NORTH EAST AND NORTH CUMBRIA
Congenital Heart Disease Network

Guideline for the follow-up of children with Congenital Heart Disease from > 6 months including transition to Adult Congenital Services

Document History

Title	Guideline for the follow-up of children with Congenital Heart Disease from > 6 months including transition to Adult Congenital Services
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Owner	NENC CHD Network Board
Approved by:	NUTH congenital heart disease clinical governance team
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Version Control	
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Aims

To provide consensus based guidance to ensure that, children with Congenital Heart Disease from >6 months including transition to Adult Congenital Services have follow up clinic appointments at the appropriate interval.

Objectives

1. To provide guidance on the appropriate interval for the follow-up of children > 6 months with congenital heart disease in the outpatient setting.
2. To provide guidance on the appropriate clinic, either Paediatrician with Expertise in Cardiology (PEC), or Joint Paediatric Cardiologist and PEC.
3. To provide guidance on the appropriate clinic at transition to adult services; Local Cardiology, Local ACHD, either outreach ACHD clinic or Newcastle, depending on travel time, or Newcastle ACHD only

Background

Recommendations have already been made regarding follow-up of haemodynamically insignificant lesions, (e.g. mild valvar stenosis and small ASD/VSDs), that suggest these need only to be seen initially for diagnosis, then in later childhood and once more in late adolescence before being discharged, although this does not currently appear to be standard practice in the UK. Setting these guidelines for the North East and North Cumbria CHD Network will provide consistency of care for the children and adolescents with CHD and assist professionals in planning clinic capacity.

Diagnoses

- Pulmonary Stenosis
- Aortic Stenosis
- VSD pre and post surgery
- ASD pre and post surgery
- Mitral Regurgitation
- Aortic Regurgitation
- Patent Ductus Arteriosus pre and post ligation
- Patent Foramen Ovale
- Atrio-Ventricular Septal Defect
- Coarctation of the Aorta post surgery
- Transposition of the Great Arteries post surgery
- Total Anomalous Venous Drainage post surgery
- Glenn Shunt
- Fontan
- Cardiomyopathy
- Marfans
- Bicuspid Aortic Valve
- Atrio-Ventricular Septal Defect
- Supraventricular Tachycardia

Diagnosis	Follow-up	PEC / Joint Clinic	Transition to adult services
Pulmonary stenosis (with gradient not increasing)			
Mild (2-3m/s)	1yr, then 2yrs, then5yrly	PEC	Local cardiology follow-up with 5 yearly echo
Moderate (3-4m/s)	Yearly for the first 3yrs, then 2yrly	Joint	Local ACHD / Newcastle
Aortic stenosis (with gradient not increasing)			
Mild (2-3m/s)	1yr, then every 2yrs	PEC	Local ACHD / Newcastle
Moderate (3-4m/s)	At least yrly (more frequently if assessment dictates)	Joint	Local ACHD / Newcastle
Ventricular Septal Defect			
Small Muscular	3 – 5yrly	PEC	*Discharge with detailed letter
Small Perimembranous (Assuming no complication)	1-2yrly	PEC	Local ACHD / Newcastle
Small Perimembranous (with possible complication e.g. LV dilation / AR)	Yearly	Joint	Local ACHD / Newcastle
Atrial septal defect			
Small (<1cm) with no RV dilation	3yrs, then 5yrly	PEC	Local ACHD / Newcastle
With RV dilatation	1-2yrly until repair	Joint	ACHD Newcastle (see below if post-op)
Mitral regurgitation			
No LV dilatation	1-3yrly Depending upon the degree of MR	PEC	Local ACHD / local cardiology / Newcastle
LV dilatation	6-12 monthly Depending upon the degree of MR	Joint	Newcastle
Aortic regurgitation			
No LV dilatation	1-2yrly Depending upon AR degree	Joint / PEC	Local ACHD / Newcastle
LV dilatation	6-12 monthly	Joint	Local ACHD / Newcastle
Patent ductus arteriosus			
Haemodynamically significant	Closure (see post-op guidance below)		
Haemodynamically insignificant	3yrly	PEC	*Discharge with detailed letter

Patent Foramen Ovale	Discharge. Mention scuba diving etc.	PEC	N/A
Post-op follow up: Typically 2-6 wks (FRH), 6 months (FRH) and then 1yr (FRH / PEC); Subsequent f/u dependent on diagnosis and presence of residual lesions (see below)			
Atrial septal defect			
Surgical closure	2-5yrly dependent on presence of residual lesion. *Consider discharge at Clinician's discretion	Joint	Local ACHD / Newcastle
Device closure	2-5yrly dependent on presence of residual lesion. *Consider discharge at Clinician's discretion	Joint	Local ACHD / Newcastle
Atrio-Ventricular Septal Defect			
No significant residual defect	2yrly	Joint	Local ACHD / Newcastle
Residual defect (e.g. LAVVR / LVOTO / PPM)	6 -12monthly	Joint	Local ACHD / Newcastle
Patent ductus arteriosus			
Surgical ligation	Discharge at 6months if no residual lesion	Joint	
Device occlusion	Discharge at 6months if no residual lesion	Joint	
Residual lesion (arch / LPA obstruction)	6-12monthly dependent on degree	Joint	Local ACHD / Newcastle
Coarctation of the aorta (surgical repair)			
No residual narrowing	2yrly	Joint	Local ACHD / Newcastle
Residual narrowing present	Yearly	Joint	Local ACHD / Newcastle
Coarctation of the aorta (catheter intervention)	Yearly	Joint	Local ACHD / Newcastle
Transposition of the great arteries			
No residual lesion	1-2yrly	Joint	Local ACHD / Newcastle
Residual lesion present (e.g. Branch PS, Neo-AR)	Yearly	Joint	Local ACHD / Newcastle
Tetralogy of Fallot			
No residual lesion	1-2yrly	Joint	Local ACHD / Newcastle
Residual lesion (e.g. RVOTO / branch PS / PR	Yearly	Joint	Local ACHD / Newcastle

Total anomalous pulmonary venous drainage			
No residual lesion	1-2yrly	Joint	Local ACHD / Newcastle
Residual lesion present (e.g. PV stenosis)	Yearly	Joint	Local ACHD / Newcastle
Single ventricle			
Post-Stage 1			
<6 months	See separate guide		
>6 months	6-12monthly	Joint	Newcastle
Post-Glenn / Fontan	6–12monthly	Joint	Newcastle
Aortopathy – Marfans‡			
No aortic dilatation(Z score <2)	2yrly	PEC	Local Cardiologist / ACHD / Newcastle
Mild aortic dilatation(2 < Z score < 3.5)	Yearly	PEC	Local Cardiologist / Local ACHD / Newcastle
Moderate or severe aortic dilatation(Z score > 3.5)	6-12monthly	Joint	Local ACHD / Newcastle
Aortopathy – Bicuspid aortic valve‡			
No aortic dilatation(Z score <2)	2yrly	PEC	Local Cardiologist / Local ACHD / Newcastle
Mild aortic dilatation(2 < Z score < 3.5)	1-2yrly	PEC	Local Cardiologist / Local ACHD / Newcastle
Moderate or severe aortic dilatation(Z score > 3.5)	6-12monthly	Joint	Local ACHD / Newcastle
Supraventricular tachycardia			
Medical therapy / awaiting EPS	Follow up dependent on symptom burden and degree of control Typical follow up Birth to 6 months: 6 weekly > 6months: 6 monthly to 1yrly Consider discontinuing medication (with or without	Newcastle	Newcastle

	Transoesphageal EPS) at 1yr		
Post-EPS	3 months, 1yrDischarge at 1yr if successful	Newcastle	Newcastle
Inherited arrhythmia Syndromes			
LQTS, CPVT, Brugada	Follow up dependent on symptom burden and degree of control Birth to 6 months: 6 weekly > 6months 6months to 1yrly		

*Discharge letter should be detailed, for example, including information regarding infective endocarditis (tiny PDA/muscular VSD) and atrial arrhythmia as well as device erosion (ASD). It should also include details of who to contact should there be any concerns.
‡1.For aortic root echo measurements and Z scores please refer to Freeman paediatric aortopathy echo guideline
2. For patients with bicuspid aortic valve consider more frequent clinic follow up if AS or AR
3. In presence of high risk features, such as family history of aortic dissection or rapid aortic growth (≥0.8 cm/y before2 y of age, ≥0.5cm/y after 2 y of age) consider more frequent clinic review
4. Increased aortic growth rate may occur during puberty with somatic growth so may require increased surveillance at this time

Appendix

NENC Outreach clinics and Cardiologists with an interest in ACHD‡	
North Tees (Cardiologist with an interest in ACHD)	Helen Oxenham
North Tees (Outreach)	Louise Coats
James Cook (Cardiologist with an interest in ACHD)	Pamela Brown
James Cook (Outreach)	Justyna Rybicka
CDDFT	Jeni Crilley
Sunderland and South Tyneside	Shahid Junejo
Gateshead Health (Cardiologist with an interest in ACHD)	Ray Meleady
North Cumbria (Cardiologist with an interest in ACHD)	Justin Barclay
Northumbria (Cardiologist with an interest in ACHD)	Thomas Green

‡Refer to Newcastle if no Local Cardiologist with an interest in ACHD

NENC Outreach clinics and Paediatricians with expertise in Cardiology	
North Tees (PEC)	Madhu Podalakur, Priya Mauree
North Tees (Outreach)	Rachel Carnall
South Tees (PEC)	Jonathan Wyllie, Lekshmy Prasad
South Tees (Outreach)	Kaitav Adhvaryu
CDDFT (PEC)	Carla Pimentel
Sunderland and South Tyneside (PEC)	Satyam Veeratterapillay
North Cumbria (PEC)	Yee Mon Aung
North Cumbria (Outreach)	Neil Seller

Follow up definitions

- PEC: Follow up primarily by Paediatrician with expertise in Cardiology
- Joint follow-up:
    - Alternating PEC and FRH
    - Local review in joint outreach clinic
- Local ACHD: Local Cardiologist with an interest in ACHD
- Newcastle: FRH cardiologist seeing patient at FRH or in outreach clinic