Paediatric Congenital Heart Disease Standards: Level 3 – Local Children's Cardiology Centres

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Contents

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 Standards: Level 3 – Local Children's Cardiology Centres.

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 Congenital Heart Disease Standards: Level 3 – Local Children's Cardiology Centres

Standard	Paediatric	Implementation timescale
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. New-borns with a murmur and otherwise clinically well 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	Immediate

Standard	Paediatric	Implementation timescale
	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 • 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 held record 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	Within 1 year

Standard	Paediatric	Implementation timescale
	collectively they provide a national service); e. address how congenital cardiac surgeons, 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 an 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.	
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
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	Immediate

Standard	Paediatric	Implementation timescale
	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.	
	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 supra-regional services will be accessed via the CHD network.	Immediate

Standard	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

Standard	Paediatric	Implementation timescale
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

Standard	Paediatric	Implementation timescale
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. All patients under the care of a local children's cardiology centre should have a named paediatrician (ideally a PEC) responsible for coordinating care for children and young people after discharge from a CSSC, for referrals to local services and for communication between health professionals.	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

Standard	Paediatric	Implementation timescale
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
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	Immediate

Standard	Paediatric	Implementation timescale
	b. a dedicated bereavement officer.	

Standard	Paediatric	Implementation timescale
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. facilities 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

Standard	Paediatric	Implementation timescale
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

Standard	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	Immediate

Standard	Paediatric	Implementation timescale
	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.	

Standard	Paediatric	Implementation timescale
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, working with children with learning disabilities, life support, pain management, infection control, end-of-life care, 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 and community paediatric nurses. 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	Within 1 year

Standard	Paediatric	Implementation timescale
	career progression. A formal annual training plan should be in place.	
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

Standard	Paediatric	Implementation timescale
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. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and 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

Standard	Paediatric	Implementation timescale
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
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

Standard	Paediatric	Implementation timescale
G1(L3)	Each Local Children’s Cardiology Centre should participate in research.	Immediate
G2(L3)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

Standard	Paediatric	Implementation timescale
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, family and carers must be helped to understand the patient's condition, the effect it may have on their health and future life, what signs and symptoms should be considered 'normal' for them 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. tattoos, piercings and intradermal procedures; f. school and careers; g. travel;	Immediate

Standard	Paediatric	Implementation timescale
	h. welfare benefits; i. social services; and j. community services.	
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 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
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	Immediate

Standard	Paediatric	Implementation timescale
	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.	
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
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

Standard	Paediatric	Implementation timescale
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

Standard	Paediatric	Implementation timescale
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
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

Standard	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.	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

Standard	Paediatric	Implementation timescale
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. Peer to peer support should also be offered.	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
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

Standard	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	Immediate

Standard	Paediatric	Implementation timescale
	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.	
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.	

Standard	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. There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.	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 Fetal Cardiac Nurse Specialist 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 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 FCNS will act as the point of contact for the family throughout pregnancy for support and further information.	Immediate

Standard	Paediatric	Implementation timescale
K6(L3)	At diagnosis a plan must be agreed with the Specialist Children's Surgical Centre, the specialist fetal-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
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 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

Standard	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 potential for organ and tissue donation should be discussed. The family/carers and all the professionals involved will receive a written summary of this care plan	Immediate

Standard	Paediatric	Implementation timescale
	and will be offered regular opportunities to discuss any changes with the lead doctor.	
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
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

Standard	Paediatric	Implementation timescale
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
L18(L3)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate

Standard	Paediatric	Implementation timescale
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, transport of the body and sign-posting of funeral services 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

Standard	Paediatric	Implementation timescale
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
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

Standard	**Paediatric**	**Implementation timescale**
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
M6(L3)	Local Children's Cardiology Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate