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Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children's Surgical Centres

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Document Status

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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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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 1 – Specialist Children's Surgical 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 1 - Specialist Children’s Surgical Centres

Standard	Paediatric	Implementation timeline
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network’s host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network. Each network should develop a business plan.	Within 6 months
A2(L1)	Each Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of children and young people with congenital heart disease. The model of care will ensure that all congenital cardiac care including investigation, cardiology and surgery, is carried out only by congenital cardiac specialists (including paediatricians with expertise in congenital (BCCA definition)). The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist Children’s Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity, obstetric and neonatal services, children’s services, transition, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist Children’s Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for fetal services, maternity services, neonatal services and intensive care services to ensure a joined-	Within 6 months

Standard	Paediatric	Implementation timeline
	up approach with treatment continuity.	
A4(L1)	Specialist Children’s Surgical Centres will adhere to their Congenital Heart Network’s clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialist Children’s Surgical Centre, the Specialist Children’s Cardiology Centres and Local Children’s Cardiology Centres, according to local circumstances; and f. address how Specialist Children’s Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	Immediate
A5(L1)	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Critically ill children must be transferred/retrieved in accordance with the standards set out within the designation standards for Paediatric Intensive Care services.	Immediate

Standard	Paediatric	Implementation timeline
	c. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Immediate
A7(L1)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Within six months
A8(L1)	Congenital Heart Networks will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years
Cardiological Interventions		
A9(L1)	Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre; b. allow neonates with *patent ductus arteriosus* to receive surgical ligation in the referring neonatal intensive care unit (level 3)[1] provided that the visiting surgical team is dispatched	Within 3 years

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

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

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

Standard	Paediatric	Implementation timeline
Telemedicine and IT		
A16(L1)	Each Congenital Heart Network will have telemedicine facilities as required to link designated hospitals in the network (Specialist Surgical Centres, Specialist Cardiology Centres and Local Cardiology Centres, according to local circumstances) and with other Congenital Heart Networks. The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric cardiac services; and e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate.	Within 3 years
A17(L1)	Each congenital heart network must make arrangements for CHD clinicians and paediatricians (inc. PECs) within the network to be able to access patient records and imaging systems in all Specialist Surgical Centres and Specialist Cardiology Centres in the network.	3 years
Multidisciplinary Team (MDT)		
A18(L1)	Each Specialist Children's Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the network. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate

Standard	Paediatric	Implementation timeline
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will be pathway driven, and adjusted according to the needs of different aspects of the service (for example: assessment, post-operative care, clinic, pathological and audit meetings). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, a paediatric cardiologist and a paediatric intensivist.	Immediate
A21(L1)	Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months. Network patient representatives will be invited to participate in these meetings.	Immediate
Network Leadership		
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	Within 6 months
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months
A24(L1)	Each Congenital Heart Network will have a formally appointed Network Manager responsible for the	Within 6 months

Standard	Paediatric	Implementation timeline
	management of the network, and the conduct of network business.	

Standard	Paediatric	Implementation timetable
B1(L1)	Each Specialist Children's Surgical Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including 24/7 paediatric surgery and interventional cardiology cover. A consultant ward round will occur daily. Each Specialist Children's Surgical Centre must provide a 24/7 emergency telephone advice service for patients and their family with urgent concerns about deteriorating health.	Within 6 months
B2(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist Children's Surgical Centre; or b. the child/young person must be referred to an alternative Specialist Children's Surgical Centre where a surgeon/interventionist has the appropriate skills. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT.	Immediate
B3(L1)	Arrangements must be in place in each Specialist Children's Surgical Centre both for consultant interventional paediatric cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	Immediate
B5(L1)	Specialist Children's Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.	Immediate

Standard	Paediatric	Implementation timetable
B6(L1)	Each Specialist Children's Surgical Centre will have a formally nominated paediatric CHD lead with responsibility for the service at the Specialist Children's Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	Within 6 months
B7(L1)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
Surgery		
B8(L1)	All paediatric cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in paediatric cardiac disease.	Immediate
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: 1 in 3 immediate, 1 in 4 within 5 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR). VAD surgery and cardiac transplant surgery may also be counted.	Teams of at least three immediate, teams of at least four within 5 years 125 operations:

Standard	Paediatric	Implementation timetable
		immediate
B11(L1)	Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland.	Immediate
	Cardiology	
B12(L1)	All paediatric congenital cardiology must be carried out by specialist paediatric cardiologists.	Immediate
B13(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one consultant paediatric cardiologist per half million population served by the network, working flexibly across the network.	Within 3 years
B14(L1)	Each Specialist Children's Surgical Centre must deliver 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover for the Specialist Children's Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4. The rota may deliver care for both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B15(L1)	Consultant interventional cardiology cover must be provided by consultant interventional paediatric cardiologists providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. This could include interventional cardiologists based at a Specialist Children's Surgical Centre or a Specialist Children's Cardiology Centre. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for interventionists only to undertake procedures for which they have the	Within 1 year

Standard	Paediatric	Implementation timetable
	appropriate competence. The rota will deliver care for both children and adults. If this means that the interventionist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	
B16(L1)	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B17(L1)	Cardiologists performing therapeutic catheterisation in children and young people with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year. The Lead Interventional Cardiologist in a team must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B18(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one expert electrophysiologist experienced in paediatric cardiac disease. There must be appropriate arrangements for cover by a competent person.	Immediate
B19(L1)	Paediatric electrophysiology procedures must only be undertaken by an expert electrophysiologist experienced in the management of paediatric arrhythmias.	Immediate
B20(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a 'running' member of staff without other duties and with specific knowledge of the location	Immediate

Standard	Paediatric	Implementation timetable
	of equipment required in congenital interventional catheterisation; and d. a nurse with experience of paediatric cardiac catheterisation.	
B21(L1)	Each Specialist Surgical Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B22(L1)	Each Specialist Children's Surgical Centre will have a continuous, immediate and documented availability of specialised cardiac paediatric anaesthetists with full training (in accordance with the Royal College of Anaesthetists' Guidelines and Paediatric Intensive Care Society Standards) and competence in managing paediatric cardiac cases including a specialist paediatric cardiac on-call rota which is separate from the intensive care rota.	Immediate
B23(L1)	At each Specialist Children's Surgical Centre a paediatric cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	Within 6 months
B24(L1)	Each Specialist Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.	Immediate

Standard	Paediatric	Implementation timetable
Intensive Care		
B25(L1)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.	Immediate
B26(L1)	Paediatric Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Children and young people must be cared for by children's nurses with appropriate training and competencies in paediatric cardiac critical care.	Immediate
Nursing		
B27(L1)	Each Specialist Children's Surgical Centre must have a formally nominated lead CHD nurse with responsibility for the service at the Specialist Children's Surgical Centre, providing professional and clinical leadership and support to the team of children's cardiac specialist nurses across the network.	Within 6 months
B28(L1)	Nursing care must be provided by a team of nursing staff trained in the care of children and young people who have received cardiac surgery. The paediatric cardiac inpatient nursing team will be led by a senior children's nurse with specialist knowledge and experience in the care of children and young people and in paediatric cardiology and cardiac surgery.	Immediate
B29(L1)	Each Specialist Children's Surgical Centre will employ a minimum of 1 WTE children's cardiac specialist nurse per 600 000 catchment population, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum seven, and location of these nurses will depend on geography, population and the configuration of the network. Networks must demonstrate that the role of each Children's Cardiac Nurse Specialist meets the minimum requirements of the Royal College of Nursing role description. Included in these numbers will be at least 1 WTE Fetal Cardiac Nurse Specialist, shared with the fetal network, to provide expert information and on-	Within 1 year

Standard	Paediatric	Implementation timetable
	going support to parents who have a fetal diagnosis of congenital heart disease and 1 WTE designated Children's Cardiac Transition Nurse to coordinate the transition process across the network. Each child/young person must have access to a Children's Cardiac Nurse Specialist and complex patients will have a named CCNS responsible for coordinating their care, and who acts as a liaison between the clinical team, the child/young person and parents/carers. There must be regular contact between the named CCNS and high risk children/young people and their families, at a frequency determine by need.	
Psychology		
B30(L1)	Each Specialist Children's Surgical Centre must employ a minimum of 0.25 WTE practitioner psychologists (with experience of working with CHD) per 100 children and young people undergoing cardiac surgery each year. In addition, 1 WTE practitioner psychologist must be employed for each network. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network. The lead psychologist should provide training and mentorship to the other psychologists in the network.	Within 3 year
Administrative Staffing		
B31(L1)	Each Specialist Children's Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
B32(L1)	Each Specialist Surgical Centre must have a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1 WTE assistant, responsible for audit	Within 6 months

Standard	Paediatric	Implementation timetable
	and database submissions in accordance with necessary timescales.	
Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)		
B33(L1)	Each Specialist Children's Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B34(L1)	Each Specialist Surgical Centre will have an identified bereavement officer.	Immediate
B35(L1)	Each Specialist Children's Surgical Centre must have a minimum of 2 WTE dedicated play specialists.	Immediate

Standard	Paediatric	Implementation timeline
C1(L1)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a. accommodation for at least two family members to stay; b. the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c. access to refreshments; d. facilities suitable for the storage and preparation of simple meals; e. 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 should be provided without charge.	Within 6 months
C2(L1)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C3(L1)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by dedicated play specialist teams.	Immediate
C4(L1)	Specialist Children's Surgical Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate
C5(L1)	There must be facilities, including access to maternity staff, that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate

Standard	Paediatric	Implementation timeline
C6(L1)	Parents/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate
C7(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C8(L1)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C9(L1)	Specialist Children's Surgical Centres should ideally have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.	Immediate

Standard	Paediatric	Implementation timescale
The following specialties or facilities **must be located on the same hospital site** as **Specialist Children's Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).		
D1(L1)	Paediatric Cardiology.	Immediate
D2(L1)	Paediatric Airway Team capable of complex airway management (composition of the team will vary between institutions).	Immediate
D3(L1)	Paediatric Intensive Care Unit (PICU): Level 3 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards and NHS England's service specification for Paediatric Intensive Care). High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	Immediate
D4(L1)	Specialised paediatric cardiac anaesthesia.	Immediate
D5(L1)	Perioperative extracorporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Paediatric Surgery.	30 minute call to bedside: Immediate Co-location: within 3 years
D7(L1)	Paediatric Nephrology/Renal Replacement Therapy.	30 minute call to bedside:

Standard	Paediatric	Implementation timescale
		Immediate Co-location: within 3 years
D8(L1)	Paediatric Gastroenterology.	30 minute call to bedside: Immediate Co-location: within 3 years
D9(L1)	Each Specialist Children's Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography. There must be a 24/7 congenital echocardiography service with access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes, with facilities for advanced techniques including 3D and speckle tracking. Specialist Children's Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents; if not provided on site they must have access to these investigations. Specialist Children's Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network.	Within 6 months

Standard	Paediatric	Implementation timescale
	Specialist Children's Surgical Centres must offer invasive diagnostic investigation and treatment, including: a. catheter intervention; b. electrophysiological intervention; c. pacemaker insertion and extraction; and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment where clinically indicated). These services must be available 24/7.	

<table>
<tr><th>Standard</th><th>Paediatric</th><th>Implementation timescale</th></tr>
<tr><td colspan="3">The following specialties or facilities should be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.
Specialist Children's Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).</td></tr>
<tr><td>D10(L1)</td><td>Whether or not adult and paediatric CHD services are on the same site, congenital heart surgeons, congenital interventional cardiologists and congenital electrophysiologists must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.
[This standard recognises shared staffing and out-of-hours cover.]</td><td>Within 1 year</td></tr>
<tr><td>D11(L1)</td><td>Adult cardiology interventionist (to provide thrombolysis, clot removal and back-up for catheter lab emergencies including acute dissection).</td><td>Immediate</td></tr>
<tr><td>D12(L1)</td><td>Vascular Surgery or other surgeon competent to undertake vascular/microvascular repairs in children.</td><td>Immediate</td></tr>
<tr><td>D13(L1)</td><td>Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).</td><td>Immediate</td></tr>
<tr><td>D14(L1)</td><td>Multidisciplinary paediatric pain management service.</td><td>Immediate</td></tr>
<tr><td>D15(L1)</td><td>Bereavement Support, including nurses trained in bereavement support.</td><td>Immediate</td></tr>
</table>

Standard	**Paediatric**	**Implementation timescale**
The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.		
D16(L1)	Paediatric Neurology.	Immediate
D17(L1)	Paediatric Respiratory Medicine.	Immediate
D18(L1)	Neonatology.	Immediate
D19(L1)	Clinical Haematology.	Immediate
D20(L1)	Infection control team experienced in the needs of paediatric cardiac surgery patients.	Immediate
D21(L1)	Paediatric Neurosurgery.	Immediate
D22(L1)	Child Psychiatry (with dedicated sessions and 24/7 on call).	Immediate
D23(L1)	Clinical biochemistry (including toxicology).	Immediate
D24(L1)	Pharmacy (with dedicated sessions for CHD and 24/7 on-call for urgent supply and advice).	Immediate
D25(L1)	Paediatric Endocrinology.	Immediate
D26(L1)	Paediatric Orthopaedics.	Immediate
D27(L1)	Plastic surgery.	Immediate

Standard	Paediatric	Implementation timescale
D28(L1)	Microbiology and Infectious diseases.	Immediate
D29(L1)	Safeguarding team/social work (as per national standards).	Immediate

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

Standard	Paediatric	Implementation timescale
D43(L1)	Paediatric Rheumatology.	Immediate
D44(L1)	Gynaecology.	Immediate
D45(L1)	Paediatric Urology.	Immediate
D46(L1)	Speech and language, with dedicated sessions for CHD, including swallow assessment with timely access to video fluoroscopy.	Immediate

Standard	Paediatric	Implementation timescale
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, working with children with learning disability, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and PICU medical and nursing team will complete mandatory basic 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(L1)	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist Children's Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology and paediatric cardiac surgery, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum, and to the training of Paediatricians with expertise in cardiology.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems. Specialist Children's Surgical Centres must provide resources sufficient to support these	Within 6 months

Standard	Paediatric	Implementation timescale
	educational needs across the network.	
E6(L1)	Specialist Children's Surgical Centres must provide sufficient Cardiac Clinical Nurse Educators to deliver standardised training and competency-based education programmes across the Congenital Heart Network including linked neonatal units. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months
E7(L1)	Governance arrangements across the Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Within 6 months

Standard	Paediatric	Implementation timescale
F1(L1)	Each Specialist Children's Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years as part of the national programme.	Within 1 year
F2(L1)	Each Specialist Children's Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. 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
F4(L1)	Each Specialist Children's Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Surgical Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist Children's Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local Children's Cardiology Centres. Audit of clinical	Within 6 months

Standard	Paediatric	Implementation timescale
	practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Within 6 months
F9(L1)	Each Specialist Children's Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	Each Specialist Children's Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate

Standard	Paediatric	Implementation timescale
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All children/young people who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Last minute cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a child/young person needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the child/young person or parents/carers wish(es). Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be involved in any relevant discussions.	Immediate
F18(L1)	When a Specialist Children's Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre, or Specialist Children's Cardiology Centre if appropriate.	Immediate
F19(L1)	A children's cardiac nurse specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate

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

Standard	Paediatric	Implementation timescale
G1(L1)	Each Specialist Children's Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of paediatric cardiac disease and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, and Local Children's Cardiology Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of children and young people with CHD and their families.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate
G4(L1)	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(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L1)	Every family/carer (and young person, as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Children and young people, 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, parents' and carers' understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. 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(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that parents, carers, children and young people are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate
H5(L1)	Sufficient information must be provided to allow informed decisions to be made, including supporting parents, carers and young people in interpreting publicly available data that support choice. The following should also be described: a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; d. outcomes at units under consideration; and e. consideration of the closest unit to the patient's home.	Immediate
H6(L1)	Specialist Children's Surgical Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another Specialist Children's Surgical Centre, and in interpreting publically available data that supports patient choice.	Immediate
H7(L1)	Information must be made available to parents and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be	Immediate

Standard	Paediatric	Implementation timescale
	precisely documented. Information must be interpreted or transcribed as necessary.	
H8(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place for parents and carers, children and young people to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H9(L1)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H10(L1)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Surgical Centres must make this feedback openly available, to children, young people, families/carers and the general public, together with outcome of relevant local and national audits. Specialist Children's Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H11(L1)	Each Specialist Children's Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate

Standard	Paediatric	Implementation timescale
H12(L1)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young person throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Immediate
H13(L1)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain diagnosis and management of the child's condition and to provide relevant literature.	Within 6 months
H14(L1)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child's condition, and providing psychosocial support to promote family (and child/young person's) adaptation and adjustment.	Immediate
H15(L1)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H16(L1)	Where children/young people, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H17(L1)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H18(L1)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate) in plain language to retain in the patient's personal record in accordance	Immediate

Standard	Paediatric	Implementation timescale
	with national guidance.	
H19(L1)	Parents, carers and all health professionals involved in the child’s care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H20(L1)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H21(L1)	Where surgery or intervention is planned, the child/young person and their parents or carers must have the opportunity to visit the Specialist Children’s Surgical Centre in advance of admission (as early as possible) to meet the team, including the Children’s Cardiac Nurse Specialist that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H22(L1)	Children/young people and their parents/carers must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Consent must be taken in line with GMC guidance.	Immediate
H23(L1)	A Children’s Cardiac Nurse Specialist must be available to support parents and children/young people throughout the consent process. When considering treatment options, parents, carers (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H24(L1)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H25(L1)	Parents, patients and carers must be provided with information on how to claim travel expenses and	Immediate

Standard	Paediatric	Implementation timescale
	how to access social care benefits and support.	
H26(L1)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months
H27(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person as appropriate or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the patient and parents to discuss concerns about treatment must be offered.	Immediate

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

Standard	Paediatric	Implementation timescale
I7(L1)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L1)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I10(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

Standard	Paediatric	Implementation timescale
Family Planning Advice		
J1(L1)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L1)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L1)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Within 1 year

Standard	Paediatric	Implementation timescale
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(L1)	Obstetric services caring for patients with congenital heart disease must offer fetal cardiac diagnosis and management protocols as an integral part of the service offered to patients with congenital heart disease.	Immediate
K2(L1)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported. There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.	Immediate
K3(L1)	Each congenital heart network will agree and establish protocols with obstetric, fetal maternal medicine units, tertiary neonatal units, local neonatal units and paediatrics teams in their Congenital Heart Network for the care and treatment of pregnant women whose fetus has been diagnosed with a major heart condition. The protocols must meet the relevant NHS Fetal Anomaly Screening Programme and British Congenital Cardiac Association Standards.	Immediate
K4(L1)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K5(L1)	All women with a suspected or confirmed fetal cardiac anomaly must be seen by : • an obstetric ultrasound specialist within three working days of the referral being made; and • a fetal cardiology specialist within three days of referral and preferably within two working days if possible. If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal	Immediate

Standard	Paediatric	Implementation timescale
	cardiology specialist. (This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service users.)	
K6(L1)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K7(L1)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate
K8(L1)	A 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 with the Cardiologist and the 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
K9(L1)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate

Standard	Paediatric	Implementation timescale
K10(L1)	At diagnosis, a plan must be agreed between 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
K11(L1)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with the local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate
K12(L1)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

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(L1)	Each Specialist Children's Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L1)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The 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 and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate

Standard	Paediatric	Implementation timescale
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L1)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L1)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L1)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L1)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
Discharge and out-of-hospital care		
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate

Standard	Paediatric	Implementation timescale
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L1)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
Management of a Death (whether expected or unexpected)		
L16(L1)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L1)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L1)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L1)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an	Immediate

Standard	Paediatric	Implementation timescale
	opportunity to collect memories of their child.	
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
Ongoing support after the death of a child/young person		
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to offer the opportunity for 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

Standard	Paediatric	Implementation timescale
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L1)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

Standard	Paediatric	Implementation timescale
M1(L1)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All children and young people with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	Immediate
M3(L1)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	Specialist Children's Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease.	Immediate
M6(L1)	Specialist Children's Surgical Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate