



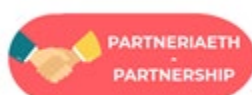
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Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Specialised Services Service Specification: CP214

Adult Congenital Heart Disease Services (Levels 1 and 2) for people aged 16 and over

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Version 1.0*



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Statement

Welsh Health Specialised Services Committee (WHSSC) commission Adult Congenital Heart Disease Services (ACHD) (Level 1 and 2) for people aged 16 years and over in accordance with the criteria outlined in this specification.

In creating this document WHSSC has reviewed the requirements and standards of care that are expected to deliver this service.

Disclaimer

WHSSC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this document.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of Adult Congenital Heart Disease (ACHD) (Levels 1 and 2) for people aged 16 years and over resident in Wales. This Service Specification has been adapted from the [NHS England Service Specification and Standards for Congenital Heart Disease](#).

This service will only be commissioned by the Welsh Health Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

The National CHD Standards also specify the requirements relating to the care taking place in [Level 3 services \(Local ACHD Centres\)](#). This activity is commissioned by the individual Health Boards and is therefore outside of the scope of this specification. Nevertheless Level 3 services are part of the Congenital Heart Network of Care and it is expected that Adult level 1 and 2 services will work in partnership to ensure all patient care is of a consistent, high quality. WHSSC, on behalf of NHS Wales will develop a Level 3 Service Specification in collaboration with the Level 3 centres.

1.1 Plain Language Summary

Congenital heart disease (CHD) is a general term for a range of birth defects that affect the normal way the heart works. The term "congenital" means the condition is present from birth.

1.2 Background

ACHD affects people aged 16 and over living with a heart defect acquired during fetal development.

CHD can be diagnosed antenatally, during childhood or may remain undetected until adult life. Most patients with ACHD will require access to expert care and advice throughout their lives. The patient's condition will require regular monitoring, supported by diagnostic investigations.

The adult with CHD may require a variety of interventions including transcatheter intervention, cardiac surgery, invasive electrophysiology and pacing procedures, advanced heart failure management, palliative care and transplantation. The majority of ACHD patients will require on-going follow up and treatment in adult life in a centre with expertise in adult congenital heart disease.

Many ACHD patients will have had palliative surgery or catheter procedures in childhood, others will have undergone definitive repair but may have significant residual hemodynamic lesions and others may have had no specific treatment but require intervention in the future.

Transition into ACHD is usually around 16 years of age and will normally be completed by the age of 18. Transition should be managed by expert staff from both paediatric and adults background and in accordance with patient needs to ensure a smooth transition to adult care.

It is anticipated that there will also be a group of patients who will enter the service as adults having no previous exposure to cardiac services as children.

The model of care is based on an overarching principle of the CHD Network with agreed pathways and protocols between the 3 levels of care (described in section 2.2).

ACHD must partner with the paediatric, fetal and obstetric cardiac services within the network to ensure that robust and co-ordinated communication, planning and co-operation exists.

Standards of care have been developed through the NHS England Congenital Heart Disease Review and form the basis of this service specification. These standards are based on the principle of a Network Model of care. Adult, Paediatric and fetal services must work together in CHD Networks to deliver care through the 3 levels of provider care as described in Section 2.2.

The standards encompass the whole pathway and are subdivided into categories A to M as outlined below:

- A. The Network Approach
- B. Staffing and Skills
- C. Facilities
- D. Interdependencies
- E. Training and Education
- F. Organisation, governance and audit
- G. Research
- H. Communication with Patients
- I. Transition
- J. Pregnancy and Contraception
- K. Fetal diagnosis
- L. Palliative care and Bereavement
- M. Dental.

1.3 Epidemiology

The demography of CHD is changing, largely as a consequence of successful surgery in childhood. There are increasing numbers of adults with CHD with a prevalence of more than 4 per 1000 adults.

The number of patients with complex disease is increasing with 10% of the ACHD population now falling within the complex group.

1.4 Aims and Objectives

The aim of this service specification is to define the requirements and standards of care essential for delivering ACHD services.

The objectives of this service specification are to:

- detail the specifications required to deliver ACHD services for people who are residents in Wales
- ensure minimum standards of care are set for the use of ACHD services
- ensure equitable access to ACHD services
- identify centres that are able to provide ACHD Services for Welsh patients
- improve outcomes for people accessing ACHD Services.

1.5 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
 - All Wales Policy: [Making Decisions in Individual Patient Funding requests](#) (IPFR).
- **WHSSC policies and service specifications**
 - Specialist Services: Fetal Medicine (In Development)
- **Relevant NHS England policies**
 - [Adult Congenital Heart Disease \(ACHD\) Specification, 23rd May 2016](#)
 - [Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres, 23rd May 2016](#)
 - [Adult Congenital Heart Disease Standards: Level 2 – Specialist ACHD Centres, 23rd May 2016](#)
 - [Adult Congenital Heart Disease Standards: Level 3 – Local ACHD Centres, 23rd May 2016](#)
 - [Paediatric Congenital Heart Disease Service Specification – 23rd May 2016](#)
 - [Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children’s Surgical Centres, 23rd May 2016](#)

- [Paediatric Congenital Heart Disease Standards: Level 2 - Specialist Children's Cardiology Centres, 23rd May 2016](#)
- [Paediatric Congenital Heart Disease Standards: Level 3 - Local Children's Cardiology Centres, 23rd May 2016](#)

2. Service Delivery

The Welsh Health Specialised Services Committee commission the service of ACHD (Levels 1 and 2) for people 16 years and over with CHD, in-line with the criteria identified in this specification.

2.1 Access Criteria

The service is for people with CHD aged 16 and over and are transitioning from Paediatric services and also for people aged 16 and over with suspected CHD.

2.2 Service description overview

CHD is a life-long condition and most patients will require access to specialised care, including monitoring, provided by appropriately trained specialists throughout their lifetime.

The model of care for adults with CHD is based on an overarching principle of a Congenital Heart Network.

Across the Network the units are categorised into levels of care and services are based around these levels: (see also section 2.3)

- **Level 1: Specialist ACHD Surgical Centres**
These centres manage the most highly complex diagnostics and care, including all surgery and interventional cardiology.
- **Level 2: Specialist ACHD Cardiology Centres**
These centres provide the same level of specialist medical care as Level 1, but they do not provide surgery or interventional cardiology, with the exception of atrial septal defect (ASD) at selected hospitals treating adults. Level 2 centres focus on diagnosis, plus ongoing care and management of CHD.
- **Level 3: Local ACHD Centres**
Services are delivered from local hospitals run by general paediatricians/cardiologists with a special interest in CHD. They provide initial diagnosis and ongoing monitoring and care, including joint outpatient clinics with specialists from Level 1 and 2 centres.

The service model implemented in Wales is based on a modified "hub and spoke" approach. It was necessary to modify the hub and spoke model for Wales as the combined population of South East, West and part of Mid Wales is insufficient to support a fully operational Level 1 CHD centre in Wales (requiring >300 operations/year and a team of 3 CHD surgeons).

The University Hospital of Wales provide the Level 2 hub for South Wales with outreach clinics at each Health Board. Specialist ACHD services,

including cardiac surgery and assessment of patients with complex disease are provided at Bristol for South Wales.

Level 1 and Level 2 services for parts of Powys and North Wales are provided at Manchester Royal Infirmary, Queen Elizabeth Hospital, Birmingham and Liverpool Heart and Chest Hospital.

2.2.1 Referrals

Patients who require intervention or wider expertise to manage their medical care can be referred in to the ACHD service from several routes including:

- Secondary and Tertiary care consultants (elective or emergency).
- Formal transition from Paediatric CHD service.
- The patients GP.

Upon referral to the ACHD service, the service should:

- Provide a 24/7 telephone advice and assessment service.
- Provide clinically appropriate inpatient facilities to stabilise and monitor patients.
- Carry out a core MDT assessment of all referred patients with a new diagnosis of significant CHD within 3 months for non-urgent referrals.
- At point of transfer to the adult service all transition patients from paediatric cardiology will have a formal baseline assessment. This will include detailed discussion on prognosis, aetiology and potential warning signs which require urgent review.

2.2.2 Transition from Paediatric to adult CHD Services

The process of transitioning from paediatric to ACHD care should be initiated no later than the 12th birthday taking into account individual circumstances and special needs. Paediatric and Adult Congenital Heart Network centres will develop close working relationships to ensure smooth and effective transition of patients to appropriate facilities, minimising loss of patients to follow up during the process. "Lost to follow up" rates must be recorded and discussed by the network.

- The ACHD service will accept referrals of appropriate young people from the paediatric cardiac network.
- All young people requiring ongoing congenital cardiac care/monitoring should be seen at least once by an ACHD cardiologist and ACHD Specialist Nurse in a specialist MDT transfer clinic or equivalent and be supported by age appropriate information and lifestyle advice.
- Particular needs of young people with learning disabilities and their parents/carers should be considered, and reflected in an individual tailored transition plan.

- The Children's Cardiac Transition Nurse will act as a liaison between young people, their carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the transition process.
- The network should provide age-appropriate written and/or electronic information to patients and their families/carers, covering the full range of social and health-related advice.
- Each Congenital Heart Network should agree and provide formalised operational transition policy consistent with the congenital heart disease standards and the generic specification for transition produced by the paediatric medicine CRG.

2.2.3 Adult Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the Specialist ACHD Surgical Centre. This includes all patients being considered for a complex catheter intervention, surgery or innovative procedures.
- Each MDT discussion should generate a signed record of the discussion and the final outcome. Outcomes from MDT and investigations should be routinely conveyed back to the patient's local cardiologist.
- When considering patients for complex catheter intervention or surgery (including out of hours and in emergencies) the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Intensivist. Otherwise the composition of the MDT should be pathway driven, and adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinic-pathological and audit meetings).
- Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing to participate in the decision-making about their patient and for ongoing training and development.
- The attendance and activities of the MDT should be maintained in a register.

2.2.4 Dental Care

The dental treatment needs of ACHD patients should be identified and addressed prior to referral for any invasive procedure. Any outstanding treatment needs should be shared with the interventional/surgical team. Patients at risk of endocarditis should have a tailored programme of care for specialised follow up. The Network will have a clear referral pathway for urgent dental assessments.

2.2.5 Pregnancy and Contraception

All female patients of childbearing age should be offered pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and nurse specialist with expertise in pregnancy in congenital heart disease. They should have access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy as opposed to unplanned and untimely pregnancy should be supported.

A multi-disciplinary cardiac obstetric service should be developed in conjunction with each Level 1 and 2 Units.

Male patients should have access to counselling and information about contraception and recurrence risk by a consultant ACHD cardiologist and nurse specialist with expertise in CHD and, where appropriate by a consultant geneticist.

Specific genetic counselling should be available for those with heritable conditions that have a clear genetic basis. All patients should be offered access to a Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about treatment.

2.2.6 Palliative or end-of-life care

The service should:

- Provide symptom control where appropriate for patients with untreatable or degenerative conditions.
- Monitor patients response on a regular basis.
- Use nationally approved palliative medicine pathways to plan care.
- Agree a named lead doctor and nurse for any patients entering a palliative care pathway who will ensure the patients and their partner/family/carer is supported up to and beyond death.
- Produce a written, agreed, individual, end-of-life plan.
- Discuss the potential for tissues and organ donation.
- Liaise actively with NHS and non NHS professional to ensure access to appropriate palliative or end-of-life services and make the patient and their partner/family/carer aware of these.
- Ensure that when a death occurs in hospital, the process that follows a death are explained verbally at the families pace and backed up with written information.
- Maintain, where possible, continuity of care, the clinical team working closely with the clinical team working closely with the bereavement team.
- Offer help with the registration of death, transport of the body and signposting of funeral services.

- Generate and publish evidence of effective palliative end-of-life care for patients /carers.

2.2.7 Patient Information

Patients should be provided with high quality information throughout their care. Patients transferring across or between networks will be accompanied by high quality information including a health record summary and management plan.

Patients/family/carers should be provided with accessible information about the service and the hospital including information about amenities in the local area, travelling, parking and public transport. Information should be available in a wide range of formats. It must be clear, understandable, culturally sensitive, evidence-based, and developmentally appropriate and take into account special needs as appropriate.

When given verbally, information should be precisely documented. Information should be interpreted or transcribed as necessary. Information should include advice relevant to the patient's condition:

- Exercise and sports participation
- Sex, contraception and pregnancy
- Dental care and endocarditis prevention
- Smoking, alcohol and drugs
- Tattoos, piercings and intradermal procedures
- Careers
- Travel
- Welfare benefits
- Social services
- Community services
- Information on the main signs and symptoms of possible complications or deterioration and what steps to take

2.2.8 Facilities and equipment

Across the CHD Network there should be facilities in place to ensure easy and convenient access for patients and their families/carers and facilities and where an inpatient stay is required, support should include:

- Accommodation for partners/family to stay
- Access to refreshments
- Facilities suitable for the storage and preparation of simple meals
- An onsite quiet room

Patients should be seen in an appropriate adult environment, ideally within a dedicated ACHD ward/OPD.

Each Specialist ACHD Surgical Centre will have local arrangements for transferring patients from airfields and helipads as required.

Telemedicine facilities should be available (as determined by the network). Provision of remote access for visiting consultants to enable immediate access to patient data.

2.2.9 Equipment infrastructure on Site

The Specialist ACHD Surgical Centre should have:

- Electrophysiology including three-dimensional mapping.
- Cardiac catheterisation laboratory(s).
- Standard, contrast, intraoperative, trans oesophageal and fetal echocardiography.
- Magnetic Resonance Imaging (MRI)
- Computerised Tomography (CT).
- Ventricular Assist programme with or without post-operative extra life support (non-nationally designated extra corporeal membrane oxygenation (ECMO).
- Access to Isotope Imaging.

2.2.10 Patient Database/Registers

Accurate coding and classification of rare disorders is necessary for determining correct management, providing information on outcome and directing research.

The ACHD Centre should ensure that all patients requiring intervention are invited to have their information collected and entered onto an appropriate data base.

All ACHD Centres should:

- ensure there are written protocols covering communication between clinicians, and between clinicians and patients
- participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiological procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research (NICOR)
- co-operate in developing a national register of research trials and outcomes

2.3 Service Specific description of provider centres

Level 1 – Specialist ACHD Surgical Centres

The specialist ACHD Surgical Centre will deliver all services that Specialist ACHD centres and local ACHD centres provide, as well as providing all ACHD surgery and interventional catheterisation. The Specialist Surgical ACHD Centre will be responsible for developing and agreeing, in partnership with other Network providers, the Network pathways, protocols and governance arrangements for patient care, including self-referrals out of network and second opinions, in line with the agreed standards of care.

Care delivered in this setting includes:

- All ACHD surgery delivered by trained congenital cardiac surgeons with anaesthetic cover provided by those with appropriate ACHD Training.
- ACHD catheter interventions including interventional pacing and electrophysiology delivered by trained congenital interventional cardiologists.
- Hybrid procedures – combined ACHD surgical/general cardiothoracic surgical working.
- Joint cardiology procedures – combined ACHD/general cardiology working.
- Complex pacing and Implantable Cardioverter-Defibrillator (ICD) procedures.
- Invasive and non-invasive imaging (including echo and dynamic assessment).
- Transition and transfer clinics.
- Working links to other specialist areas including heart/ heart-lung transplantation services, genetics, National Pulmonary Hypertension Service.
- Complex patients requiring non-cardiac surgery should be managed in this setting in order to have access to anaesthetists with ACHD experience.
- Joint management of ACHD patients with high-risk pregnancy.
- Working links to Local ACHD services as provided by Specialist ACHD Centres and Local ACHD Centres.

Level 2 – Specialist ACHD Centres

The Specialist ACHD Centre should provide expert ACHD cardiology advice and support to patients to the same standard as that provided by the Specialist ACHD Surgical Centre and working in conjunction with the Local ACHD centres will be responsible for delivering an outreach clinic.

The Specialist ACHD Centres provide ongoing management of ACHD patients along with diagnostic services, simple electrophysiology work and

management of ACHD in pregnancy. Where agreed with the network, a specialist ACHD centre may also undertake trans-catheter closure of Atrial Septal Defect (ASD) and Patent Foramen Ovale (PFO).

Care delivered in this setting includes:

- Ongoing ACHD patient management.
- Broad range of diagnostic services, including invasive and non-invasive imaging, delivered at the same quality as in the Specialist ACHD Surgical Centre.
- Cardiologists employed by the Specialist ACHD Centre and trained to the appropriate standards in intervention and diagnostic ACHD cardiology with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their specialist skills.
- Cardiologists from the Specialist ACHD Centre who visit the Specialist ACHD Surgical Centre to perform therapeutic catheterisation in patients with CHD must be the primary operator in a minimum of 50 such procedures per year averaged over a 3 year period. Under governance arrangements agreed by the Network and after individual case discussion at the network MDT, ASD and PFO closures may be undertaken at the Specialist ACHD Centre. All other congenital catheter intervention procedures must be carried out in the Level 1 centre.
- Select diagnostic catheterisation procedures may be undertaken at the Specialist ACHD Centre when agreed at the network MDT.
- Electrophysiology procedures for patients with simple congenital heart lesions may also be carried out at the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.
- Ongoing management of pacing.
- Management of ACHD in pregnancy, contraception advice and pre-pregnancy planning with an understanding of when to refer to Level 1 services.

Staffing

Level 1 Centres

Centres must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including 24/7 congenital cardiac surgical and interventional cover. A Consultant ward round should occur daily.

Surgeons

- Surgical teams must consist of a minimum of 4 Whole Time Equivalent (WTE) consultant congenital cardiac surgeons. Out of hours arrangements must take into account the requirement for surgeons to only undertake procedures for which they have

appropriate competence. A complement of 3 WTE consultant cardiac surgeons to operate as an interim arrangement is acceptable.

- Specialist ACHD Surgical Centres must enable consultant congenital cardiac surgeons to operate together on complex or rare cases.
- Each congenital cardiac surgeon must perform a minimum of 125 first operator congenital cardiac surgical procedures (auditable cases as defined by submission to NICOR with the addition of Ventricular Assisted Devices (VAD's) insertion procedures and cardiac transplantation) each year, averaged over a 3 year period.

Cardiologists

- Specialist surgical centres must be staffed by a minimum of 4 WTE consultant specialist ACHD consultant cardiologists.
- Each Centre must be staffed by at least 2 interventional specialist cardiologists who may be included in the 4.
- Each consultant congenital interventionist must be a primary operator in a minimum of 50 congenital procedures per year, averaged over a 3 year period.
- There must be a designated lead interventionist who must be a primary operator in a minimum of 100 procedures per year, averaged over a 3 year period.
- Each Specialist ACHD Surgical Centre must be staffed by a minimum of 1 expert electrophysiologist experiences in ACHD.
- Each Specialist ACHD Surgical Centre will have a congenital cardiac imaging specialist in both cardiac MRI and cardiac CT.
- Each Specialist ACHD Surgical Centre will have a lead for congenital echocardiography who is [European Association of Cardiovascular imaging](#) (EACVI) accredited.

Nurses

- Each Specialist ACHD Surgical Centre will have a senior nurse with specialist knowledge and experience in the care of patients with CHD including those undergoing congenital cardiac surgery. They will lead a dedicated team of nursing staff in the care of adults undergoing cardiac surgery.
- Each Specialist ACHD Surgical Centre will provide 1 individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver competency-bases programmes across the network.
- Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses whose role will extend across the network
- Each patient with significant CHD must have a names specialist ACHD nurse responsible for co-ordinating their care.

- The ACHD nurse specialists will work closely with the Children's Cardiac Transition Nurse to coordinate the transfer process for each patients.

Other

- Each Specialist ACHD Surgical Centre will have a lead doctor and nurse for safeguarding vulnerable adults.
- Each Specialist ACHD Surgical Centre will have an identified bereavement officer.
- Perfusion services and staffing must be accredited by the [College of Clinical Perfusion Scientists of Great Britain and Ireland](#).
- Each Specialist ACHD Surgical Centre will employ a minimum of 2 WTE practitioner psychologists, one of whom will have responsibility for delivering services across the network.

Level 2 Centres

Centres must provide appropriately trained and experienced medical and nursing staff. Each Level 2 centre will have:

Cardiologists

- A lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD and at least 1 cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD (each cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist).
- A dedicated consultant led cardiology on call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.
- A formally nominated ACHD Lead cardiologist with responsibility for the service at the Specialist centre, who works across the network.
- Cardiologists trained to the appropriate standards in interventional and diagnostic ACHD catheterisation.

Nurses

- A minimum of 2 WTE specialist nurses with an interest in ACHD, whose role is extended across the network.

The precise number above the minimum of 2 and the location of these nurses will depend on geography, population and the configuration of the network.

Other

- A team of electrophysiology scientists (technicians) who should have/ be working towards accreditation.
- Access to a clinical psychology service integrated within the ACHD Team.

- Congenital Heart Imaging specialist expert in Cardiac MRI and cardiac CT.
- Identified member of staff to ensure high quality data input to the network database.
- Staff should participate in the weekly Network MDT.

2.4 Interdependencies with other services or providers

All centres providing care for adults with congenital heart disease must conform to the standards for interdependency as laid out in Section D – Interdependencies of the CHD Standards (2016) for [Level 1](#) and [Level 2](#) Centres. They have not been included in detail here for brevity.

2.5 Exclusion Criteria

This specification excludes:

- Patients with congenital syndromes which present with cardiovascular problems in adolescent or adult life, e.g. Marfan syndrome, muscular dystrophy or other hereditary conditions may be appropriately looked after by alternative specialists at individual units.
- Adult critical care
- Transplantation
- Pre-implantation genetic diagnosis
- Investigational drugs and procedures that are part of a research protocol.

2.6 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.7 Patient Pathway

The pathway will be individualised according to the patient needs, however patients will move between the 3 levels of service described above. Patients with moderate or severe complexity may be cared for in either the Specialist ACHD Centre or the Specialist ACHD Surgical Centre. Patients with simple lesions may be cared for in their local ACHD Centre.

It is not anticipated that patient will follow a linear pathway through the 3 levels of care but move between levels as appropriate and determined by the Networks protocols and Multidisciplinary (MDT) planning.

2.8 Service provider/Designated Centre

Level 1 Centres

- The Bristol Heart Institute
University Hospitals Bristol and Weston NHS Foundation Trust
Bristol Royal Infirmary
Bristol
BS2 8HW
- Liverpool Heart and Chest Hospital
Thomas Drive
Liverpool
L14 3PE
- Queen Elizabeth Hospital
Mindelshon Way
Edgbaston
Birmingham
B15 2WB

Level 2 Centres

- University Hospital of Wales
Heath Park Way
Cardiff
CF14 4XW
- Manchester Royal Infirmary
Oxford Road
Manchester
M13 9WL

2.9 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties.

3.1 Quality Indicators (Standards)

The ACHD service must provide the following information /data:

- Patient reported outcome and experience metrics
- 3 year rolling partial risk adjusted 30 day mortality data
- 3 year validated partial risk adjusted 30 day mortality data
- Response to suspected/confirmed fetal diagnosis
- Waiting times (in days) for elective congenital cardiac surgery
- Last minute cancellations of elective surgical procedures
- Un-planned interventions within 30 days of catheter or surgical intervention
- Details of any unexpected complications of surgery or treatment
- Detail of any formal complaints involving inpatients
- Hospital acquired infection rates.

3.2 National Standards

The providers will work to the national standards set out in the NHS England ACHD Standards. For brevity here these can be found via the links below:

- [Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres, 23rd May 2016](#)
- [Adult Congenital Heart Disease Standards: Level 2 – Specialist ACHD Centres, 23rd May 2016](#)

3.3 Other quality requirements

- the provider will participate in a UK wide peer review process
- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings.

4. Performance monitoring and Information Requirement

4.1 Performance Monitoring

WHSSC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

WHSSC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

As well as the quality indicators set out in Section 3 the providers will be expected to monitor and report to their responsible network against the full list of Key Performance indicators described below.

- Total patient cohort
- Weeks wait for new patients (local Consultant)
- Weeks wait for new patients (visiting specialist)
- Delay (weeks) for local consultant follow up (FU) (No. of weeks past planned FU date that patients are actually seen)
- Delay (weeks) for visiting specialist FU (No. of weeks past planned FU date that patients are actually seen)
- Number of FU overdue
- DNA Rate (%)

The above metrics must be reported to the CHD Network Board on a Quarterly basis.

4.3 Date of Review

This document is scheduled for review before 2025 where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

6. Putting Things Right

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for [NHS Putting Things Right](#). For services provided outside NHS Wales the patient or their representative should be guided to the [NHS Trust Concerns Procedure](#), with a copy of the concern being sent to WHSSC.

6.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

Annex i Codes

| Code Category | Code | Description |
|---------------|--|--|
| ICD | Q208 | Other congenital malformations of cardiac chambers and connections |
| | Q209 | Congenital malformation of cardiac chambers and connections, unspecified |
| | Q218 | Other congenital malformations of cardiac septa |
| | Q219 | Congenital malformation of cardiac septum, unspecified |
| | Q221 | Congenital pulmonary valve stenosis |
| | Q222 | Congenital pulmonary valve insufficiency |
| | Q223 | Other congenital malformations of pulmonary valve |
| | Q224 | Congenital tricuspid stenosis |
| | Q228 | Other congenital malformations of tricuspid valve |
| | Q229 | Congenital malformation of tricuspid valve, unspecified |
| | Q230 | Congenital stenosis of aortic valve |
| | Q231 | Congenital insufficiency of aortic valve |
| | Q232 | Congenital mitral stenosis |
| | Q233 | Congenital mitral insufficiency |
| | Q238 | Other congenital malformations of aortic and mitral valves |
| | Q239 | Congenital malformation of aortic and mitral valves, unspecified |
| | Q244 | Congenital subaortic stenosis |
| | Q246 | Congenital heart block |
| | Q248 | Other specified congenital malformations of heart |
| | Q249 | Congenital malformation of heart, unspecified |
| | Q254 | Other congenital malformations of aorta |
| | Q257 | Other congenital malformations of pulmonary artery |
| | Q258 | Other congenital malformations of great arteries |
| | Q259 | Congenital malformation of great arteries, unspecified |
| | Q260 | Congenital stenosis of vena cava |
| | Q268 | Other congenital malformations of great veins |
| Q269 | Congenital malformation of great vein, unspecified | |

Annex ii Abbreviations and Glossary

Abbreviations

| | |
|--------------|------------------------------------|
| IPFR | Individual Patient Funding Request |
| WHSSC | Welsh Health Specialised Services |
| CHD | Congenital Heart Disease |
| ACHD | Adult Congenital Heart Disease |
| ASD | Atrial Septal Defect |
| PFO | Patent Foramen Ovale |

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC is a joint committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.