

# Document Control

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<b>Stakeholders Consulted (list all)</b> <ul style="list-style-type: none"> <li>&gt; Dr Sarah Vause (Consultant in Fetal and Maternal Medicine, St Mary's Hospital MFT)</li> <li>&gt; Dr Zora Castling (Consultant Obstetrician and fetal Medicine, Liverpool Women's Hospital)</li> </ul>			
<b>Approved By: ACHD Ratification Task &amp; Finish Group on behalf of the North West CHD Network Board</b>			

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# Adult Congenital Heart Disease (ACHD) Referral Pathway

Date: 30/11/2022

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Clinical Lead)



## Contents

Target Audience.....	4
Patients Affected.....	4
Non-Congenital Heart Disease Patients.....	4
Referral Guidelines.....	4
List of ACHD Clinics across the North West of England and North Wales (Table 1) .....	6
How to Refer.....	7
Who to Contact.....	8
Cardiac Maternity Service (Table 2) .....	8
ACHD Referral Pathway (Diagram 1) .....	10
Patient Suspected of Having Pulmonary Hypertension Secondary to ACHD (ACHD-PH).....	10
References.....	11



## Target Audience

Physicians or Nurses within the North West, North Wales and the Isle of Man Operational Delivery Network.

## Patients affected

Patients  $\geq 18$  years of age with a new diagnosis of congenital heart disease or patients under existing follow up in paediatric cardiology transitioning to adult congenital cardiology follow up.

## Non-Congenital Heart Disease Patients

There are patients within the regional paediatric cardiology service who may require follow up by other specialist adult cardiology clinics for example:

- Inherited Cardiac Conditions (ICC)
- Heart failure
- Valve surveillance clinics

This includes patients with a history of Kawasaki syndrome, dilated cardiomyopathy or myocarditis; inherited cardiac conditions e.g. hypertrophic cardiomyopathy or channelopathies and those with a history of rheumatic fever. The referral pathway for these patients lies outside this current guideline.

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All patients under regular paediatric cardiology follow up with a diagnosis of congenital heart disease should be referred for follow up in the adult congenital cardiology service on at least one occasion for an initial assessment. Follow up will be determined following initial review.

Most patients with congenital heart disease require lifelong follow up. Some, however, may be discharged, or it may be more appropriate to be followed up by local cardiology services with advice as required. Some patients may already be followed up in clinics where there is joint care being provided. Below is guidance on what conditions can be discharged or managed centrally or locally:

## Referral Guidelines

Patients who may be discharged after an initial ACHD review:

- > Atrial septal defect (ASD)
  - > Early surgical repair
  - > No residual defect
  - > Normal cardiac size
  - > Normal function

- > Normal ECG
- > **Ventricular septal defect (VSD)**
  - > Early surgical closure or spontaneous closure
  - > Normal conduction on the ECG
- > **Patients with a Patent Foramen Ovale (PFO)**
- > **Patients with a Patent Ductus Arteriosus (PDA)**
  - > With device closure or coiling

**Patients who could be followed locally by acquired cardiology with return referral if needed or joint care:**

- > Small restrictive ventricular septal defect (peri-membranous or muscular)
- > Small atrial septal defect (shunt <1.5:1)
- > Mild pulmonary stenosis or pulmonary regurgitation
- > Bicuspid aortic valve with mild stenosis and/or regurgitation and no aortopathy
- > Mild mitral regurgitation

**Patients who can be managed jointly in a peripheral clinic with periodic review by an ACHD specialist:**

- > Late atrial septal defect surgical repair (adult) or device closure (device size >24mm)
- > Atrioventricular septal defect with excellent repair
- > Valve replacements or post valvotomy
- > Tetralogy of Fallot with good repair <moderate pulmonary incompetence
- > Repaired coarctation of the aorta with excellent repair (simple coarctation)
- > Isolated coarctation of the aorta not requiring intervention and normotensive

**Patients who are best cared for by an ACHD cardiologist- centrally or locally with:**

- > A restrictive ventricular septal defect with aortic regurgitation
- > Atrioventricular septal defect with >moderate left or right atrioventricular valve regurgitation (LAVVR/RAVVR)
- > Tetralogy of Fallot with >moderate Pulmonary Regurgitation (PR)
- > Sub or supra-aortic stenosis
- > Ross procedure
- > Dysplastic aortic valve/Bicuspid Aortic Valve (BAV) with >moderate Aortic Incompetence (AI) or Aortic Stenosis (AS) +/-aortopathy
- > Complex coarctation
- > Truncus arteriosus
- > Shone's complex
- > Transposition of the great arteries (Mustard, Senning, Rastelli, Arterial Switch)
- > Pulmonary atresia with or without ventricular septal defect
- > Ebstein's anomaly
- > Fontan circulation

- > Unrepaired single ventricle physiology
- > ACHD-PH & Eisenmenger's syndrome

## List of ACHD Clinics across the North West of England and North Wales Table 1:

Hospital	Contact	Telephone Number
<b>Liverpool Heart &amp; Chest Hospital NHS Foundation Trust</b> Thomas Drive Liverpool L14 3PE	<b>ACHD Cardiologists:</b> Dr Reza Ashrafi (EP/Devices) Dr Damien Cullington (Clinical Lead) Dr Jaspal Dua Dr Sarah Elgamal (Imaging) Dr Petra Jenkins (PH) Dr Vasileios Papaioannou (PH) Dr Julia Jones	Switchboard: 0151 600 1616
	<b>Specialist Nurses - Adult Congenital Heart Disease</b>	Tel: 0151 254 3333 Mobile: 07542229889
<b>Manchester University NHS Foundation Trust,</b> Manchester Heart Centre, MRI, Oxford Road, Manchester, M13 9WL	<b>ACHD Cardiologists</b> Dr Damien Cullington (Clinical Lead), Dr Jaspal Dua Dr Petra Jenkins (PH) Dr Vasileios Papaioannou (PH and general ACHD) Dr Julia Jones	Switchboard: 0161 276 1234
	<b>Cardiologists with a special interest in ACHD</b> Professor Bernard Clarke	
	<b>Specialist Nurses - Adult Congenital Heart Disease</b>	0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse
<b>Manchester University NHS Foundation Trust,</b> Wythenshawe Hospital, Southmoor Road, Wythenshawe	<b>Consultant Cardiologist with an interest in ACHD</b> Dr Anita Macnab <b>ACHD Cardiologist</b> Dr Reza Ashrafi	Tel: 0161 998 7070

M23 9LT	<b>Specialist Nurses - Adult Congenital Heart Disease</b>	0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse
<b>Betws Cadwalader University Health Board –</b> Wrexham Maelor Hospital, Croesnewydd Road, Wrexham, LL13 7TD	<b>Consultant Cardiologist with an interest in ACHD</b> Dr Raj Thaman <b>ACHD Cardiologist</b> Dr Petra Jenkins (Based at LHCH)	Tel: 01978 727 801
	Nicola Coates <b>Specialist Nurse - Adult Congenital Heart Disease</b>	Tel: 01978 727 801
<b>Blackpool Teaching Hospitals NHS Foundation Trust,</b> Blackpool Victoria Hospital, Whinney Heys Road, Blackpool, FY3 8NR	<b>ACHD Cardiologist</b> Dr Vasileios Papaoiannou (Refer to LHCH FAO of Blackpool ACHD)	Tel: 0151 254 3350
	<b>Specialist Nurses – Adult Congenital Heart Disease</b> via the helpline at Liverpool Heart & Chest Hospital	Tel: 0151 254 3333

## How to refer

All new diagnoses of congenital heart disease should be referred in writing either generically to the 'Consultant ACHD Cardiologist' or specifically to a consultant member of the Level 1 team either centrally at Liverpool Heart and Chest NHS Foundation Trust or at the peripheral clinic that they visit. Patients will either then receive an appointment or advice will be given back to the referrer suggesting local follow up.

Patients who have been identified as being lost to follow up should be referred in writing either generically to the 'Consultant ACHD Cardiologist' or specifically to a consultant member of the Level 1 team either centrally at Liverpool Heart and Chest NHS Foundation Trust or at the peripheral clinic that they visit. Patients will either then receive an appointment or advice will be given back to the referrer suggesting local follow up.

For acute advice, the ACHD consultant on-call should be contacted via switchboard at Liverpool Heart and Chest NHS Foundation Trust on 0151 600 1616.



## Who to Contact

The ACHD on-call team are available for urgent advice twenty-four hours a day, seven days a week and can be contacted via the switchboard at Liverpool Heart and Chest NHS Trust on 0151 600 1616.

Dr Reza Ashrafi  
Dr Damien Cullington  
Dr Jaspal Dua  
Dr Sarah Elgamal  
Dr Petra Jenkins  
Dr Vasileios Papaioannou  
Dr Julia Jones

ACHD Specialist nursing team can be contacted Monday to Friday 8am to 6pm  
**07542229889**

Fiona Andrews  
Lisa Devitt  
Lorraine English  
Anna Harrison  
Sharon Hughes  
Julie Ollerhead  
Linsha George

## Cardiac Maternity Service

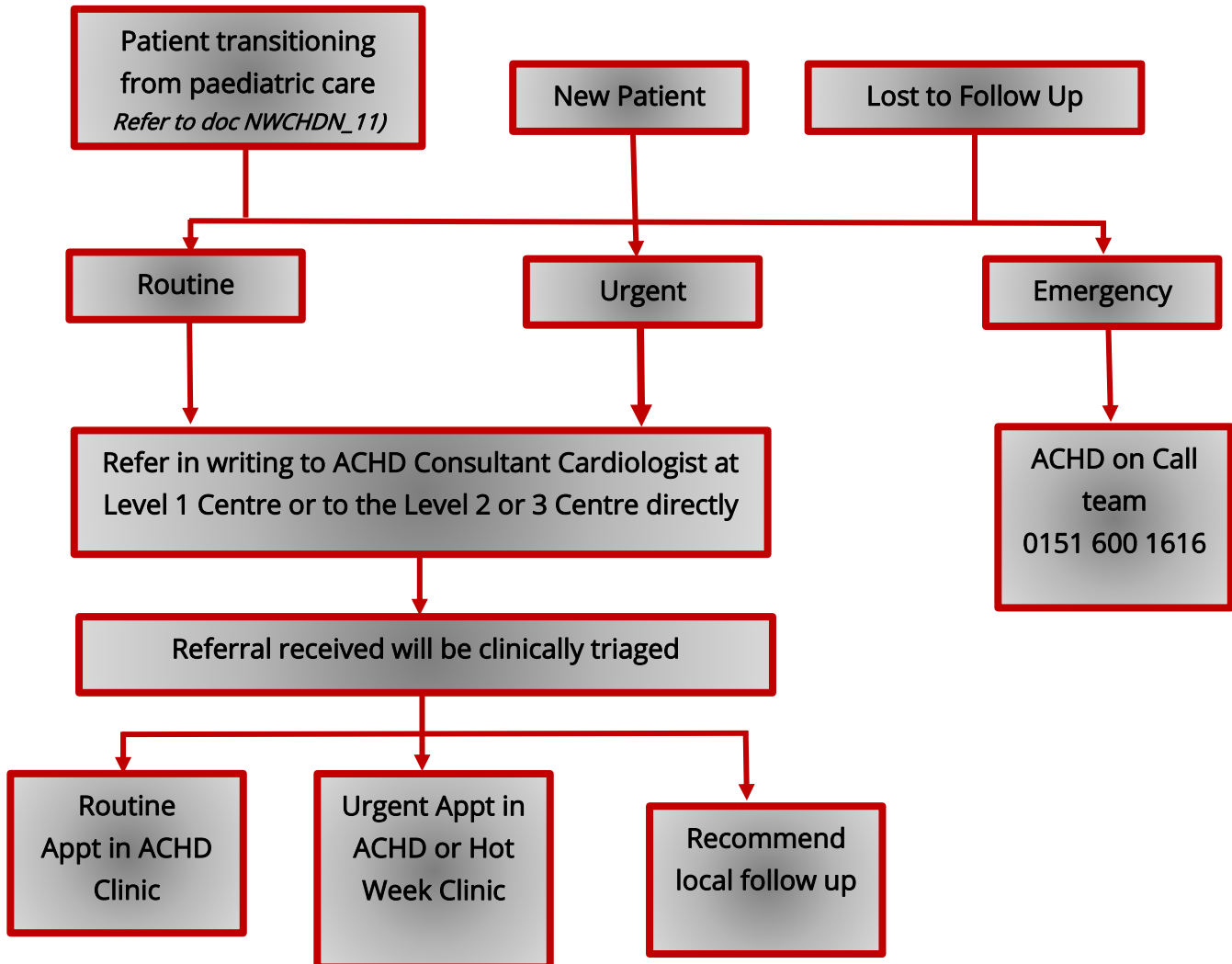
The Cardiac Maternity Service provides preconceptual, antenatal, intrapartum and postpartum care for women with all types of cardiac disease in pregnancy including congenital heart disease. Saint Mary's Hospital (part of MFT) is the North West Level 1 provider for maternity care for women with congenital heart disease, but with women being managed locally, when appropriate. Guidance regarding referrals is provided within the Greater Manchester and Eastern Cheshire Strategic Clinical Network 'Cardiac disease in pregnancy' guideline <https://www.england.nhs.uk/north-west/gmec-clinical-networks/our-networks/maternity/resources/>

Table 2: Contact details for Cardiac Maternity Service

Hospital	Contact	Telephone Number
<b>Manchester University NHS Foundation Trust,</b> Saint Mary's Hospital Oxford Road, Manchester, M13 9WL	<b>Obstetricians</b> Dr Sarah Vause Dr Anna Roberts Dr Sam Bonner	All consultants can be contacted via the MFT Switchboard: 0161 276 1234
	<b>Cardiologists</b> Professor Bernard Clarke Professor Bernard Keavney Dr Damien Cullington	Obstetric Cardiology Service Secretary: 0161 276 6426
	<b>ACHD Specialist Nurses - MRI</b>	0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse
<b>Liverpool Women's NHS Foundation Trust</b> Crown Street Liverpool L8 7SS	<b>Obstetricians</b> Dr Zora Castling Dr Naomi McGuiness	LWH Switch Board 0151 708 9988
	<b>Cardiologists</b> Dr Reza Ashrafi & Dr Damien Cullington Consultant Adult Congenital Cardiologists Liverpool Heart and Chest Hospital	LHCH Switchboard 0151 600 1616
	Dr Vishal Sharma Consultant Cardiologist Royal Liverpool University Hospital	The Royal Liverpool Switchboard 0151 706 2000
	<b>ACHD Specialist Nurses -</b> via the helpline at Liverpool Heart & Chest Hospital	Tel: 0151 254 3333

Diagram 1

## ACHD Referral Pathway



## Patient Suspected of Having Pulmonary Hypertension Secondary to ACHD (ACHD-PH)

Manchester Royal Infirmary is the designated level 2 centre for the provision of ACHD-PH care. There are shared care arrangements in place with Sheffield Pulmonary vascular Disease Unit (PVDU). This is relevant for ACHD patients only who require assessment at the ACHD-PH clinic. They can be referred directly to that service by writing to the two designated ACHD Cardiologists as outlined in table 1.

## References

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2014 PACES/HRS Expert Consensus Statement on the Recognition and Management of  
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Force for the management of adult congenital heart disease of the European Society of  
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