



**Paediatric
Congenital Heart
Disease
Specification**

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

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1 Document summary

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

There are eight documents:

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

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

- A – The Network Approach
- B – Staffing and skills
- C – Facilities
- D – Interdependencies
- E – Training and education
- F – Organisation, governance and audit
- G – Research
- H – Communication with patients
- I – Transition
- J – Pregnancy and contraception
- K – Fetal diagnosis
- L – Palliative care and bereavement
- M – Dental

2 Paediatric Cardiac Services Specification

Service Specification No.	<i>E05/S/a</i>
Service	Paediatric Cardiac Services
Commissioner Lead	Anthony Prudhoe
Provider Lead	N/A
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

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.

The Congenital Heart Disease Standards specify the requirements relating to the care taking place in Level 3 services (Local Children's Cardiac 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 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.

1.2 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.

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 (NHS England Congenital Heart Disease Standards, 2015).

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

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

Network Care Levels:

- Level 1: Specialist Children’s or ACHD Surgical Centres
- Level 2: Specialist Children’s or ACHD Cardiology Centres
- Level 3: Local Children’s or ACHD 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, should be delivered as close to home as possible. It is expected that Networks will collaborate together to ensure uniformity of care throughout the healthcare system

1.4 Evidence Base

[Monro, Paediatric and Congenital Cardiac Services Review, DH, 2003](#)

[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	Ensuring people have a positive experience of	✓

4	care	
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓

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

- Post Procedural Mortality: 3 year validated partial risk adjusted 30 day mortality after paediatric cardiac surgery
- 1 year rolling unvalidated partial risk adjusted 30 day mortality after paediatric cardiac surgery
- 30 day unplanned re intervention rate following congenital cardiac surgery and catheter intervention (NICOR defined procedure)
- Cancellations on day of operation for non-clinical reasons
- Post catheter intervention complication rate
- Mothers with suspected CHD in fetus seen by an obstetric ultrasound specialist and a fetal cardiology specialist within 3 days of referral
- Mothers with suspected CHD in fetus seen by specialist cardiac nurse on the day of 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 Service Aims and Objectives

Service Aims

The Children's Heart Service aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing care from point of diagnosis to exiting the service. The service will manage all patients diagnosed with heart disease before their 16th birthday, with the exception of some forms of inherited heart disease.

The service for children's heart disease aims to:

- Deliver best outcomes for patients, with lowest mortality, minimal disability and an improved opportunity for a better quality of life for survivors
- Consistently meet the standards of care (2015) and provide resilient 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:

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

3.2.1 Overview

This specification covers the following service areas:

- Fetal cardiology services
- Paediatric congenital heart disease services
- Paediatric acquired heart disease services

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- Paediatric cardiac surgery and invasive cardiology services
- Paediatric cardiac electrophysiology services
- Paediatric specialist cardiovascular imaging

The model of care for children with heart disease is based on an overarching principle of a Congenital Heart Network. Working in partnership with the Adult 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 fetal medicine, maternity, neonatal and paediatric intensive care.

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

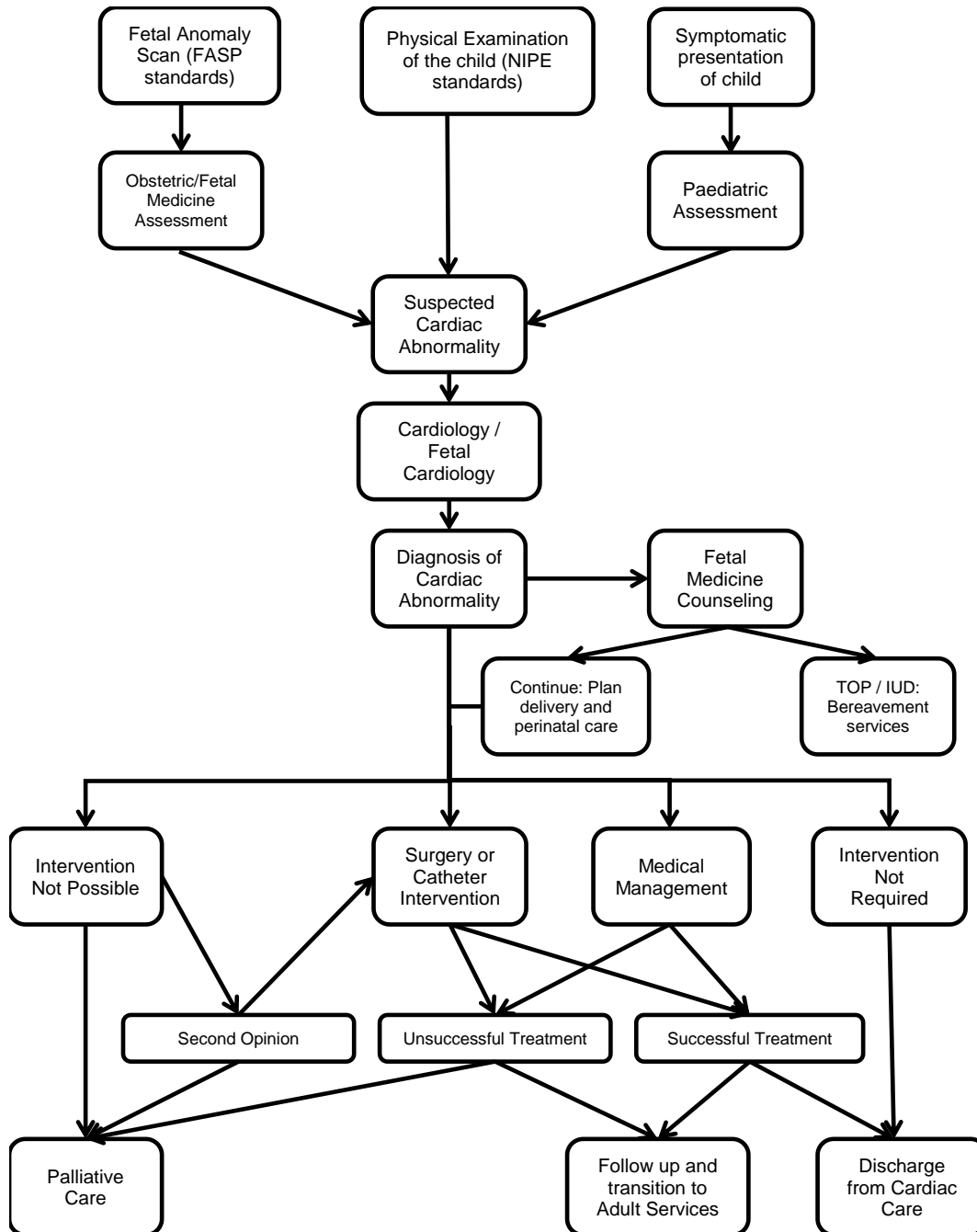
Across the whole Congenital Heart Network there must be facilities in place to ensure easy and convenient access for patients and their families/carers and facilities and where an inpatient stay is needed, support should include:

- Accommodation for parents/carers/siblings 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 paediatric environment, ideally within a dedicated paediatric cardiology ward/OPD space.

Parents or carers and where appropriate patients must be supported to actively participate in decision making at every stage of their care.

3.2.2 Patient care pathway



3.2.3 Referral

Patients enter the paediatric cardiac pathway through:

- Prenatal diagnosis.
- Physical examination of an asymptomatic infant or child (including NIPE).
- 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.

Upon referral the appropriate paediatric cardiac service will:

- See referrals within 3 days and preferably within 2 working 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.

3.2.4 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 cardiac nurse specialist)

3.2.5 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.
- The fetal cardiac team will discuss options available to the family in a non-

directive, caring and supportive way with direction given to publically available information

- A Fetal Cardiac Nurse Specialist 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.
- A named clinician and specialist nurse will be identified
- 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 fetus.

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, 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 specialist 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.
- 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.

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).

3.2.6 Leaving the Pathway

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

The process of transitioning from paediatric to ACHD care must be initiated no later than 12 years of age taking into account individual circumstances and special needs.

- 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.
- 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.
- 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.
- Clear care plans (or transition "passports") must be agreed for further management in a clearly specified setting
- A named children's cardiac transition nurse will act as a main point of contact and provide support to the young person and their family. They will also function 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
- Peer to peer support should be offered
- 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

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. The potential for organ and tissue donation should be discussed.

- 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 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.
- When a death occurs in hospital, the processes that follow a death including legal aspects need to be explained verbally, at the family's pace and backed up with written information. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.
- 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.

3.2.7 Processes

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.

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, surgery or innovative procedures
- Each MDT discussion must generate a signed record of the discussion and the final outcome.
- When considering patients for complex catheter intervention or surgery (including out of hours and in emergencies) the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Intensivist. Otherwise the composition of the MDT should be pathway driven, and adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinic-pathological and audit

meetings).

- Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing to participate in the decision-making about their patient and for ongoing training and development.
- The attendance and activities of the MDT should be maintained in a register.

Communication

- 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
- Patients and their carers must be given sufficient information for them to understand and contextualise their congenital heart condition. Information provided should include any aspect of life that is relevant to them including: exercise and sports participation, sex, contraception, pregnancy, dental care, endocarditis prevention, smoking, alcohol and drugs; tattoos, piercings and intradermal procedures, school, career, travel, welfare benefits, social services and community services.
- Sufficient information must be provided to patients and carers to allow informed decisions to be made. This should include help interpreting publicly available data, information on other clinical specialties offered by alternative units (particularly for patients with co-morbidities), accessibility of alternative units, patient facilities offered by alternative units, outcomes at units under consideration and consideration of the closest unit to the patient's home.
- Patients and Carers must be offered support in obtaining further opinions or referral to another Specialist Children's Surgical Centre
- Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service. This feedback should be openly available together with outcome of relevant local and national audits. It should also be taken into account when planning and delivering services.

Governance

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

- Regular continuous clinical audit and quality improvement.
- Regular network multidisciplinary team (MDT) clinical meetings.
- Regular network meetings to review dashboard metrics including PRAiS mediated VLAD outcomes and unplanned re-interventions, discussion of mortality, morbidity, adverse events and resultant action plans.
- Regular network meetings of the wider clinical team (including network patient representatives) at least every 6 months, for issues such as agreement of protocols, review of audit data and monitoring of performance.

Patient registers/database

- 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 Heart Disease Audit (NCHDA) housed within 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 Service Description of Provider Centres within Paediatric Heart Networks

The Network must demonstrate a robust policy for collaboration with other Networks and with NHS commissioners for audit, including formal inter-unit peer review every five years.

The Specialist Children's Surgical Centre 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)

- 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 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.

3.4 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). 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.

4. Applicable Service Standards

Infrastructure requirements

4.1 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 congenital heart disease standards (2015). They have not been included in detail here for brevity.

4.2 Congenital Heart 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 responsible 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.
- Each Congenital Heart Network will have a formally appointed Network Manager responsible for the management of the network, and the conduct of network business.
- 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.

4.2.1 Specialist Children's Surgical Centres

- 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.
- 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 four WTE consultant congenital cardiac surgeons. Units will have a period of five years to achieve this standard. Out-of-hours arrangements must take into account the requirement

for surgeons only to undertake procedures for which they have the appropriate competence. A complement of 3 WTE consultant congenital cardiac surgeons will be acceptable in the interim.

- SCSCs must provide 24/7 surgical care across the spectrum of neonatal and paediatric surgical emergencies (with the exception of cardiac transplantation) with Consultant call to bedside response time of 30 minutes
- 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 (paediatric and ACHD) surgical procedures (auditable cases as defined by submission to NICOR with the addition of VAD implantation procedures and cardiac transplantation) 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 than 1 in 4 and ensuring a Consultant call to bedside response time of 30 minutes
- A Consultant ward round will occur daily
- Consultant interventional cardiology cover must be 24/7 with a rota no more frequent than 1 in 4. Congenital interventionists based at other hospitals may participate in this rota. 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 expert electrophysiologist experienced in paediatric cardiac disease with appropriate arrangements for cover by a competent person
- 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.

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- Each SCSC will provide sufficient clinical cardiac nurse educators to deliver competency-based programs for nurses across the network
- Each Congenital Heart Network will employ a minimum of either 7 WTE children's cardiac nurse specialists or 1 per 600,000 of the catchment population (whichever is the larger) distributed across the network according to geography and population. Included in this complement will be at least 1 WTE fetal cardiac nurse specialist and 1 WTE children's cardiac transition nurse

Other

- 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.
- Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland
- 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.
- Each SCSC must employ practitioner psychologists at a ratio of 0.25 WTE per 100 children undergoing cardiac surgery each year. A further minimum of 1 WTE practitioner psychologist must be employed to support the service across the network.
- 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.
- Each SCSC 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 SCSC will have telemedicine facilities to link with the SCSC.
- Each SCSC should have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.
- Equipment infrastructure on site: Electrophysiology including three-dimensional mapping ; standard, contrast, intraoperative, transesophageal and fetal 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.

4.2.2 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.

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

- 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.
- 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.

- The Network Children's Cardiac Psychologist will support the SCCC with an appropriate number of Children's Cardiac Psychology sessions based on site.
- 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 congenital heart disease standards (2015).
- 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).

4.2.3 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) who must have received training in accordance with the RCPCH/RCP 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
- 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 nurse 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.
- The Network Children's Cardiac Psychologist will support the LCCC with an appropriate number of Children's Cardiac Psychology sessions
- 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 congenital heart disease standards (2015).
- 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 2016. The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision.
5.2 Applicable CQUIN goals (See Schedule 4 Part E) Change annually.
6. Location of Provider Premises
TBC
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			
3 year rolling partial risk adjusted 30 day mortality data	To be determined after first year submissions	NICOR validated submitted annual data	Non-compliance with contract General Conditions 8 & 9
3 year validated partial risk adjusted 30 day mortality data	To be determined after first year submissions	Unvalidated in house data submitted quarterly	Non-compliance with contract General Conditions 8 & 9
Domain 2: Enhancing the quality of life of people with long-term conditions			
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Unplanned re-intervention rate within 30 days of catheter or surgical intervention	To be determined after first year submissions	Number of re-interventions divided by total number of catheter or surgical intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter or surgical intervention	To be determined after first year submissions	Number of complications divided by total number of procedures	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			
Responses to Patient Experience Surveys on CHD services	To be determined after first year submissions	Positive response to questionnaire on patient experience	Non-compliance with contract General Conditions 8 & 9
Last minute cancellation of elective surgical procedures	To be determined after first year submissions	Last minute cancellations of elective procedures divided by total	Non-compliance with contract General Conditions 8 & 9

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Paediatric Cardiac Services Specification

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

Classification: Official
Paediatric Cardiac Services Specification

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
positive Clostridium/MRSA difficile cultures		difficile/MRSA cultures divided by total number of inpatient stays	

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 be 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 minimise 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 2016](#)
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
- 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 2 RCNs 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

