

Document Control

Title: Adult Congenital Heart Disease Referral Pathway			
Document Reference: NWCHDN_20			
Authors: <ul style="list-style-type: none"> > Dr Reza Ashrafi (ACHD/EP Consultant Cardiologist, LHCH NHS Foundation Trust). > Dr Damien Cullington (Clinical Lead and Network Co-Director, ACHD Consultant Cardiologist, LHCH NHS Foundation Trust). 		Lead Clinician: Dr Damien Cullington (Network Co-Director, ACHD Consultant Cardiologist, LHCH NHS Foundation Trust).	
Network: North West, North Wales and Isle of Man Congenital Heart Disease Operational Delivery Network			
Version	Date Issued	Status	Comment/ Change/ approval
V2.0	09/10/25	Draft	Sent to DC for review
V2.1	17/11/25	Draft	DC amended document and suggested addition of ESC guidelines as reference
V2	18/12/2025	FINAL	References updated
Main Contact: Dr Damien Cullington		Phone: 0151 600 1616 (via Secretary) Email: northwestchdnetwork@alderhey.nhs.uk	
Superseded Documents: Version 1 (30th November 2025)			
Issue Date: 12th January 2026		Review Date: January 2029	
Review Cycle: 3 years			
Stakeholders Consulted (list all)			
Approved By: ACHD Ratification Task & Finish Group on behalf of the North West CHD Network Board Date: 12th January 2026			
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Adult Congenital Heart Disease (ACHD) Referral Pathway v2

Date: 12th January 2026



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Target Audience

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

Patients affected

Patients ≥ 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.

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 right heart size
 - > Normal function
 - > Normal ECG

- > Small defect, a haemodynamically insignificant shunt and no RV volume loading (and aged >55 years)
- > **Ventricular septal defect (VSD)**
 - > Early surgical closure or spontaneous closure
 - > Normal conduction on the ECG
 - > Small, muscular VSD and haemodynamically insignificant (and aged >55 years)
- > **Patients with a patent foramen ovale (PFO)**
- > **Patients with mild pulmonary stenosis/regurgitation (and aged >55 years)**
- > **Patients with a Patent Ductus Arteriosus (PDA)**
 - > With device closure or coiling
 - > Without device closure and haemodynamically insignificant

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 (and aged <55 years)
- > Bicuspid aortic valve with mild stenosis and/or regurgitation and no aortopathy
- > Mild mitral regurgitation
- > Mild tricuspid regurgitation
- > Mild coarctation of the aorta (and no prior repair)

Patients who may 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 should receive regular care 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 (Manchester Royal Infirmary clinic)

List of ACHD Clinics across the Northwest of England and North Wales

Table 1:

Hospital	Contact	Telephone Number
Liverpool Heart & Chest Hospital NHS Foundation Trust Thomas Drive Liverpool L14 3PE	ACHD Cardiologists: Dr Reza Ashrafi (EP/Devices) Dr Damien Cullington (Clinical Lead) Dr Jaspal Dua Dr Sarah Elgamal (Imaging) Dr Petra Jenkins (PH) Dr Julia Jones Dr Vasileios Papaioannou (PH)	Switchboard: 0151 600 1616
	Specialist Nurses - Adult Congenital Heart Disease Anna Harrison (Lead nurse) Fiona Andrews Lisa Devitt Lorraine English Linsha George Sharon Hughes Julie Ollerhead	Tel: 0151 254 3333 Mobile: 07542229889
Manchester University NHS Foundation Trust, Manchester Heart Centre, MRI, Oxford Road, Manchester, M13 9WL	Visiting ACHD Cardiologists Dr Damien Cullington (Clinical Lead), Dr Jaspal Dua Dr Petra Jenkins (PH) Dr Vasileios Papaioannou (PH and general ACHD)	Switchboard: 0161 276 1234

	<p>Dr Julia Jones</p> <p>Cardiologists with a special interest in ACHD Professor Bernard Clarke</p>	
	<p>Specialist Nurses - Adult Congenital Heart Disease Laura Jole Melanie Menzies Kate Shammas</p>	<p>0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse</p>
<p>Manchester University NHS Foundation Trust, Wythenshawe Hospital, Southmoor Road, Wythenshawe M23 9LT</p>	<p>Consultant Cardiologist with an interest in ACHD Dr Anita Macnab Visiting ACHD Cardiologist Dr Reza Ashrafi</p>	<p>Tel: 0161 998 7070</p>
	<p>Specialist Nurses - Adult Congenital Heart Disease</p>	<p>0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse</p>
<p>Betws Cadwalader University Health Board – Wrexham Maelor Hospital, Croesnewydd Road, Wrexham, LL13 7TD</p>	<p>Consultant Cardiologist with an interest in ACHD Dr Raj Thaman Visiting ACHD Cardiologist Dr Petra Jenkins (Based at LHCH)</p>	<p>Tel: 01978 727 801</p>
	<p>Nicola Coates Specialist Nurse - Adult Congenital Heart Disease</p>	<p>Tel: 01978 727 801</p>
<p>Blackpool Teaching Hospitals NHS Foundation Trust, Blackpool Victoria Hospital, Whinney Heys Road, Blackpool, FY3 8NR</p>	<p>Visiting ACHD Cardiologists Dr Vasileios Papaoiannou Dr Julia Jones <i>(Refer to LHCH FAO of Blackpool ACHD)</i></p>	<p>Tel: 0151 254 3350</p>
	<p>Specialist Nurses – Adult Congenital Heart Disease via the helpline at Liverpool Heart & Chest Hospital</p>	<p>Tel: 0151 254 3333</p>

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 (Manchester Royal Infirmary; Wythenshawe Hospital; Blackpool Victoria Hospital or Wrexham Maelor Hospital). Patients will then either 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 consultant is available for urgent advice (for health care professionals) 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 (EP/Devices plus cardio-obstetrics)
Dr Damien Cullington (Clinical Lead, plus cardio-obstetrics)
Dr Jaspal Dua
Dr Sarah Elgamal
Dr Petra Jenkins
Dr Julia Jones
Dr Vasileios Papaioannou

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

Anna Harrison (Lead nurse)
Fiona Andrews
Lisa Devitt
Lorraine English
Linsha George

Sharon Hughes
Julie Ollerhead

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. St 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. Referrals to Liverpool Women's Hospital, St Mary's or Lancashire Teaching Hospital (Preston) are made via the North West Maternal Medicine Network website [Northwest Maternal Medicine Network for Safer Pregnancy](#)

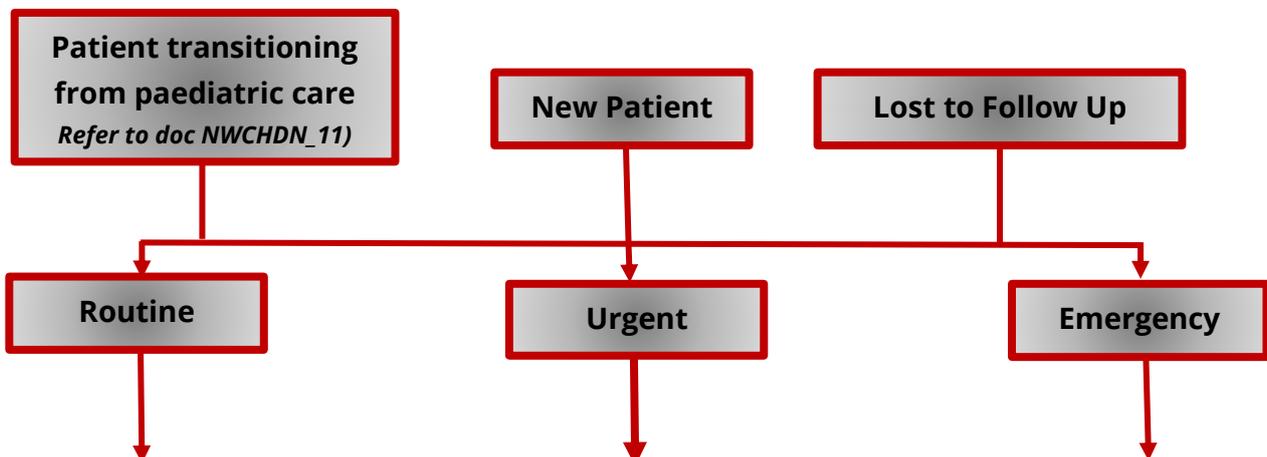
Table 2: Contact details for Cardiac Maternity Service

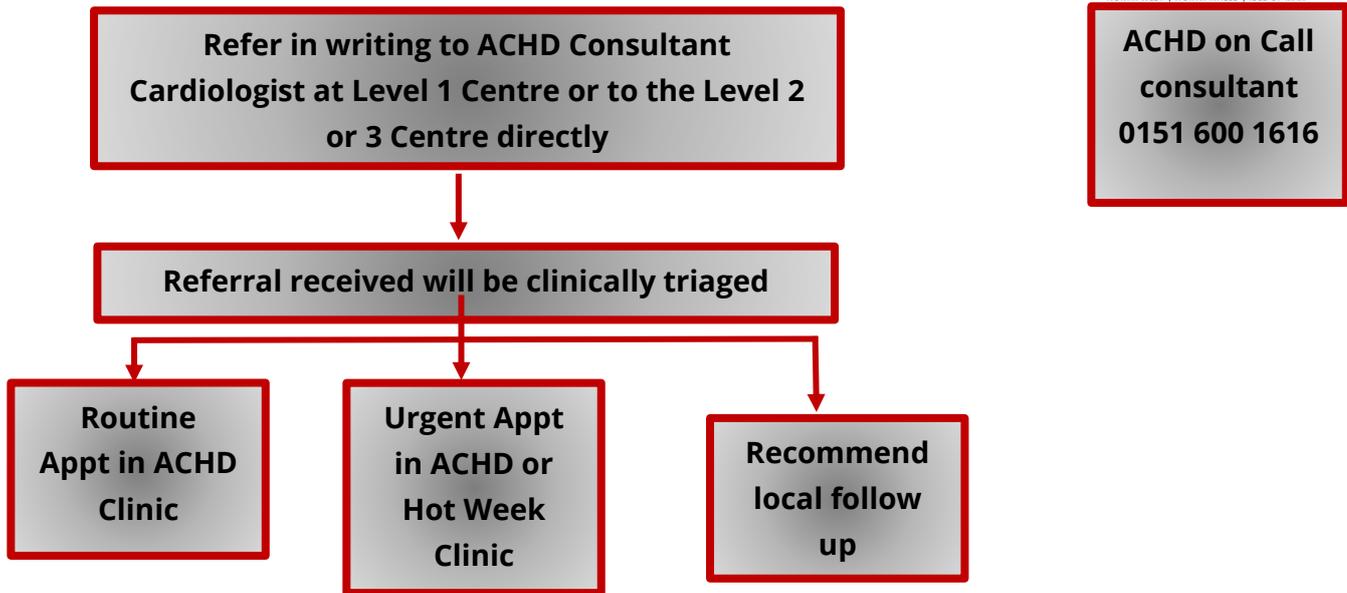
Hospital	Contact	Telephone Number
Manchester University NHS Foundation Trust, Saint Mary's Hospital Oxford Road, Manchester, M13 9WL	Consultant Obstetricians Dr Anna Roberts Dr Sam Bonner Consultant Cardiologists Professor Bernard Clarke Professor Bernard Keavney Dr Damien Cullington Dr Omar Asgar	All consultants can be contacted via the MFT Switchboard: 0161 276 1234 Obstetric Cardiology Service Secretary: 0161 276 6426
	ACHD Specialist Nurses - MRI	0161 276 1234 Bleep: 6994 Voicera: ask for ACHD Nurse
Liverpool Women's NHS Foundation Trust Crown Street Liverpool L8 7SS	Consultant Obstetricians Dr Naomi McGuinness Dr Louise Simcox Consultant Cardiologists Dr Reza Ashrafi & Dr Damien Cullington Consultant Adult Congenital Cardiologists Liverpool Heart and Chest Hospital	LWH Switch Board 0151 708 9988 LHCH Switchboard 0151 600 1616

	Dr Vishal Sharma Consultant Cardiologist Royal Liverpool University Hospital	The Royal Liverpool Switchboard 0151 706 2000
	ACHD Specialist Nurses – via the helpline at Liverpool Heart & Chest Hospital	Tel: 0151 254 3333

Diagram 1

ACHD Referral Pathway





Patient With Suspected 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

2018 AHA/ACC guidelines for the management of adults with congenital heart disease
http://www.onlinejacc.org/content/early/2018/08/09/j.jacc.2018.08.1029?_ga=2.60852132.9406661.1535710896-1058041045.1535710896

2014 AHA/ACC Guideline for the Management of Patients With Valvular Heart Disease
 A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines
<http://www.onlinejacc.org/content/63/22/e57>

2014 PACES/HRS Expert Consensus Statement on the Recognition and Management of Arrhythmias in Adult Congenital Heart Disease
[https://www.heartrhythmjournal.com/article/S1547-5271\(14\)00513-X/fulltext](https://www.heartrhythmjournal.com/article/S1547-5271(14)00513-X/fulltext)

2020 ESC Guidelines for the management of adult congenital heart disease: The Task Force for the management of adult congenital heart disease of the European Society of Cardiology (ESC)

<https://academic.oup.com/eurheartj/advance-article/doi/10.1093/eurheartj/ehaa554/5898606>

2017 ESC/EACTS Guidelines for the management of valvular heart disease

<https://academic.oup.com/eurheartj/article/38/36/2739/4095039#supplementary-data>

2018 ESC Scientific Document Group, Arrhythmias in congenital heart disease: a position paper of the European Heart Rhythm Association (EHRA), Association for European Paediatric and Congenital Cardiology (AEPC), and the European Society of Cardiology (ESC) Working Group on Grown-up Congenital heart disease, endorsed by HRS, PACES, APHRS, and SOLAECE

<https://academic.oup.com/europace/article/20/11/1719/4944677>

2025 ESC Guidelines for the management of cardiovascular diseases during pregnancy: The Task Force for the Management of Cardiovascular Diseases during Pregnancy of the European Society of Cardiology (ESC), European Heart Journal, Volume 46, Issue 43, 14 November 2025, Pages 4462–4568, <https://doi.org/10.1093/eurheartj/ehaf193>

<https://www.escardio.org/Guidelines/Clinical-Practice-Guidelines/CVD-and-Pregnancy>