



**Adult Congenital  
Heart Disease  
(ACHD)  
Specification**

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## **Document Title: Adult Congenital Heart Disease (ACHD) Specification**

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- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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## 1 Document summary

The following document is part of a suite of documents setting out adult and paediatric standards and service specifications for congenital heart disease services in England, agreed by the NHS England Board on 23 July 2015 and effective from 1 April 2016. This one is the Adult Congenital Heart Disease (ACHD) Specification.

There are eight documents:

- Adult Congenital Heart Disease (ACHD) Specification
- Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres
- Adult Congenital Heart Disease Standards: Level 2 – Specialist ACHD Centres
- Adult Congenital Heart Disease Standards: Level 3 – Local ACHD Centres
- Paediatric Congenital Heart Disease Specification
- Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children’s Surgical Centres
- Paediatric Congenital Heart Disease Standards: Level 2 – Specialist Children’s Cardiology Centres
- Paediatric Congenital Heart Disease Standards: Level 3 – Local Children’s Cardiology Centres

To encompass the whole patient pathway each set of standards is subdivided into categories A to M 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

## 2 Adult Congenital Heart Disease (ACHD) Specification

<b>Service Specification No.</b>	E05/S/b
<b>Service</b>	Adult Congenital Heart Disease (ACHD)
<b>Commissioner Lead</b>	Anthony Prudhoe
<b>Provider Lead</b>	n/a
<b>Period</b>	12 months
<b>Date of Review</b>	

### 1. Population Needs

#### 1.1 National/local context and evidence base

This specification covers all Adult Congenital Heart Disease (CHD) activity (surgery and cardiology), taking place in the Specialist Adult CHD Surgical Centres (Level 1 services) and Specialist ACHD Centres (Level 2 services), including activity undertaken by the Specialist Centres on an outreach basis where it is delivered as part of a provider network.

The Congenital Heart Disease Standards specify the requirements relating to the care taking place in Level 3 services (Local ACHD Centres). This activity is commissioned by Clinical Commissioning Groups and is therefore outside 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 with Level 3 providers to ensure all patient care is of a consistent, high quality.

This specification excludes the following which are covered by separate service specifications, each of which can be located on the NHS England website - [www.england.nhs.uk](http://www.england.nhs.uk):

- Inherited Cardiology Conditions (A09/s/c)
- Non Congenital Cardiac Surgery (A10/s/a)
- Services falling within the Complex Invasive Cardiology CRG (A09)
- Heart and Lung Transplantation Service (all ages) (A18/S/(HSS)/a)

#### 1.2 Background

Adult Congenital Heart Disease (ACHD) affects people aged 16 and over living with a heart defect acquired during fetal development. The demography of Congenital Heart Disease is changing. Largely as a consequence of successful cardiac surgery in

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childhood, there are increasing numbers of adults with congenital heart disease with a prevalence of more than 4 per 1000 adults. The number of patients with complex disease is increasing with 10% of the adult congenital heart disease population now falling within the complex group. Congenital heart disease 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 ACHD 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. The transition into ACHD is usually around 16 years of age. Transition to the ACHD service will normally be completed by age 18 and should be managed by expert staff from both paediatric and adult backgrounds 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 Congenital Heart Network, with agreed pathways and protocols for referral between the three levels. Adult Congenital Heart Services must partner with the Paediatric (and fetal) Cardiac Services within the network to ensure that robust and co-ordinated communication, planning and co-operation exists.

### **1.3 Current Service Provision**

Standards of care have been developed through the NHS England Congenital Heart Disease Review and form the basis of this service specification (Congenital Heart Disease Review Standards Group, 2015).

The Standards of Care are based on the principle of a Network Model. Fetal, Paediatric and Adult services will work together in Congenital Heart Networks to deliver care through three "Levels" of provider as described in the Standards of Care.

Each standard has a timescale for achievement ranging from those that must be achieved immediately to those which must be achieved within 5 years. The timescales are provided in the standards document.

Network Care Levels:

- Level 1: Specialist ACHD or Children's Surgical Centres
- Level 2: Specialist ACHD or Children's Cardiology Centres
- Level 3: Local ACHD or Children's Cardiology Centres

It is expected that Paediatric and Adult services will work in partnership within the network to deliver high quality, safe and effective services as locally as possible, throughout the patient's lifetime of care. The exact size and geography of the Network will depend on local need and circumstances and will be determined in partnership with NHS England Commissioners. As much non-interventional treatment as is safe to do so, should be delivered as close to home as possible. It is expected that Networks will collaborate together to ensure uniformity of care throughout the healthcare system

#### 1.4 Evidence Base

##### [2011 BCCA/BCS/BCIS Guidelines on Intervention for ACHD](#)

DH – 2006 – A Commissioning Guide For Services for Young People and Grown Ups with Congenital Heart Disease (GUCH). This document has not been archived and the following should be placed in the internet browser:

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4134696.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4134696.pdf)

##### [NHS England – April 2013 – Review of Adult Congenital Heart Disease Services – Engagement on Proposed Model of Care and Draft Designation Standards – 11/4/13 – 10/5/13](#)

Adult congenital heart disease interventions: recommendations from a Joint Working Group of the British Congenital Cardiac Association, British Cardiovascular Intervention Society, and the British Cardiovascular Society, [Cardiology in the Young](#) / Volume 23 / Issue 01 / February 2013, pp 68-74

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-term conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	✓
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓



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An updated quality dashboard is now operational. Currently assessed outcome measures include the following:

- Patient reported experience metrics;
- Response to suspected/confirmed fetal diagnosis;
- Last minute cancellations;
- Unplanned re-interventions;
- Complications;
- Complaints; and
- Hospital acquired infection rates

The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision.

### **3. Scope**

#### **3.1 Service Aims and Objectives**

##### **Service Aims**

The Adult Congenital Heart Service aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing the whole lifetime of care. The service will manage known ACHD patients transitioning from paediatric services and identify/diagnose adults with congenital heart disease, who are, by definition, aged 16 years and over (recognising that the process of transition to adult services may not be completed until the age of 18 years).

The service for Adult Congenital Heart Disease aims to:

- Deliver best outcomes for patients, with lowest mortality, reduced disability and an improved opportunity for a better quality of life for survivors
- Consistently meet the standards of care (2016) and provide resilient 24/7 care
- Ensure that patients have co-ordinated care throughout the entire pathway, and feel supported and informed during their cardiac journey.
- Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home
- Demonstrate clinical outcomes in line with national and international standards for adults with congenital heart disease

##### **Service Objectives**

The objectives of the service are to improve life expectancy and quality of life for adults with Congenital Heart Disease by:

- Development of Congenital Heart Networks to deliver a standardised model of

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- care which meets national service standards
- Providing high quality, timely and accurate diagnosis
  - Agreeing treatment plans with patients (and their families)
  - Undertaking safe and effective congenital heart surgery and catheter intervention
  - Providing appropriate counselling and psychological support to patients and their families
  - Ensuring smooth and managed transition from paediatric to adult care
  - Supporting patients to manage their ACHD condition independently in order that they can live a life less hindered by their condition
  - Ensuring effective communication between patients, families and service providers that is sensitive to the physical, psychological and emotional needs of the patient and their family
  - Provide an individualised palliative care and bereavement service
  - Systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist (e.g. Somerville Foundation Patient Experience Questionnaire)

### **3.2 Service description/care pathway**

#### **Overview**

Congenital heart disease 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 congenital heart disease is based on an overarching principle of a Congenital Heart Network. Working in partnership with the Paediatric Congenital Heart services the network will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the centre's specific care levels described below. The Congenital Heart Networks will also be expected to link closely with related networks covering areas such as heart and heart/lung transplantation.

Networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.

Across an individual Network the units have been categorised into level of care as follows:

#### Network Care Levels:

- Level 1: Specialist ACHD Surgical Centres
- Level 2: Specialist ACHD Centres
- Level 3: Local ACHD Centres

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

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- Accommodation for partners/family members to stay (without charge)
- Access to refreshments
- Facilities suitable for the storage and preparation of simple meals; and
- An on-site quiet room completely separate from general facilities (levels 2 & 3)

Patients should be seen in an appropriate adult environment, ideally within a dedicated ACHD ward/OPD space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.

Patients must be supported to actively participate in decision making at every stage of their care.

### **Patient Pathway**

Although the pathway will be individualised according to the individual patient need, patients will move between the three levels of service described above. Patients with moderate or severe complexity may be cared for either in the Specialist ACHD Centre or the Specialist ACHD Surgical Centre and patients with simple congenital lesions may be cared for in their Local ACHD Centre. It is not anticipated that patients will follow a linear path through the three levels of care, but move between levels as appropriate and determined by Network protocols and multidisciplinary team (MDT) planning. ACHD patients with complex lesions may be seen in local Level 3 centres in collaboration with a specialist from Level 1 or 2 through joint clinics.

Pathways must involve transition from paediatric congenital heart services and have appropriate links with other adult specialties as defined in section 6.

### **Referrals**

Patients will be referred into the Adult Congenital Heart Service from several routes including:

- From Secondary and Tertiary care Consultants (elective or emergency)
- Formal transition from Paediatric Congenital Heart Services
- The patient's GP

Upon referral to the ACHD service, the service will:

- Provide a 24/7 telephone advice and assessment service
- Provide inpatient facilities to stabilise and monitor clinically appropriate patients
- Carry out a core ACHD MDT assessment of all referred patients with a new diagnosis of significant congenital heart disease, within three 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 of condition and potential warning signs which require urgent review.

## **Transition from paediatric to adult CHD services**

Transition from paediatric to adults with congenital heart disease services (ACHD)

The process of transitioning from paediatric to ACHD care must be initiated no later than the 12<sup>th</sup> 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 must 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 must 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 must 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 must 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.

## **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 must generate a signed record of the discussion and the final outcome.
- 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

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development.

- The attendance and activities of the MDT should be maintained in a register.

### **Definition of Adult Congenital Heart Surgery and Intervention**

The definitions of which surgical procedures should only be carried out by accredited Congenital Cardiac Surgeons are attached in appendix 1.

### **Initial Care**

The appropriate Adult CHD Service will:

- establish a baseline against which disease progression and response to treatment can be measured;
- agree the need for any therapeutic intervention, either specific or supportive;
- offer treatment to all patients who might potentially benefit (eligibility for treatment to be determined as set out in relevant guidelines or as clinically indicated); and
- provide patients and their families/carers with written and/or electronic material relating to the ACHD condition in an appropriate format.

### **Ongoing care**

The appropriate Adult CHD Service will hold/provide:

- regular patient reviews as per national guidelines or clinical practice with written and electronic records of current treatment and patient response;
- access to inpatient and critical care facilities where appropriate;
- access to other specialised services, e.g. PAH, transplantation, etc., as appropriate;
- appropriate access to pharmaceutical therapy;
- patient-centred services, sensitive to the individual's physical, psychological and emotional needs and supported through the provision of patient-appropriate information;
- access to appropriate shared care arrangements with other ACHD service providers; and
- ACHD Nurse Specialist telephone advice service for patients and their families/carers, healthcare professionals and non-healthcare and voluntary sector professionals.

### **Dental Care**

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

## **Pregnancy and Contraception**

All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease. They must have ready 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 multidisciplinary cardiac obstetric service will be developed in conjunction with each Level 1 and 2 unit.

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

Specific genetic counselling must be available for those with heritable conditions that have a clear genetic basis. All patients must be offered access to a Practitioner 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 attachment.

## **Leaving the Pathway - Palliative or end-of-life care**

The appropriate cardiac service will:

- provide symptom control where appropriate for patients with untreatable or degenerative conditions;
- monitor patient response on a regular basis;
- use nationally approved palliative medicine pathways to plan care;
- agree a named lead doctor and nurse for any patient entering a palliative care pathway who will ensure the patient and their partner/family/carers are supported up to and beyond death;
- produce a written, agreed, individual, end-of-life care plan;
- discuss the potential for tissues and organ donation;
- liaise actively with NHS and non-NHS professionals to ensure access to appropriate palliative or end-of-life services and make the patient and their partner/family/carers aware of these;
- ensure that when a death occurs in hospital, the processes that follow a death including legal aspects are explained verbally, at the family's pace and backed up with written information.
- maintain, where possible, continuity of care, the clinical team working closely with the bereavement team.
- offer help with the registration of the death, transport of the body and sign-posting of funeral services.
- generate and publish evidence of effective palliative or end-of-life care for patients / carers.

## **Governance**

The Network will have a Governance Framework in place which includes arrangements for:

- Regular continuous clinical audit and quality improvement.
- Regular network multidisciplinary team (MDT) meetings.
- Regular network meetings including reflection on: mortality, morbidity and adverse incidents.
- Regular audit days including discussion of adverse events and resultant action plans.
- Regular network meetings of the wider clinical team (including network patient representatives) at least every 6 months, for issues such as agreement of protocols, review of audit data and monitoring of performance.

## **Patient registers/database**

Accurate coding and classification of rare disorders is necessary for determining correct management, providing information on outcome and directing research. The value of such registers to patients is discussed in the chapter 'Empowering those affected by rare conditions' in the Department of Health's 2012 document 'Consultation on the United Kingdom Plan for Rare Diseases'.

The ACHD Centre will ensure that all patients requiring intervention are invited to have their information collected and entered onto the appropriate national database.

All ACHD Centres must:

- 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); and
- co-operate in developing a national register of research trials and outcomes.

## **Patient Information**

Patients will 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 records summary and management plan. Patients/family/carers must 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 must be made available in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely

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documented. Information must 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; and
  - information on the main signs and symptoms of possible complications or deterioration and what steps to take.
- (not an exhaustive list)

### **Annual reports**

The Congenital Heart Network will produce annual audit and governance reports covering ACHD services.

### **Administration**

All units within the Network will provide appropriate administrative support to ensure timely organisation of system and process across the whole pathway.

## **3.3 Service description of Provider Centres within Adult Congenital Heart Networks**

### **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 ACHD Surgical 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 / ACHD cardiology working.
- Joint surgical procedures – combined ACHD / general cardiothoracic surgical working.



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- Joint cardiology procedures – combined ACHD / general cardiology working.
- Complex pacing and 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 service, 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.
- Local ACHD services as provided by Specialist ACHD Centres and Local ACHD Centres.
- Provide leadership for training, development and research across the network.

### **Level 2 - Specialist ACHD Centres**

Will provide expert ACHD cardiology advice and support to patients to the same standard as that provided by the Specialist ACHD Surgical Centre and will deliver all services provided at the Local ACHD Centres. The Specialist ACHD Centres will provide ongoing management of ACHD patients along with diagnostic services, simple electrophysiology work and management of ACHD in pregnancy. Where agreed by the network, a specialist ACHD centre may also undertake transcatheter closure of ASD and PFO. Specialist ACHD Centre will have a Lead Specialist ACHD Cardiologist who spends at least 0.8 WTE clinical time on ACHD and at least one cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD.

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 interventional and diagnostic ACHD cardiology shall be provided 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 congenital heart disease must be the primary operator in a minimum of 50 such procedures per year averaged over a three-year period. Under governance arrangements agreed by the network and after individual case discussion at network MDT, ASD and PFO closure may be undertaken at the Specialist ACHD centre. All other congenital catheter intervention procedures must only be carried out in the Level 1 centre.
- Selected 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 Specialist ACHD Centres if specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.

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- Ongoing management of pacing.
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to Level 1 services

### **Level 3 - Local ACHD Centres (Commissioned by Clinical Commissioning Groups)**

Will provide ongoing outpatient care for patients with simple defects. They will deliver long-term follow-up/shared care in liaison with the Congenital Heart Network, local DGHs and primary care. It is anticipated that care will be provided by a local cardiologist with additional training in congenital heart disease in collaboration with a specialist ACHD cardiologist from a Level 1 or 2 centre, They will refer patients to different settings within the Network according to the agreed protocols/pathways. The Cardiologist with a special interest in ACHD will have a formal liaison role between the Congenital Heart Network and the Local ACHD Centre.

Care delivered in this setting includes:

- Basic cardiac diagnostic services (ECG and transthoracic Echo).
- Dental management, information and care.
- Monitoring of anticoagulation and blood chemistry.
- Joint working with palliative care.

#### **4. Population covered**

The service outlined in this specification is for patients ordinarily resident in England(\*); or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

(\* ) Note: For the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

Specifically, the service is commissioned for all ACHD patients and patients referred with a suspected ACHD condition. To ensure Equity of Access, wherever possible, access to the service should be according to common routes, policies and criteria that do not disadvantage any relevant patient group. It should be noted that around 10% of patients have some form of learning disability. Patients from BAME communities are also found in greater numbers than the general population.

#### **5. Any acceptance and exclusion criteria and thresholds**

##### **5.1 Acceptance Criteria**

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- All adult patients diagnosed with ACHD

In common with most other types of healthcare provided by the NHS, patients are likely to enter the ACHD model of care via a general hospital or primary care, unless diagnosed during antenatal or post-birth care. In which cases, the proposed model relates to care provided to adults with congenital heart disease who are, by definition, aged 16 years and over (recognising that the process of transition to adult services may not be completed until the age of 18 years).

It is also 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, with congenital heart conditions.

## 5.2 Exclusions

The specification excludes -

- Patients with congenital syndromes which present with cardiovascular problems in adolescence 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

## 6. Interdependencies with other services/providers

All units providing care for adults with congenital heart disease must conform to the standards for interdependency as laid out in section D of the appropriate level of the congenital heart disease standards (2016). They have not been included in detail here for brevity.

## 7. Applicable Service Standards

All units delivering care to adults with congenital heart disease should meet the NHS England Congenital Heart Disease Standards 2015..

### 7.1 Infrastructure Requirements

The precise shape of each Congenital Heart Network should be determined by local need and local circumstances, including geography and transport and agreed by Area Team Commissioners.

All healthcare professionals in the Network must take part in a programme of continuing professional development as required by their registering body/professional association. This should include specialist education and training and statutory mandatory training.

The Network will have a formal annual training plan in place to ensure ongoing education and professional development. Clinical Nurse Educators must be provided to deliver Network-wide standardised training/competency-based programmes ensuring continuing professional development of nursing staff.

### **7.1.2 Level 1: Specialist ACHD Surgical 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 will occur daily.

#### **Surgeons**

- Surgical teams must consist of a minimum of four WTE consultant congenital cardiac surgeons. Units will have a period of five years to achieve this standard. Out-of-hours arrangements must take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. A complement of 3 WTE consultant congenital cardiac surgeons will be acceptable in the interim.
- 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 VAD insertion procedures and cardiac transplantation) each year, averaged over a three year period.

#### **Cardiologists**

- Specialist surgical centres must be staffed by a minimum of four WTE consultant specialist ACHD cardiologists. Units will have a period of three years to achieve this standard.
- Each Centre must be staffed by at least two interventional specialist cardiologists, who may be included in the minimum of four.
- Each consultant congenital interventionist must be primary operator in a minimum of 50 congenital procedures per year, averaged over a three-year period.
- There must be a designated lead interventionist who must be primary operator in a minimum of 100 procedures per year, averaged over a three-year period.
- Each Specialist ACHD Surgical Centre must be staffed by a minimum of one expert electrophysiologist experienced in adult congenital cardiac disease. There must be appropriate arrangements for cover by a competent person
- Each Specialist ACHD Surgical Centre will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each Specialist ACHD Surgical Centre will have a lead for congenital echocardiography (EACVI accredited).

## **Nursing**

- Each Specialist ACHD Surgical Centre will have a senior nurse with specialist knowledge and experience in the care of patients with congenital heart disease including those undergoing congenital cardiac surgery. They will lead a dedicated team of nursing staff trained in the care of adults undergoing cardiac surgery.
- Each Specialist ACHD Surgical Centre will provide one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver competency-based programs 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 congenital heart disease must have a named 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 patient.

## **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 two WTE practitioner psychologists, one of whom will have responsibility for delivering services across the network
- Each Specialist ACHD Surgical Centre will have local arrangements for transferring patients from airfields and helipads as required.
- Equipment infrastructure on site: Electrophysiology including three-dimensional mapping; cardiac catheterisation laboratory; , standard, contrast, interoperative, transesophageal and fetal echocardiography; Magnetic Resonance Imaging (MRI); Computerised Tomography (CT); ventricular assist programme with or without post-operative extra corporeal life support (non-nationally designated extracorporeal membrane oxygenation(ECMO)); and access to Isotope Imaging.

### **7.1.3 Level 2: Specialist ACHD Centres**

- A lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD and at least one 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).
- Dedicated consultant-led cardiology on-call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.
- A formally nominated Clinical ACHD Lead with responsibility for the service at the Specialist ACHD Centre, who works across the network, and separate

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clinical leads from the relevant specialties including; nursing, ICU, and anaesthesia.

- Cardiologists trained to the appropriate standards in interventional and diagnostic ACHD catheterisation will be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their skills.
- Specialist ACHD Cardiologists who undertake ASD/PFO closure locally or visit the Specialist ACHD Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures each year (PFO closure will be countable), averaged over a three-year period.
- Electrophysiology will usually be undertaken at the Surgical Centre but may be undertaken at the Specialist ACHD Centre if agreed at a joint MDT meeting with the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.
- Congenital Heart imaging specialist expert in Cardiac MRI and cardiac CT.
- A minimum of 2 WTE trained specialist designated registered nurses with a specialist interest in ACHD, whose role extends across the network. Access to a clinical psychology service integrated within the ACHD team.
- Identified member of staff to ensure high quality data input to the network database.
- A team of congenital echocardiography scientists (technicians) who should have/be working towards appropriate accreditation.
- Telemedicine facilities (as determined by the Network).
- Ensure that visiting staff from the Specialist ACHD Surgical Centre have remote access to their own IT systems and enable immediate access to patient data.
- Participation in the weekly Network MDT.

#### **7.1.4 Level 3: Local ACHD Centres**

- At least 1 Consultant Cardiologist with an interest in ACHD.
- Staff should be encouraged to attend Network MDTs to participate in decision making where necessary (Lead Cardiologist to attend at least 6 times per annum).
- Lead Cardiologist to liaise with other secondary and primary care colleagues linking to the Network appropriately.
- The Cardiologist with an interest should have a named Mentor in either the Specialist ACHD Centre or Specialist ACHD Surgical Centre.
- Designated 0.25 WTE registered nurse with a specialist interest in ACHD to participate in clinics, provide support to inpatients and deal with requests for telephone advice.
- Nurses must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre to enhance development of clinical knowledge and skills/enable professional development and career progression.
- An identified link nurse as point of contact for the Network.
- Ensure that staff out-reaching from the Specialist ACHD Surgical or Specialist ACHD Centre have remote access to their own IT systems and enable

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immediate access to patient data.

- Assist the Network with providing core curriculum level training as per the Royal Colleges of Physicians Training Board within their catchment area.
- Identified member of staff to ensure high quality data input to the network database.
- Telemedicine facilities (as determined by the Network) .
- A Cardiac Physiologist with training in congenital echocardiography.
- Appropriate facilities and staff to undertake: Electrocardiography, Transthoracic Echocardiography, Chest X-Ray, Exercise Testing/six minute walk test, 24 hour tapes, event recorders and ambulatory blood pressure monitoring, theatre facilities/anaesthetic support for provision of specialist dental treatment or arrangements to refer patients on where appropriate.
- Dedicated room space for practitioner psychologists, cardiac nurse specialists and social workers to carry out therapeutic work.
- Facilities in place to ensure easy and convenient access for partners/family/carers.
- Robust reporting arrangements for reporting of adverse incidents and dissemination across the Network as determined by Network Governance Arrangements.
- Robust policy for collaboration with the Network for clinical audit, research and administration.

Core standards relating to the specification include:

- NHS England Specialised Services ACHD Standards (2015)
- Safe and Sustainable - Decision Making Business Case (2012)
- Chapter 8 (Arrhythmias and Sudden Cardiac Death, 2005) of the National Service Framework for Heart Disease (2000)
- Adult Congenital Heart Disease Commissioning Guide (2006).

**Additional standards for consideration:**

The national pulmonary hypertension service and heart and lung transplantation services are a necessary part of a comprehensive service for adults who require specialised cardiology or cardiac surgery services.

The principle that underpins the national guidance is that of age-appropriate, safe and effective services as locally as possible, not local services as safely as possible. Care is therefore centralised in specialist centres to ensure depth and breadth of coverage, specialist clinical support and age-appropriate care across the age range with defined aspects of care delivered in shared care services outside the specialist surgical centres.

NICE Guidance

- [IPG67 Balloon dilatation of pulmonary valve stenosis. June 2004](#)
- [IPG74 Balloon angioplasty with or without stenting for coarctation or recoarctation of the aorta in adults and children: guidance July 2004](#)
- [IPG 86 Endovascular atrial septostomy. August 2004.](#)
- [IPG 95 Radiofrequency valvotomy for pulmonary atresia. October 2004](#)

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- [IPG 310 Placement of pectus bar for pectus excavatum \(also known as MIRPE or the Nuss procedure\). August 2009](#)
- [IPG 336 Transcatheter endovascular closure of perimembranous ventricular septal defect](#)
- [NICE guidance on PFO 2010 PFO in divers](#)
- [NICE guidelines on PFO closure for the prevention of cerebral embolic stroke 2013](#)
- [Percutaneous Pulmonary Valve Implantation for Right Ventricular Outflow Tract Dysfunction](#)

**8. Applicable quality requirements and CQUIN goals**

*There are no specific Adult Congenital Heart CQUINS*

**9. Location of Provider Premises**

TBC

**10. Individual Service User Placement**

N/A



## **Appendix 1: Definition of ACHD Surgery and Intervention**

This is a definition of which Cardiac Surgical Operations should be carried out only by Cardiac Surgeons who are currently revalidated in Congenital Cardiac Surgery\* and should be performed only in a designated ACHD Specialist Surgical Centre after approval by that unit's Multidisciplinary Team (MDT). These operations are termed "ACHD Surgery" and the outcomes of these operations will be audited by the UK Congenital Cardiac Audit Database. The referral route for these patients is via the Adult Congenital Cardiologist. Advice, as well as direct clinical care, will be available round the clock from designated ACHD Specialist Surgical Centre teams.

### **Section A: ACHD surgery includes all cardiac surgery in an adult who:**

1. ***Has had cardiac disease diagnosed, operated or intervened on in childhood.***

This includes surgery for the residua or sequelae of interventional management of congenital cardiac lesions.

2. ***Presents with a new primary diagnosis of Congenital Heart Disease.***

This includes Coarctation of the Aorta as well as structural cardiac lesions.

3. ***Is a Woman of Child Bearing Age with congenital heart disease***

All these patients **MUST** be seen by an ACHD Cardiologist and **MUST** be discussed at an ACHD MDT prior to surgery or intervention.

### **Section B: ACHD surgery does not necessarily include:**

1. ***Situations in which the primary cardiac pathology is adult acquired disease.***

Any secondary, minor congenital cardiac lesion should be discussed with the "Specialist" ACHD team prior to the decision to operate and a joint procedure (general adult cardiac surgeon and ACHD surgeon) should be considered where recommend by the MDT.

2. ***Surgery for Aortopathy***, which should be carried out by a specialist Aortopathy team which may be a Specialist Surgical Centre ACHD team depending on local arrangements.

3. ***Surgery of the Aortic Valve, including the Bicuspid Aortic Valve***, the overwhelming majority of which will be undertaken by general adult cardiac surgeons. However, in view of the specific expertise of congenital cardiac surgery, careful consideration must be given to the need to refer to a Specialist Surgical Centre ACHD Team, in the following scenarios where a general cardiac surgeon should rarely operate.

a. Patients less than 30 years of age.

b. Patients requiring:

1. Aortic Annulus Enlargement Procedures (Konno)

2. Aortic Autograft Surgery (Ross)

3. Aortic Valve Repair, especially for more complex congenital lesions.

If a patient needs such complex surgery on the aortic valve, then it should be performed by either the ACHD surgeon or general adult cardiac surgeon dependent on the decision of the ACHD MDT and the local arrangements for aortic surgery. Joint consultant (Congenital and General) operating is encouraged. Occasional practice in complex Aortic surgery by a surgeon without appropriately experienced multidisciplinary support is not acceptable.

**Section C: Surgery for immediately life threatening presentations of congenital heart disease, which, in less urgent scenarios, would qualify as ACHD surgery:**

The risks of transfer to a distant ACHD Specialist Surgical Centre should be balanced against the risks of delaying surgery, where time allows taking advice from the ACHD Specialist Surgical Centre. It is explicitly recognised that Cardiac teams must be supported to act in rare and demanding scenarios (e.g. dissection and endocarditis) where the individual patient is best served by “**Immediate Generalist**” rather than “**Delayed Specialist**” intervention.

*\* In addition, all Surgeons who achieved CCT in cardiothoracic surgery after 2014 will be required to appear on the GMC Sub-Specialty register of ‘Congenital Cardiac Surgery’.*

**Atrial Septal Defect and Patent Foramen Ovale Closures**

**Atrial Septal Defect**

Surgery for Atrial Septal Defects (ASD) should be undertaken by congenital surgeons within an ACHD Specialist Surgical Centre. The argument that this has historically been done by non-congenital surgeons is not relevant as:

- a) We are re-designing the service to achieve excellence of care now and in the future
- b) Morbidity etc. is a big issue in a low risk situation like ASD
- c) Essential for surgical numbers and training
- d) The overall aim is to concentrate expertise

As a key issue between surgery and catheter closure is decision making, catheter treatment should be undertaken in either a specialist ACHD surgical centre (L1) or a specialist ACHD centre (L2) to allow joined-up MDT planning.

Interventional closures of ASDs will usually be undertaken at a Specialist ACHD Surgical Centre, but ASD closures may be undertaken at a Specialist ACHD Centre providing certain conditions are met:

- All interventional ASD closures must only be undertaken under network agreed governance arrangements including oversight by the network lead congenital interventionist.
- All cases of ASD must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT where the intervention should be performed and by whom.
- ASD closure may be undertaken at a Specialist ACHD Centre only for patients with an adult diagnosis of CHD, with an ASD without additional complicating features.
- All procedures must be reported to the NICOR congenital audit.
- ASD closures may only to be undertaken at sites where vascular surgeons and cardiac surgeons are available to provide back-up and surgical retrieval of devices
- All interventionists must undertake a minimum volume of procedures as required by the ACHD standards.

**Patent Foramen Ovale**

**Closure of PFO is not considered a part of the spectrum of conditions covered by the term ACHD, and the management of PFOs is therefore not covered by this model.** This does not preclude PFO closure from being performed in ACHD services within the Congenital Heart Network.

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**Appendix Two**

**Quality standards specific to the service using the following template:**

<b>Quality Requirement</b>	<b>Threshold</b>	<b>Method of Measurement</b>	<b>Consequence of breach</b>
<b>Domain 1: Preventing people dying prematurely</b>			
3 year rolling partial risk adjusted 30 day mortality data	To be determined after first year submissions	NICOR validated submitted annual data	Non-compliance with contract General Conditions 8 & 9
3 year validated partial risk adjusted 30 day mortality data	To be determined after first year submissions	Unvalidated in house data submitted quarterly	Non-compliance with contract General Conditions 8 & 9
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>			
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>			
Unplanned re-intervention rate within 30 days of catheter or surgical intervention	To be determined after first year submissions	Number of re-interventions divided by total number of catheter or surgical intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter or surgical intervention	To be determined after first year submissions	Number of complications divided by total number of procedures	Non-compliance with contract General Conditions 8 & 9
<b>Domain 4: Ensuring that people have a positive experience of care</b>			
Responses to Patient Experience Surveys on CHD services	To be determined after first year submissions	Positive response to questionnaire on patient experience	Non-compliance with contract General Conditions 8 & 9
Last minute cancellation of elective surgical procedures	To be determined after first year submissions	Last minute cancellations of elective procedures divided by total number of surgical procedures	Non-compliance with contract General Conditions 8 & 9
Formal complaints	To be	Number of formal	Non-compliance

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Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Involving Inpatients	determined after first year submissions	written complaints involving patients admitted under the care of the paediatric cardiac service divided by total number of inpatient stays	with contract General Conditions 8 & 9
Waiting time (in days) for elective congenital cardiac surgery	To be determined after first year submissions	Mean waiting times and number of patients where time from decision to admit to admission was greater than 126 days divided by total number of elective surgical procedures	Non-compliance with contract General Conditions 8 & 9
<b>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</b>			
Data Quality Index (validated from NICOR)	90%	Unit NCHDA DQI	Non-compliance with contract General Conditions 8 & 9
Proportion of inpatients under care of the paediatric cardiac service acquiring new positive Clostridium/MRSA difficile cultures	To be determined after first year submissions	Number of inpatients under care of the paediatric cardiac service acquiring new positive Clostridium difficile/MRSA cultures divided by total number of inpatient stays	Non-compliance with contract General Conditions 8 & 9

