Congenital Heart Disease: Draft Standards and Service Specifications for consultation

Contents

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	*E05/S/a*
Service	Paediatric Cardiac Services
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

This specification will be subject to change in line with the outcome of NHS England's current review of Congenital Heart Services and the standards of care produced as a result of this process.

This specification covers all Paediatric Cardiac activity (surgery and cardiology), taking place in the Specialist Children's Surgical Centres (Level 1 services) and Specialist Children's Cardiology 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.

Paediatric Cardiac Services provide all cardiac care for children with heart abnormalities from the point of diagnosis to transition to adult services. This includes patients with congenital heart disease, inherited and acquired cardiac conditions.

The Congenital Heart Disease Standards include care taking place in Level 3 services (Local Children's Cardiology Centres). This activity is currently commissioned by Clinical Commissioning Groups and 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 Children's Level 1 and 2 services will work in partnership with Level 3 providers to ensure all patient care is of a consistent, high quality. Moreover, it is expected that networks will collaborate together to ensure uniformity of care throughout the healthcare system.

1.1 National/local context and evidence base

Background

Congenital heart disease (CHD) is one of the major categories of illness that, if treated, can restore health and improve quality of life. It constitutes the bulk of the paediatric cardiac workload. Currently 5-9 / 1,000 babies born in England will suffer from some form of Congenital Heart Disease (CHD). In 2012 this resulted in 4716 paediatric cardiac surgical procedures. Office of National Statistics 2012 data based on the 2011 Census, shows that the national population has increased at a greater rate than previously estimated, predicting an ongoing increase in the number of paediatric cardiac surgical procedures. Between 2001 and 2011 there has been an increase of 22% in the national birth rate with a corresponding rise in the number of paediatric cardiac surgical procedures taking place of 27%. Of note the increase of 400,000 (13 per cent) under-five-year-olds throughout England and Wales in this period is particularly pronounced in urban city areas.

Current Service Provision

The standards of care developed through the Safe and Sustainable process were approved by the JCPCT and not subsequently challenged by the judicial review or Independent Reconfiguration Panel. Revision of these has been an ongoing process and the draft final version of the standards of care produced by the Congenital Heart Disease Review Standards Group forms the basis of this service specification. Each Standard has an associated timescale within which units must be compliant. These range from immediate compliance to within 3 years and are detailed in the standards document.

These standards use a network model of care to provide age-appropriate, safe and effective services as locally as possible. 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. Children's Congenital Heart Services must partner with Adult Congenital Cardiac Services within the network to ensure that robust and co-ordinated communication, planning and co-operation exists to allow a smooth transition from diagnosis through to adulthood. Within a network the hospitals delivering children's cardiac care are configured in up to three levels. All must be able to demonstrate compliance with the appropriate level service standards:

- Level 1: Specialist Children's Surgical Centres (SCSC)
- Level 2: Specialist Children's Cardiology Centres (SCCC)
- Level 3: Local Children's Cardiology Centres (LCCC)

The exact configuration of any individual network will be determined by the outcome of the current Congenital Heart Disease Review due to report in 2015. During the current service review each Specialist Children's Surgical Centre (Level 1) will :

- maintain appropriate collaborative network relationships between units (Level 1, 2 and 3) in order to maintain a good outcome for patients;
- provide operational activity data on a monthly basis to Area Team Commissioners, i.e. The "Transition Dashboard"; and
- communicate consistently with families, staff and referrers regarding the progress of

the ongoing review.

Evidence Base

Draft Congenital Heart Disease Standards Level 1-3

Paediatric and Congenital Cardiac Services Review (2002),

Chapter 8 (Arrhythmias and Sudden Cardiac Death, 2005) of the National Service Framework for Heart Disease (2000)

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**	✓

The Clinical Reference Group have developed a quality dashboard for implementation in 2014/15. Proposed outcome measures include the following:

- Post Procedural Mortality – Crude annual 30 day and 1 year mortality for individual types of procedure (as published by NICOR). 3 year rolling partial risk adjusted total 30 day mortality.
- 30 day unplanned re-operation/ re intervention rate (NICOR defined procedure)
- Cancellations on day of operation for non clinical reasons
- Post catheter intervention complication rate
- Mothers with suspected CHD in fetus seen within 5 days
- Mothers with suspected CHD in fetus seen by specialist cardiac nurse at diagnosis

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 Aims and objectives of service

Service Aims

The service for paediatric 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 draft standards of care (2014);
- provide resilient and comprehensive 24/7 care;
- communicate effectively with other specialised services as required to ensure high quality care for children with co-morbidities
- provide age-appropriate, safe and effective services as locally as possible;
- ensure that parents and children 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;
- systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist
- demonstrate clinical outcomes in line with national and international standards for children with cardiac conditions adjusted for case mix.

Service Objectives

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

- developing Congenital Heart Networks to deliver a standardised model of paediatric heart disease service that meets national quality standards;
- providing high quality, timely and accurate diagnosis;
- agreeing treatment plans with patients and their families;
- undertaking safe and effective paediatric cardiac surgery and catheter intervention;
- providing appropriate counselling and psychological support to patients and their families;
- supporting patients and their families so they can aspire to 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;
- ensuring smooth and managed transition from paediatric to adult care; and
- providing an individualised palliative care and bereavement service.

3.2 Service description/care pathway

This specification covers the following service areas:

- Paediatric congenital heart disease services

- Paediatric acquired heart disease services
- Paediatric cardiac surgery and invasive cardiology services
- Fetal cardiology services
- Paediatric cardiac electrophysiology services
- Paediatric specialist cardiovascular imaging

Service description of Provider Centres within a Congenital Heart Network

The model of care for children with heart disease is based on an overarching principle of a congenital heart network, which will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the following centre's specific care level.

- (Level 1) Specialist Children's Surgical Centres (SCSC)
- (Level 2) Specialist Children's Cardiology Centres (SCCC)
- (Tier 3) Local Children's Cardiology Centres (LCCC)

Paediatric Cardiac Services should be aligned within the network with fetal and adult congenital services such that the transition from fetus → child, child → adolescent and adolescent → adult, follows a joined-up approach with continuity of care. Children's cardiac services will form part of a larger Congenital Heart Network to facilitate seamless transition through the constituent services. It is expected that the regional networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS.

The Specialist Children's Surgical Centres will provide active leadership in the Congenital Heart Networks. They will work with the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres within the Network to:

- manage and develop referral and care pathways;
- manage and develop treatment and transfer pathways;
- develop network policies, protocols, and procedures;
- performance monitor through agreed governance arrangements;
- undertake audit, professional training and development;
- facilitate the development of as much care and treatment as possible close to the child's home;
- manage the transition to adult services; and
- continually review the pathways to ensure they provide the best care and support for parents and their children.

Specialist Children's Surgical Centres (SCSCs) (Level 1)

- Specialist Children's Surgical Centres (SCSCs) will perform all surgical and interventional procedures on children and provide a full range of diagnostic tests for fetal and paediatric patients.
- SCSCs will provide assessment and follow-up services for children who live locally.
- Consultant Cardiologists from the SCSC will provide an outreach outpatient

service in conjunction with paediatricians with special expertise in cardiology at Local Children’s Cardiology Centres within their network.
- The SCSC will host weekly multidisciplinary team meetings to discuss patient management. They will facilitate regular face-to-face and teleconference attendance by Specialist Children’s Cardiology and Local Children’s Cardiology Centres.
- SCSCs along with other units providing care within a congenital heart network will hold regular multidisciplinary meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.
- SCSCs will develop and implement a system of ‘patient-held records’ that will be used throughout the network ensuring joined-up treatment and care.

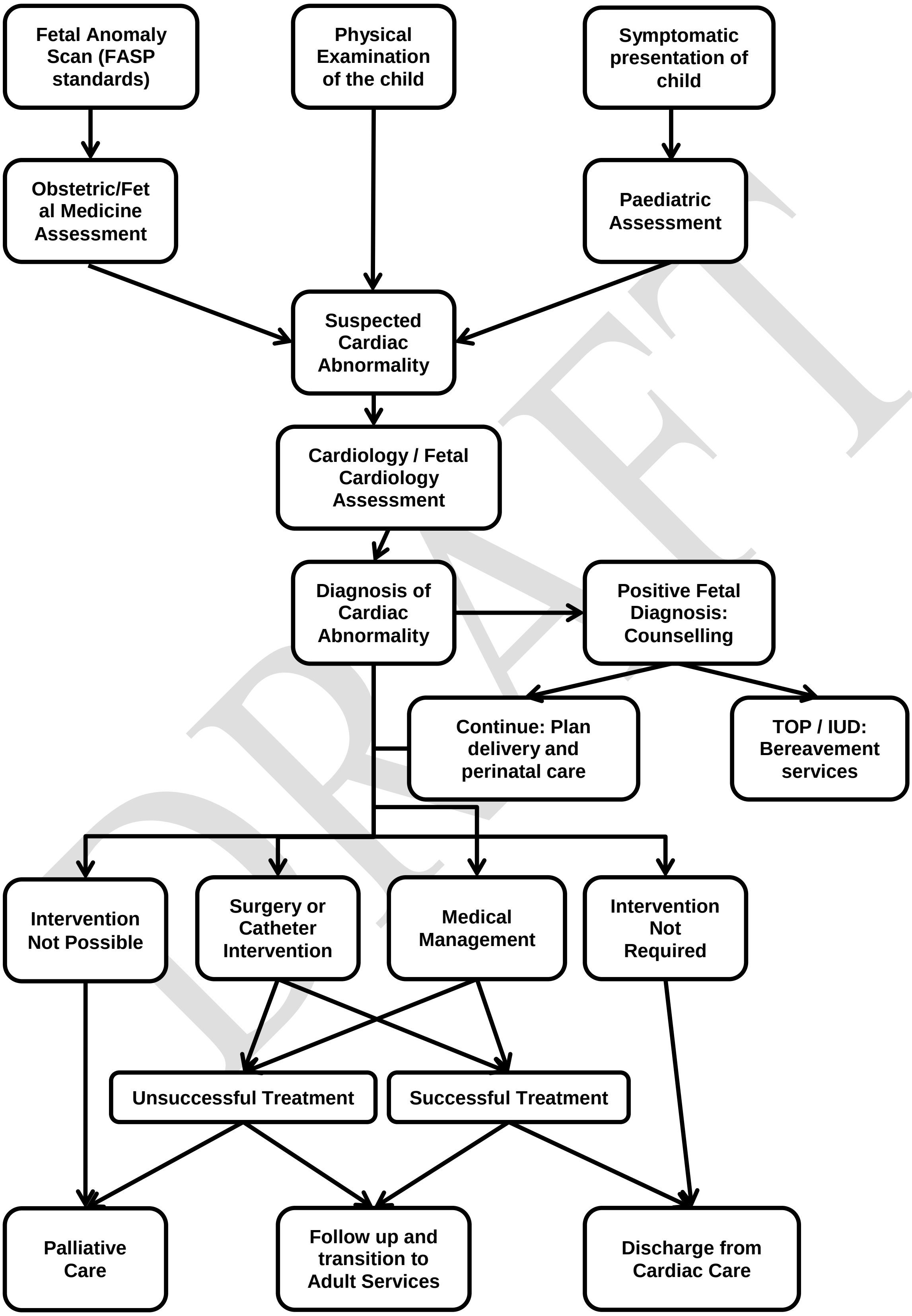
Specialist Children’s Cardiology Centres (SCCC) (Level 2)

- The team of Consultant Paediatric Cardiologists will provide all paediatric cardiac medical services including assessment of new referrals and ongoing inpatient and outpatient medical management of children with heart disease.
- Consultant Cardiologists from the SCCC will provide an outreach outpatient service in conjunction with paediatricians with special expertise in cardiology at Local Children’s Cardiology Centres within their network.
- Children who need surgical or interventional procedures will be referred by the SCCC to the SCSC.
- If clinically indicated, emergency balloon atrial septostomy and temporary pacing may be conducted in a SCCC following clear Network guidelines,

Local Children’s Cardiology Centres (LCCC) (Level 3))

- LCCC will be available in some local hospitals. The team will include a Consultant Paediatrician with Expertise in Cardiology.
- Each LCCC will be allocated a named Consultant Paediatric Cardiologist from the SCCC or SCSC. They will undertake combined outreach clinics regularly at the LCCC and provide a link between the two hospitals.
- Local children with suspected heart disease may initially be referred to the LCCC where inpatient and outpatient management can be undertaken. When a higher level of expertise is needed, children will be referred to the SCCC or SCSC.

Patient care pathway



Referral

Patients enter the paediatric cardiac pathway through:

- Prenatal diagnosis.
- Physical examination of an asymptomatic infant or child.
- Symptomatic infant or child.

Patients are routinely referred through:

- Obstetric Ultrasound Department, Fetal Medicine Department; Obstetrician, Midwife.
- Neonatal /Paediatric Centres; Paediatrician.
- Primary Care; Patient’s GP.

The appropriate paediatric cardiac service will:

- See referrals within 3 days following detection of a cardiac abnormality during fetal anomaly scan.
- Screen pregnancies at increased risk of fetal cardiac anomaly.
- Provide 24/7 telephone advice for referral or for patients with an acute illness that may be related to their cardiac abnormality. (Under an agreed provider network).
- Provide inpatient facilities to urgently transfer stabilise and monitor appropriate referrals.
- See routine outpatient referrals within standard NHS waiting time guidelines.
- Where appropriate provide access to and co-ordinate results and assessment from a range of diagnostic tests and from expertise in other specialties.

Initial Care

The appropriate paediatric cardiac service will:

- Establish an accurate and complete diagnosis of congenital heart disease.
- Establish a baseline against which disease progression and response to treatment can be measured.
- Carry out a multidisciplinary team (MDT) assessment of all referred patients with significant congenital heart disease within three months.
- Agree the need for any 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.
- Provide age-appropriate verbal, written and/or electronic material in an understandable format about the congenital cardiac condition to patients and their families/carers.
- Provide a clear contact/support pathway for parents /carers (Named Specialist nurse)

Ongoing Care

Prenatal diagnosis

- A fetal cardiologist or a paediatric cardiologist with expertise in fetal cardiology will make or confirm the diagnosis and explain the condition, likely management and prognosis.

- They will discuss options available to the family in a non-directive, caring and supportive way with direction given to publically available information
- A fetal or children's cardiac specialist nurse will be present when the diagnosis is explained to the parents, or make contact with them to provide information and support on the day of diagnosis.
- Written information regarding the condition, pathways discussed, available support services including contact details of local and national support groups will be provided.
- All relevant information will be communicated to network clinical teams involved.
- A management plan for the pregnancy and delivery will be discussed with fetal medicine unit, local obstetric unit, local paediatric team, neonatal team and parents.
- A decision will be made as to whether delivery should be at or close to the SCSC in all cases where the baby may require immediate surgery or catheter intervention.
- A children's cardiac nurse specialist/fetal cardiac nurse specialist telephone advice service will be available for patients and their families/carers, healthcare professionals and non-healthcare and voluntary sector professionals.
- Fetal medicine specialists either at local hospital or specialist centre should ensure there is a complete assessment of the whole baby.

Children with a Confirmed Cardiac Abnormality

The appropriate paediatric cardiac service will:

- Provide regular patient reviews as per national guidelines or clinical practice with written and electronic records of current treatment and patient response.
- Provide access to inpatient and critical care facilities where appropriate.
- Provide access to National specialised services, e.g. pulmonary arterial hypertension (PAH), transplantation, as appropriate.
- Deliver appropriate pharmaceutical therapy.
- Provide patient-centred services, sensitive to the individual's physical, psychological and emotional needs and supported through the provision of patient-appropriate information.
- All patients must have access to a children's cardiac specialist nurse and complex patients will have a named children's cardiac nurse responsible for co-ordinating their care
- Facilitate appropriate shared care arrangements with other paediatric congenital heart disease service providers.
- Provide children's cardiac specialist nurse telephone advice service for patients and their families/carers, healthcare, non-healthcare and voluntary sector professionals.

General Paediatric Care

- All paediatric cardiac service providers will follow the standards outlined in the Specification for Children's Services (attached as Annex 1 to this Specification).

Leaving the Pathway

Palliative or end-of-life care

The appropriate paediatric cardiac service will:

- Use nationally approved paediatric palliative medicine pathways to plan palliative care.
- Agree a named lead doctor and nurse for any patient entering a palliative care pathway who will ensure the child and their family are supported up to and beyond death.
- Produce a written, agreed, individual, end-of-life care plan after consultation with the child, their family/carers and all healthcare professionals likely to be involved in the care of the child.
- Liaise actively with NHS and non-NHS professionals to ensure access to appropriate palliative or end-of-life services and make the child and their family/carers are aware of these.
- Ensure that support for the child and their family/carers continues in the community with access to hospital support 24/7.
- After death, the family should be contacted by a children's cardiac specialist nurse within 1 working week at a mutually agreed time and location, to offer support.
- Within 6 weeks of death the family should be contacted by the lead doctor and offered the opportunity to meet and discuss their child's death with the hospital team.
- Generate and publish evidence of effective palliative or end-of-life care for patients / carers.

Adverse Outcomes

- When patients experience an adverse outcome from treatment or care, medical and nursing staff must maintain open and honest communication with patients and their families according to the NHS "Being Open" framework (2009).
- A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family.

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

The process of transitioning from paediatric to ACHD care will take place between 12 and 18 years of age taking into account individual circumstances.

Paediatric and ACHD 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 services.
- All young people requiring long term congenital cardiac care must be seen at least once by an ACHD cardiologist and ACHD nurse specialist in a specialist MDT transfer clinic or equivalent.

- A children's cardiac transition nurse will act as a liaison between young people, their carers, the children's cardiac nurse specialist, ACHD nurse specialist and wider multidisciplinary team to facilitate the transition process.
- The network must provide age-appropriate information in an appropriate format to the patients and families/carers, covering the full range of social and health-related advice
- Each CHD network must agree and provide formalised operational transition policy consistent with the congenital heart disease standards and with the generic specification for transition produced by the paediatric medicine CRG.

Processes

Paediatric Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the SCSC. This includes all patients being considered for a complex catheter intervention or surgery.
- 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 Anaesthetist. 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.

Patient registers/database

- All children transferring between services will be accompanied by high quality information, including a health records summary and a management or follow up plan. Note: The health records summary will be a standard national template developed and agreed by the Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and NHS commissioners.
- There will be written protocols covering communication between clinicians, clinicians and parents / carers and between clinicians and children / young people. The protocols will be developed and agreed with local referring Paediatricians, Paediatric Cardiologists, Children's Cardiac Specialist Nurses, Clinical Psychologists and Patient Groups.
- All centres must 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), as appropriate.
- All centres delivering care to children with cardiac abnormalities will co-operate in

developing a national register of research trials and outcomes.

Annual reports

Congenital Heart Networks will produce annual audit and governance reports covering paediatric cardiac services.

3.3 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). 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 black and minority ethnic (BME) communities are also found in greater numbers than the general population.

(*) 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.

Acceptance criteria

- Pregnancy with either suspected fetal heart disease or at high risk of fetal heart disease
- All patients (including patients with congenital heart disease and inherited/ acquired conditions) , before the sixteenth birthday at referral, with suspected or confirmed heart disease. In some cases it may be appropriate to offer choice to older teenagers (up to the eighteenth birthday).

Exclusions

The specification excludes:
- Major airway surgery undertaken by Congenital Cardiac Surgical teams

This service specification applies to any patient with a congenital heart condition requiring treatment, and whose condition enters them onto this pathway of care. This pathway may develop before birth in cases with a prenatal diagnosis.

Supra-Regional Services

- Potential candidates for paediatric cardiac transplantation (including implantation of a mechanical support device as a bridge to transplantation) must be referred to a designated paediatric cardiac transplant centre. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer policies, protocols and procedures in respect of transplant patients.

- Similar arrangements exist for the referral of children and young adults with severe pulmonary hypertension to the national pulmonary hypertension service.

Interdependencies with other services/providers

All units providing care for children with heart disease must conform to the standards for interdependency as laid out in section D of the appropriate Tier of the draft congenital heart disease standards (2014). They have not been included in detail here for brevity.

4. Applicable Service Standards

Infrastructure requirements

Network Requirements

- The exact configuration of an individual network will be agreed locally with area commissioners.
- The Congenital Heart Network will include fetal cardiac, paediatric cardiac and adult congenital cardiac services.
- Separate Congenital Heart Networks will not work independently of each other. There will be regular collaboration to ensure equality of care throughout the health service.

Network Staffing

- Each Network will have a formally appointed Network Clinical Director from within the network itself.
- The Network Clinical Director will provide clinical leadership across the network and be responsibility for the network’s service overall.
- The Director will be supported by separate clinical leads for surgery, cardiac intervention, fetal cardiology, paediatric heart disease, adult congenital heart disease, cardiac intensive care and anaesthesia.
- Each Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.
- Appropriate managerial and administrative support for the effective operation of the network is the joint responsibility of all constituent units.
- Each Network will have annual training plans in place, to ensure ongoing education and professional development for all healthcare professionals involved in the care of children with congenital heart problems.

Specialist Children’s Surgical Centres

- Each SCSC will have a formally nominated paediatric CHD lead who will support the Network Clinical Director. Each SCSC will also have a formally nominated lead CHD nurse. Both will have responsibility for the service at the SCSC, with additional responsibilities across the network.

Surgeons
- Surgical teams must consist of a minimum of 4 WTE consultant congenital cardiac surgeons. Units will have a period of three years to achieve this standard.
- SCSCs must provide 24/7 surgical care across the spectrum of neonatal and paediatric surgical emergencies (with the exception of cardiac transplantation)
- .
- SCSCs 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) each year, averaged over a three-year period.

Cardiologists
- SCSCs must be staffed by a minimum of 1 consultant paediatric cardiologist per half-million population served by the network, working flexibly across the network
- SCSCs must provide 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover, with rotas no more frequent than1 in 4. This may include congenital interventional cardiologists based at other hospitals.
- 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 SCSC must be staffed by a minimum of one electrophysiologist experienced in paediatric cardiac disease.
- Each SCSC will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each SCSC will have a lead for congenital echocardiography (EACVI accredited or retrospective equivalent experience).
- Each SCSC will have a lead for fetal cardiology who has fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology SAC or AEPC. Units will require more than one cardiologist with training in fetal cardiology to meet the requirements of the fetal cardiology standards.

Nursing
- Each SCSC will have a senior children’s nurse with specialist knowledge and experience in the care of children in paediatric cardiology and cardiac surgery. They will lead a dedicated team of nursing staff trained in the care of children who have received cardiac surgery.
- Each SCSC will provide sufficient clinical cardiac nurse educators to deliver competency-based programs for nurses across the network
- Each Congenital Heart Network will have a minimum of 7 WTE children’s cardiac nurse specialists distributed as appropriate across the network.
- Each Congenital Heart Network will have at least 1 WTE fetal cardiac nurse specialist.
- Each Congenital Heart Network will have at least 1 WTE designated children’s cardiac transition nurse.

Other

- SCSCs must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, within legally compliant rotas, including 24/7 paediatric surgery and interventional cardiology cover. A consultant ward round must occur daily.
- Each SCSC will have a team of congenital echocardiography scientists (technicians), with a designated lead who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service.
- The provision of 1 WTE Practitioner psychologist for each 400 children and young adults undergoing cardiac surgery each year and a further 1 WTE for each 5,000 children and young people with CHD.
- Children who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a designated paediatric cardiothoracic transplant centre.
- The SCSC will have a paediatric palliative care service able to provide good quality end-of-life care in hospital and with well developed shared-care palliative services with the community.
- Each SCSC must have a minimum of 1 WTE dedicated paediatric cardiac data collection manager, with at least 1 WTE assistant, responsible for timely audit and database submissions.
- Each SCSC must have a minimum of 2 WTE dedicated play specialists.
- Equipment infrastructure on site: Electrophysiology; standard, contrast, intraoperative, transesophageal and feta echocardiography (echo); cardiac catheterisation laboratory; Magnetic Resonance Imaging (MRI); Computerised Tomography (CT); post-operative extra corporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO)); and access to Isotope Imaging.

Specialist Children's Cardiology Centres (SCCCs)

- Congenital Heart Networks may be supported by one or more SCCC. 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.
- Each SCCC must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within legally compliant rotas

Cardiologists

- Each SCCC will be staffed by a minimum of 4 WTE Consultant Paediatric Cardiologists, in addition to the 1 WTE per half million of the population covered by the centre.
- Each SCCC will have a designated Clinical Paediatric Cardiology lead with responsibility for service provision within the SCCC.
- Each SCCC will have separate leads for relevant clinical specialties (e.g. fetal,

echocardiography, cardiac intensive care) that will have a direct link and collaborative working partnership with the leads in the SCSC.

- Leads at the SCCC may also take on a similar role for the Network.
- Interventional cardiologists from the SCCC who undertake procedures at the SCSC must perform at least 50 procedures a year, averaged over a three-year period.
- Paediatric Intensive Care Unit (PICU) Consultants with appropriate skills in paediatric cardiac intensive care must be available to the PICU 24/7, in line with Paediatric Intensive Care Society standards.

Nursing

- Each SCCC must have a formally nominated Nursing Clinical Lead who has a direct collaborative working partnership with the Lead Nurse for the network and has specified time working in paediatric cardiology.
- Each SCCC must have designated registered children's nurses with a special interest in paediatric cardiology, trained and educated in the care of children and young people with heart disease.
- There must be a minimum of two registered children's nurses allocated to the children's cardiology beds who are trained according to the RCN competency framework.
- An appropriate number of Children's Cardiac Nurse Specialists will be based at the SCCC and supported by the team at the Specialist Surgical Centre. Where a fetal cardiology service exists this must be supported by a Children's cardiac nurse specialist with experience in fetal counselling.

Other

- Children referred to the SCCC must be seen and cared for in age-appropriate inpatient and outpatient environments, staffed by professionals experienced in the care of children and young people with heart disease.
- Each SCCC will have a team of Congenital Echocardiography scientists (technicians) who should have, or be working towards, EACVI accreditation. The number will depend on the configuration of the service.
- Each SCCC must have access to a Clinical Psychology Service for children, and for parents and carers.
- Each SCCC must have an identified member of staff to ensure high quality data input into the network database.
- Each SCCC will provide administrative support to ensure availability of medical records, organise clinics, type letters, arrange investigations, ensure timely results of investigations, arrange follow-up and respond to parents in a timely fashion.
- Each SCCC will have telemedicine facilities to link with the SCSC.
- SCCC will follow Congenital Heart Network pathways of care and management of congenital heart defects agreed with the SCSC and in line with the draft congenital heart disease standards (2014).
- Each SCCC will provide all non-invasive investigations (including electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure monitoring, treadmill exercise testing, high quality echocardiography facilities, CT and MRI).

Local Children's Cardiology Centres (LCCC)

- Congenital Heart Networks will be supported by LCCC. 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.
- LCCC will have a named Consultant Paediatrician with expertise in cardiology (PEC).
- Each PEC will hold an honorary contract with the SCSC and/or the SCCC to enhance continued professional development and facilitate good working relationships.
- LCCC will have a locally designated registered children's nurses with a specialist interest in children's cardiology, trained and educated in the care of cardiac children and young people. 0.25 WTE must be available to participate in cardiology clinics.
- LCCC must have access to a Clinical Psychology Service for children, parents and carers.
- LCCC will provide administrative support to ensure availability of medical records, organise clinics, type letters, arrange investigations, ensure timely results of investigations, arrange follow-up and respond to parents in a timely fashion.
- LCCC will follow Congenital Heart Network pathways of care and management of congenital heart defects agreed with the SCSC and in line with the draft congenital heart disease standards (2014).
- LCCC will have telemedicine facilities to link with the SCSC.
- LCCC will provide basic non-invasive investigations (including basic electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure monitoring and high quality echocardiography facilities).

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

SCSCs must complete the quality dashboard introduced by the congenital cardiac CRG in 2014. The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision. Such changes may be introduced prior to 2015.

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

Not applicable.

6. Location of Provider Premises

To be introduced following the outcome of the current congenital cardiac review in 2015.

7. Individual Service User Placement

Not applicable

Appendix 1:

Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
1 year 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 rolling 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
Domain 2: Enhancing the quality of life of people with long-term conditions			
Response to Somerville Foundation survey on transition to adult care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Unplanned reintervention rate within 30 days of catheter intervention	To be determined after first year submissions	Number of reinterventions divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter intervention	To be determined after first year submissions	Number of complications divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			
Same day cancellation of elective surgical procedures	To be determined after first year submissions	Number of same day cancellations of elective procedures divided by total number of surgical procedures	Non-compliance with contract General Conditions 8 & 9
% Patients with suspected CHD seen within 3 days of sonographic identification	To be determined after first year submissions	Number seen within 3 days from date of referral divided by total referrals with suspected CHD seen within time period	Non-compliance with contract General Conditions 8 & 9
% Patients with confirmed diagnosis seen by specialist cardiac nurse at time of diagnosis	To be determined after first year submissions	Number seen by specialist cardiac nurse divided by Total diagnoses within time period	Non-compliance with contract General Conditions 8 & 9
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Data Quality Index (validated from NICOR)	To be determined after first year submissions	Unit NICOR DQI	Non-compliance with contract General Conditions 8 & 9

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Total surgical case load	To be determined after first year submissions	Number of NICOR defined surgical procedures in 1 year	Non-compliance with contract General Conditions 8 & 9
Total catheter intervention caseload	To be determined after first year submissions	Number of NICOR defined catheter intervention procedures in 1 year	Non-compliance with contract General Conditions 8 & 9

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would fundamental to all services.

The generic aspects of care:

- The Care of Children in Hospital (Health Services Circular (HSC) 1998/238) requires that:
- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services*, Department of Health & Department for Education and Skills, 2004)

Paediatric Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' Department of Health 13732 March 2010).

Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer and review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements.

- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required.
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to CPD.
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training (1). All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training (2) and should maintain the competencies so acquired (3). These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery and catheter intervention, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (MRI) scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

References:

1. Guidelines for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists 2010 www.rcoa.ac.uk
2. Certificate of Completion of Training in Anaesthesia 2010
3. Continuing Professional Development matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx
- Staffing profiles and training - essential QNIC standards should apply.
- The child / young person's family are allowed to visit at any time of day taking account of the child / young person's need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child / young person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child / young person.

Applicable national standards

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes *HBN 23 Hospital Accommodation for Children and Young People* NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies

(National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002).”Facing the Future” Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (*Seeking Consent: working with children* Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:
- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
    - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
    - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
    - reporting the alleged abuse to the appropriate authority
    - reviewing the person’s plan of care to ensure that they are properly supported following the alleged abuse incident.

- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

Key Service Outcomes

General

Implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) leads to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is expected to contribute to improvements in health inequalities and public health outcomes. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Transition

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. When children and young people who use paediatric services are moving to access adult services these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

Environment

All hospital settings should meet the *Standards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).

The *National Minimum Standards for Providers of Independent Healthcare*, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)
- All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.
- All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate
- All registered providers must ensure safe use and management of medicines,

by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensuring that staff handling medicines have the competency and skills needed for children and young people’s medicines management
- Ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- They meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health Publications, 2006, London

	Paediatric	Implementation timeline
	Specialist Children's Surgical Centres	
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network's host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network.	Within 6 months
A2(L1)	Specialist Children's Surgical Centres in partnership with the Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of children and young people with congenital heart disease. The model of care will ensure that all congenital cardiac care is carried out only by congenital cardiac specialists (including investigation, cardiology and surgery). The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist Children's Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity and obstetric services, children's services, transition, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist Children's Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for fetal services, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.	Within 6 months
A4(L1)	Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network,	Immediate

	Paediatric	Implementation timeline
	including at the Specialist Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; and f. address how Specialist Children's Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	
A5(L1)	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Critically ill children must be transferred/retrieved in accordance with the standards set out within the designation standards for Paediatric Intensive Care services. c. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	Immediate
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Immediate
A7(L1)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Within six months
A8(L1)	Specialist Children's Surgical Centres will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years
	Cardiological Interventions	
A9(L1)	Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place	Within 3 years

	Paediatric	Implementation timeline
	within a Specialist Children's Surgical Centre; b. allow neonates with *patent ductus arteriosus* to receive surgical ligation in the referring neonatal intensive care unit (level 3)[1] provided that the visiting surgical team is dispatched from a designated Specialist Children's Surgical Centre and is suitably equipped in terms of staff and equipment (this is the sole exception to the requirement that heart surgery must be performed in a designated Specialist Children's Surgical Centre). It will be for each Congenital Heart Network to determine whether this arrangement is optimal (rather than transferring the neonate to the Specialist Children's Surgical Centre) according to local circumstances, including a consideration of clinical governance and local transport issues; c. ensure that emergency balloon atrial septostomy and temporary pacing, if undertaken outside of a Specialist Children's Surgical Centre, can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process; d. ensure that patients requiring electrophysiology must be treated in dedicated paediatric services, with paediatric cardiac surgical support not adult services; and e. enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist Children's Surgical Centre or in another Specialist Children's Surgical Centre, if the need arises.	
	Non-Cardiac Surgery	
A10(L1)	Specialist Children's Surgical Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment by a Congenital Heart team, including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, the most appropriate location for that surgery or investigation, and advice to paediatricians across the Congenital Heart Network.	Immediate
	External Relationships	
A11(L1)	Each Specialist Children's Surgical Centre must have a close network relationship with all maternity and fetal medicine services within their network and be able to demonstrate the operation of joint protocols.	Immediate

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[1] Neonatal intensive care units (NICUs) are sited alongside specialist obstetric and feto-maternal medicine services, and provide the whole range of medical neonatal care for their local population, along with additional care for babies and their families referred from the neonatal network. Many NICUs in England are co-located with neonatal surgery services and other specialised services. Medical staff in a NICU should have no clinical responsibilities outside the neonatal and maternity services. A minimum of a 1:1 qualified nurse staff-to-baby ratio is provided at all times (some babies may require a higher staff-to-baby ratio for a period of time): Toolkit for High Quality Neonatal Services; DH 2009

	Paediatric	Implementation timeline
A12(L1)	Each Specialist Children's Surgical Centre must have a close network relationship with any ACHD providers within their Congenital Heart Network and be able to demonstrate the operation of joint transition protocols.	Immediate
A13(L1)	Each Congenital Heart Network must contain at least one Specialist Children's Surgical Centre in a formal network relationship with the Specialist ACHD surgical service, Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, evidenced by agreed joint referral and care protocols. Each Specialist Children's Surgical Centre must have a formal network relationship with the following, evidenced by agreed joint referral and care protocols: a. the paediatric cardiothoracic transplant centres; b. the national Pulmonary Hypertension Service; and c. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities.	Immediate
A14(L1)	Children and young people who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a designated paediatric cardiothoracic transplant centre. The referring specialist is responsible for explaining to the patient and their family the transplant pathway and the risks and benefits of referral and any alternative pathways to inform patient choice. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	Immediate
A15(L1)	Each Specialist Children's Surgical Centre must have a close relationship with all community paediatric services in their network, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
	Telemedicine and IT	
A16(L1)	Each Specialist Children's Surgical Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances) and with other Congenital Heart Networks. The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to:	Within 3 years

	Paediatric	Implementation timeline
	a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric cardiac services.	
A17(L1)	Each Specialist Children's Surgical Centre must cooperate to allow visiting paediatric cardiologists and PECs from the network to gain remote access to the Specialist Children's Cardiology Centre or Local Children's Cardiology Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A18(L1)	Each Specialist Children's Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will 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). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, a paediatric cardiologist and a paediatric intensivist.	Immediate
A21(L1)	The Specialist Children's Surgical Centres and services within the Congenital Heart Network will hold regular multidisciplinary team meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.	Immediate
	Network Leadership	

	Paediatric	Implementation timeline
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	Within 6 months
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
A1(L2)	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist Children's Cardiology Centres where appropriate. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Within 6 months
A2(L2)	Each Specialist Children's Cardiology Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	Each Specialist Children's Cardiology Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. Prenatally diagnosed congenital heart defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be referred to the network fetal cardiac service. Counselling will take place including discussion about the location of the delivery of the baby. b. Newborns with a murmur and otherwise clinically well Care may be provided at the Specialist Children's Cardiology Centre. c. Neonates and infants diagnosed with congenital heart defects Each Specialist Children's Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate. d. New referrals from GPs and paediatricians Local hospitals will refer children/young people to a Specialist Children's Cardiology Centre/Local Children's Cardiology Centre, as necessary, for the following categories of referrals: • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness • Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease	Within 6 months

	Paediatric	Implementation timescale
	e. Ongoing care of children and young people diagnosed with congenital heart defects Local hospitals will refer children/young people to the Specialist Children's Cardiology Centre or Local Children's Cardiology Centre as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.	
A4(L2)	Specialist Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialist Children's Surgical Centres, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres according to local circumstances; f. address how Specialist Children's Cardiology Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. provide 24/7 cover by consultant paediatric cardiologists for specialist advice.	Immediate
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Within 6 months
A6(L2)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will comply with a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	

	Paediatric	Implementation timescale
A7(L2)	Specialist Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways of care that will: a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre; and b. ensure that emergency balloon atrial septostomy and temporary pacing, if undertaken in a Specialist Children's Cardiology Centre can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process.	Within 6 months
	Non-Cardiac Surgery	
A8(L2)	Specialist Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of a pre-operative risk assessment by a Congenital Heart team including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.	Immediate
	External Relationships	
A9(L2)	Each Specialist Children's Cardiology Centre must have a close network relationship with all maternity and fetal medicine services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist Children's Cardiology Centre must have a close network relationship with any ACHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist Children's Cardiology Centre must demonstrate formal working relationships with: a. network Specialist Children's Surgical Centres and Local Children's Cardiology Centres, according to local circumstances; b. the paediatric cardiothoracic transplant centres; c. the national Pulmonary Hypertension Service; and d. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities.	Within 6 months
A12(L2)	Each Specialist Children's Surgical Centre must have a close relationship with all community paediatric services in their network, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate

	Paediatric	Implementation timescale
	Telemedicine and IT	
A13(L2)	Each Specialist Children's Cardiology Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Children's Surgical Centres and Local Children's Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric services.	Within 3 years
A14(L2)	Each Specialist Children's Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist Children's Surgical Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A15(L2)	Each Specialist Children's Cardiology Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist Children's Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT.	Within 1 year
A17(L2)	Staff from the Specialist Children's Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A18(L2)	The composition of the MDT will 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).	Immediate

	Paediatric	Implementation timescale
	Network Leadership	
A19(L2)	Each Specialist Children's Cardiology Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the Network. The postholder must have specified time working in paediatric cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
A1(L3)	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local Children's Cardiology Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Immediate
A2(L3)	Each Local Children's Cardiology Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L3)	Local Children's Cardiology Centres must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care as defined as part of network arrangements. Each Local Children's Cardiology Centre will provide pathways of care and management of congenital heart defects agreed with the Congenital Heart Network: a. Prenatally diagnosed congenital heart defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be referred to the network fetal cardiac service. Counselling will take place including discussion about the location of the delivery of the baby. b. Newborns with a murmur and otherwise clinically well Care may be provided at the Local Children's Cardiology Centre. c. Neonates and infants diagnosed with congenital heart defects Each Local Children's Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate. d. New referrals from GPs and paediatricians Following review by the Paediatrician with Expertise in Cardiology, children/young people will be referred to a Specialist Surgical Centre or Children's Cardiology Centre, as necessary, for the following: • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness	Immediate

	Paediatric	Implementation timescale
	• Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease e. Ongoing care of children and young people diagnosed with congenital heart defects Local hospitals will refer children/young people to the Local Children's Cardiology Centre as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.	
A4(L3)	Local Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialised Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; f. address how Local Children's Cardiology Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. deliver joint clinics between a paediatric cardiologist and a paediatrician with a expertise in cardiology in a Local Children's Cardiology Centre. Local Children's Cardiology Centres will provide weekday cover for CHD advice from a local network of PECs.	Within 1 year
A5(L3)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Within 6 months

	Paediatric	Implementation timescale
A6(L3)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L3)	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre. Local Children's Cardiology Centres may not undertake any paediatric cardiac surgeries, planned interventional catheter procedures or diagnostic catheter procedures as part of their investigation into congenital heart disease. Local Children's Cardiology Centres may undertake coronary angiography and cardioversion.	Immediate
	Non-Cardiac Surgery	
A8(L3)	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of pre-operative risk assessment by a Congenital Heart team including a paediatrician with expertise in cardiology and paediatric anaesthetists, in discussion with a paediatric cardiologist, for patients requiring non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.	Immediate
	Emergency Care	
A9(L3)	When children or young people with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local Children's Cardiology Centres will seek advice from the local PEC or a paediatric cardiologist at a specialist centre on appropriate care and management.	Immediate
	External Relationships	
A10(L3)	Each Local Children's Cardiology Centre must demonstrate formal working relationships with the network Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, according to local circumstances. Other supraregional services will be accessed via the CHD network.	Immediate

	Paediatric	Implementation timescale
A11(L3)	Local Children's Cardiology Centres must have a close relationship with local community paediatric services, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
	Telemedicine and IT	
A12(L3)	Each Local Children's Cardiology Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	Within 3 years
A13(L3)	Each Local Children's Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre system and enable immediate access to patient data.	Within 6 months
	Multidisciplinary Team (MDT)	
A14(L3)	Staff from across the Local Children's Cardiology Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.	Immediate
A15(L3)	Each designated paediatrician with expertise in cardiology will attend (in person or by VC link) the weekly network MDT meeting at least six times per year, and must also attend the annual network meeting. This requirement will be reflected in job plans.	Within 1 year
A16(L3)	Each designated paediatrician with expertise in cardiology will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Within 1 year
A17(L3)	Each Local Children's Cardiology Centre must have identified registered children's nurses with an interest and training in children's and young people's cardiology.	Within 1 year

	Paediatric	Implementation timetable
	Specialist Children's Surgical Centres	
B1(L1)	Each Specialist Children's Surgical Centre 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 paediatric surgery and interventional cardiology cover. A consultant ward round will occur daily.	Within 6 months
B2(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist Children's Surgical Centre; or b. the child/young person must be referred to an alternative Specialist Children's Surgical Centre where a surgeon/interventionist has the appropriate skills.	Immediate
B3(L1)	Arrangements must be in place in each Specialist Children's Surgical Centre both for consultant interventional paediatric cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	Immediate
B5(L1)	Specialist Children's Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.	Immediate
B6(L1)	Each Specialist Children's Surgical Centre will have a formally nominated paediatric CHD lead with responsibility for the service at the Specialist Children's Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	Within 6 months
B7(L1)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Surgery	
B8(L1)	All paediatric cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in	Immediate

	Paediatric	Implementation timetable
	paediatric cardiac disease.	
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: within 3 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).	Within 3 years
	Cardiology	
B11(L1)	All paediatric congenital cardiology must be carried out by specialist paediatric cardiologists.	Immediate
B12(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one consultant paediatric cardiologist per half million population served by the network, working flexibly across the network.	Within 3 years
B13(L1)	Each Specialist Children's Surgical Centre must deliver 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover for the Specialist Children's Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4. The rota may deliver care for both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B14(L1)	Consultant interventional cardiology cover must be provided by consultant interventional paediatric cardiologists providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. This could include interventional cardiologists based at a Specialist Children's Surgical Centre or a Specialist Children's Cardiology Centre. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for interventionists only to undertake procedures for which they have the appropriate competence.	Within 1 year

	Paediatric	Implementation timetable
	The rota will deliver care for both children and adults. If this means that the interventionist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	
B15(L1)	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B16(L1)	Cardiologists performing therapeutic catheterisation in children and young people with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year; the Lead Cardiologist must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B17(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one electrophysiologist experienced in paediatric cardiac disease.	Immediate
B18(L1)	Paediatric electrophysiology procedures must only be undertaken by an electrophysiologist experienced in the management of paediatric arrhythmias.	Immediate
B19(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and d. a nurse with experience of paediatric cardiac catheterisation.	Immediate
B20(L1)	Each Specialist Children's Surgical Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B21(L1)	Each Specialist Children's Surgical Centre will have a continuous, immediate and documented availability of specialised cardiac paediatric anaesthetists with full training (in accordance with the Royal College of Anaesthetists' Guidelines and Paediatric Intensive Care Society	Immediate

	Paediatric	Implementation timetable
	Standards) and competence in managing paediatric cardiac cases including a specialist paediatric cardiac on-call rota which is separate from the intensive care rota.	
B22(L1)	At each Specialist Children's Surgical Centre a paediatric cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	Within 6 months
B23(L1)	Each Specialist Children's Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.	Immediate
	Intensive Care	
B24(L1)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.	Immediate
B25(L1)	Paediatric Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Children and young people must be cared for by children's nurses with appropriate training and competencies in paediatric cardiac critical care.	Immediate
	Nursing	
B26(L1)	Each Specialist Children's Surgical Centre must have a formally nominated lead CHD nurse with responsibility for the service at the Specialist Children's Surgical Centre, providing professional and clinical leadership and support to the team of children's cardiac specialist nurses across the network.	Within 6 months
B27(L1)	Nursing care must be provided by a dedicated team of nursing staff trained in the care of children and young people who have received cardiac surgery. The paediatric cardiac inpatient nursing team will be led by a senior children's nurse with specialist knowledge and experience in the care of children and young people and in paediatric cardiology and cardiac surgery.	Immediate
B28(L1)	Each Specialist Children's Surgical Centre will employ a minimum of 7 WTE children's cardiac specialist nurses, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the	Within 1 year

	Paediatric	Implementation timetable
	minimum seven, and location of these nurses will depend on geography, population and the configuration of the network. Networks must demonstrate that the role of each Children's Cardiac Nurse Specialist meets the minimum requirements of the Royal College of Nursing role description. Each child/young person must have access to a Children's Cardiac Nurse Specialist and complex patients will have a named CCNS responsible for coordinating their care, and who acts as a liaison between the clinical team, the child/young person and parents/carers.	
B29(L1)	Each Congenital Heart Network will ensure that there is at least 1 WTE Fetal Cardiac Nurse Specialist, shared with the fetal network, to provide expert information and on-going support to parents who have a fetal diagnosis of congenital heart disease.	Within 1 year
B30(L1)	Each Congenital Heart Network must have a minimum of 1 WTE designated Children's Cardiac Transition Nurse, employed by the Specialist Children's Surgical Centre, (in addition to the network's seven children's cardiac nurse specialists) to coordinate the transition process across the network.	Within 6 months
	Psychology	
B31(L1)	Each Specialist Children's Surgical Centre must employ a minimum of 1 WTE practitioner psychologist (with experience of working with CHD) per 400 children and young people undergoing cardiac surgery each year. In addition, each Congenital Heart Network must have 1 WTE practitioner psychologist, employed by the Specialist Children's Surgical Centre, per 5,000 children and young people with CHD. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network.	Within 1 year
	Administrative Staffing	
B32(L1)	Each Specialist Children's Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
B33(L1)	Each Specialist Children's Surgical Centre must have a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales.	Within 6 months
	Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)	

	Paediatric	Implementation timetable
B34(L1)	Each Specialist Children's Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B35(L1)	Each Specialist Children's Surgical Centre will have an identified bereavement officer.	Immediate
B36(L1)	Each Specialist Children's Surgical Centre must have a minimum of 2 WTE dedicated play specialists.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
B1(L2)	Each Specialist Children's Cardiology Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Medical	
B3(L2)	Each Specialist Children's Cardiology Centre must be staffed by a minimum of 4 WTE specialist paediatric cardiologists (in addition to the one consultant paediatric cardiologist per half million population across the network). These cardiologists will work flexibly across the network.	Within 3 years
B4(L2)	Each Specialist Children's Cardiology Centre must provide a specialist paediatric cardiologist on-call rota. Rotas must be no more frequent than 1 in 4.	Immediate
B5(L2)	Each Specialist Children's Cardiology Centre will have a formally nominated Clinical Paediatric Cardiology Lead with responsibility for the service at the Specialist Children's Cardiology Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist Children's Cardiology Centre will have separate clinical leads identified from the relevant specialties, including fetal cardiology and nursing (and ICU and anaesthesia, if such provision exists) who have a direct link and collaborative working partnership with the lead roles in the Specialist Children's Surgical Centre.	Within 6 months
B6(L2)	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B7(L2)	Paediatric cardiologists based at the Specialist Children's Cardiology Centre who visits the Specialist Children's Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year, averaged over a three-year period.	Immediate
B8(L2)	Each Specialist Children's Cardiology Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases.	Immediate

	Paediatric	Implementation timescale
	There will be shared protocols for cross-sectional imaging across the network.	
B9(L2)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.	Immediate
	Nursing	
B10(L2)	Specialist Children’s Cardiology Centres must have locally designated registered children’s nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.	Immediate
B11(L2)	There must at all times be a minimum of two registered children’s nurses allocated to the operational children’s cardiology beds who are trained according to the Royal College of Nursing competency framework.	Immediate
B12(L2)	Each Specialist Children’s Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate
B13(L2)	The network Children’s Cardiac Nurse Specialist Team, will support the Specialist Children’s Cardiology Centre. An appropriate number of Children’s Cardiac Nurse Specialists will be based at the Specialist Children’s Cardiology Centre (the number will depend on geography, population and the congenital heart network).	Within 1 year
	Psychology	
B14(L2)	Each Specialist Children’s Cardiology Centre must have access to a clinical psychology service that is integrated with the ACHD team.	Immediate
	Administrative	
B15(L2)	Each Specialist Children’s Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist Children’s Cardiology Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
	Other	

	Paediatric	Implementation timescale
B17(L2)	Each Specialist Children's Cardiology Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.	Immediate
B18(L2)	Each Specialist Children's Cardiology Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B19(L2)	Each Specialist Children's Cardiology Centre will have a dedicated bereavement officer.	Immediate

	Paediatric	Implementation timescale
	Local Children’s Cardiology Centres	
B1(L3)	Each Local Children’s Cardiology Centre must be staffed by at least one Consultant Paediatrician with expertise in cardiology (PEC) who is closely involved in the organisation, running of and attendance in the Local Children’s Cardiology Centre. Each PEC must have received training in accordance with the Royal College of Paediatrics and Child Health and Royal College of Physicians one-year joint curriculum in paediatric cardiology (or gained equivalent competencies as agreed by the Network Clinical Director). Each PEC must spend a minimum 20% of his/her total job plan (including Supporting Professional Activities) in paediatric cardiology (in accordance with the British Congenital Cardiac Association definitions). Each PEC must be part of a Congenital Heart Network. Each PEC must work with a link/named Consultant Paediatric Cardiologist from either the Specialist Children’s Surgical Centre or Specialist Children’s Cardiology Centre and take responsibility for the running of regular joint paediatric cardiology clinics with the visiting Consultant Paediatric Cardiologist. Each PEC will hold an honorary contract with the Specialist Children’s Surgical Centre and/or the Specialist Children’s Cardiology Centre and have the opportunity to attend clinical and educational opportunities in order to maintain expertise and facilitate good working relationships there as part of their job plan.	Within 1 year
B2(L3)	Local Children’s Cardiology Centres must have locally designated registered children’s nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.	Within 1 year
B3(L3)	Each Local Children’s Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
B4(L3)	Each Local Children’s Cardiology Centre must have a locally designated 0.25 WTE registered children’s nurse with a specialist interest to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
B5(L3)	The network Children’s Cardiac Nurse Specialist Team will provide support, education and a link to the outpatient and ward nursing staff at the Local Children’s Cardiology Centre. A local link nurse will be identified who can be a point of contact within the Local Children’s Cardiology Centre.	Immediate
B6(L3)	Each Local Children’s Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.	Within 6 months

	Paediatric	**Implementation timescale**
B7(L3)	Each Local Children's Cardiology Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
B8(L3)	Each Local Children's Cardiology Centre must have a cardiac physiologist with training in congenital echocardiography.	Within 1 year
B9(L3)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
B10(L3)	Each Local Children's Cardiology Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding children; and b. a dedicated bereavement officer.	Immediate

	Paediatric	Implementation timeline
	Specialist Children's Surgical Centres	
C1(L1)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) ability of parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation should be provided without charge.	Within 6 months
C2(L1)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C3(L1)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by dedicated play specialist teams.	Immediate
C4(L1)	Specialist Children's Surgical Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate
C5(L1)	There must be facilities, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate
C6(L1)	Parents/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate
C7(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable.	Immediate

	Paediatric	Implementation timeline
	Each hospital must have a documented process for providing support with travel arrangements and costs.	
C8(L1)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C9(L1)	Specialist Children's Surgical Centres should ideally have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
C1(L2)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L2)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) ability of parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation should be provided without charge.	Within 6 months
C3(L2)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C4(L2)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by play specialist teams.	Immediate
C5(L2)	Specialist Children's Cardiology Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate
C6(L2)	Parents/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.	Immediate
C7(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
C1(L3)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L3)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) ability for parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation must be provided without charge.	Within 6 months
C3(L3)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C4(L3)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by play specialist teams.	Immediate
C5(L3)	Children and young people must have access to education resources.	Immediate
C6(L3)	Parents/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.	Immediate
C7(L3)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist Children's Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L1)	Paediatric Cardiology.	Immediate
D2(L1)	Paediatric Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L1)	Paediatric Intensive Care Unit (PICU): Level 3 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards). High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	Immediate
D4(L1)	Specialised paediatric cardiac anaesthesia.	Immediate
D5(L1)	Post-operative extra corporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Paediatric Surgery.	Within 3 years
D7(L1)	Paediatric Nephrology/Renal Replacement Therapy.	Within 3 years
D8(L1)	Paediatric Gastroenterology.	Within 3 years
D9(L1)	Each Specialist Children's Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography. There must be a 24/7 congenital echocardiography service with access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes, with facilities for advanced techniques including 3D and speckle tracking.	Within 6 months

	Paediatric	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist Children's Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
	Specialist Children's Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents; if not provided on site they must have access to these investigations. Specialist Children's Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. Specialist Children's Surgical Centres must offer invasive diagnostic investigation and treatment, including: a. catheter intervention; b. electrophysiological intervention; c. pacemaker insertion and extraction; and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment where clinically indicated). These services must be available 24/7.	

	Paediatric	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist Children's Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D10(L1)	Specialist Adult Congenital Heart Surgery and Intervention. [This standard recognises shared staffing and out-of-hours cover.]	Within 3 years

	Paediatric	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist Children's Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D11(L1)	Adult cardiology interventionist (to provide thrombolysis, clot removal and back-up for catheter lab emergencies including acute dissection).	Within 3 years
D12(L1)	Vascular Surgery or other surgeon competent to undertake vascular/microvascular repairs in children.	Within 3 years
D13(L1)	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	Within 3 years
D14(L1)	Multidisciplinary paediatric pain management service.	Within 3 years
D15(L1)	Bereavement Support, including nurses trained in bereavement support.	Within 3 years

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D16(L1)	Paediatric Neurology.	Immediate
D17(L1)	Paediatric Respiratory Medicine.	Immediate
D18(L1)	Neonatology.	Immediate
D19(L1)	Clinical Haematology.	Immediate
D20(L1)	Infection control team experienced in the needs of paediatric cardiac surgery patients.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D21(L1)	Paediatric Neurosurgery.	Immediate
D22(L1)	Child Psychiatry (with dedicated sessions and 24/7 on call).	Immediate
D23(L1)	Clinical biochemistry (including toxicology).	Immediate
D24(L1)	Pharmacy (with dedicated sessions for CHD and 24/7 on-call for urgent supply and advice).	Immediate
D25(L1)	Paediatric Endocrinology.	Immediate
D26(L1)	Paediatric Orthopaedics.	Immediate
D27(L1)	Plastic surgery.	Immediate
D28(L1)	Microbiology and Infectious diseases.	Immediate
D29(L1)	Safeguarding team/social work (as per national standards).	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the next working day.** The services must be experienced in caring for patients with congenital heart disease.	
D30(L1)	Paediatric Ear, Nose and Throat (seven day working week).	Immediate
D31(L1)	General Paediatrics (seven day working week).	Immediate
D32(L1)	Breast Feeding Support (seven day working week).	Immediate
D33(L1)	Obstetrics and Midwifery (seven day working week).	Immediate
D34(L1)	Psychology, with dedicated sessions for CHD.	Immediate
D35(L1)	Paediatric Dietician with dedicated sessions for CHD	Immediate
D36(L1)	Social Work Services.	Immediate
D37(L1)	Clinical Genetics.	Immediate
D38(L1)	Paediatric Dentistry.	Immediate
D39(L1)	Paediatric Immunology.	Immediate
D40(L1)	Dermatology.	Immediate
D41(L1)	Sexual health.	Immediate
D42(L1)	Feto-maternal medicine.	Immediate
D43(L1)	Paediatric Rheumatology.	Immediate
D44(L1)	Gynaecology.	Immediate
D45(L1)	Paediatric Urology.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the next working day.** The services must be experienced in caring for patients with congenital heart disease.	
D46(L1)	Speech and language, with dedicated sessions for CHD, including swallow assessment with access to video fluoroscopy.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Specialist Children's Cardiology Centres.** They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L2)	Paediatric Cardiology.	Immediate
D2(L2)	Paediatric Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L2)	Paediatric Intensive Care Unit (PICU): Level 3 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards). High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	Immediate
D4(L2)	Each Specialist Children's Cardiology Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The exact range of equipment and investigations will be agreed with the network. The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker interrogation and follow up, as well as standard, transesophageal and fetal echocardiography. The availability of contrast echocardiography is desirable. Specialist Children's Cardiology Centres must be able to access contrast echocardiography, tilt testing, cardio-pulmonary exercise testing (CPEX), the six-minute walk test in children and adolescents. There must be 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. These services must be available 24/7 where clinically indicated.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D5(L2)	Paediatric Surgery.	Immediate
D6(L2)	Paediatric anaesthetist who works closely with specialist paediatric cardiac anaesthetists in the network.	Immediate
D7(L2)	Paediatric Nephrology.	Immediate
D8(L2)	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	Immediate
D9(L2)	Bereavement Support, including nurses trained in bereavement support.	Immediate
D10(L2)	Multidisciplinary paediatric pain management service.	Immediate
D11(L2)	Paediatric Gastroenterology.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D12(L2)	Paediatric Neurology.	Immediate
D13(L2)	Paediatric Respiratory Medicine.	Immediate
D14(L2)	Neonatology.	Immediate
D15(L2)	Paediatric Neurosurgery.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D16(L2)	Child Psychiatry with dedicated sessions.	Immediate
D17(L2)	Paediatric Endocrinology.	Immediate
D18(L2)	Paediatric Orthopaedics.	Immediate
D19(L2)	Plastic surgery.	Immediate
D20(L2)	Vascular surgery.	Immediate
D21(L2)	Clinical Haematology.	Immediate
D22(L2)	Infection control nurse experienced in the needs of paediatric cardiac patients.	Immediate
D23(L2)	Clinical Biochemistry (including toxicology).	Immediate
D24(L2)	Pharmacy (24/7 on-call required for urgent supply and advice).	Immediate
D25(L2)	Microbiology and Infectious diseases.	Immediate
D26(L2)	Learning Disability Team.	Immediate
D27(L2)	Safeguarding team/social work (as per national standards).	Immediate

	Paediatric	Implementation timescale
	Advice and consultation must be available from the following specialties at least by the next working day. The services must be experienced in caring for patients with congenital heart disease.	
D28(L2)	Paediatric Ear, Nose and Throat.	Immediate
D29(L2)	General Paediatrics (seven day working week).	Immediate
D30(L2)	Psychology.	Immediate
D31(L2)	Paediatric Dietician.	Immediate
D32(L2)	Breastfeeding Support (seven day working week).	Immediate
D33(L2)	Social Work Services.	Immediate
D34(L2)	Obstetrics and Midwifery (seven day working week).	Immediate
D35(L2)	Clinical Genetics.	Immediate
D36(L2)	Paediatric Dentistry.	Immediate
D37(L2)	Paediatric Immunology.	Immediate
D38(L2)	Feto-maternal medicine.	Immediate
D39(L2)	Dermatology.	Immediate
D40(L2)	Sexual health.	Immediate
D41(L2)	Paediatric Rheumatology.	Immediate
D42(L2)	Gynaecology.	Immediate

	Paediatric	Implementation timescale
	Advice and consultation must be available from the following specialties at least by the next working day. The services must be experienced in caring for patients with congenital heart disease.	
D43(L2)	Paediatric Urology.	Immediate
D44(L2)	Speech and language, including swallow assessment with access to video fluoroscopy.	Immediate

	Paediatric	**Implementation timescale**
	The following specialties or facilities must be located **on the same hospital site** as **Local Children's Cardiology Centres.**	
D1(L3)	In and Outpatient Paediatric and Adolescent Services.	Immediate
D2(L3)	Prenatal diagnostic services, obstetrics, midwifery and breast-feeding support and neonatal services.	Immediate
D3(L3)	General adult cardiology services.	Immediate
D4(L3)	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital Paediatric service – either from Specialist Cardiology Centres or from Specialist Surgical Centres in accordance with network protocols**.**	Immediate
D5(L3)	Each Local Children's Cardiology Centre must provide standard non-invasive diagnostic imaging capabilities with access, across the network, to CT and MRI scanning. The exact range of equipment and investigations will be agreed with the Network. The range of cardiac physiological investigations to which the Local Children's Cardiology Centre must have access include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, 24 hour tapes, event recorders; and ambulatory blood pressure monitoring, as well as standard, and fetal echocardiography. Local Children's Cardiology Centres must be able to access cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents. There must be 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes. There must be the facility to store and transfer digital recordings of radiological and echocardiographic images. Governance arrangements across the Children's Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Surgical Centre	
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and PICU medical and nursing team will complete mandatory level 1 training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth level 2-4 training.	Immediate
E3(L1)	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist Children's Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology and paediatric cardiac surgery, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum, and to the training of Paediatricians with expertise in cardiology.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems. Specialist Children's Surgical Centres must provide resources sufficient to support these educational needs across the network.	Within 6 months
E6(L1)	Specialist Children's Surgical Centres must provide sufficient Cardiac Clinical Nurse Educators to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Paediatric	Implementation timescale
E7 (L1)	Governance arrangements across the Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Within 6 months

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and PICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L2)	Each Specialist Children's Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.	Within 6 months
E6(L2)	Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. Each Specialist Children's Cardiology Centre must have one clinical educator who is responsible for ensuring the continuing professional development of nursing staff in the Specialist Children's Cardiology Centre. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months
E7 (L2)	Governance arrangements across the Children's Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Within 6 months

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Level 3: Local Children's Cardiology Centres

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
E1(L3)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L3)	All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L3)	Each Local Children's Cardiology Centre must assist the Specialist Children's Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all specialty doctors within their network catchment area.	Immediate
E4(L3)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.	Within 1 year
E5(L3)	Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. They will be responsible for ensuring the continuing professional development of nursing staff in the Local Children's Cardiology Centre. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
E6(L3)	Nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.	Within 1 year
E7(L3)	Paediatricians with expertise in cardiology (PECs) should have a named cardiologist within the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre who acts as a mentor; this mentor would normally be the link cardiologist.	Immediate

	Paediatric	Implementation timescale
F1(L1)	Each Specialist Children's Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L1)	Each Specialist Children's Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F4(L1)	Each Specialist Children's Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Surgical Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist Children's Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local Children's Cardiology Centres. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Within 6 months
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Within 6 months

	Paediatric	Implementation timescale
F9(L1)	Each Specialist Children's Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	Each Specialist Children's Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All children/young people who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Same-day cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a child/young person needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the child/young person or parents/carers wish(es). Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be involved in any relevant discussions.	Immediate
F18(L1)	When a Specialist Children's Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre, or Specialist Children's Cardiology Centre if appropriate.	Immediate

	Paediatric	Implementation timescale
F19(L1)	A children's cardiac nurse specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate
F20(L1)	Each Specialist Children's Surgical Centre must implement a pain control policy that includes advice on pain management at home.	Immediate
F21(L1)	Advice must be taken from the acute pain team for all children/young people who have uncontrolled severe pain. Particular attention must be given to children/young people who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	Immediate
F22(L1)	Each Specialist Children's Surgical Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate
F23(L1)	Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F24(L1)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
F1(L2)	Each Specialist Children's Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F3(L2)	Each Specialist Children's Cardiology Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist Children's Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children's Surgical Centre.	Within 6 months
F5(L2)	Each Specialist Children's Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year
F8(L2)	Each Specialist Children's Cardiology Centre must participate in national programmes for audit and must submit data on any emergency procedures, electrophysiology procedures and endocarditis, to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate

	Paediatric	Implementation timescale
F9(L2)	Each Specialist Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist Children's Cardiology Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist Children's Cardiology Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
F13(L2)	Each Specialist Children's Surgical Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate
F14(L2)	Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F15(L2)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.	Immediate

DRAFT CHD Standards: Section F: Organisation, governance and audit
Level 3: Local Children’s Cardiology Centres

	Paediatric	Implementation timescale
	Local Children’s Cardiology Centres	
F1(L3)	Each Local Children’s Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L3)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F3(L3)	Each Local Children’s Cardiology Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local Children’s Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L3)	Each Local Children’s Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children’s Surgical Centre.	Within 6 months
F5(L3)	Each Local Children’s Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L3)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L3)	Each Local Children’s Cardiology Centre must participate in relevant national programmes for audit and must submit data to the Specialist Children’s Surgical or Specialist Children’s Cardiology Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F8(L3)	Each Local Children’s Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.	Within 1 year

	Paediatric	Implementation timescale
F9(L3)	Each Local Children's Cardiology Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence guidance.	Immediate
F10(L3)	Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F11(L3)	Each Local Children's Cardiology Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate

	Paediatric	Implementation timescale
G1(L1)	Each Specialist Children's Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of paediatric cardiac disease and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist Children's Centres and Specialist Children's Cardiology Centres, and Local Children's Cardiology Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of children and young people with CHD and their families.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
G1(L2)	Each Specialist Children's Cardiology Centre must participate in research.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
G1(L3)	Each Local Children's Cardiology Centre should participate in research.	Immediate

	Paediatric	Implementation timescale
H1(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L1)	Every family/carer (and young person, as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Children and young people, parents and carers must be helped to understand the patient's condition, the effect it may have on their health and future life and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person, parents' and carers' understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. school and careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that parents, carers, children and young people are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate
H5(L1)	Sufficient information must be provided to allow informed decisions to be made, including supporting parents, carers and young people in interpreting publicly available data that support choice. The following should also be described:	Immediate

	Paediatric	Implementation timescale
	a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; and d. consideration of the closest unit to the patient's home.	
H6(L1)	Specialist Children's Surgical Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another Specialist Children's Surgical Centre, and in interpreting publically available data that supports patient choice.	Immediate
H7(L1)	Information must be made available to parents and carers 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H8(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place for parents and carers, children and young people to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H9(L1)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H10(L1)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Surgical Centres must make this feedback openly available, to children, young people, families/carers and the general public, together with outcome of relevant local and national audits. Specialist Children's Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate

	Paediatric	Implementation timescale
H11(L1)	Each Specialist Children's Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H12(L1)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young person throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Immediate
H13(L1)	Each Specialist Children's Surgical Centre must provide a 24/7 emergency telephone advice service for patients and their family with urgent concerns about deteriorating health.	Within 6 months
H14(L1)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain diagnosis and management of the child's condition and to provide relevant literature.	Within 6 months
H15(L1)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child's condition, and providing psychosocial support to promote parental (and child/young person's) adaptation and adjustment.	Immediate
H16(L1)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H17(L1)	Where children/young people, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H18(L1)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H19(L1)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate) in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate

	Paediatric	Implementation timescale
H20(L1)	Parents, carers and all health professionals involved in the child's care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H21(L1)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H22(L1)	Where surgery or intervention is planned, the child/young person and their parents or carers must have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team, including the Children's Cardiac Nurse Specialist that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H23(L1)	Children/young people and their parents/carers must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Preliminary consent may be taken by any member of the medical team, at a pre-admission clinic or visit. Final consent will be taken by the operating consultant.	Immediate
H24(L1)	A Children's Cardiac Nurse Specialist must be available to support parents and children/young people throughout the consent process. When considering treatment options, parents, carers (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H25(L1)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H26(L1)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H27(L1)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months
H28(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person as appropriate or their family/carers) will ensure continuity and	Immediate

	Paediatric	Implementation timescale
	consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the patient and parents to discuss concerns about treatment must be offered.	

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
H1(L2)	Specialist Children's Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L2)	Every family/carer (and young person as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L2)	Children and young people, parents and carers must be helped to understand the patient's condition, the effect it may have on their health and future life and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person's, parents' and carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. school and careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L2)	Information must be made available to parents, carers, children and young people 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L2)	Specialist Children's Cardiology Centres must demonstrate that arrangements are in place for parents/carers and children and young people	Immediate

	Paediatric	Implementation timescale
	to be given an agreed, written management plan, in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	
H6(L2)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L2)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Cardiology Centres must make this feedback openly available to patients, families/carers and the general public, together with outcome of relevant local and national audits. Specialist Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Cardiology Centres must demonstrate ongoing structured liaison with patient and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L2)	Each Specialist Children's Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H9(L2)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Immediate
H10(L2)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain the diagnosis and management of the child/young person's condition and to provide relevant literature.	Immediate
H11(L2)	The Children's Cardiac Nurse Specialist will support parents/carers by explaining the diagnosis and management plan of the child/young person's condition, and providing psychosocial support to promote parental (and child/young person's) adaptation and adjustment.	Immediate

	Paediatric	Implementation timescale
H12(L2)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L2)	Where patients, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H14(L2)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate), in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H16(L2)	Parents, carers and all health professionals involved in the child's care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist Children's Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist Children's Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L2)	A Children's Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate

	Paediatric	Implementation timescale
H21(L2)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L2)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L2)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care.	Within 1 year
H24(L2)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person if appropriate or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the patient and parents to discuss concerns about treatment must be offered.	Immediate

	Paediatric	**Implementation timescale**
	Local Children's Cardiology Centres	
H1(L3)	Local Children's Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L3)	Every family/carer (and young person as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L3)	Children and young people, parents and carers must be helped to understand the patient's condition, the effect it may have on their health and future life and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person's, parents' and carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention d. smoking, alcohol and drugs e. school and careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L3)	Information must be made available to parents, carers, children and young people 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L3)	Local Children's Cardiology Centres must demonstrate that arrangements are in place for parents/carers, children and young people to be	Immediate

	Paediatric	Implementation timescale
	given an agreed, written management plan, in a language they can understand that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	
H6(L3)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L3)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local Children's Cardiology Centres must make this feedback openly available, to children and young people, families/carers and the general public, together with outcome of relevant local and national audits. Local Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Local Children's Cardiology Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L3)	Each Local Children's Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H9(L3)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Within 6 months
H10(L3)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain the diagnosis and management of the child/young person's condition and to provide relevant literature.	Within 1 year
H11(L3)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child/young person's condition, and providing psychosocial support to promote parental (and child's/young person's) adaptation and adjustment.	Immediate

	Paediatric	Implementation timescale
H12(L3)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L3)	Where patients, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H14(L3)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H15(L3)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate), in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H16(L3)	Parents, carers and all health professionals involved in the child's care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L3)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H18(L3)	Local Children's Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	Immediate
H19(L3)	Where surgery or intervention is planned, Local Children's Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L3)	A Children's Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate

	Paediatric	Implementation timescale
H21(L3)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L3)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L3)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.	Within 1 year
H24(L3)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person, as appropriate, or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the child/young person and parents/carers to discuss concerns about treatment must be offered.	Immediate

DRAFT CHD Standards: Section I: Transition
Level 1: Specialist Children's Surgical Centres

	Paediatric	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L1)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L1)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L1)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I5(L1)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L1)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L1)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L1)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family.	Immediate
I9(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging	Immediate

	Paediatric	Implementation timescale
	results and the care plan.	
I10(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

	Paediatric	Implementation timescale
I1(L2)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L2)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L2)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I5(L2)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L2)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L2)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L2)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family.	Immediate
I9(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging	Immediate

	Paediatric	Implementation timescale
	results and the care plan.	
I10(L2)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L2)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

DRAFT CHD Standards: Section I: Transition
Level 3: Local Children's Cardiology Centres

	Paediatric	Implementation timescale
I1(L3)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L3)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L3)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L3)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I5(L3)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L3)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L3)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L3)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family.	Immediate
I9(L3)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate

	Paediatric	Implementation timescale
I10(L3)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L3)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L3)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Within 1 year

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L1)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L1)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. 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.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L1)	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.	Within 1 year
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards; section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L2)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L2)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. 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.	Immediate
J3(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	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.	Immediate
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards, section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L3)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist or paediatrician with expertise in cardiology and a nurse specialist with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
J2(L3)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. 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.	Immediate
J3(L3)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L3)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist or paediatrician with expertise in cardiology and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
J5(L3)	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.	Immediate
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards, section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
K1(L1)	Obstetric services caring for patients with congenital heart disease must offer fetal cardiac diagnosis and management protocols as an integral part of the service offered to patients with congenital heart disease.	Immediate
K2(L1)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported.	Immediate
K3(L1)	Each Specialist Children's Surgical Centre will agree and establish protocols with obstetric, feto-maternal medicine units, tertiary neonatal units, local neonatal units and paediatrics teams in their Congenital Heart Network for the care and treatment of pregnant women whose fetus has been diagnosed with a major heart condition. The protocols must meet the relevant NHS Fetal Anomaly Screening Programme and British Congenital Cardiac Association Standards.	Immediate
K4(L1)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K5 (L1)	All women with a suspected or confirmed fetal cardiac anomaly must be seen by : • an obstetric ultrasound specialist within three working days of the referral being made; and • a fetal cardiology specialist within three days of referral and preferably within two working days if possible. If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist. (This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service users.)	Immediate
K6(L1)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K7(L1)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate
K8(L1)	A Children's Cardiac Nurse Specialist (CCNS) (who has been appropriately trained in counselling for fetal CHD) will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide	Immediate

	Paediatric	Implementation timescale
	information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The CCNS/Fetal Cardiac Nurse Specialist (FCNS) must work with the Cardiologist and the fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The CCNS/FCNS will act as the point of contact for the family throughout pregnancy for support and further information.	
K9(L1)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate
K10(L1)	At diagnosis, a plan must be agreed between the Specialist Children's Surgical Centre, the specialist feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K11(L1)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with the local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate
K12(L1)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

	Paediatric	Implementation timescale
K1(L2)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported.	Immediate
K2(L2)	Specialist Children's Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children's Surgical Centre in their Congenital Heart Network.	Immediate
K3(L2)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K4(L2)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K5 (L2)	All women with a suspected or confirmed fetal cardiac anomaly must be seen by : • an obstetric ultrasound specialist within three working days of the referral being made; and • a fetal cardiology specialist within three days of referral and preferably within two working days if possible. If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist. (This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service users.)	Immediate
K6(L2)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate
K7(L2)	A Children's Cardiac Nurse Specialist (CCNS) (who has been appropriately trained in counselling for fetal CHD) will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The CCNS/Fetal Cardiac Nurse Specialist (FCNS) must work with the Cardiologist and the fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The CCNS/FCNS will act as the point of contact for the	Immediate

	Paediatric	Implementation timescale
	family throughout pregnancy for support and further information.	
K8(L2)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate
K9(L2)	At diagnosis, a plan must be agreed with the Specialist Children's Surgical Centre, the specialist feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K10(L2)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Children's Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with their local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate
K11(L2)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including a timetable, for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

	Paediatric	Implementation timescale
K1(L3)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported.	Immediate
K2(L3)	Local Children's Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children's Surgical Centre in their Congenital Heart Network.	Immediate
K3(L3)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenial Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K4(L3)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K5(L3)	A Children's Cardiac Nurse Specialist (who has been appropriately trained in counselling for fetal CHD) will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The CCNS/Fetal Cardiac Nurse Specialist (FCNS) must work in collaboration with the Cardiologist and fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The CCNS/FCNS will act as the point of contact for the family throughout pregnancy for support and further information.	Immediate
K6(L3)	At diagnosis a plan must be agreed with the Specialist Children's Surgical Centre, the specialist feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K7(L3)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Children's Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with their local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate

	Paediatric	Implementation timescale
K8(L3)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children’s Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

	Paediatric	Implementation timescale
	Palliative Care Note: **Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L1)	Each Specialist Children's Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L1)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L1)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L1)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L1)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Paediatric	Implementation timescale
L10(L1)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L1)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L1)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L1)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L1)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.	Immediate

	Paediatric	Implementation timescale
L20(L1)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L1)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

	Paediatric	**Implementation timescale**
	Palliative Care Note: **Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L2)	Each Specialist Children's Cardiology Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L2)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L2)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L2)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L2)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L2)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L2)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Paediatric	Implementation timescale
L10(L2)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L2)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L2)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L2)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L2)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L2)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L2)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L2)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.	Immediate

	Paediatric	Implementation timescale
L20(L2)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L2)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L2)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

DRAFT CHD Standards: Section L: Palliative Care and Bereavement
Level 3: Local Children's Cardiology Centres

	Paediatric	Implementation timescale
	Palliative Care **Note: Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L3)	Each Local Children's Cardiology Centre must provide access to a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the family/carers. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service at the Specialist Children's Surgical or Specialist Children's Cardiology Centre.	Immediate
L2(L3)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L3)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L3)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L3)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L3)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L3)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L3)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate

	Paediatric	Implementation timescale
L9(L3)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L3)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L3)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L3)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L3)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L3)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L3)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L3)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L3)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate

	Paediatric	Implementation timescale
L18(L3)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L3)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L3)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L3)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L3)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L3)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L3)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L3)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L3)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L3)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate

	Paediatric	Implementation timescale
L28(L3)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

DRAFT CHD Standards: Section M: Dental
Level 1: Specialist Children’s Surgical Centres

	Paediatric	Implementation timescale
M1(L1)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All children and young people with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	Immediate
M3(L1)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	Specialist Children’s Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease.	Immediate

DRAFT CHD Standards: Section M: Dental
Level 2: Specialist Children's Cardiology Centres

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
M1(L2)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist Children's Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist Children's Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children's Surgical Centre.	Immediate

	Paediatric	**Implementation timescale**
	Local Children's Cardiology Centres	
M1(L3)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L3)	Each Local Children's Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L3)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L3)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L3)	Local Children's Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children's Surgical Centre.	Immediate

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	
Service	Adult Congenital Heart Disease (ACHD)
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

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:

- Inherited Cardiology Conditions (A09/s/c) http://www.england.nhs.uk/wp-content/uploads/2013/06/a09-cardi-inheri-card-con.pdf
- Non Congenital Cardiac Surgery (A10/s/a) http://www.england.nhs.uk/wp-content/uploads/2013/06/a10-cardi-surgery-adult.pdf
- Services falling within the Complex Invasive Cardiology CRG as described in the CRG web page: http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-

a/a09/

- Heart and Lung Transplantation Service (all ages)

http://www.england.nhs.uk/wp-content/uploads/2013/06/a18-heart-lung-trans-all.pdf

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 childhood, there are increasing numbers of adults with congenital heart disease with a prevalence of more than 4 per 1000 adults. The number of ACHD patients with complex disease is increasing with 10% of the 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, April 2014).

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.

The Standards provide timescales for achievement of each standard ranging from standards which must be achieved immediately to standards which must be achieved within 3 years. The timescale for each standard is 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

Whilst working to the implementation of Networks of care, service providers will be expected to demonstrate their compliance with the standards in line with the NHS England Service Specification Derogation Policy. During transition to Network arrangements services are expected to:

- Maintain appropriate collaborative network relationships between units (Level 1 – Level 3) in order to maintain a good outcome for patients
- Communicate consistently with families, staff and referrers regarding the progress of the ongoing review

1.4 Evidence Base

Draft Congenital Heart Disease Standards Levels 1-3, 2014.

2013 BCCA/BCS/BCIS Guidelines on Intervention for ACHD
http://www.bcis.org.uk/resources/ACHD_interventions_Oct_20111.doc

DH – 2006 – A Commissioning Guide For Services for Young People and Grown Ups with Congenital Heart Disease (GUCH)
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

http://democracy.leeds.gov.uk/documents/s93411/Review%20of%20Adults%20with%20Congenital%20Heart%20Disease%20-%20engagement%20on%20revised%20proposals%20-%20Appendix%201.pdf

May 14 – First View Article – Cardiology in the Young
http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8828368

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**	✓

The Congenital Heart Clinical Reference Group (CRG) has developed a quality dashboard for implementation in 2014/15. 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

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 (2014) 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

3.2 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 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

3.2.1. 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:

- 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.

3.3. 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.

3.3.1 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.

3.3.2. 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 or surgery.
- 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 Anaesthetist. 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.

3.3.3 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.
- 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. A 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. These procedures must only be carried out only in the Level 1 centre.
- Electrophysiology procedures for patients with simple congenital heart lesions may also be carried out at Specialist ACHD Centresif specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.
- 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.
-

3.3.4 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.

3.4 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.

3.5 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.

3.6 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.

3.7 Pregnancy and Contraception

All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologistand 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.

3.8 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 will take place between 12 and 18 years of age, taking into account individual circumstances.
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 draft congenital heart disease standards and the generic specification for transition produced by the paediatric medicine CRG.

3.9 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;
- 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; and
- generate and publish evidence of effective palliative or end-of-life care for patients / carers.

3.10 Governance

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

- Clinical audit.
- 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 meetings between networks to ensure uniformity of care throughout the healthcare system.

3.11 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)
- co-operate in developing a national register of research trials and outcomes.

3.12 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 beclear, understandable, culturally sensitive, evidence-based, developmentally appropriateand take into accountspecial needs as appropriate. When given verbally, information must be precisely 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;
- 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)

3.13 Annual reports

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

3.14. Administration

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

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

- 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 draft congenital heart disease standards (2014). 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 draft standards produced by the Congenital Heart Disease Review Standards Group, April 2014.

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 three 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.
- 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) 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 electrophysiologist experienced in adult congenital cardiac disease.
- 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.
- 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 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 visit the Specialist ACHD Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures each year, 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 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 Specialised Services Draft ACHD Standards (2014)
- 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 http://publications.nice.org.uk/balloon-dilatation-of-pulmonary-valve-stenosis-ipg67
- IPG74 Balloon angioplasty with or without stenting for coarctation or recoarctation of the aorta in adults and children: guidance July 2004 http://guidance.nice.org.uk/IPG74
- IPG 86 Endovascular atrial septostomy. August 2004. http://guidance.nice.org.uk/IPG86
- IPG 95 Radiofrequency valvotomy for pulmonary atresia. October 2004 http://publications.nice.org.uk/radiofrequency-valvotomy-for-pulmonary-atresia-ipg95/the-procedure
- IPG 310: Placement of pectus bar for pectus excavatum (also known as MIRPE or the Nuss procedure). August 2009 http://guidance.nice.org.uk/IPG310
- IPG 336. Transcatheter endovascular closure of perimembranous ventricular septal defect.

http://guidance.nice.org.uk/IPG336 March 2010

- NICE guidance on PFO 2010 PFO in divers http://guidance.nice.org.uk/IPG371
- NICE guidelines on PFO closure in stroke 2013 http://guidance.nice.org.uk/IPG472
- Percutaneous Pulmonary Valve Implantation for Right Ventricular Outflow Tract Dysfunction

https://www.nice.org.uk/guidance/IPG436

8. Applicable quality requirements and CQUIN goals

There are no specific Adult Congenital Heart CQUINS (May 2014)

9.. Location of Provider Premises

The Provider’s Premises are located at:

ONLY LIST PROVIDERS IF THERE HAS BEEN A FORMAL DESIGNATION PROCESS.

10. Individual Service User Placement

Insert details including price where appropriate of any individual service user placement e.g. mental health. This is likely to be relevant where the service provides tailored specialist placements. It may also be used to record any specialist equipment that is provided as part of an individual care pathway.

Appendix 1

A 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 also be located in specialised ACHD centre to allow joined-up MDT planning. The advantages of this are around the number of interventional catheterisations, training of ACHD interventionists and facilitation of data collection for national audits within NICOR. **Within the ACHD model of care, ASD closure should only be undertaken in the Specialist ACHD Surgical Centre**. This ensures that congenital cardiac surgery co-location is available should it be needed. There should be flexibility within the network to enable cardiologists with skills from Specialist ACHD Centres to continue to undertake interventional work in Specialist ACHD Surgical Centres by local planning.

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.

Appendix Two

Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
Pending			
Domain 2: Enhancing the quality of life of people with long-term conditions			
Response to Somerville Patient Survey on outpatient care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Unplanned reintervention rate within 30 days of catheter intervention	To be determined after first year submissions	Number of re-interventions divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter intervention	To be determined after first year submissions	Number of complications divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			
Response to Somerville Patient Survey on Inpatient care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Adequate information provided at discharge	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Same day cancellation of elective surgical procedures	To be determined after first year submissions	Number of same day cancellations of elective procedures divided by total number of surgical	Non-compliance with contract General Conditions 8 & 9

Quality Requirement	**Threshold**	**Method of Measurement**	**Consequence of breach**
		procedures	
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Total surgical case load	To be determined after first year submissions	Number of NICOR defined surgical procedures in 1 year	Non-compliance with contract General Conditions 8 & 9
Total catheter intervention caseload	To be determined after first year submissions	Number of NICOR defined catheter intervention procedures in 1 year	Non-compliance with contract General Conditions 8 & 9

	Adult	Implementation timeline
	Specialist ACHD Surgical Centres	
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network's host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network.	Within 6 months
A2(L1)	Specialist ACHD Surgical Centres in partnership with the Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of patients with congenital heart disease throughout their life. The model of care will ensure that all congenital cardiac care is carried out only by congenital cardiac specialists (including investigation, cardiology and surgery). [See Appendix A for definition of adult CHD surgery.] The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist ACHD Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity and obstetric services, children's services, transition from paediatric congenital cardiac services, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist ACHD Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for fetal services, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.	Within 6 months
A4(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how specialist ACHD cardiologists will work across the network, including at the Specialist ACHD Surgical Centre, the	Immediate

	Adult	Implementation timeline
	Specialist ACHD Centres and Local ACHD Centres, according to local circumstances; and f. address how Specialist ACHD Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	
A5(L1)	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	Immediate
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Immediate
A7(L1)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Within 6 months
A8(L1)	Specialist ACHD Surgical Centres will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years
	Cardiological Interventions	
A9(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all ACHD surgery, therapeutic interventions, including atrial septal defect closure, and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]; and b. enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist ACHD Surgical Centre or in another Specialist ACHD Surgical Centre, if the need arises.	Within 3 years
	Non-Cardiac Surgery	
A10(L1)	Specialist ACHD Surgical Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, the most appropriate location for that surgery and advice to non-ACHD cardiologists across the Congenital Heart Network.	Immediate

	Adult	Implementation timeline
	External Relationships	
A11(L1)	Each Specialist ACHD Surgical Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A12(L1)	Each Specialist ACHD Surgical Centre must have a close network relationship with any paediatric CHD providers within their Congenital Heart Network and be able to demonstrate the operation of joint transition protocols.	Immediate
A13(L1)	Each Congenital Heart Network must contain at least one Specialist ACHD Surgical Centre in a formal network relationship with the Specialist Children's Surgical service, Specialist ACHD Centres and Local ACHD Centres, evidenced by agreed joint referral and care protocols. Each Specialist ACHD Surgical Centre must have a formal network relationship with the following, evidenced by agreed joint referral and care protocols: a. the cardiothoracic transplant centres including one staffed by transplant surgeons with a congenital practice; b. the national Pulmonary Hypertension Service; and c. a cardiac pathologist with expertise in congenital cardiac abnormalities.	Immediate
A14(L1)	Patients who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a cardiothoracic transplant centre. The referring specialist is responsible for explaining to the patient the transplant pathway and the risks and benefits of referral and any alternative pathways, to inform patient choice. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	Immediate
A15(L1)	Each Specialist ACHD Surgical Centre must have a close relationship with all community adult services in their network, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
	Telemedicine and IT	
A16(L1)	Each Specialist ACHD Surgical Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Centres and Local ACHD Centres, according to local circumstances) and with other Congenital Heart Networks.	Within 3 years

	Adult	Implementation timeline
	The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	
A17(L1)	Each Specialist ACHD Surgical Centre must cooperate to allow visiting specialist ACHD cardiologists from Specialist ACHD Centres to gain remote access to the Specialist ACHD Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A18(L1)	Each Specialist ACHD Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will 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). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, an ACHD cardiologist and an intensivist.	Immediate
A21(L1)	The Specialist ACHD Surgical Centres and services within the Congenital Heart Network will hold regular multidisciplinary team meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.	Immediate
	Network Leadership	
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult	Within 6 months

	Adult	Implementation timeline
	congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months

	Adult	Implementation timescale
	Specialist ACHD Centres	
A1(L2)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist ACHD Centres where appropriate. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Within 6 months
A2(L2)	Each Specialist ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	Each Specialist ACHD Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. New referrals from GPs, cardiologists and local hospitals b. Ongoing care of patients diagnosed with congenital heart defects	Within 6 months
A4(L2)	Specialist ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how specialist ACHD cardiologists will work across the network, including at the Specialist ACHD Surgical Centres, the Specialist ACHD Centres and Local ACHD Centres, according to local circumstances; f. address how Specialist ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. provide 24/7 advice via an on-call rota comprised predominantly of general consultant cardiologists who will have contact details for the on-call ACHD specialists in the network.	Immediate
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Within 6 months
A6(L2)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary	Immediate

	Adult	Implementation timescale
	(with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	
	Cardiological Interventions	
A7(L2)	Specialist ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways of care that will require all ACHD surgery and therapeutic interventions, including atrial septal defect closure, and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definitions of ACHD surgery and intervention].	Within 6 months
	Non-Cardiac Surgery	
A8(L2)	Specialist ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate
	External Relationships	
A9(L2)	Each Specialist ACHD Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist ACHD Centre must have a close network relationship with any paediatric CHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist ACHD Centre must demonstrate formal working relationships with: a. network Specialist ACHD Surgical Centres and Local ACHD Centres, according to local circumstances; b. the cardiothoracic transplant centres, including one staffed by transplant surgeons with a congenital practice; c. the national Pulmonary Hypertension Service; and d. a cardiac pathologist with expertise in congenital cardiac abnormalities.	Within 6 months
A12(L2)	Each Specialist ACHD Surgical Centre must have a close relationship with all community adult services in their network, to ensure the	Immediate

	Adult	Implementation timescale
	provision of a full range of community adult support services particularly for patients with complex medical and social needs.	
	Telemedicine and IT	
A13(L2)	Each Specialist ACHD Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Surgical Centres and Local ACHD Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	Within 3 years
A14(L2)	Each Specialist ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist ACHD Surgical Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A15(L2)	Each Specialist ACHD Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist ACHD Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT meeting, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT meeting.	Within 1 year
A17(L2)	Staff from the Specialist Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A18(L2)	The composition of the MDT will 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).	Immediate

	Adult	Implementation timescale
A19(L2)	Specialist ACHD Centres will routinely refer patients to their primary network MDT meeting. Exceptions to this principle will include the exercise of patient choice and, when justified by a consideration of the clinical facts of the individual case, the exercise of referrer choice. In all cases when a patient is referred 'out of network' the Specialist ACHD Centre must inform the Specialist ACHD Surgical Centre in writing of the reasons for referral.	Immediate
	Network Leadership	
A20(L2)	Each Specialist ACHD Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the network. The postholder must have specified time working in ACHD cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

	Adult	Implementation timescale
	Local ACHD Centres	
A1(L3)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local ACHD Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Immediate
A2(L3)	Each Local ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L3)	Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. New referrals from GPs, cardiologists and local hospitals b. Ongoing care of patients diagnosed with congenital heart defects	Immediate
A4(L3)	Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialised Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; f. address how Local ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. deliver joint clinics between a specialist ACHD cardiologist and a cardiologist with an interest in ACHD in a Local ACHD Centre. Local ACHD Centres will provide weekday cover for CHD advice from a local network of consultant cardiologists with expertise in CHD.	Within 1 year

	Adult	Implementation timescale
A5(L3)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Within 6 months
A6(L3)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, therapeutic interventions and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre. Local ACHD Centres may not undertake any ACHD surgeries, planned interventional catheter procedures or diagnostic catheter procedures as part of their investigation into congenital heart disease. [See Appendix A for the definition of ACHD Surgery and Interventions.]	Immediate
	Non-Cardiac Surgery	
A8(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate
	Emergency Care	
A9(L3)	When patients with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local ACHD Centres will seek advice from the local cardiologist with expertise in CHD or an ACHD cardiologist at a specialist centre on appropriate care and management.	Immediate
	External Relationships	
A10(L3)	Each Local ACHD Centre must demonstrate formal working relationships with the network Specialist ACHD Surgical Centres and Specialist ACHD Centre, according to local circumstances. Other supraregional services will be accessed via the CHD network.	Immediate

	Adult	Implementation timescale
A11(L3)	Local ACHD Centres must have a close relationship with local community adult services, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
	Telemedicine and IT	
A12(L3)	Each Local ACHD Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Surgical Centres and Specialist ACHD Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	Within 3 years
A13(L3)	Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to their own Specialist ACHD Surgical Centre or Specialist ACHD Centre system and enable immediate access to patient data.	Within 6 months
	Multidisciplinary Team (MDT)	
A14(L3)	Staff from across the Local ACHD Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.	Immediate
A15(L3)	Each Local ACHD Centre cardiologist with an interest in ACHD must participate (at least six times per year) in specialist MDT meetings led by the Specialist ACHD Surgical Centre, either in person or via telemedicine facilities, and must also attend the annual network meeting. This requirement will be reflected in job plans.	Within 1 year
A16(L3)	Each cardiologist with an interest in ACHD will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Within 1 year
A17(L3)	Each Local ACHD Centre must have identified registered nurses with an interest and training in ACHD.	Within 1 year

	Adult	Implementation timetable
	Specialist ACHD Surgical Centres	
B1(L1)	Each Specialist ACHD Surgical Centre 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 surgery and interventional cardiology cover. A consultant ward round will occur daily.	Within 6 months
B2(L1)	Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist ACHD Surgical Centre; or b. the patient must be referred to an alternative Specialist ACHD Surgical Centre where a surgeon/interventionist has the appropriate skills.	Immediate
B3(L1)	Arrangements must be in place in each Specialist ACHD Surgical Centre both for consultant interventional specialist ACHD cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	Immediate
B5(L1)	Specialist ACHD Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to centre referrals.	Immediate
B6(L1)	Each Specialist ACHD Surgical Centre will have a formally nominated ACHD lead with responsibility for the service at the Specialist ACHD Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	Within 6 months
B7(L1)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Surgery	
B8(L1)	All adult congenital cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in	Immediate

	Adult	Implementation timetable
	adult congenital heart disease. [See Appendix A for the definition of what qualifies as ACHD surgery.]	
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist ACHD Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: within 3 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).	Within 3 years
	Cardiology	
B11(L1)	All adult congenital cardiology must be carried out by specialist ACHD cardiologists.	Immediate
B12(L1)	Each Specialist ACHD Surgical Centre must be staffed by a minimum of 4 WTE consultant specialist ACHD cardiologists. Each ACHD Cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist.	Within 3 years
B13(L1)	Each Specialist ACHD Surgical Centre must deliver 24/7 elective and emergency care, including consultant specialist ACHD cardiology on-call cover for the Specialist ACHD Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4. The on-call rota must ensure cover by appropriately trained specialists in care of both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B14(L1)	Each Specialist ACHD Surgical Centre must be staffed by at least two interventional specialist cardiologists (ACHD or paediatrics), who may be included in the number referred to in standard B12(L1).	Within 1 year
B15(L1)	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.	Within 6 months

	Adult	Implementation timetable
B16(L1)	Cardiologists performing therapeutic catheterisation in patients with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year; the Lead Cardiologist must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B17(L1)	Each Specialist ACHD Surgical Centre must be staffed by an electrophysiologist experienced in ACHD.	Immediate
B18(L1)	ACHD electrophysiology procedures must only be undertaken by an electrophysiologist experienced in the management of arrhythmias with congenital heart disease.	Immediate
B19(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and d. a nurse with experience of congenital cardiac catheterisation.	Immediate
B20(L1)	Each Specialist ACHD Surgical Centre must be staffed by a congenital cardiac imaging specialist who may be a cardiologist or a radiologist, expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B21(L1)	Each Specialist ACHD Surgical Centre will have 24/7 anaesthetic support by consultants experienced in the management of ACHD patients.	Immediate
B22(L1)	At each Specialist ACHD Surgical Centre an ACHD cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	Within 6 months
B23(L1)	Each Specialist ACHD Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity. All scientists	Within 1 year

	Adult	Implementation timetable
	should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	
	Intensive Care	
B24(L1)	Intensive Care Unit (ICU) consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
B25(L1)	Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Patients must be cared for by nurses with appropriate training and competencies in adult congenital cardiac critical care.	Immediate
	Nursing	
B26(L1)	Each Specialist ACHD Surgical Centre must have a formally nominated lead ACHD nurse with responsibility for the service at the Specialist ACHD Surgical Centre, providing professional and clinical leadership and support to the team of ACHD specialist nurses across the network.	Within 6 months
B27(L1)	Nursing care must be provided by a dedicated team of nursing staff trained in the care of young people and adults who have received cardiac surgery. The ACHD inpatient nursing team will be led by a senior nurse with specialist knowledge and experience of congenital cardiology and cardiac surgery.	Immediate
B28(L1)	Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum five, and location of these nurses will depend on geography, population and the configuration of the network. Each patient must have a named Specialist ACHD Nurse responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and partner/family or carers.	Within 1 year
B29(L1)	The ACHD nurse specialists will work closely with the Children's Cardiac Transition Nurse to coordinate the transfer process for each patient.	Within 6 months
	Psychology	
B30(L1)	Each Specialist ACHD Surgical Centre must employ a minimum of 1 WTE practitioner psychologist (with experience of working with CHD)per 400 patients undergoing cardiac surgery each year.	Within 1 year

	Adult	Implementation timetable
	In addition, each Congenital Heart Network must have 1 WTE practitioner psychologist, employed by the Specialist ACHD Surgical Centre, per 5,000 adult patients with CHD. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network.	
	Administrative Staffing	
B31(L1)	Each Specialist ACHD Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients and partners/family or carers in a timely fashion.	Immediate
B32(L1)	Each Specialist ACHD Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.	Within 6 months
	Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)	
B33(L1)	Each Specialist ACHD Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.	Immediate
B34(L1)	Each Specialist ACHD Surgical Centre will have an identified bereavement officer.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
B1(L2)	Each Specialist ACHD Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, 7 days a week within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Medical	
B3(L2)	Each Specialist ACHD Centre must be staffed by: a. one lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD; and b. 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.	Within 3 years
B4(L2)	Each Specialist ACHD Centre must provide a dedicated consultant-led cardiology on-call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.	Immediate
B5(L2)	Each Specialist ACHD Centre will have a formally nominated Clinical ACHD Lead with responsibility for the service at the Specialist ACHD Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist ACHD Centre will have separate clinical leads identified from the relevant specialties, including nursing, ICU, and anaesthesia who have a direct link and collaborative working partnership with the lead roles in the Specialist ACHD Surgical Centre.	Within 6 months
B6(L2)	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.	Within 6 months
B7(L2)	Specialist ACHD Cardiologists based at the Specialist ACHD Centre who visit the Specialist ACHD Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year, averaged over a three-year period.	Immediate
B8(L2)	Electrophysiology will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre if	Immediate

	Adult	Implementation timescale
	specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network agreed governance arrangements.	
B9(L2)	Each Specialist ACHD Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B10(L2)	Intensive Care Unit consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
	Nursing	
B11(L2)	Specialist ACHD Centres must have locally designated registered nurses with a specialist interest in adult congenital heart disease, trained and educated in the assessment, treatment and care of patients with CHD.	Immediate
B12(L2)	Each Specialist ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate
B13(L2)	Each Specialist ACHD Centre will employ a minimum of 2 WTE specialist ACHD nurses whose role will extend throughout the network. The precise number, above the minimum two, and location of these nurses will depend on geography, population and the configuration of the network.	Within 1 year
	Psychology	
B14(L2)	Each Specialist ACHD Centre must have access to a clinical psychology service that is integrated with the ACHD team.	Immediate
	Administrative	
B15(L2)	Each Specialist ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist ACHD Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients, partners/family or carers in a timely fashion.	Immediate
	Other	

	Adult	Implementation timescale
B17(L2)	Each Specialist ACHD Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	Immediate
B18(L2)	Each Specialist ACHD Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.	Immediate
B19(L2)	Each Specialist ACHD Centre will have a dedicated bereavement officer.	Immediate

DRAFT CHD Standards: Section B: Staffing and skills
Level 3: Local ACHD Centres

	Adult	Implementation timescale
	Local ACHD Centres	
B1(L3)	The Local ACHD Centre must be staffed by at least one consultant cardiologist with an interest in ACHD.	Within 1 year
B2(L3)	Each Local ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
B3(B3)	Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
B4(B3)	ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.	Immediate
B5(L3)	Each Local ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Within 6 months
B6(L3)	Each Local ACHD Centre will provide administrative support to ensure availability of medical records, to organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients, partners/family or carers in a timely fashion.	Immediate
B7(L3)	Each Local ACHD Centre must have a cardiac physiologist with training in congenital echocardiography.	Within 1 year
B8(L3)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
B9(L3)	The Local ACHD Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding vulnerable adults; and b. a dedicated bereavement officer.	Immediate

	Adult	Implementation timeline
	Specialist ACHD Surgical Centres	
C1(L1)	There must be facilities in place to ensure easy and convenient access for partners/family/carers. Facilities and support include: a) accommodation for partners/family members to stay; b) access to refreshments; c) facilities suitable for the storage and preparation of simple meals; and d) an on-site quiet room completely separate from general facilities Family accommodation should be provided without charge.	Within 6 months
C2(L1)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, ideally within a dedicated ACHD ward space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C3(L1)	Patients must have access to general resources including books, magazines and free wifi.	Immediate
C4(L1)	There must be facilities, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate
C5(L1)	Patients and their partners/family/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate
C6(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C7(L1)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C8(L1)	Specialist ACHD Surgical Centres must have local arrangements for transferring patients from airfields and helipads.	Immediate

DRAFT CHD Standards: Section C: Facilities
Level 2: Specialist ACHD Centres

	Adult	Implementation timescale
	Specialist ACHD Centres	
C1(L2)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L2)	There must be facilities in place to ensure easy and convenient access for partners/ family/carers. Facilities and support include: a) accommodation for partners/family members to stay; b) access to refreshments; c) facilities suitable for the storage and preparation of simple meals; and d) an on-site quiet room completely separate from general facilities. Family accommodation should be provided without charge.	Within 6 months
C3(L2)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C4(L2)	Patients must have access to general resources including books, magazines and free wifi.	Immediate
C5(L2)	Patients and their partners/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.	Immediate
C6(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
C1(L3)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L3)	There must be facilities in place to ensure easy and convenient access for partners/family/carers.	Within 6 months
C3(L3)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C4(L3)	Patients must have access to general resources including books, magazines and free wifi.	Immediate
C5(L3)	Patients and their partners/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.	Immediate
C6(L3)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist ACHD Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L1)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L1)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L1)	Intensive Care Unit: Level 3, capable of multi-organ failure support. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L1)	Specialised congenital cardiac anaesthesia.	Immediate
D5(L1)	Ventricular assist programme with or without extracorporeal life support . (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Adult cardiac surgery.	Immediate
D7(L1)	Vascular services including surgery and Interventional Radiology.	Immediate
D8(L1)	Each Specialist ACHD Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography. Specialist ACHD Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations. Specialist ACHD Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. Specialist ACHD Surgical Centres must offer invasive diagnostic investigation and treatment, including:	Within 6 months

	Adult	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist ACHD Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
	a. catheter intervention; b. electrophysiological intervention; c. implantable cardioverter defibrillator (ICD) and pacemaker insertion and extraction (including Cardiac Resynchronization Therapy - CRT); and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment (where clinically indicated). These services must be available 24/7.	

	Adult	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D9(L1)	Specialist Paediatric Congenital Cardiac Surgery and Intervention. [This standard recognises shared staffing and out-of-hours cover.]	Within 3 years
D10(L1)	General Surgery.	Within 3 years
D11(L1)	Nephrology/Renal Replacement Therapy.	Within 3 years
D12(L1)	Gastroenterology.	Within 3 years

DRAFT CHD Standards: Section D: Interdependencies
Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D13(L1)	Physiotherapy (service must be integrated with the ACHD team).	Within 3 years
D14(L1)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Within 3 years
D15(L1)	Gynaecology.	Within 3 years
D16(L1)	Neonatal unit (NICU): Level 3.	Within 3 years
D17(L1)	Microbiology and infectious diseases.	Within 3 years
D18(L1)	Neurology.	Within 3 years
D19(L1)	Neurosurgery.	Within 3 years
D20(L1)	Obstetric unit with maternal fetal medicine specialist(s).	Within 3 years
D21(L1)	Respiratory medicine.	Within 3 years
D22(L1)	Urology.	Within 3 years
D23(L1)	Pain management service.	Within 3 years
D24(L1)	Bereavement Support, including nurses trained in bereavement support.	Within 3 years

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D25(L1)	Clinical Haematology.	Immediate
D26(L1)	Clinical biochemistry.	Immediate
D27(L1)	Orthopaedics.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in patients with congenital heart disease.	
D28(L1)	Ear, Nose and Throat	Immediate
D29(L1)	Psychology.	Immediate
D30(L1)	Dietician.	Immediate
D31(L1)	Clinical Genetics.	Immediate
D32(L1)	Dentistry.	Immediate
D33(L1)	Clinical Immunology.	Immediate
D34(L1)	Dermatology.	Immediate
D35(L1)	Sexual health.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in patients with congenital heart disease.	
D36(L1)	Cardiac rehabilitation.	Immediate
D37(L1)	Occupational therapy.	Immediate
D38(L1)	Psychiatry.	Immediate
D39(L1)	Gynaecology	Immediate

DRAFT CHD Standards: Section D: Interdependencies
Level 2: Specialist ACHD Centres

	Adult	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Specialist ACHD Centres.** They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L2)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L2)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L2)	Intensive Care Unit: Level 3, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L2)	Each Specialist ACHD Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, transesophageal and fetal echocardiography. Specialist ACHD Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. These services must be available 24/7.	Immediate

DRAFT CHD Standards: Section D: Interdependencies
Level 2: Specialist ACHD Centres

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D5(L2)	General Surgery.	Immediate
D6(L2)	Cardiac anaesthetist who works closely with specialist congenital cardiac anaesthetists in the network.	Immediate
D7(L2)	Nephrology.	Immediate
D8(L2)	Physiotherapy (service must be integrated with the ACHD team).	Immediate
D9(L2)	Bereavement Support, including nurses trained in bereavement support.	Immediate
D10(L2)	Pain management service.	Immediate
D11(L2)	Gastroenterology.	Immediate
D12(L2)	Clinical biochemistry.	Immediate
D13(L2)	Clinical Haematology.	Immediate
D14(L2)	Ear nose and throat.	Immediate
D15(L2)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Immediate
D16(L2)	Gynaecology.	Immediate
D17(L2)	Neonatal Intensive Care Unit (NICU): Level 3 – for newborns of mothers with CHD	Immediate
D18(L2)	Microbiology and infectious diseases.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. They must function as part of the extended multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D19(L2)	Neurology.	Immediate
D20(L2)	Neurosurgery.	Immediate
D21(L2)	Obstetric Unit with Maternal Fetal Medicine Specialist/s.	Immediate
D22(L2)	Orthopaedics.	Immediate
D23(L2)	Respiratory medicine.	Immediate
D24(L2)	Urology.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D25(L2)	Learning Disability Team.	Immediate

	Adult	Implementation timescale
	Advice and consultation must be available from the following services at least by the following working day. The services must be experienced in patients with congenital heart disease.	
D26(L2)	Clinical Genetics.	Immediate
D27(L2)	Dentistry.	Immediate
D28(L2)	Clinical Immunology.	Immediate
D29(L2)	Dermatology.	Immediate
D30(L2)	Sexual Health.	Immediate
D31(L2)	Cardiac rehabilititation.	Immediate
D32(L2)	Diabetes.	Immediate
D33(L2)	Neurosurgery.	Immediate
D34(L2)	Occupational Therapy	Immediate
D35(L2)	Palliative Care.	Immediate
D36(L2)	Psychiatry.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Local ACHD Centres.**	
D1(L3)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L3)	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital– either from Specialist ACHD Centres or from Specialist ACHD Surgical Centres in accordance with network protocols.	Immediate
D3(L3)	Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: a. blood testing; b. electrocardiogram (ECG) available 24/7; c. transthoracic echocardiogram; d. chest X-ray; e. exercise testing/six-minute walk test; f. 24 hour tapes, event recorders; and g. ambulatory blood pressure monitoring.	Immediate

DRAFT CHD Standards: Section E: Training and Education
Level 1: Specialist ACHD Centres

	Adult	Implementation timescale
	Specialist ACHD Surgical Centres	
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and ICU medical and nursing team will complete mandatory level 1 training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth level 2-4 training.	Immediate
E3(L1)	Nurses working within Specialist ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist ACHD Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in ACHD cardiology, ACHD surgery and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems. Specialist ACHD Surgical Centres must provide resources sufficient to support these educational needs across the network.	Within 6 months
E6(L1)	Each Specialist ACHD Surgical Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Adult	Implementation timescale
	Specialist ACHD Centres	
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and ICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	Nurses working within Specialist ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, with a formal annual training plan in place.	Within 1 year
E4(L2)	Each Specialist Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in in ACHD cardiology and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.	Within 6 months
E6(L2)	Each Specialist ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Specialist ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Adult	Implementation timescale
	Local ACHD Centres	
E1(L3)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L3)	All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L3)	Each Local ACHD Centre must assist the Specialist ACHD Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all adult cardiology trainees within their network catchment area.	Immediate
E4(L3)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.	Within 1 year
E5(L3)	Each Local ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Local ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
E6(L3)	Nurses working within Local ACHD Centres 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 enabling professional development and career progression. A formal annual training plan should be in place.	Within 1 year
E7(L3)	Cardiologists with an interest in ACHD should have a named cardiologist within the Specialist ACHD Surgical Centre or Specialist ACHD Centre who acts as a mentor; this mentor would normally be the link cardiologist.	Immediate

DRAFT CHD Standards: Section F: Organisation, governance and audit
Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
F1(L1)	Each Specialist ACHD Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L1)	Each Specialist ACHD Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings to discuss patient care pathways, guidelines and protocols; c. regular network meetings whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F4(L1)	Each Specialist ACHD Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Surgical Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist ACHD Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local ACHD Centres. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Within 6 months
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Within 6 months

	Adult	Implementation timescale
F9(L1)	Each Specialist ACHD Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	Each Specialist ACHD Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist ACHD Centres and Local ACHD Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Same-day cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a patient needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the patient wishes. Specialist ACHD Centres and Local ACHD Centres must be involved in any relevant discussions.	Immediate
F18(L1)	When a Specialist ACHD Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist ACHD Surgical Centre or Specialist ACHD Centre, if appropriate.	Immediate
F19(L1)	An ACHD Nurse Specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate

	Adult	Implementation timescale
F20(L1)	Each Specialist ACHD Surgical Centre must implement a pain control policy that includes advice on pain management at home.	Immediate
F21(L1)	Advice must be taken from the acute pain team for all patients who have uncontrolled severe pain. Particular attention must be given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	Immediate
F22(L1)	Each Specialist ACHD Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate
F23(L1)	Each Specialist ACHD Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F24(L1)	Each Specialist ACHD Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient's home or other agencies.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
F1(L2)	Each Specialist ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings to discuss patient care pathways, guidelines and protocols; c. regular network meetings whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F3(L2)	Each Specialist ACHD Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L2)	Each Specialist ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year
F8(L2)	Each Specialist ACHD Centre must participate in national programmes for audit and must submit data on electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate

	Adult	Implementation timescale
F9(L2)	Each Specialist ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist ACHD Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist ACHD Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
F13(L2)	Each Specialist ACHD Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate
F14(L2)	Each Specialist ACHD Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F15(L2)	Each Specialist ACHD Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient's home or other agencies.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
F1(L3)	Each Local ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L3)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.	Within 1 year
F3(L3)	Each Local ACHD Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L3)	Each Local ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L3)	Each Local ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L3)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L3)	Each Local ACHD Centre must participate in relevant national programmes for audit and must submit data to the Specialist ACHD Surgical or Specialist ACHD Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F8(L3)	Each Local ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Within 1 year
F9(L3)	Each Local ACHD Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local ACHD Centres will follow mandatory National Institute for Health and Care Excellence guidance.	Immediate

	Adult	Implementation timescale
F10(L3)	Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F11(L3)	Each Local ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate

	Adult	Implementation timescale
G1(L1)	Each Specialist ACHD Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of ACHD and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist ACHD Surgical Centres and Specialist ACHD Centres, and Local ACHD Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
G1(L2)	Each Specialist ACHD Centre must participate in research.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
G1(L3)	Each Local ACHD Centre should participate in research.	Immediate

DRAFT CHD Standards: Section H: Communication with patients
Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
H1(L1)	Specialist ACHD Surgical Centres must demonstrate that arrangements are in place that allow patients to participate in decision-making at every stage in their care.	Immediate
H2(L1)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact in order to be able to actively participate in decision-making at every stage in their care, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that patients are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate
H5(L1)	Sufficient information must be provided to allow the patient to make informed decisions, including supporting patients, partners, family or carers in interpreting publicly available data that support choice. The following should also be described:	Immediate

	Adult	Implementation timescale
	a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; and d. consideration of the closest unit to the patient's home.	
H6(L1)	Specialist ACHD Surgical Centres must demonstrate that patients, partners, family and carers are offered support in obtaining further opinions or referral to another Specialist ACHD Surgical Centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H7(L1)	Information must be made available to patients, partners, family and carers 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H8(L1)	Specialist ACHD Surgical Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H9(L1)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H10(L1)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Surgical Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Specialist ACHD Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H11(L1)	Each Specialist ACHD Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate

	Adult	Implementation timescale
H12(L1)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Immediate
H13(L1)	Each Specialist ACHD Surgical Centre must provide a 24/7 emergency telephone advice service for patients with urgent concerns about deteriorating health.	Within 6 months
H14(L1)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide literature.	Within 6 months
H15(L1)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H16(L1)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H17(L1)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H18(L1)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H19(L1)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H20(L1)	Patients, partners, family or carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H21(L1)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate

DRAFT CHD Standards: Section H: Communication with patients

Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
H22(L1)	Where surgery or intervention is planned, patients and carers must have the opportunity to visit the Specialist ACHD Surgical Centre well in advance of admission (as early as possible) to meet the team, including the ACHD Specialist Nurse that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H23(L1)	Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Preliminary consent may be taken by any member of the medical team, at a pre-admission clinic or visit. Final consent will be taken by the operating consultant	Immediate
H24(L1)	An ACHD Specialist Nurse must be available to support patients and carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H25(L1)	Patients and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H26(L1)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H27(L1)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months
H28(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centre	
H1(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L2)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L2)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact in order to be able to actively participate in decision-making at every stage in their care including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L2)	Information must be made available to patients, partners, family or carers 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed,	Immediate

	Adult	Implementation timescale
	written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	
H6(L2)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L2)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Specialist ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and partners/family /carers must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L2)	Each Specialist ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L2)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Immediate
H1(L2)0	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide relevant literature.	Immediate
H11(L2)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H12(L2)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities.	Immediate

	Adult	Implementation timescale
	Support for people with learning disabilities must be provided from an appropriate specialist or agency.	
H13(L2)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	Immediate
H14(L2)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient’s personal record in accordance with national guidance.	Immediate
H16(L2)	Patients, partners, family and carers and all health professionals involved in the patient’s care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L2)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H21(L2)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L2)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate

	Adult	Implementation timescale
H23(L2)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care.	Within 1 year
H24(L2)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
H1(L3)	Local ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L3)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L3)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact in order to be able to actively participate in decision-making at every stage in their care including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and their partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention d. smoking, alcohol and drugs e. careers; f. travel; g. welfare benefits; h. social services; and i. community services.	Immediate
H4(L3)	Information must be made available to patients, partners, family and carers 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 documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L3)	Local ACHD Centres must demonstrate that arrangements are in place for patients, partners, family and carers to be given an agreed, written	Immediate

	Adult	Implementation timescale
	management plan in a language they can understand that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	
H6(L3)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L3)	Patients, partners, families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Local ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and their partners/families/carers must be informed of the action taken following a complaint or suggestion made. Local ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L3)	Each Local ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L3)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carer throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Within 6 months
H10(L3)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide relevant literature.	Within 1 year
H11(L3)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H12(L3)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities.	Immediate

	Adult	Implementation timescale
	Support for people with learning disabilities must be provided from an appropriate specialist or agency.	
H13(L3)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	Immediate
H14(L3)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L3)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient’s personal record in accordance with national guidance.	Immediate
H16(L3)	Patients, partners, family or carers and all health professionals involved in the patient’s care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L3)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L3)	Local ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L3)	Where surgery or intervention is planned, Local ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L3)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H21(L3)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L3)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L3)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their	Within 1 year

	Adult	Implementation timescale
	care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	
H24(L3)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L1)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L1)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I4(L1)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L1)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	Immediate
I8(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual	Immediate

	Adult	Implementation timescale
	tailored transition plan.	
I9(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Immediate

	Adult	Implementation timescale
I1(L2)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. ‘Lost to follow-up’ rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L2)	There will not be a fixed age of transition from children’s to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I4(L2)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient’s care plan indicates that they do not require long-term follow-up.	Immediate
I5(L2)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient’s wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L2)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	Immediate
I8(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual	Immediate

	Adult	Implementation timescale
	tailored transition plan.	
I9(L2)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Immediate

	Adult	Implementation timescale
I1(L3)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L3)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L3)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.	Immediate
I4(L3)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L3)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L3)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L3)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	Immediate

	Adult	Implementation timescale
I8(L3)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L3)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Within 1 year

	Adult	Implementation timescale
	Family Planning Advice	
J1(L1)	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.	Immediate
J2(L1)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health and safe forms of contraception specific to their condition must be provided. 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.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All 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.	Immediate
J5(L1)	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.	Within 1 year
	Pregnancy and Planning Pregnancy	
J6(L1)	Each Specialist ACHD Surgical Centre must be staffed by Specialist ACHD Cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	Immediate
J7(L1)	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 2-4) risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with expertise in pregnancy in women with congenital heart disease.	Immediate
J8(L1)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care	Immediate

	Adult	Implementation timescale
	with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J9(L1)	Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at an obstetric unit at the Specialist ACHD Surgical Centre, or close by (for example at the network linked obstetric unit) during pregnancy, delivery and the puerperium.	Immediate
J10(L1)	Women with moderate or high risk conditions, who are not at risk of requiring such emergency surgery or intervention during pregnancy, may be managed at an obstetric unit outside the Specialist ACHD Surgical Centre with specific network agreement and advice from the specialist centre.	Immediate
J11(L1)	Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.	Immediate
J12(L1)	Each Specialist ACHD Surgical Centre must have a specialist tertiary maternity unit on the same hospital site or in a neighbouring hospital that functions as part of the extended multidisciplinary team. Consultants Obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease or an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The multidisciplinary team must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Immediate
J13(L1)	Regular joint clinics will be provided with the Specialist ACHD Cardiologist with expertise in congenital heart disease in pregnancy, Specialist Obstetrician and with access to an Obstetric Anaesthetist. Regular specialist multidisciplinary team case conferences must take place across the network with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia, haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.	Immediate

	Adult	Implementation timescale
	Family Planning Advice	
J1(L2)	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 who have expertise in pregnancy in congenital heart disease.	Immediate
J2(L2)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. 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.	Immediate
J3(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by an ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	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.	Immediate
	Pregnancy and Planning Pregnancy	
J6(L2)	Each Specialist ACHD Centre must be staffed by Specialist ACHD cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	Immediate
J7(L2)	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 2-4) risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (Consultant Obstetrician) with expertise in pregnancy in women with congenital heart disease.	Immediate
J8(L2)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care	Immediate

	Adult	Implementation timescale
	with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J9(L2)	Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at an obstetric unit at the Specialist ACHD Surgical Centre or close by (for example at the network linked obstetric unit), during pregnancy, delivery and the puerperium.	Immediate
J10(L2)	Women with moderate or high risk conditions, who are not at risk of requiring such intervention during pregnancy, may be managed at an obstetric unit outside the Specialist ACHD Surgical Centre with specific network agreement and advice from the specialist centre.	Immediate
J11(L2)	Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.	Immediate
J12(L2)	Each Specialist ACHD Centre must have a specialist tertiary maternity unit on the same hospital site or in a neighbouring hospital that functions as part of the extended multidisciplinary team. Consultants Obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease or an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The multidisciplinary team must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Immediate
J13(L2)	Regular joint clinics will be provided with the Specialist ACHD Cardiologist with expertise in congenital heart disease in pregnancy, Specialist Obstetrician and with access to an Obstetric Anaesthetist. Regular specialist multidisciplinary team case conferences must take place across the network with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia, haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.	Immediate

	Adult	Implementation timescale
	Family Planning Advice	
J1(L3)	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist or cardiologist with special interest in congenital heart disease who have expertise in pregnancy in congenital heart disease. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
J2(L3)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. 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.	Immediate
J3(L3)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L3)	All 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. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
J5(L3)	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.	Immediate
	Pregnancy and Planning Pregnancy	
J6(L3)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease at a Specialist ACHD Surgical Centre or Specialist ACHD Centre immediately once they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any	Immediate

	Adult	Implementation timescale
	choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J7(L3)	The Local ACHD Centre may care for pregnant women with ACHD in whom pregnancy presents a low maternal risk at the onset of pregnancy. It should be acknowledged that as pregnancy proceeds, complications such as severe pre-eclampsia may alter this risk assessment.	Immediate

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L1)	Each Specialist ACHD Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	Immediate
L2(L1)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L1)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L1)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L1)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Adult	Implementation timescale
L10(L1)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L1)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L1)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate
L17(L1)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L1)	Patients will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the	Immediate

	Adult	Implementation timescale
	partner/family or carers before a death has occurred, if they have specifically requested to meet them.	
L20(L1)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L1)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with	Immediate

	Adult	Implementation timescale
	appropriate services to arrange this.	

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L2)	Each Specialist ACHD Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	Immediate
L2(L2)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L2)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L2)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L2)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L2)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L2)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Adult	Implementation timescale
L10(L2)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L2)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L2)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L2)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L2)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate
L17(L2)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L2)	Patients will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L2)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the	Immediate

	Adult	Implementation timescale
	partner/family or carers before a death has occurred, if they have specifically requested to meet them.	
L20(L2)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L2)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L2)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with	Immediate

	Adult	Implementation timescale
	appropriate services to arrange this.	

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L3)	Each Local ACHD Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service at the Specialist ACHD Surgical or Specialist ACHD Centre.	Immediate
L2(L3)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L3)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L3)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L3)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L3)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L3)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate

	Adult	Implementation timescale
L8(L3)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L3)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L3)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L3)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L3)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L3)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L3)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L3)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L3)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate

	Adult	Implementation timescale
L17(L3)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L3)	Patients will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L3)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L3)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L3)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.	Immediate
L22(L3)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L3)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L3)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	
L25(L3)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L3)	Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any	Immediate

	Adult	Implementation timescale
	complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	
L27(L3)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L3)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.	Immediate

	Adult	Implementation timescale
M1(L1)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All patients with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	Immediate
M3(L1)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	Specialist ACHD Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for patients with congenital heart disease.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
M1(L2)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate

DRAFT CHD Standards: Section M: Dental
Level 3: Local ACHD Centres

	Adult	Implementation timescale
	Local ACHD Centres	
M1(L3)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L3)	Each Local ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L3)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L3)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L3)	Local ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate

Appendix A: 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[1] 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 with CHD of Child Bearing Age***
   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***
   This 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

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[1] 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'.

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.

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 is a big issue in a low risk situation like ASD
c. It is 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 also be located in specialised ACHD centre to allow joined-up MDT planning. The advantages of this are around the number of interventional catheterisations, training of ACHD interventionists and facilitation of data collection for national audits within NICOR. **Within the ACHD model of care, ASD closure should only be undertaken in the Specialist Surgical Centre.** This ensures that congenital cardiac surgery co-location is available should it be needed. There should be flexibility within the network to enable cardiologists with skills from Specialist Cardiology Centres to continue to undertake interventional work in Specialist Surgical Centres by local planning.

Patent Foramen Ovale

Patent Foramen Ovale (PFO) normally presents or is detected in a broad clinical context (e.g. neurology, stroke etc). It is not normally associated with other structural heart diseases requiring other medical or surgical expertise. It is currently managed well in the medical community despite the uncertainty regarding appropriate treatments. **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.** Audit of PFO closure should be submitted to the BCIS registry.

This does not preclude PFO closure from being performed in ACHD services within the congenital heart network.