

Clinical Guideline

# REGIONAL REFERRAL GUIDANCE ADULT PATIENTS WITH CONGENITAL HEART DISEASE IN SOUTH WEST ENGLAND

<b>SETTING</b>	South West England and South Wales
<b>GUIDELINE FOR</b>	Cardiology teams in South West England and South Wales hospitals
<b>PATIENT GROUP</b>	Adult patients with congenital heart disease

## GUIDANCE

**All patients** should be seen by an ACHD cardiologist at least once for initial assessment and decision on best pathway for follow-up. This will depend on the complexity (see Table) and the expertise of the local cardiologist. In general most patients with moderate and all patients with severe complexity should be seen in the joint clinic with the ACHD cardiologist.

Patients should be offered the option of having their care managed locally, given the extensive network of peripheral clinics offered by the Bristol ACHD centre. It should be noted, however, that specialist nurse input is not currently possible in all Level 3 centres.

New patients transferred from children's services should be seen in Young Adult Clinics, which take place once a year in each Level 3 centre with the ACHD cardiologist. They may choose to come to the Young Adult Clinic in Bristol.

The following patients can be discharged:

- Atrial septal defect with early surgical repair
- Small muscular ventricular septal defect
- Mild native pulmonary stenosis

### Classification of congenital heart disease complexity

#### MILD

- Isolated congenital aortic valve disease and bicuspid aortic disease
- Isolated congenital mitral valve disease (except parachute valve, cleft leaflet)
- Mild infundibular or supralvalvar pulmonary stenosis
- Isolated small ASD / perimembranous VSD or PDA
- Repaired secundum ASD (surgical or device) in adulthood
- Repaired sinus venosus ASD, VSD or PDA with no sequelae

#### MODERATE (repaired or unrepaired)

Atrioventricular septal defect  
Anomalous pulmonary venous drainage

- Anomalous coronary artery from PA or opposite sinus, coronary fistulae
- Unrepaired moderate-large ASD including sinus venosus ASD
- Unrepaired moderate PDA/VSD
- Moderate to severe RVOTO (including operated and branch PA stenosis)
- Tetralogy of Fallot
- Double chamber RV
- Coarctation of the aorta
- Ebstein's anomaly
- Subaortic and supra-aortic stenosis
- Ventricular septal defect with sequelae inc aortic regurgitation
- Marfan's syndrome, hereditary aortopathies, Turner's syndrome
- Sinus of Valsalva aneurysm/ TGA with arterial switch
- Post Ross operation

### SEVERE

- Any cyanotic ACHD
- Double outlet right ventricle
- Interrupted aortic arch
- Any univentricular heart
- Truncus arteriosus
- All transposition of the great arteries (except arterial switch)
- Pulmonary atresia (all forms)
- Fontan circulation
- Any CHD with pulmonary vascular disease (e.g. Eisenmenger physiology†)

†all patients with Eisenmenger physiology (or any with PH) should be referred to the BHI Pulmonary Hypertension Service, for consideration of pulmonary vasodilator therapy.

### List of Peripheral Clinics Carried out in South West England by ACHD Cardiologists

Location	Cardiologist Locally Responsible for ACHD	Visiting ACHD Cardiologist
Gloucester	Dr David Lindsay	Dr Stephanie Curtis
Swindon	Dr William McCrae	Dr Radwa Bedair
Taunton	Dr Mark Dayer	Dr Stephanie Curtis
Barnstaple	Dr Dushen Tharmaratnam Dr Chris Gibbs	Dr Radwa Bedair
Exeter	Dr Manish Gandhi Dr Alan Taylor	Dr Radwa Bedair
Torbay	Dr Catherine Blakemore	Dr Mark Turner
Truro	Dr Georgina Ooues	Dr Greg Szantho

**RELATED  
DOCUMENTS**

Clinical Protocols for Individual ACHD Lesions  
Regional Referral Pathway for Cardiac Disease in Pregnancy

**REFERENCES**

Baumgartner H et al. 2020 ESC Guidelines for the management of adult congenital heart disease. Eur Heart J. 2020 00, 1-83.

Stout et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease. Journal of the American College of Cardiology Aug 2018, 25255; DOI: 10.1016/j.jacc.2018.08.1029

**AUTHORISING  
BODY**

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**SAFETY**

None

**QUERIES**

**Bristol:** Contact any of the following via UHBristol switchboard – 0117 923 0000

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Dr G Szanthy, Consultant Cardiologist  
Dr M Turner, Consultant Cardiologist  
Dr R Bedair, Consultant Cardiologist

**Cardiff:** Specialist ACHD Team – Cardiff via UHWales switchboard - 029 2074 7747

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Dr DG Wilson  
ACHD Co-ordinator Elizabeth Corris – 02920 743 892  
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**South Wales:** Lead Local Health Board Cardiologists:

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