Guy's and St Thomas'
NHS Foundation Trust NHS

Adult Congenital Heart Disease (ACHD) service

Cardiac Physiologist/Clinical Scientist Led ACHD Clinic

Standard Operating Procedure

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Cardiac Physiologist/Clinical Scientist training and education requirements

- Be compliant with the code of conduct for Cardiac Physiologist/Clinical Scientist led clinics approved by the cardiovascular department.
- Must have full Transthoracic Echocardiography (TTE) accreditation in Congenital Heart Disease (CHD) with the European Association of Cardiovascular Imaging (EACVI) and/or British Society of Echocardiography (BSE).
- Will have appropriate training in clinical history taking and clinical assessment.
- Will have adequate training in all relevant Information Technology (IT) systems used for the clinic.
- During the initial stage, will observe ACHD clinics in the department with the Consultant Cardiologists, SpRs or Fellows and Cardiac Nurse Specialists to gain exposure to outpatient practice.
- Will undertake subsequent practice under supervision with the aim to complete a minimum of 25 cases.
- The Physiologist/Clinical Scientist will then ideally work alongside the senior team until their competency to work alone is agreed and they are comfortable to do so.

Standard Operating Procedure

✓ Administrative

- The ACHD Physiologist Led Clinic occurs on alternate Tuesdays at Guy's Hospital (clinical code CARG-24, echo room 2).
- A total of 7 patients are booked into each clinic, in 1 hour slots - the first patient is at 9:00 AM, with a 30 minute break at 1:00PM and the last patient is at 3:30 PM.
- Administrative oversight for the clinic is provided by the ACHD Assistant Service Manager. The bookings are completed by one of the ACHD secretaries, and the clinic letters are finalised by the ACHD CNS admin assistant.

- How to contact the service:

  - For clinical queries, call the ACHD CNS team via GSTT switchboard, extension xxxx.

  - For booking queries, email xxxx.

✓ Clinical

- Type of patients: new and/or follow-up patients referred by ACHD clinical staff from GSTT or from the wider ACHD network, but under a named ACHD Consultant from GSTT (see list of appropriate pathologies).
- The clinic preparation process involves a thorough preparation by reading each patient's medical history, previous clinical letters, tests results etc.
- The patient receives a standard appointment letter, explaining that they will see a Physiologist/Clinical Scientist on the day and that they should bring any relevant medical information, for example, and their current list of medication.
- On the day of their clinic appointment, the patient will register at the Cardiac Outpatient (OP) Department's (OPD) reception desk, before they undergo a 12-lead Electrocardiogram (ECG) and standard clinical observations with an OP nurse.
- The patient is seen in clinic by the Physiologist/Clinical Scientist. A clinical assessment and history taking is carried out, following specific guidance (see appendix 1).
- A Full ACHD Standard TTE is performed and reported, according to departmental ACHD protocols.
- Each patient is given a verbal outcome from their clinic assessment, including a summary and follow-up plan. An additional flyer is given to every patient with additional general clinical guidance and ACHD contact information.
- Any non-urgent queries or concerns must be discussed with the named ACHD Consultant before finalising the clinical outcome and clinic letter. If appropriate, the clinical case can be presented at the weekly ACHD multidisciplinary team meeting (MDM) for further discussion.
- Any case that requires more urgent clinical review and discussion should follow the departmental escalation protocol for ACHD outpatients.
- All clinical notes and outcomes are saved in the hospital electronic patient record.

- Physiologist /Scientist will create a clinic letter using a specific template. Once the clinic letter is finalised by the administrative team, it is sent to the patient's General Practitioner (GP), with a copy to the patient by post. If clinical advice is obtained from the named ACHD Consultant, it should be included within the clinic letter (see appendix 2).

- Different types of clinical outcomes:
  - "Clinical Review" for visits within 6 months up to 5 years' time
  - "DNA - Return to review"
  - "Discharge to GP"
  - "Discharge to ACHD Consultant"

- Did Not Attend (DNA) policy:

- 1st DNA: Reschedule to next available appointment.

- 2nd DNA: Send a DNA letter explaining the importance of the appointment and at the 3rd DNA we may have to discharge the patient back to the GP.

- 3rd DNA: Discuss it with the named ACHD Consultant before taking the final decision to discharge the patient back to their GP.

List of appropriate pathologies seen in the ACHD Cardiac Physiologist/Clinical Scientist Led Clinic

- **Mild structural and functional conditions** considered in the 2020 European Society Cardiology ACHD guidelines.
- Additional pathologies have been added outside of the 2020 ACHD Guideline, based on ACHD Consultant and Cardiac Physiologist/Clinical Scientist consensus.
- Up to **mild to moderate conditions** may be appropriate if a patient is clinically stable, at the discretion of the referring Consultant. If necessary, these referrals can be discussed with the lead Physiologist/Scientist, however, this is not mandatory.
- **Follow-up recommendations are based on 2020 European Society Cardiology ACHD guidelines and/or ACHD Consultant consensus.**

Appropriate pathology	Pathology description	Follow-up recommendations
• Isolated congenital bicuspid aortic valve (BAV) disease	• Normal BAV function **and/or** aortic root is <40mm	• 5 years
	• Mild to moderate BAV disease (peak velocity <3m/s) **and/or** aortic root is <45mm	• 3 years
• Post aortic valve replacement for bicuspid aortic valve disease	• Post aortic valve replacement with mild dysfunction without high risk clinical features **and/or** aortic root is <40mm	• 3-5 years
	• Post aortic valve replacement with mild to moderate dysfunction (peak velocity <3m/s) without high risk clinical features **and/or** aortic root is <45mm	• 3 years
• Isolated congenital mitral valve disease (excluding parachute valve and cleft leaflet)	• Mild valve disease • Mild to moderate disease	• 5 years • 3 years
• Isolated pulmonary valve disease (infundibular, valvular, supravalvular)	• Mild disease • Mild to moderate disease	• 5 years • 3 years
• Isolated Ebstein's anomaly	• Mild valve disease • Mild to moderate disease	• 3 years • 1 -3 years
• Isolated small unrepaired secundum atrial septal defect (ASD)	• Restrictive secundum ASD shunt with normal or mildly dilated right ventricle (RV) size, preserved function and evidence of normal pulmonary pressure • Evidence of more right heart dilatation **and/or** new tricuspid regurgitation	• 3-5 years • To be confirmed after discussion with the referring ACHD Consultant

Appropriate pathology	Pathology description	Follow-up recommendations
• Post ASD & Patent Foramen Ovale (PFO) device closure.	• Post-device closure for secundum ASD, sinus venosus ASD, and PFO	• 1 year (after the device) • If no complications, every 5 years
• Post ASD surgical closure (any type)	• Post-surgical closure	• 1 year (after the surgery) • If no complications, every 5 years
• Isolated small unrepaired VSD (perimembranous and muscular)	• Restrictive shunt with normal left heart size, normal left ventricular function, no aortic regurgitation (AR) and no evidence of double-chambered physiology • Evidence of left heart dilatation, new AR or double-chambered physiology	• 3-5 years • To be confirmed after discussion with the referring ACHD Consultant
• Post VSD device closure (perimembranous and muscular)	• Post-device closure	• 1 year (after the device) • If no complications, every 3-5 years
• Post VSD surgical closure (any type)	• Post-surgical closure	• 1 year (after the surgery) • If no complications, every 5 years
• Isolated small unrepaired Patent Ductus Arteriosus (PDA)	• Restrictive shunt with evidence of left heart dilatation	• To be confirmed after discussion with the referring ACHD Consultant
• Post PDA closure	• Post-device	• 1 year (after the device) • If no complications, every 5 years

Appendices

Appendix 1 – Clinical history taking questionnaire for a patient with VSD

Clinic Notes Form

Clinic date and site:

Patient details:

Diagnose(s):

1.

2.

Previous Procedure(s):

1.

2.

Medication (s):
Allergies:

Age:

Occupation/Part-time:

Exercise (activity, distance) and tolerance (if not advice promotion):

Chest pain/ Tightness (Site Onset Characteristic Radiation Associated symptom Timing Exacerbation Severity):

Syncope or Pre-syncope:

Dizziness or Lightheadedness:

SOB or Dyspnoea / Exertional SOB / Orthopnoea / Paroxysmal Nocturnal Dyspnoea:

Palpitations / Arrhythmia:

Oedema, location(s) and extension(s):

NYHA class (I – IV):

Other admission to Hospital:

Other on-going treatments:

Smoker (If quit ask when and how):

Drink habits (units of alcohol a week):

Recreational drugs:

IE awareness (dentist visit, importance of a good dental hygiene at home, as well as the avoidance of tattoos and body piercing):

Contraception and advice:

Family history of CHD, screening and pregnancy plan (increased chance to transmit congenital heart disease to a future offspring; pregnancy counselling service is available if needed; pre-natal foetal should be performed on any future children):

On examination:
He/she looked well. Previous xxxx scar has normal appearance.
Weight was xxkg and height xxxcm. Pulse xxbpm, regular and strong. Blood pressure xxx/xxmmHg. Saturation xx% on air. JVP not raised.
No right ventricular heave or thrill. Pan-systolic murmur, loudest at the lower left sternal edge. No oedema or hepatomegaly. Chest clear.

12 lead ECG: Sinus rhythm at xxbpm, normal axis. Normal intervals and QRS progression. No repolarisation abnormalities.

Echocardiogram:

Other exams to check:

Follow-up plan and advices: Overall, Mr/Mrs is clinically stable from cardiovascular perspective. We will arrange follow up with repeat echo in the ACHD Physiologist/Scientist Led Clinic in x years.

Contact advice: In the meantime, he/she knows that our team can be contacted via the telephone numbers and email address above if there is any queries or concerns. PIFU for clinical review flyer given to patient.

Appendix 2 – Clinical letter template for a patient with VSD

Clinic date and site:

Patient details:

Diagnose(s):

1.

2.

Previous Procedure(s):

1.

2.

Medication (s):
Allergies:

It has been a pleasure to review Mr/Miss/Mrs in the Adult Congenital Heart Disease (ACHD) Physiologist Led Clinic today. He/She is on this clinic under watchful surveillance for known xxxx.

Mr/Miss/Mrs is now xx years old and working as xxxxxxx. He/She remains active doing xxx with a good exercise tolerance and no cardiac symptoms. There are no other medical problems that need to be reported and overall he/she feels there has been no significant change since the last visit in xx.

He/She is a non-smoker who drinks xx units of alcohol a week. He/She keeps a good hygiene at home and attends the dentist regularly. He/She is aware of our advice about the importance of keeping yearly visits to the dentist, as well the importance to avoid any tattoos or piercings, body piercings, in way to prevent bacterial infection in the heart (endocarditis).

(Given the previous episode of infected endocarditis in xxx, we would still recommend that he/she has antibiotic prophylaxis prior to any significant dental work).

Miss/Mrs is taking/not taking contraception and is aware of our advice that she may have any type of contraception that she feels comfortable with, in any form / is recommended to have Progestin-only contraception.

Miss/Mrs does not have family history of congenital heart disease and I explained that if she becomes pregnant there is an increased chance to transmit a congenital heart disease to a future offspring. Therefore, a pregnancy counselling service is available and that a 20 weeks foetal scan is recommended on any future children. She understands and agrees with the plan.

Mr does not have family history of congenital heart disease. He also does not have family plans at the moment, however, I also explained that should this change, the future female partner should inform the antenatal team of his cardiac history and a 20 weeks foetal scan is recommended. He understands and agrees with the plan.

On examination he/she looked well. Previous xxxx scar has normal appearance, albeit keloid areas. Weight was xxxkg and height xxxcm. Pulse xxbpm, regular and strong. Blood pressure xxx/xxmmHg. Saturation xx% on air. JVP not raised. No right ventricular heave or thrill. There 2 heart sounds and no murmur. There is a pansystolic murmur, loudest at the lower left sternal edge. No evidence of oedema or hepatomegaly. Chest clear.

12 lead ECG: Sinus rhythm at xxbpm, normal axis. Normal intervals and QRS progression. No repolarisation abnormalities.

Echocardiogram: LV is normal size with xxmm. Normal volumes and normal function. Perimembranous VSD, peak gradient left to right above xxmmHg. Trivial aortic regurgitation. RV is normal size and systolic function without evidence of mid cavity RV obstruction.

Overall, Mr/Mrs is clinically stable from cardiovascular perspective. We will arrange follow up with repeat echo in the ACHD Physiologist Led Clinic **in x years.** In the meantime, he/she knows that our team can be contacted via the telephone numbers and email address above if there is any queries or concerns. In addition to that, I gave him the PIFU for clinical review flyer with extra information about how to contact us in the meantime.

Yours sincerely,

Dario Freitas, Clinical Scientist in Cardiology, ACHD Department

Copy to the Patient

Copy to the GP

Cc' Dr xxx, ACHD Consultant at GSTT