

Clinical Guideline

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

SETTING	South West England and South Wales
GUIDELINE FOR	Cardiology teams in South West England and South Wales hospitals
PATIENT GROUP	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 ideally will 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 surgical/device repair and no sequelae
- Small muscular ventricular septal defect
- Mild native pulmonary stenosis
- Mild non-progressive supra-aortic stenosis

Classification of congenital heart disease complexity

MILD

- Isolated congenital aortic valve disease
- Isolated congenital mitral valve disease
- Mild infundibular or supra-valvar 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, coronary fistulae
- Unrepaired moderate-large ASD including sinus venosus ASD
- Unrepaired PDA/VSD with haemodynamic consequences
- Moderate to severe RVOTO (including operated and branch PA stenosis)
- Tetralogy of Fallot
- Double chamber RV
- Coarctation of the aorta
- Subaortic and supra-aortic stenosis
- Ventricular septal defect with sequelae including aortic regurgitation
- Marfan's syndrome, hereditary aortopathies, Turner's syndrome
- Sinus of Valsalva aneurysm
- Transposition of the great arteries (TGA) with arterial switch
- Post Ross operation

SEVERE

- Any cyanotic ACHD
- Ebstein's anomaly
- Double outlet right ventricle
- Interrupted aortic arch
- Any univentricular heart or Fontan circulation
- Truncus arteriosus
- All TGA (unless arterial switch with mild residual lesions)
- Pulmonary atresia (all forms)
- 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

Appendix 1 – Evidence of Learning from

Incidents

The following table sets out any incidents/ cases which informed either the creation of this document or from which changes to the existing version have been made.

Incidents	Summary of Learning
n/a	

Table A

REFERENCES	<ul style="list-style-type: none"> 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, 735-1097. Canadian Adult Congenital Heart Network (www.cachnet.org)
RELATED DOCUMENTS AND PAGES	ClinicalGuidelineForCardiacDiseasePreExistingOrPre-1.pdf
AUTHORISING BODY	Cardiac Executive Group, Bristol Heart Institute
SAFETY	None
QUERIES AND CONTACT	<p>Bristol: Contact any of the following via UHBW switchboard – 0117 923 0000 Dr S Curtis Dr G Szanthy Dr M Turner Dr R Bedair ACHD Specialist Nurse Team 0117 342 6599</p> <p>Cardiff: via UHWales switchboard - 029 2074 7747 Dr S MacDonald Dr H Wallis Dr DG Wilson Dr N Masani ACHD Specialist Nurse Team 02920 744 580</p> <p>South Wales: Lead Local Health Board Cardiologists: Abertawe Bro Morgannwg LHB Dr H Wallis 01639 862049 Dr C Weston & Dr M Heatley 01792 205666 ext 30836 Aneurin Bevan LHB Dr P Campbell 01633 238863 Cwm Taf LH Dr C Williams 01443 443642 Hywel Dda LHB Dr H Wallis 01639 862049</p>
AUDIT REQUIREMENTS	Adherence to guideline will be audited periodically as part of ACHD departmental audit

Plan Elements	Plan Details
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The Dissemination Lead is:	Dr Stephanie Curtis
Is this document: A – replacing the same titled, expired SOP, B – replacing an alternative SOP, C – a new SOP:	A
If answer above is B: Alternative documentation this SOP will replace (if applicable):	
This document is to be disseminated to:	South West and South Wales Congenital Heart Network
Method of dissemination:	Email
Is Training required:	No

Document Change Control

Date of Version	Version Number	Lead for Revisions	Type of Revision	Description of Revision
Nov 2020	2	Consultant Cardiologist	Minor	Updated contacts and related documents Atrial septal defect with surgical"/device" repair "and no sequelae" added. "Mild non-progressive supra-aortic stenosis" added. Under Classification of complexity- SEVERE: "with mild residual lesions" added to All TGA (unless arterial switch)