) Review and management locally without any additional involvement of the cardiologists (non-significant cardiac disease only)
- (c) Review and management locally with input from the cardiologists - discussion and review of data (e.g. ECG, Echo, monitors, etc.)
- (d) Review and referral to cardiologist

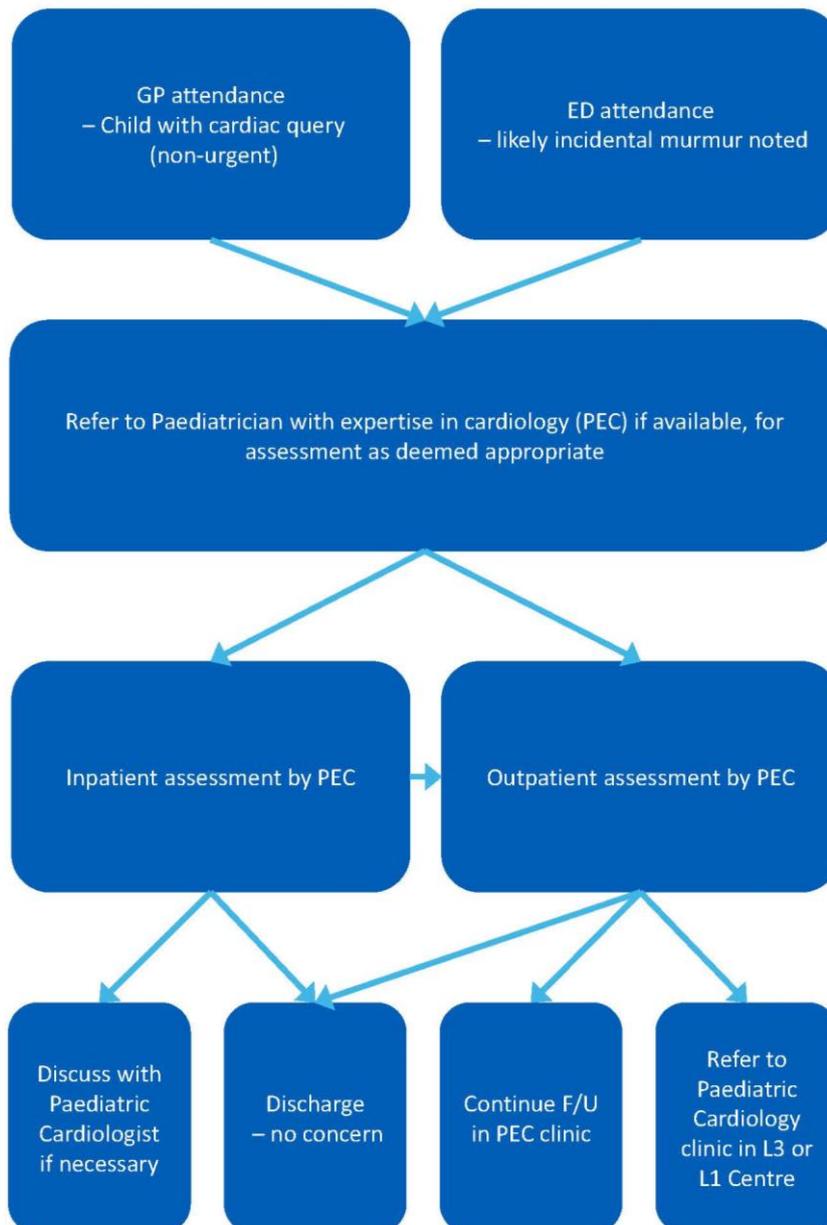
(e) A one off review by the cardiologists with further management by the local team

(f) Follow up with the cardiologists in the Joint Network Cardiology Clinics

(g) Follow up and management at the tertiary (Level 1) cardiac centre

**All new patients with a cardiac problem needing follow up must be seen or discussed in detail with a tertiary cardiologist at least once, and a management and follow-up plan agreed.**

**Management of a child with Cardiac query (routine referrals)**



## 7. Children with complex cardiac problems

Children with complex heart conditions need careful monitoring of their cardiac condition. In addition, many of these children will need general paediatric input in relation to nutrition, growth, development, and other systemic concerns (e.g. syndromes). In these cases, the principle link should be between the local general paediatrician or the local PEC and the tertiary cardiac service.

When children with a known cardiac problem presents to acute paediatric services the initial management (resuscitation and stabilisation) will be the responsibility of the local acute paediatric team and follow the principles of the Resuscitation, Stabilisation and Transfer Pathway which may include the advice and/or transfer to a tertiary cardiac service.

These children should in general be being seen by a paediatric cardiologist from EMCHC for their cardiac issues, ideally, jointly with their local PEC. Children and adolescents with complex heart disease are mainly (but likely not exclusively);

- (a) Inter-stage (between operations that are staged) e.g. BT shunts, PA bands
- (b) After completion of palliative surgeries (as opposed to a complete repair)
- (c) After completion of complete repair for those children who need lifelong cardiology reviews and are at a higher risk for cardiac problems (e.g. Tetralogy of Fallot, Coarctation of aorta, etc.)
- (d) Those with prosthetic valve replacements
- (e) Post transplant patients with joint FU agreements

## 8. Inpatient discharge arrangements

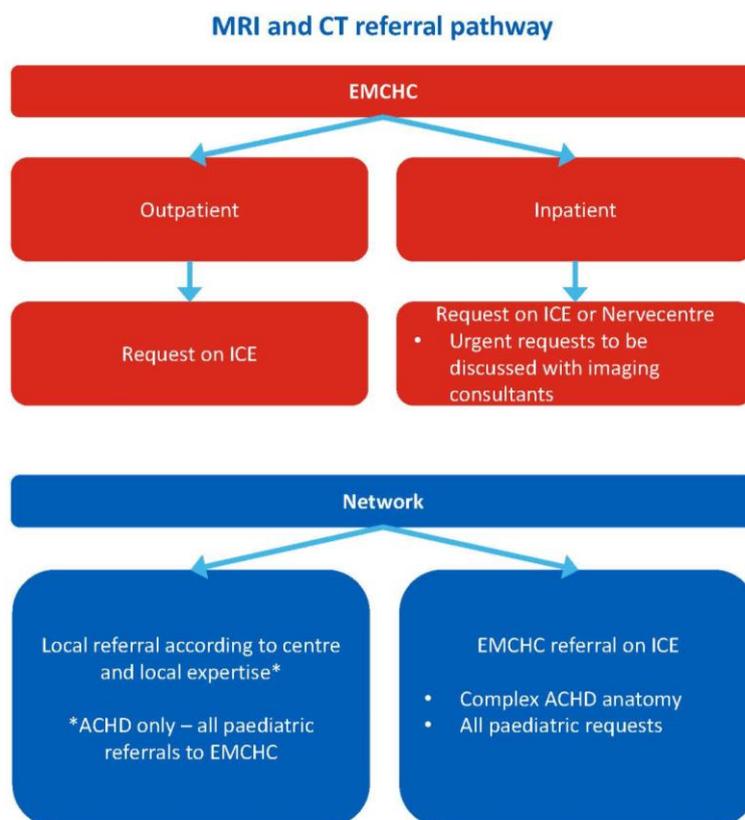
Patients that are discharged home from EMCHC are given a handheld copy of their discharge summary. A copy is sent via post to their local PEC/ Link Cardiologist, GP, Health Visitor and any other relevant agencies.

Most patients who have had a procedure will have their initial follow up at EMCHC with 'repatriation' to their local hospital outreach clinic as soon as is clinically appropriate.

In patient transfers will only occur by direct communication with the receiving centre Paediatrician/ Cardiologists and will be accompanied by a clear management and follow up plan.

## 9. Cross-sectional imaging

Cross-sectional imaging services at EMCHC routinely include Cardiac MRI and CT angiography for both children and adults with congenital heart disease. This is an essential part of the service for providing valuable diagnostic information for children and adults with congenital heart disease and sustaining the Congenital Cardiology and Surgical programme with EMCHC.



- Confirmation of renal function needed for all CT and MRI requests
- ACHD patients requiring GA (severe claustrophobia, LD and special needs): inform imaging consultants by email that request has been made
- For patients with pacemakers / ICDs – confirm MRI compatibility with pacing

## 10. 24-hour access to specialist advice

EMCHC recognise the need for health care professionals from across the Network and indeed around the country to be able to source specialist advice on our patients at any hour of any day or night. Both our Paediatric and ACHD Consultant Cardiologists provide 24/7 on call rotas for advice, planned or unplanned reviews & admissions, procedures and other investigations. Consultants and Registrars are best contacted via UHL Switchboard.

## 11. Centre to Centre referrals

Centre to Centre referrals and access to second opinion (to include transplant centres and Pulmonary Hypertension Services)

For EMCHC patients for whom the MDT opinion is that that a further (external) opinion or opinions are needed to support patient management decisions, this will be agreed and the reasons documented at the MDT. For EMCHC patients for whom the MDT has agreed that their needs would be best served by a procedure in a different centre, it will be determined by the MDT which clinician will make the formal referral in writing (as well usually by telephone or face to face), and ensure that appropriate imaging and physiological information is transferred. Where referral is due to need for individual operator expertise, the EMCHC team will endeavour that a member of the EMCHC team will join the operating team elsewhere if the operator is unable to come to EMCHC, in order to continue to build our own institutional and individual expertise.

### Centre to Centre referrals and access to second opinions

As the UK's leading ECMO (extracorporeal membrane oxygenation centre), EMCHC has a well-developed system for receiving, assessing and prioritising external referrals, involving documented MDT discussion between ECMO, intensive care, surgical and cardiology consultants as appropriate.

For EMCHC patients for whom the MDT opinion is that that a further opinion or opinions are needed to support patient management decisions, this will be agreed and the

reasons and time frame required is documented at the MDT. This may be a request for an overall management opinion or for a specific surgical or interventional opinion. It will be determined at the MDT precisely who will take responsibility for soliciting this depending on the nature of the query. It is the responsibility of this clinician to ensure the appropriate individuals are contacted in writing (as well as usually by telephone or face to face), that appropriate imaging and physiological information is transferred, and the opinion is returned to the MDT in a timely manner. The acceptable time frame for this will vary with circumstance, complexity, and mode of image transfer. For urgent inpatients this will usually be within 24-48 hours. Patients / parents will be kept informed as to the processes involved as clinically appropriate

For EMCHC patients for whom the MDT has agreed that their needs would be best served by a procedure in a different centre, it will be determined by the MDT which clinician will make the formal referral in writing (as well usually by telephone or face to face), that appropriate imaging and physiological information is transferred. Where referral is for individual operator expertise, the EMCHC team will endeavour to release an EMCHC team member to join the operating team elsewhere in order to continue to build our own institutional and individual expertise.

### **Transplant referrals (Paediatric and ACHD)**

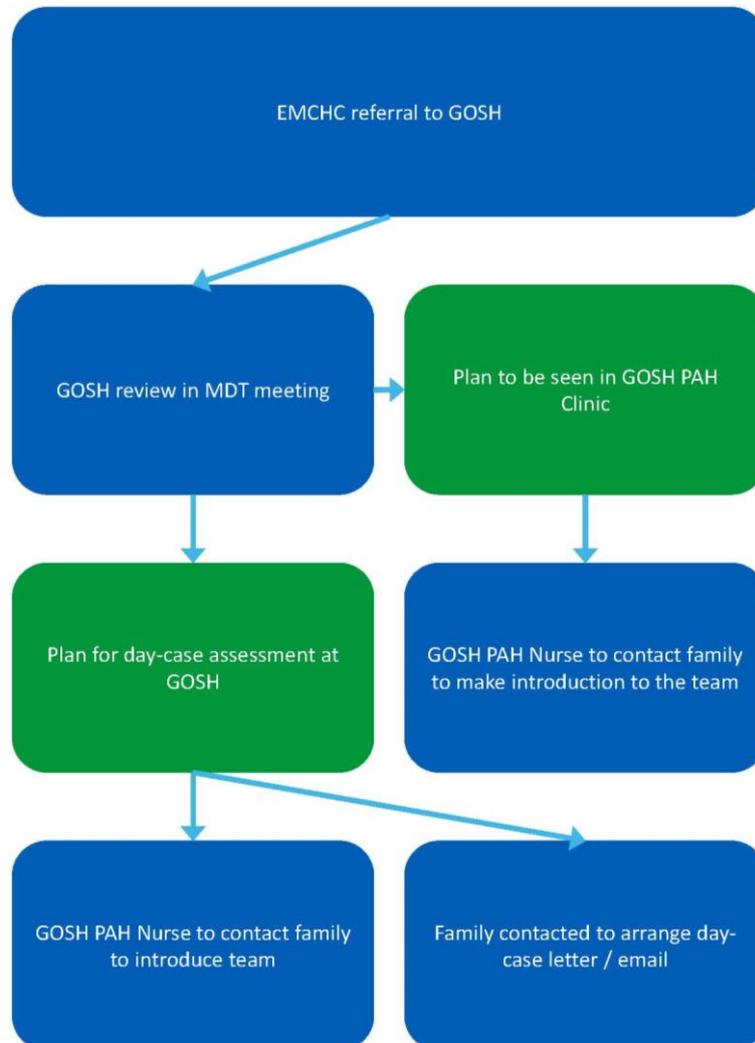
**Elective:** will be made by the patient's responsible consultant after discussion with the patient / family, in writing, usually backed up by a telephone or face to face discussion. Choice of transplant centre contacted will be driven by a number of factors including disease process, geography, and patient / parent preference. All relevant clinical information including relevant imaging will be supplied as part of the referral process.

**Emergency:** will be made by a designated member / members of the MDT as most appropriate for individual circumstance, by telephone, accompanied by electronic image transfer +/- Videoconference. Patients / family will always be involved in these discussions.

### **Pulmonary Arterial Hypertension (PAH)**

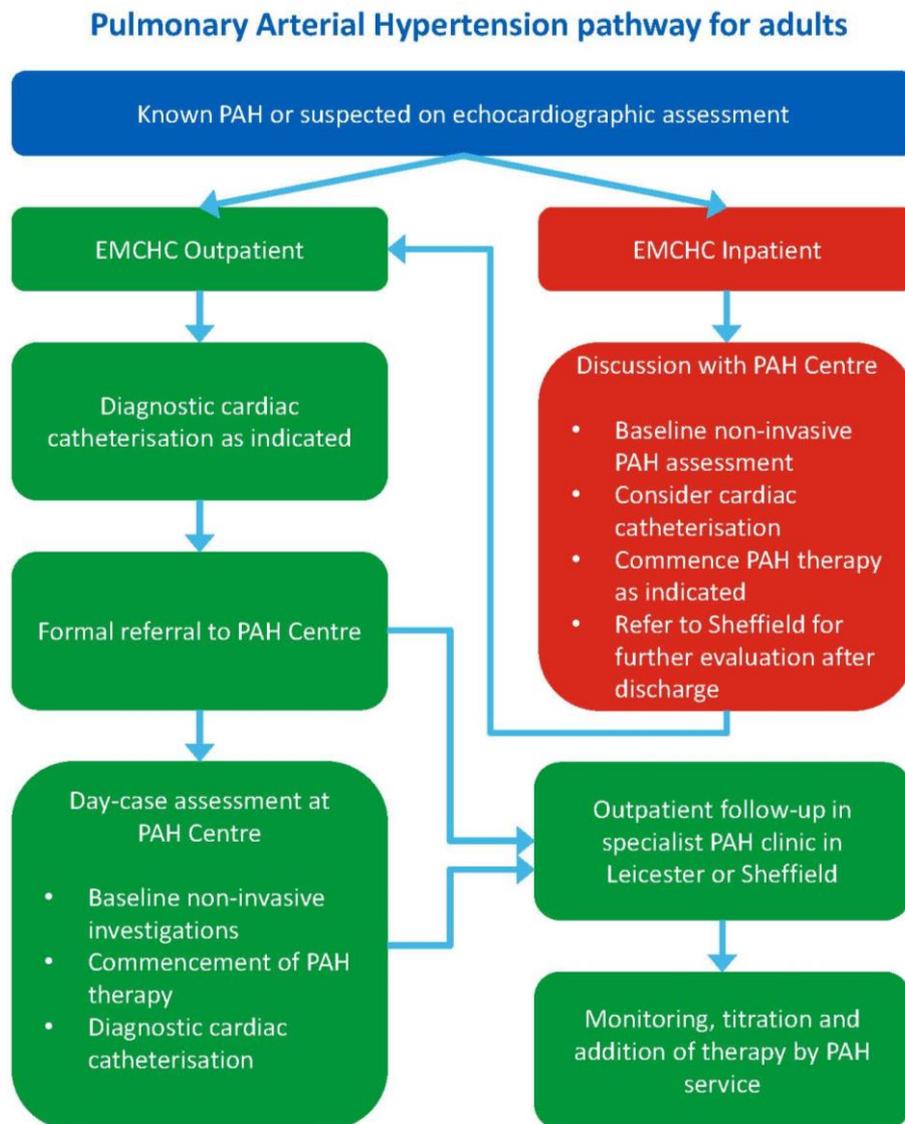
- Children in whom there is an anticipated long term (>3 months) requirement for anti-pulmonary hypertensive medication, or for whom this is considered, will be

referred to the Nationally Commissioned pulmonary hypertension service at Great Ormond Street Hospital. Parents will be involved in this decision and necessary travel implications. The referral pathway is as follows:



- Adults in whom there is an anticipated long term (>3 months) requirement for anti-pulmonary hypertensive medication, or for whom this is considered, will usually be discussed with and referred to our regional pulmonary hypertension service at Royal Hallamshire Hospital, Sheffield, with whom we have a formal network arrangement. Patients with PAH may then be seen in the Sheffield – Leicester PAH clinic at Glenfield Hospital (run quarterly) or at the Royal Hallamshire Hospital.

- For geographical considerations and for patients with chronic thromboembolic PAH, a small number of patients are referred to the PAH service at Papworth Hospital.



- Patient / parent solicited second opinions;  
All patients / families are not only entitled to, but are welcome to and on occasion encouraged to seek a second opinion about aspects of their / their child's care from other expert centres or clinicians. EMCHC clinicians will facilitate this as a matter of course, and will be happy to provide advice, support and information transfer to appropriate external experts.

Under certain circumstances, it may however be more appropriate for the patient / family to choose their own preferred external specialist. In these circumstances, the referral will be made by the family or the GP. The patient's own consultant will in those circumstances, provide any appropriate investigation results to the external clinician concerned as requested.

## 12. Self-referral

Parents of children with cardiac problems from around the region can, and do, call EMCHC via Ward 1 at LRI Kensington, for 24/7 advice. If it is felt that the child requires a hospital review, then parents will almost always be advised to take their child to their local hospital for this. The on-call cardiac team at EMCHC are expected to notify the relevant local acute paediatric service that this has been advised, and provide follow-on appropriate information and advice to their health care professionals as needed.

Adult patients are all given contact details of their named Cardiac Nurse Specialist for advice in working hours. Out of hours advice is provided through the on call cardiac registrar via the UHL switchboard.

### Managing patients who self-refer out of hours

EMCHC recognises the need for patients / parents to be able to self-refer or indeed seek expert advice from their Tertiary Cardiac expert at any time. Out of hours enquiries are usually patients / parents seeking expert advice / assistance. There are many routes through which this may be sought at EMCHC and these are described below.

### Children

1. Many of our patients have a known children's cardiac nurse specialists and are given individual contact details (mobile number, email address and office number) when we see them in our clinics, surgical or catheter preadmission or Fetal cardiac clinics.

2. All EMCHC clinic letters have the contact details for our secretaries and specialist nurses on them.
3. Team names and contact details are given out in clinics with our contact cards.
4. The office answer machine (0116 258 3338) message states that messages are listened to throughout the day but not in the evenings, weekends or bank holidays.
5. At discharge, those children who have been admitted to or been seen on our paediatric ward (Cardiac Ward 1 at LRI), are given the ward telephone number and advised that they can telephone the ward for following discharge. They are also told that if they have any acute concerns about their child they must take them to their nearest Emergency Department or call 999, rather than come to Cardiac Ward 1 unannounced. Please follow LRI Emergency Department Standard Operating Procedure (SOP) for Critical Care Pathway for Children & Young People (<16years)
6. If a parent or patient phones Ward 1 (or the Paediatric Cardiac Registrar on call), they will be offered advice (escalated to the On-Call consultant if appropriate) and if physical review is appropriate, arrangements for admission will be made if capacity on Ward 1 or arrangements will be made for review at their local Network Centre. The On Call Cardiology team will also communicate this to the on-call team in the relevant Network Centre and ask for feedback on the patient once seen.

## Adults

1. Most of our patients have a known ACHD Clinical Nurse Specialist and are given individual contact details (mobile number, email address and office number) if we see them in our network, surgical, catheter preadmission or maternal medicine clinics.
2. Team names and contact details are given out in ACHD clinics with our contact cards.
3. The office answer-machine message states that messages are listened to throughout the day but not in the evenings, weekends or bank holidays. It also informs callers that out of hours, the hospital switchboard can be asked to contact the on-call 'ACHD cardiac registrar' for advice.

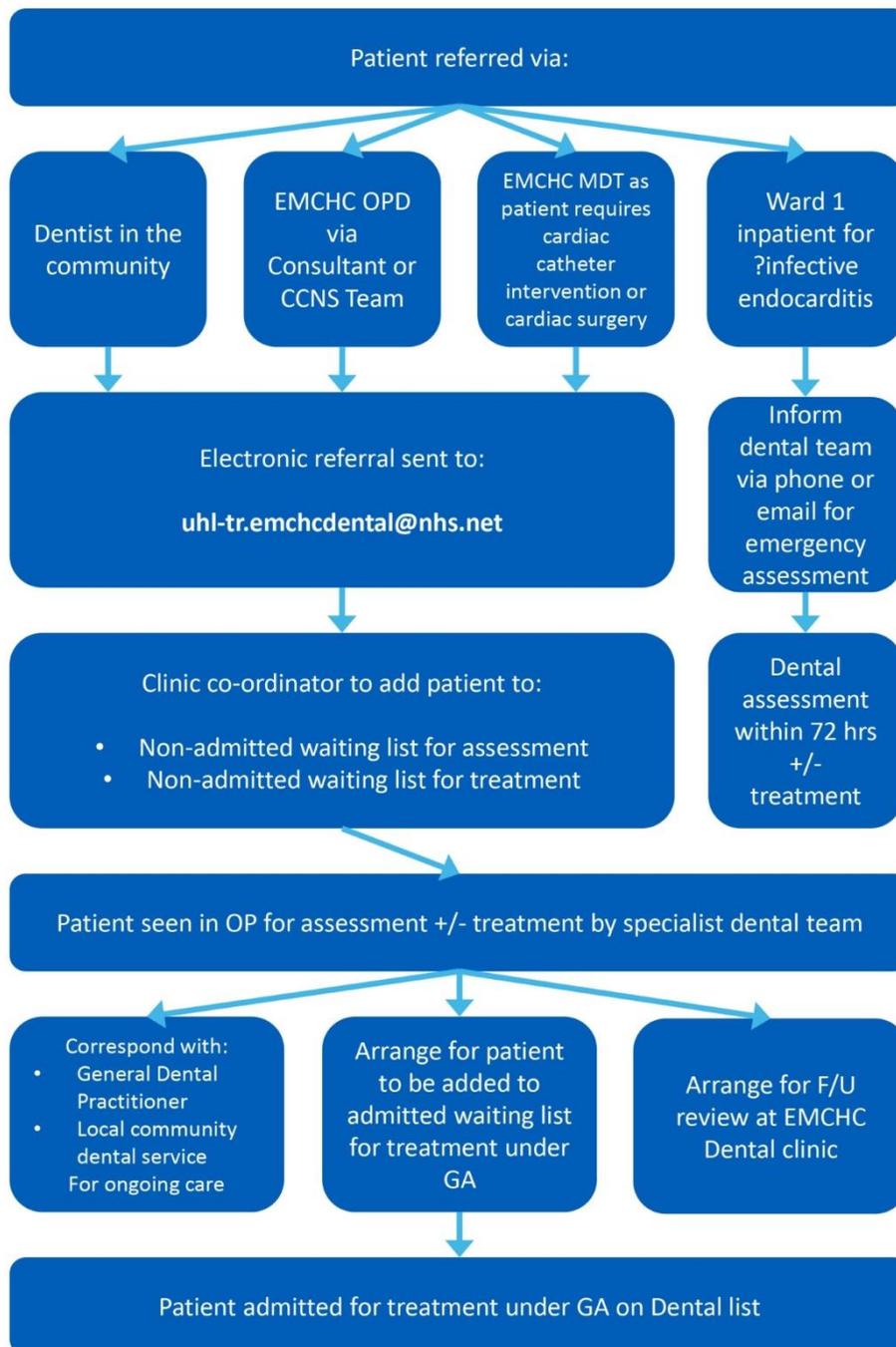
4. If a parent or patient phones the ACHD CNS team, they will be offered advice (escalated to the On-Call consultant if appropriate) and if physical review is appropriate, will either be seen at EMCHC or arrangements will be made for review at their local Network Centre. The On Call Cardiology team will also communicate this to the on-call team in the relevant Network Centre and ask for feedback on the patient once seen.
5. If we receive queries within hours and offer advice, we also encourage patients to visit walk-in centres, GP's for non-acute issues, and A&E for advice if they consider it cannot wait to be dealt with.

## 13. Urgent dental assessment

There is a pathway for all Congenital Heart Disease Patients presenting with infective endocarditis, dental pain, acute dental pain, acute dental infection or dental trauma. In addition to this all patients require a dental assessment prior to admission and acceptance for surgery.

Adults are given advice and guidance in dental health and support letters are written where required to assist with finding a dentist. There is provision for "Best Interests Meetings" for adults with learning difficulties or those who lack mental capacity prior to any surgical or cardiac interventions. There is access to specialist dentistry teams for review and treatment if required prior to cardiac procedures to ensure patients are dentally fit.

## Referral to Paediatric Dentistry within EMCHC



## 14. Transition to adulthood

There is a well-established pathway for adolescents and young people with heart problems that aims to provide a seamless transition to adult care.

Whilst many adolescents and young people may have had cardiac concerns that allow appropriate discharge to primary care services, significant numbers will need on-going care and follow up from adult cardiology services.

For this group of young people, there are a number of possible outcomes:

- (a) Discharged (if appropriate)
- (b) GP for on-going follow-up (+/- interval re referral)
- (c) Referral to Adult cardiologist with appropriate expertise e.g. Kawasaki related coronary disease, acquired heart muscle disease / inherited heart muscle or arrhythmic condition etc.
- (d) Specialist ACHD follow-up or shared care with adult cardiology

For non-Leicester patients, transition is facilitated by the provision of both paediatric and ACHD outreach clinics at many of our regional centres, often with common case-notes. However a comprehensive written transition referral is required and the patient and family will be involved in that process. Some patients may need or prefer their longer term ACHD follow-up to occur at EMCHC.

Additional information on Transition can be found on the network website at the link below.

<https://www.emchnetwork.nhs.uk/en/page/teenagers-young-people>

It is essential that during the period of Transition, patients are monitored and followed up, to reduce the risk of them being lost to follow-up.

## Transition of patients from paediatric to adult cardiology services

Without structured transfer of care from paediatric to adult cardiology services patients may suffer delayed or inappropriate care, undue emotional stress, and may even be lost to follow up. Robust systems must be in place to ensure that this does not occur and that instead a seamless transition is made between disciplines. This document details the East Midlands Congenital Heart Centre (EMCHC) policy on high quality transition arrangements.

### Aims

The transition program should provide uninterrupted health care that is patient centred, age and developmentally appropriate, flexible, and comprehensive. It should include age- appropriate education about medical conditions and promote skills in communication, decision making, self-care, and self-advocacy. It should foster greater personal and medical independence and a greater sense of control over health, healthcare decisions, and psychosocial environment. The ultimate goal of a transition program is to optimize the quality of life, life expectancy, and future productivity of young patients.

### Timing of transition

The transition process should start at 12 years of age and be sensitive to the patient's medical and developmental status as well their wishes. For the majority transition should be complete by 16 years and no later than 18 years.

### Setting

Transition should begin in the paediatric cardiology clinic and be completed in the adult clinic. Outpatient booking systems at EMCHC and in the peripheral clinics should allow for long-term follow up appointments at appropriate intervals (from a few weeks to five years). Inpatients should be managed in age appropriate areas so that on completion of the transition process patients expect to be accommodated within adult cardiology practice and feel comfortable in this setting. In the case of patients with special needs, provision should be made, when necessary, for parents and carers to stay overnight in the hospital.

## Process

It is the responsibility of the patient's named consultant that the EMCHC policy on transition is adhered to. Each patient should have a named liaison nurse as a point of contact and the EMCHC should have a named lead liaison nurse for local and regional services with appropriate training in the transition process.

Transfer of care will occur in the following settings:

- from LRI paediatric cardiology clinics to Glenfield adult congenital cardiology clinics
- from peripheral paediatric cardiology clinics in the region to the equivalent peripheral adult congenital cardiology clinics where they exist within the same trust or locality
- from peripheral paediatric cardiology clinics to Glenfield adult congenital cardiology clinics where local adult cardiology clinics do not exist
- from LRI paediatric cardiology to peripheral adult congenital clinic

The transition plan should be carefully explained to patients and their families both in clinic and a written plan provided to them and their general practitioner. A formal transition document should be produced (a detailed clinic letter will suffice) that outlines the on-going medical and social issues and this should be sent to a named adult congenital cardiologist, the patient and the patient's GP. A Transition Checklist will be filed in each patient's notes and completion will act as an 'aid memoir' to the transition process.

If outpatient transition is planned from peripheral to peripheral clinic or from Glenfield to peripheral clinic all efforts should be made to provide a comparable set of notes. These must include, where possible, operation and catheter intervention reports, discharge summaries and clinic letters. Clear instruction should be given to administration staff to ensure that relevant paper work is copied.

Since Congenital Heart Disease is a lifelong condition, EMCHC should have in place a clear policy and system to ensure that notes of congenital heart disease patients at EMCHC should be kept until at least 5 years after the patient's death.

## For patients and parents

Preparation for Transition should really begin at the time of diagnosis of any lifelong condition. Thus the discussion should start early, to prompt parents to 'envision a future' for their child, to consider expectations for their child's education, and their prospects for employment and ultimately for independent living. As patients are prepared to take increased responsibility for their health care, their parents will also need education and support to gradually share and then hand over this responsibility to their child.

Right from initial diagnosis, discussion with parents should therefore include reference to transitional topics (at least couched in terms of current understanding of the situation), to help parents prepare for this shift in responsibility. There should also be acknowledgement that this situation may change over the years as our understanding and management, especially of very complex conditions, evolves.

Preparing the patient for self-care should begin in early childhood and continue into adulthood to allow the development of the necessary self-care skills. The process will be individually tailored to the developmental stages of adolescence and must acknowledge impact of chronic illness. During childhood, each patient should become increasingly involved in direct discussions about his or her diagnosis, medications, and exercise limitations. In the teenage years, discussions about heart-healthy behaviours and the risks of smoking, alcohol, and drugs will be introduced and reviewed regularly. Self-care education will not terminate on transfer to adult care but will remain an on-going educational process to address life changes. Even patients who remain under the care of the same congenital cardiologist need to undergo a process of transition.

Vocational and employment advice will continue into early adulthood, with facilitated access to National Services such as 'Connexions' as appropriate. Discussions about

sex, contraception, risks of pregnancy and inheritance risk (both sexes) will be introduced in an age specific manner and may need to be reemphasised frequently.

Clear communication with the patient's primary care practitioner during this process is essential as they are often the only 'constant' during a period of significant life changes.

Summary of Health Supervision Issues for Primary Care and Hospital Follow-Up Needs

## For Patients

1. The timing of transition should be guided by emotional maturity and developmental level (as opposed to chronological age) for transition planning (Class I; Level of Evidence C).
2. The adolescent should be engaged in transition planning (Class I; Level of Evidence C).
3. The adolescent should be asked about their understanding of their disease in relation to their current health status, restrictions on activities, and future goals (Class I; Level of evidence C).
4. The adolescent should be encouraged to share concerns about QOL issues (physical restrictions, school, peers, and social relationships) (Class I; Level of Evidence C).
5. The adolescent's fears and concerns should be acknowledged in an empathetic, non- judgmental manner (Class I; Level of Evidence C).
6. The paediatric cardiology provider should initiate and work together with the adolescent on a written transition plan (Class I; Level of Evidence C).
7. Providers should begin to direct health discussions more toward the adolescent than the parent (Class I; Level of Evidence C).
8. QOL issues should be discussed privately with the adolescent (Class I; Level of Evidence C).
9. Be flexible (Class I; Level of Evidence C).

## For Parents

1. The paediatric cardiology provider should initiate discussions on transition planning in partnership with parents (Class I; Level of Evidence C).
2. The paediatric cardiology provider should solicit information about parental perceptions of their child's QOL (Class I; Level of Evidence C).
3. The paediatric cardiology provider should encourage discussion of parental understanding of their child's disease and concerns in relation to future goals (illness management, education, and career) (Class I; Level of Evidence C).
4. The paediatric cardiology provider should be non-judgmental and empathetic when acknowledging fears<sup>70</sup> (Class I; Level of Evidence C).

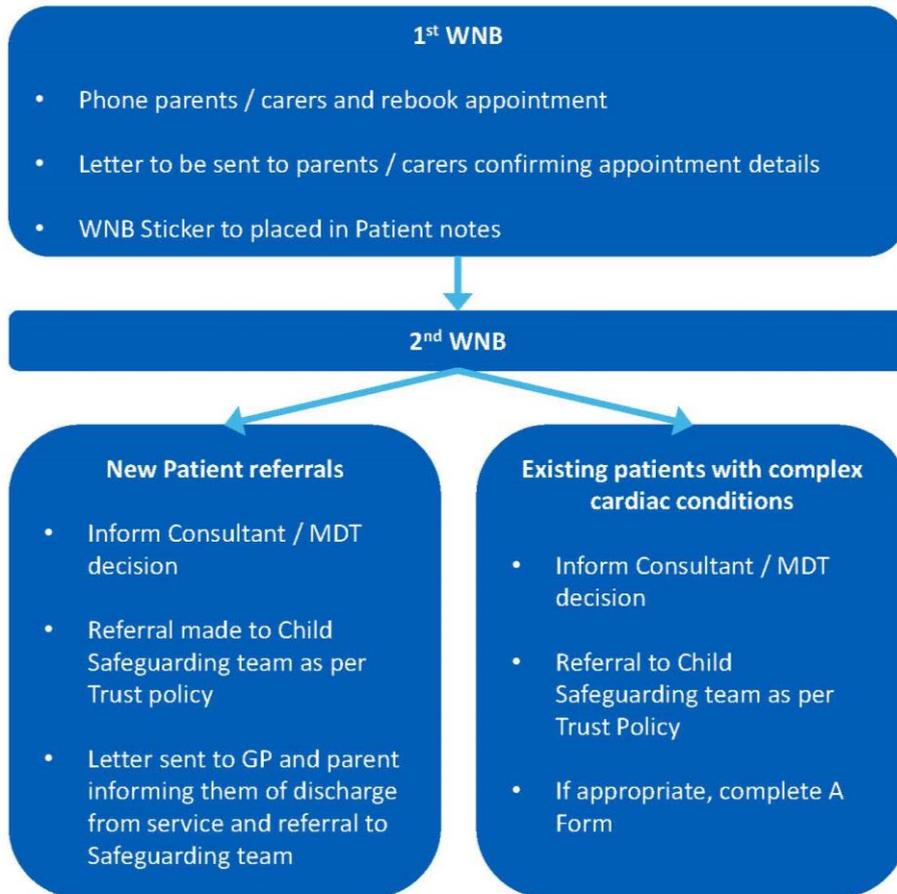
The adult congenital cardiology providers will respect the therapeutic plan that was established by their paediatric cardiology colleagues and represent this in their communications with young patients and their families. However it must also be clear that the care of congenital heart patients evolves, and is a process of continual re-evaluation. Clear and tactful communication of this to patients is essential to maintain trust and sustain healthy life-long therapeutic relationships.

## References

Adult Congenital Heart Disease (ACHD) Specification National Health Service England 2016. <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-specification-adults.pdf>

Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011 Apr 5; 123(13):1454-85.  
<http://circ.ahajournals.org/content/123/13/1454.full.pdf>

## DNA / WNB Standard Operating Procedure - Paediatrics



### DNA / WNB Label for Notes

**DNA/WNB**

Pt details Correct    Yes    No

Date Last seen :

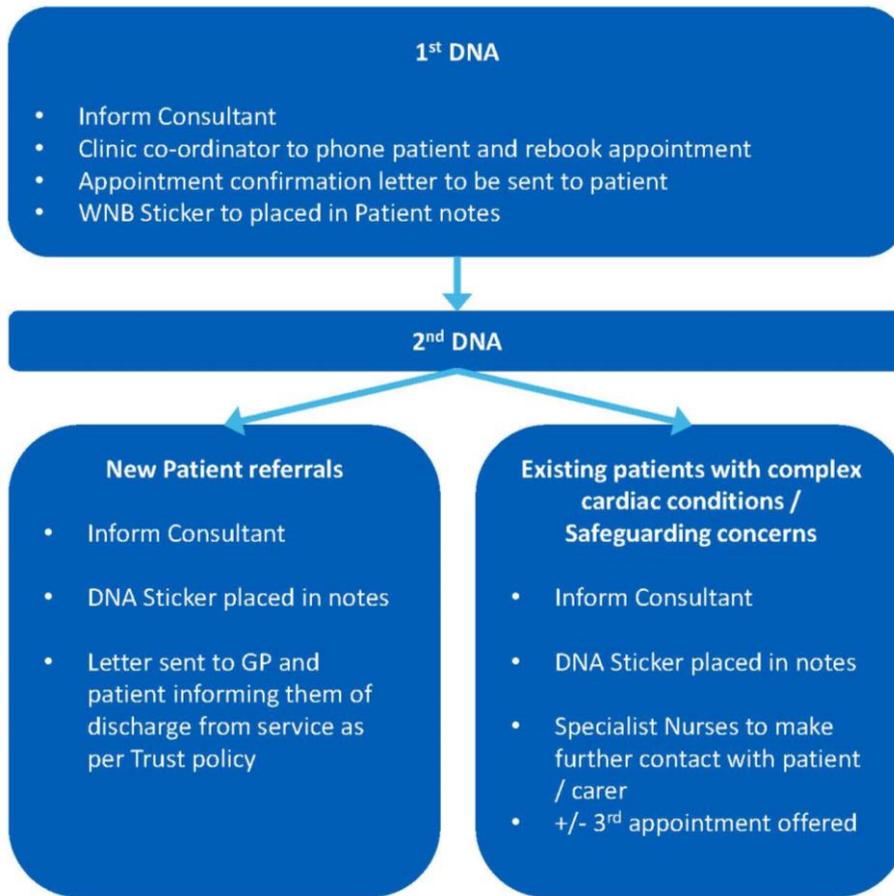
No of Previous DNA/WNB

Consultant Decision:

Rebook appointment            D/C back to GP

Ref to safeguarding team    CLN Aware

## DNA Standard Operating Procedure - Adults



### DNA / WNB Label for Notes

DNA/WNB	
Pt details Correct	Yes No
Date Last seen :	
No of Previous DNA/WNB	
Consultant Decision:	
Rebook appointment	D/C back to GP
Ref to safeguarding team	CLN Aware

## 15. Adult congenital cardiac care

Adult Congenital Cardiac patients may be referred into ACHD clinics either at EMCHC, EMCH Network clinics, or from other services including general adult cardiology, and by

GPs. Some will be referred from other specialities e.g. clinical genetics. Depending on the centre, these will initially be reviewed / triaged by the local link Cardiologist or the visiting EMCHC cardiologist themselves.

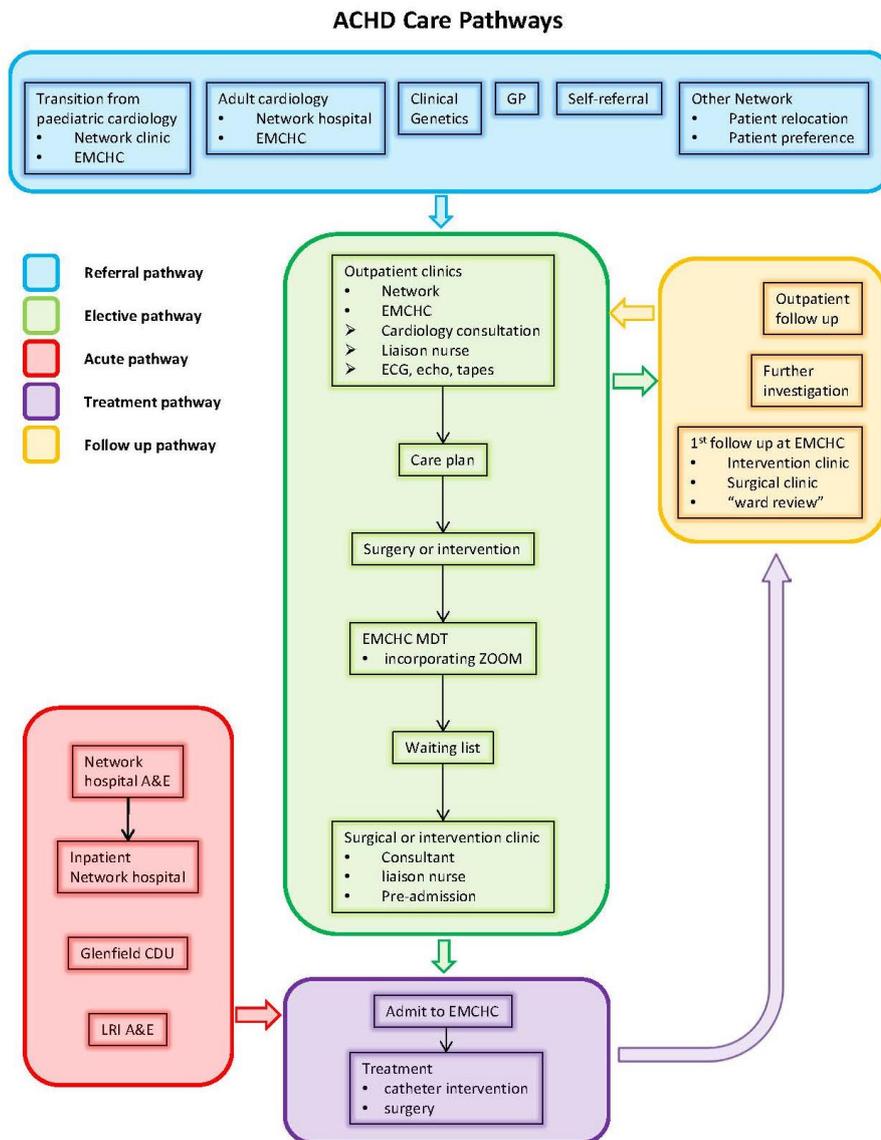
The local link cardiologist may undertake initial clinical review and echocardiography as required for these referrals and may take responsibility for prioritising and deciding which patients require tertiary cardiological review. **In principle any patient with significant congenital cardiac disease must have their case reviewed by (and usually see) a Congenital Cardiology Specialist at least once.** In practice this may mean an initial review of their case and investigations between the link cardiologist and the EMCHC ACHD consultant to provide advice and formulate a clear follow-up plan in either joint Network clinics, tertiary cardiac clinics or sometimes in the link cardiologist's own review clinics.

In a small number of centres, the initial review may be by a general cardiologist with access to technician-provided echocardiography, or they may be referred directly to the outreach ACHD clinics according to local expertise. Accordingly, the pathway for this group of patients would be:

- (a) Review and discharge if there is no significant pathology
- (b) Review and management locally without any additional involvement of the EMCHC cardiologists (minor cardiac disease only)
- (c) Review and management locally with an input from the EMCHC ACHD cardiologist - discussion and review of data (e.g. ECG, Echo, MRI / CTetc.)
- (d) Review and refer to EMCHC cardiologist
- (e) A one off review by the EMCHC cardiologists with further management by the local team
- (f) Follow up with EMCHC cardiologists in the Joint Network Cardiology Clinics
- (g) Follow up and management at the tertiary cardiac centre

All new patients with a cardiac problem needing follow up should be seen or discussed in detail with an ACHD cardiologist at least once, and a management and follow-up plan agreed.

Appendix 15 - Adult Congenital Cardiac Care



## 16. Palliative care

Children or Adults whose care is moving into end of life services are referred to their local palliative care services as geographically appropriate. Their Cardiac reviews should be made on an 'as required' basis.

## 17. Communication

For each patient, all correspondence should be simultaneously copied to their:

- (a) GP
- (b) (Child's) named paediatrician
- (c) PEC / link paediatrician / link cardiologist
- (d) Parents/primary carer/ patient
- (e) Any other teams as needed (e.g. other hospital specialists, Health visitor, Community team, social work, etc.)

Since this also constitutes the patient's on-going care plan, patients / parents are encouraged to keep copies of this in a file to constitute their hand held records. With time it is anticipated that patients will be offered these electronically. Patients and parents are already encouraged to keep multimedia copies of key investigations such as ECGs, medications etc.

## 18. Working with other relevant networks

The East Midlands Congenital Heart Network works closely with, and is reliant upon, a number of other clinical networks to ensure seamless care as close to home as possible. These include:

## Maternity

A weekly obstetric cardiology clinic at LRI provides care to pregnant women with any and all cardiac conditions, including congenital heart disease. The service caters for the local population and receives referrals from across the East Midlands as required. The East Midlands Maternal Medicine Network cardiology subgroup meets online each month to provide support, advice and care planning for higher risk cardiac patients.

## Neonatal and neonatal transport

EMCHC is part of the East Midlands Neonatal Operational Delivery Network and conforms to the care pathways designated. The underlying aim of the care pathways is to support the aim of the Network, and East and West Midlands specialised commissioning teams: namely to provide a neonatal service that ensures that mothers and babies are able to access the best and most appropriate level of care at the right place and at the right time, and as close to home as possible. This is underpinned by a focus on clinical discussions, agreement and monitoring. These pathways detail the clinical thresholds that are expected to be used in order to guide care and to clarify when discussions should take place.

Transport is provided by the [CenTre Neonatal Transport team](#)

**CenTre Transport's acute referral pathway can be found at the below link:**

<https://www.centroneonataltransport.nhs.uk/healthcare-professionals/refer-to-centre/acute-referral/>

**CenTre Transport's repatriation referral (non-emergency) pathway can be found at the below link:**

<https://www.centroneonataltransport.nhs.uk/healthcare-professionals/refer-to-centre/repatriation-referral/>

## Intensive care

Paediatric Intensive Care (PIC) in Leicester is currently run as a 'single unit in two buildings', now on the same (LRI) hospital site. Paediatric Cardiac and ECMO Intensive

Care is provided in the new and purpose built Cardiac PIC Unit (CPICU) in the Kensington building, (12 beds, current 8 staffed and funded) where it is co-located with paediatric cardiology/ cardiac surgery as well as neonatal intensive care and complex maternity services. The remaining, general intensive care services (6 beds staffed & funded) are on Level 4 Balmoral building in the CICU, with there are also 6 flexible HDU (level 2 Critical Care) beds adjacent on Ward 12. These services are therefore co-located with Children's ED and the rest of UHL's children's services and form the Leicester Childrens' Hospital. The ethos of a single service between Balmoral and Kensington is practically reinforced by close staff links at all levels. The Paediatric intensive care consultants provide 24/7 cover for both units, including resident consultant cover for EMCHC when required. Resident middle grade cover is provided by PICU registrars who are part of the paediatric middle grade rota for the East Midlands Training Rotation, ICU and ECMO Fellows, and both established, and trainee PIC Advanced Care Practitioners. A rotation for nursing staff through both units is well established.

The Paediatric component of the HeartLink ECMO Centre is also accommodated on CPICU and works closely with the CPICU team as well as the rest of the ECMO team working at Glenfield Hospital, forming one of three supra-regional ECMO centres in England undertaking neonatal, paediatric and adult ECMO. This service also retrieves neonates and children for ECMO from throughout England and Wales, either by road or by helicopter in conjunction with the Children's Air Ambulance. The Glenfield Hospital site has a dedicated helicopter pad.

## **Paediatric Intensive Care pathway: Admission & discharge criteria to CPICU & PICU**

### **Introduction & scope**

The following document provides a framework for all admissions and discharges to the Paediatric Intensive Care Unit (PICU) and the Cardiac Paediatric Intensive Care Unit (CPICU). This document only applies to patients admitted or discharged from PICU or

CPICU. The document should also apply to inter-unit transfers except where these are covered by the relevant CoMET guidance.

## Admission criteria

- All admissions to CPICU/PICU must be approved by the duty PICU Consultant.
- All admissions must have an admitting parent specialty Consultant
- Referrals to CPICU / PICU should be Consultant to Consultant when at all possible.

## Discharge criteria

- All discharges from CPICU/ PICU must be approved by the duty PICU consultant
- The parent specialty team/Consultant should be informed of the discharge
- All patients should be accompanied by a discharge summary, which should be verified by the Consultant within 24 hours
- The potential discharges should be identified at each ward round.
- Children will be identified by the PICU team as approaching “ready for discharge” status. (08:30h, 16:00h, and 20:30 h).
- Patients in the CPICU/PICU should be evaluated and considered for discharge based on the reversal of the disease process or resolution of the unstable physiologic condition that prompted admission to the unit. Suitable area for transfer (HDU/ Single room/ Ward) will be identified as per their clinical requirement.

## Suitability for transfer/discharge will be based on the following:

1. Stable haemodynamic parameters.
2. Stable respiratory status (patient extubated with stable blood gases) and airway patency.
3. Minimal oxygen requirements that do not exceed ward or HDU guidelines
4. Intravenous inotropic support, vasodilators, and antiarrhythmic drugs are no longer required or, when applicable, low/established doses of these medications can be administered safely in otherwise stable patients in a ward or HDU.
5. Cardiac dysrhythmias are controlled.

6. Neurologic stability with control of seizures.
7. Chronically mechanically ventilated patients whose critical illness has been reversed or resolved and who are otherwise stable may be discharged to a ward or to HDU if they continue to need the same level of respiratory support as before while they were at home.
8. Routine peritoneal or haemodialysis with resolution of critical illness not exceeding ward guidelines.
9. The health care team and the patient's family, after careful assessment, determine that there is no benefit in keeping the child in the CPICU / PICU or that the course of treatment is medically futile.

### Categories of discharge

- **Category 1 Routine.** Critical Care has a least one available bed. Patients will be discharged within 4 hours.
- **Category 2 Urgent.** Critical care areas have no available space i.e. reached capacity. Patients will be discharged within 2 hours
- **Category 3 Time Critical\*.** Critical Care has no available space and a critically ill patient requires immediate admission. Patient will be discharged as quickly as possible.

\*This situation is not desirable and may result in a compromise to patient safety.

### Further considerations:

ALL discharge summaries should be reviewed and signed by the Duty Consultant prior to discharge. If this is not possible they should be presented to the Duty Consultant within 25 hrs.

Discharge Summaries should be started by the night shift person and then completed after the Consultant Ward round.

Discharges should ensure the management plan is communicated clearly and child protection procedures or concerns must be specifically detailed.

It is a rare occurrence for a child to be discharged home straight from CICU/CPICU and should only be done with the specific approval of the duty PIC Consultant and Parent Specialty team.

The final decision to discharge should be confirmed by the CICU/CPICU Duty Consultant and Parent Specialty team.

### **Discharge procedure:**

Timing of patient discharge from critical care impacts on the outcome of the patient. Poor planning may result in disruption of care, delayed recovery and high readmission rates. It has been shown that discharge at night increases patient mortality. It has been recommended that transfer from critical care areas to the general ward between 20:00 and 07:00 should be avoided and documented as an adverse event if it occurs.

### **When discharging to another Ward:**

- Inform the Bed Co-ordinator of the discharge
- Inform Parent Specialty team of imminent discharge
- Complete the Discharge Summary
- Print Discharge Summary letter to accompany patient ensure signed by Consultant. Copy to the GP and referring hospital.
- Perform clinical review & early warning score immediately prior to discharge to confirm suitability
- PICU Nurse to handover to Ward Nurse

### **When discharging to another hospital:**

- Discuss with PIC Consultant and Parent Specialty team
- Inform PIC Nurse in Charge of anticipated need for transfer arrangements
- Inform accepting hospital Consultant
- Inform GP when transfer is to a hospice
- Inform accepting Ward Nurse in Charge
- Complete the Discharge Summary and ensure plans are clearly documented especially drain/central line removal

- Print Discharge Summary letter to accompany patient, ensure signed off by Consultant. Copy to the GP and referring hospital.
- Perform clinical review & early warning score immediately prior to discharge to confirm suitability
- Appropriate transfer team/nurse to accompany patient

The discharge of any patient from critical care involves planning however it is especially important to plan the discharge of long term or complex patients. Defining this group is difficult but should include all patients who have required Critical Care for greater than 2 weeks. Patients, their relatives and ward staff all need time to prepare for the discharge. Specific needs must be identified as soon as practical. Specialist services will need time to co-ordinate all aspects required for continuing care. This may take several days but the process should start before they are ready for discharge to ensure that a timely discharge from Critical Care.

### **Access to regional specialist services**

If a Specialist Service is commissioned in the Critical Care unit, it may be necessary to discharge patients to another critical care unit if they are not able to transition from critical care if the Specialist Service is no longer required. It is essential that regional specialist services are protected by avoiding any undue delay in discharge.

The possibility of discharge to another critical care facility needs not only agreement between the PICU Consultant but also agreement of the referring team in the tertiary centre and in the non-specialist unit. The patient's requirements are paramount to any change of facility.

## **Roles & responsibilities**

### **Medical Staff**

The final decision that a patient is fit for discharge/step down from critical care remains with the Critical Care Consultant. It is essential that the parent team (or their representative out of hours) is aware of all discharges.

## Nursing staff

It is the nursing staff's responsibility to ensure a safe and timely discharge of a patient from critical care areas once a bed has been identified. Unless there is an immediate threat to capacity on the critical care unit, discharges must not occur within the hours of 20:00 and 07:00. They must also ensure all documentation is complete to accompany the patient. For patients with complex needs and those classed as long-term patients, the Nurse in Charge of the receiving area must ensure that a face to face handover has been obtained whilst in the critical care unit.

## Bed Co-ordinator

It is the responsibility of the bed co-ordinator to ensure identification of an appropriate bed in conjunction with key stakeholders and within the timescale appropriate for the capacity of the critical care area. Patients should be cared for in the most appropriate setting and maximise availability of critical care capacity.

## Handover of care

The discharging team and the receiving team both have a responsibility to ensure the appropriate care of the patient being discharged. They should ensure:

- There is continuity of care facilitated by a formal structured handover of care from critical care area staff to ward staff (including both medical and nursing staff), supported by a written plan.
- That the receiving ward, with support from critical care if required, can deliver the agreed plan.

When patients are transferred to the general ward from a critical care area, they and their parents/carers should be offered information about their condition and encouraged to actively participate in decisions that relate to their recovery. The information should be tailored to individual circumstances.

## A structured handover must include:

- A summary of the critical care stay, including diagnosis and treatment and a full history of any long term and complex needs the child may have.
- A monitoring and investigation plan

- An escalation plan should deterioration of the child occur
- A plan for on-going treatment, including drugs and therapies, nutrition plan, infection status and any agreed limitations of treatment.
- Physical and rehabilitation needs

It is essential to give a detailed review of medication. Treatment to be reviewed or stopped must be clearly identified, as must the timing. Long term medications must be also considered. If these have been changed or not yet restarted this must be documented.

If there are any variations or changes to any part of the discharge plan, this should be clearly documented in the medical notes.

## Paediatric Critical Care Transport

EMCHC works closely with the Children's Medical Emergency Transport (CoMET) Service. Commissioned in 2017, the service provides:

- An acute critical care transport team operating 24/7/52 with capacity to advise on the management of critically ill children who present to an East Midlands Hospital, stabilise them and transport them to an appropriate Paediatric Cardiac Centre (PCC) facility, in line with NHS England Standards and recognised best practice. CoMET Clinicians work closely with Cardiologists and Surgeons from EMCHC as needed, to provide expert advice, through use of conference calls and a dedicated call handling service,
- A repatriation team operating weekdays and during daytime hours only, to safely transport patients to or from PCC facilities, where the level of dependency does not require the full transport service. This will most commonly be 'back transfers' to the referring hospital at the end of an episode of critical illness. The purpose of this service is to enable the most efficient use of expensive and pressurised PCC beds, to deliver care to patients in the most appropriate surroundings, and as close to home as

possible. This includes the transfer of patient from EMCHC to level 2 units or paediatric wards.

- Outreach advice and training to East Midlands hospitals in the initial care and stabilisation of acutely ill children; recognising that this improves outcomes and may reduce the need for intensive care admission. This service is provided in line with NHS England Standards and recognised best practice.

The transport team undertake acute transfers, Level 3 repatriations to intensive care facilities nearer the patient's home where appropriate and support level 2 transfers where necessary. Much transport team time is spent providing advice on resuscitation and stabilisation, managing referral logistics and supporting DGHs with advice around non-PIC transfer cases, as well as in-house and outreach training.

**The CoMET referral process and referral form can be found at the below link:**

<https://www.eastmidlandscomettransport.nhs.uk/medical-professionals/referral-process>

Most ECMO Transports are provided directly by the ECMO team itself.

## Paediatric community services

Community paediatric referral pathways are individual to each Network CCG and will vary according to them. Local centres will be expected to adhere to these pathways to ensure all children with complex needs requiring community paediatric support are able to access this appropriately.

## For adult ICU admissions, there are three EMCHC patient groups:

1. Planned post-operative admissions. These should follow the current booking process for adult cardiac surgery. In case of limited availability of ICU beds, a discussion to agree on clinical prioritisation should take place between operating surgeons prior to theatre cases starting.
2. Inpatient deterioration; Request for AICU review of inpatients should be by consultant to consultant referral whenever possible, but in emergencies the AICU specialist trainee on call should be contacted.

3. Requests for inter-hospital transfer to AICU should be referred to the duty AICU consultant by the parent speciality consultant.

## 19. Clinical governance

### Joint Cardiology Clinics

These require:

(a) **Availability** of a PEC (paediatrician with expertise in cardiology) or link paediatrician or Link Adult Cardiologist who:

1. Acts as a focus for correspondence and dissemination of changes in practice / care
2. Support links with and request for investigations from the local heart investigation department
3. Supports cardiology services locally

(b) **Infrastructure**

1. Sufficient nursing support to record and plot height, weight, BP and oxygen saturations for each patient (adult or child) and support the visiting team in the clinic
2. Minimum of ECG and current era cardiac ultrasound facilities available in the clinic, with facilities for electronic image storage and image transfer either on disc, or preferably via PACS/IEP or telemedicine.
3. Ability of the local Heart Investigation Unit to support certain cardiac monitoring procedures in adults and children (principally Holter monitoring / event recorders +/- exercise testing).

(c) **Frequency**

This will vary according to population base but needs to accommodate targets for seeing new referrals as well as maintaining acceptable planned follow-up intervals and

accommodating repatriation of patients back from tertiary centre after interventions. Additional clinics to the current complement may be added as required.

(d) **Funding**

SLA for attendance and transport costs for Consultant from EMCHC + cardiac nurse specialist.

## 20. Continuing professional development & validation of existing clinicians

It is vital that for such a service to continue to develop and maintain high quality care, the interests of the clinicians should be considered. Paediatricians who are coordinating the service should feel comfortable with the level of activity that they are expected to provide and it would be natural to expect different levels of activities being provided based on the experience, and interest of the clinician. The clinician must be supported by the local paediatric team and also the cardiologists at the tertiary centre.

Special Interest Cardiology Paediatricians are expected to have designated time within their job plans for a sessional commitment to cardiology (ideally a minimum of 2 Direct Clinical Care PAs a week, often more will be needed). This is to facilitate clinics but also MDT attendance (in person or remotely) and to complete related audit and administrative activities. It is suggested that they maintain a log of their activity to ensure a minimal level of activity. Newly appointed consultants will be expected to have achieved the RCPCH SPIN module in Cardiology as part of their CCT. It is also expected that their on-going clinical work is regularly reviewed with their EMCHC cardiologist(s) in keeping with the principles of clinical governance, revalidation and in keeping with guidelines from the GMC and the BCCA outreach guide and role descriptions (currently being updated by the BCCA and PECSiG organisations).

Link ACHD Cardiologists should have designated time within their job plans (ideally a minimum of 2 Direct Clinical Care PAs a week, often more will be needed). This is to

facilitate clinics but also MDT attendance (in person or remotely) and to complete related audit and administrative activities. It is suggested that they maintain a log of their activity to ensure a minimal level of activity. Newly appointed consultants will have achieved obligatory curriculum training in ACHD as part of their general cardiology training. EMCHC acknowledges that there is a severe shortage of cardiologists with more extended training in ACHD and that a degree of 'on the job' learning may also be required. This will occur as part of the joint clinic process, with regular communication with and support from their outreach EMCHC Cardiologist. It is also expected that their on-going clinical work is regularly reviewed with their EMCHC cardiologist(s) in keeping with the principles of clinical governance, revalidation and in keeping with guidelines from the GMC.

## 21. Education and Training / CPD

The EMCHC is committed to a holistic approach to cardiology training, and development of this service for staff and service users by providing on-going formal training, CPD and clinical governance for all health professionals involved in the provision of paediatric and adult congenital cardiology services. We welcome participation in the weekly paediatric cardiac MDTs and audit / QUICKA meetings at EMCHC along with regular network training days. Our physiologists also provide on-going echo training and support for our network technicians. We provide local fetal cardiac training and continue to further develop multidisciplinary educational programmes around our referral region. This is additionally facilitated by our new Zoom video conferencing and telemedicine facilities and will be aided by local investment in this as well.

The Network Lead Nurse will lead the education programme for nursing staff across the Network. Nurse educators are in post within EMCHC, and where possible a link nurse will be identified in each Network centre and they will be offered competency based training, mentored and supported by one of the Cardiac Nurse Specialist team.

## 22. East Midlands Congenital Heart Centre contact details

### Website

East Midlands Congenital Heart Network ([emchnetwork.nhs.uk](http://emchnetwork.nhs.uk))

### Adult Congenital Heart Service (ACHD) Office hours (9am-5pm)

- Secretaries by phone: 0116 250 2530
- Specialist nurses by phone: 0116 250 2887
- Specialist nurses by email:  
[chris.thornborough@uhl-tr.nhs.uk](mailto:chris.thornborough@uhl-tr.nhs.uk)  
[emma.sparks@uhl-tr.nhs.uk](mailto:emma.sparks@uhl-tr.nhs.uk)  
[nithisha.varghese@uhl-tr.nhs.uk](mailto:nithisha.varghese@uhl-tr.nhs.uk)  
[jincy.thomasvadayil@uhl-tr.nhs.uk](mailto:jincy.thomasvadayil@uhl-tr.nhs.uk)  
[hollie.cook@uhl-tr.nhs.uk](mailto:hollie.cook@uhl-tr.nhs.uk)

### Children's Cardiac Nurse Specialist Service Office hours (9am-5pm)

- Secretaries by phone: 0116 250 2975
- Specialist nurses by phone: 0116 258 3338
- Specialist nurses by email:  
[andrea.gray@uhl-tr.nhs.uk](mailto:andrea.gray@uhl-tr.nhs.uk)  
[sharon.bowcutt@uhl-tr.nhs.uk](mailto:sharon.bowcutt@uhl-tr.nhs.uk)  
[linda.ohare@uhl-tr.nhs.uk](mailto:linda.ohare@uhl-tr.nhs.uk)  
[tricia.martin@uhl-tr.nhs.uk](mailto:tricia.martin@uhl-tr.nhs.uk)  
[nicola.holdback@uhl-tr.nhs.uk](mailto:nicola.holdback@uhl-tr.nhs.uk)  
[catherine.simon@uhl-tr.nhs.uk](mailto:catherine.simon@uhl-tr.nhs.uk)  
[james.brown@uhl-tr.nhs.uk](mailto:james.brown@uhl-tr.nhs.uk)

## Doctors

via UHL switchboard on 0300 303 1573 then ask for the ACHD consultant on-call

## Out of hours

via UHL switchboard: 0300 303 1573

- ask for cardiology registrar on-call (who may then escalate to ACHD consultant on-call)
- Consultant to Consultant referral: ask for the Adult Congenital Heart Disease (ACHD) consultant on-call

## 23. Abbreviations and definitions

### Abbreviation

A&E

ACHD

ACP

ACR

AICU

ANNB

ANNP

APLS

APTT

BCCA

BP

### Definition

Accident and Emergency

Adult Congenital Heart Disease

Advanced Clinical Practitioners

Urine albumin to creatinine ratio

Adult Intensive Care Unit

Antenatal and Newborn Screening

Advanced Neonatal Nurse Practitioner

Advanced Paediatric Life Support

Activated Partial Thromboplastin Clotting Time

British Congenital Cardiac Association

Blood Pressure

<b>BSE</b>	Bovine spongiform encephalopathy
<b>BT shunts</b>	Blalock-Thomas-Tausig shunt
<b>CCT</b>	Certificate of Completion of Training
<b>CD</b>	Controlled Drugs
<b>CenTre</b>	CenTre Neonatal Transport Service
<b>CHD</b>	Congenital Heart Disease
<b>CICU</b>	Children's Intensive Care Unit
<b>CMG</b>	Clinical Management Group
<b>CMV</b>	Cytomegalovirus
<b>CNN</b>	Central Newborn Network
<b>CoMET</b>	Children's Medical Emergency Transport Service
<b>CPAP</b>	Continuous positive airway pressure
<b>CPD</b>	Continual Professional Development
<b>CRP</b>	C-reactive protein
<b>CT</b>	Computerised Tomography
<b>CVL</b>	Central Venous Line
<b>CXR</b>	Chest X Ray
<b>DGH</b>	District General Hospital
<b>DNA</b>	Did Not Attend
<b>EAE</b>	Experimental autoimmune encephalomyelitis
<b>ECG</b>	Electro Cardiograph

