



**Paediatric
Congenital Heart
Disease Standards:
Level 2 – Specialist
Children’s
Cardiology Centres**

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

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1 Document summary

The following document is part of a suite of documents setting out adult and paediatric standards and service specifications for congenital heart disease services in England, agreed by the NHS England Board on 23 July 2015 and effective from 1 April 2016. This document is the Paediatric Congenital Heart Disease Standards: Level 2 – Specialist 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 2 – Specialist Children’s Cardiology Centres

Standard	Paediatric	Implementation timescale
A1(L2)	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist Children’s Cardiology Centres where appropriate.	Within 6 months
A2(L2)	Each Specialist Children’s Cardiology Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	<p>Each Specialist Children’s Cardiology Centre will adhere to their Congenital Heart Network’s clinical protocols and pathways to care for:</p> <ul style="list-style-type: none"> 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 Specialist Children’s Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate. d. New referrals from GPs and paediatricians Local hospitals will refer children/young people to a Specialist Children’s Cardiology Centre/Local Children’s Cardiology Centre, as necessary, for the following categories of 	Within 6 months

Standard	Paediatric	Implementation timescale
	<p>referrals:</p> <ul style="list-style-type: none"> • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness • Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease <p>e. Ongoing care of children and young people diagnosed with congenital heart defects</p> <p>Local hospitals will refer children/young people to the Specialist Children’s Cardiology Centre or Local Children’s Cardiology Centre as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.</p>	
A4(L2)	<p>Specialist Children’s Cardiology Centres will adhere to their Congenital Heart Network’s clinical protocols and pathways to care that will:</p> <ol style="list-style-type: none"> a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that 	Immediate

Standard	Paediatric	Implementation timescale
	<p>collectively they provide a national service);</p> <p>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 Centres, the Specialist Children’s Cardiology Centres and Local Children’s Cardiology Centres according to local circumstances;</p> <p>f. address how Specialist Children’s Cardiology Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and</p> <p>g. provide 24/7 cover by consultant paediatric cardiologists for specialist advice.</p>	
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Within 6 months
A6(L2)	<p>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.</p> <p>The health records summary will comply with a standard national template developed and agreed by Specialist Children’s Surgical Centres, representatives of the Congenital Heart Networks and commissioners.</p>	Immediate
Cardiological Interventions		
A7(L2)	<p>Specialist Children’s Cardiology Centres will adhere to their Congenital Heart Network’s clinical protocols and pathways of care that will:</p> <p>a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children’s Surgical Centre; and</p>	Within 6 months

Standard	Paediatric	Implementation timescale
	b. ensure that emergency balloon atrial septostomy and emergency temporary pacing, if undertaken in a Specialist Children’s Cardiology Centre can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process.	
Non-Cardiac Surgery		
A8(L2)	Specialist Children’s Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of a pre-operative risk assessment by a Congenital Heart team including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.	Immediate
External Relationships		
A9(L2)	Each Specialist Children’s Cardiology Centre must have a close network relationship with all maternity and fetal medicine services, neonatal services including neonatal transport services, within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist Children’s Cardiology Centre must have a close network relationship with any ACHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist Children’s Cardiology Centre must demonstrate formal working relationships with: <ul style="list-style-type: none"> a. network Specialist Children’s Surgical Centres and Local Children’s Cardiology Centres, according to local circumstances; b. the paediatric cardiothoracic transplant centres; 	Within 6 months

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 Level 2 – Specialist Children’s Cardiology Centres. Section A – The Network Approach

Standard	Paediatric	Implementation timescale
	<ul style="list-style-type: none"> c. the national Pulmonary Hypertension Service; and d. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities. 	
A12(L2)	Each Specialist Children’s Surgical Centre must have a close relationship with all community paediatric services in their network, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
Telemedicine and IT		
A13(L2)	<p>Each Congenital Heart Network will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Surgical Centres and Local Cardiology Centres, according to local circumstances).</p> <p>The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to:</p> <ul style="list-style-type: none"> a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric services. e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate. 	Within 3 years
A14(L2)	Each Specialist Children’s Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist Children’s Surgical Centre system, and enable immediate access to patient data.	Immediate

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 Level 2 – Specialist Children’s Cardiology Centres. Section A – The Network Approach

Standard	Paediatric	Implementation timescale
Multidisciplinary Team (MDT)		
A15(L2)	Each Specialist Children’s Cardiology Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist Children’s Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT.	Within 1 year
A17(L2)	Staff from the Specialist Children’s Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A18(L2)	The composition of the MDT will be pathway driven, and adjusted according to the needs of different aspects of the service (for example: assessment, post-operative care, clinic, pathological and audit meetings).	Immediate
Network Leadership		
A19(L2)	Each Specialist Children’s Cardiology Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the Network. The post holder must have specified time working in paediatric cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

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Level 2 – Specialist Children’s Cardiology Centres. Section B - Staffing and skills

Standard	Paediatric	Implementation timescale
B1(L2)	Each Specialist Children’s Cardiology Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
Medical		
B3(L2)	Each Specialist Children’s Cardiology Centre must be staffed by a minimum of 4 WTE specialist paediatric cardiologists (in addition to the one consultant paediatric cardiologist per half million population across the network). These cardiologists will work flexibly across the network.	Within 3 years
B4(L2)	Each Specialist Children’s Cardiology Centre must provide a specialist paediatric cardiologist on-call rota. Rotas must be no more frequent than 1 in 4.	Immediate
B5(L2)	Each Specialist Children’s Cardiology Centre will have a formally nominated Clinical Paediatric Cardiology Lead with responsibility for the service at the Specialist Children’s Cardiology Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist Children’s Cardiology Centre will have separate clinical leads identified from the relevant specialties, including fetal cardiology and nursing (and ICU and anaesthesia, if such provision exists) who have a direct link and collaborative working partnership with the lead roles in the Specialist Children’s Surgical Centre.	Within 6 months
B6(L2)	Cardiologists employed by the Specialist Children’s Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children’s Surgical Centre to maintain and	Within 6 months

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Level 2 – Specialist Children’s Cardiology Centres. Section B - Staffing and skills

Standard	Paediatric	Implementation timescale
	develop their specialist skills.	
B7(L2)	Paediatric cardiologists based at the Specialist Children’s Cardiology Centre who visits the Specialist Children’s Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year, averaged over a three-year period.	Immediate
B8(L2)	Each Specialist Children’s Cardiology Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B9(L2)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.	Immediate
Nursing		
B10(L2)	Specialist Children’s Cardiology Centres must have locally designated registered children’s nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.	Immediate
B11(L2)	There must at all times be a minimum of two registered children’s nurses allocated to the operational children’s cardiology beds who are trained according to the Royal College of Nursing competency framework.	Immediate
B12(L2)	Each Specialist Children’s Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate
B13(L2)	The network Children’s Cardiac Nurse Specialist Team, will support the Specialist Children’s Cardiology Centre. An appropriate number of Children’s Cardiac Nurse Specialists will be based at	Within 1 year

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Standard	Paediatric	Implementation timescale
	the Specialist Children’s Cardiology Centre (the number will depend on geography, population and the congenital heart network).	
Psychology		
B14(L2)	The Network Children’s Cardiac Psychologist will support the Specialist Children’s Cardiology Centre. An appropriate number of Children’s Cardiac Psychology sessions will be based at the Specialist Children’s Cardiology Centre (the number will depend on geography, population and the congenital heart network).	Immediate
Administrative		
B15(L2)	Each Specialist Children’s Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist Children’s Cardiology Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
Other		
B17(L2)	Each Specialist Children’s Cardiology Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.	Immediate
B18(L2)	Each Specialist Children’s Cardiology Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B19(L2)	Each Specialist Children’s Cardiology Centre will have a dedicated bereavement officer.	Immediate

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Level 2 – Specialist Children’s Cardiology Centres. Section C - Facilities

Standard	Paediatric	Implementation timescale
C1(L2)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children’s cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L2)	<p>There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include:</p> <ul style="list-style-type: none"> 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. <p>Family accommodation should be provided without charge.</p>	Within 6 months
C3(L2)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C4(L2)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by play specialist teams.	Immediate
C5(L2)	Specialist Children’s Cardiology Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate

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Standard	Paediatric	Implementation timescale
C6(L2)	Parents/carers must be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate
C7(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

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Level 2 – Specialist Children’s Cardiology Centres. Section D - Interdependencies

Standard	Paediatric	Implementation timescale
<p>The following specialties or facilities must be located on the same hospital site as Specialist Children’s Cardiology Centres. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes).</p>		
D1(L2)	Paediatric Cardiology.	Immediate
D2(L2)	Paediatric Airway Team capable of complex airway management (composition of the team will vary between institutions).	Immediate
D3(L2)	<p>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.</p> <p>High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.</p>	Immediate
D4(L2)	<p>Each Specialist Children’s Cardiology Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The exact range of equipment and investigations will be agreed with the network.</p> <p>The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker interrogation and follow up, as well as standard, transesophageal and fetal echocardiography. The availability of contrast echocardiography is desirable.</p> <p>Specialist Children’s Cardiology Centres must be able to access contrast echocardiography, tilt testing, cardio-pulmonary exercise testing (CPEX), the six-minute walk test in children and adolescents.</p> <p>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,</p>	Immediate

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Standard	Paediatric	Implementation timescale
	<p>including suitable fetal echo probes.</p> <p>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.</p> <p>These services must be available 24/7 where clinically indicated.</p>	

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

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 Level 2 – Specialist Children’s Cardiology Centres. Section D - Interdependencies

Standard	Paediatric	Implementation timescale
<p>The following specialties or facilities should ideally be located on the same hospital site as Specialist Children’s Cardiology Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within 30 minutes) and a visit or transfer of care within four hours if needed. The services must be experienced in caring for patients with congenital heart disease.</p>		
D12(L2)	Paediatric Neurology.	Immediate
D13(L2)	Paediatric Respiratory Medicine.	Immediate
D14(L2)	Neonatology.	Immediate
D15(L2)	Paediatric Neurosurgery.	Immediate
D16(L2)	Child Psychiatry with dedicated sessions.	Immediate
D17(L2)	Paediatric Endocrinology.	Immediate
D18(L2)	Paediatric Orthopaedics.	Immediate
D19(L2)	Plastic surgery.	Immediate
D20(L2)	Vascular surgery.	Immediate
D21(L2)	Clinical Haematology.	Immediate
D22(L2)	Infection control nurse experienced in the needs of paediatric cardiac patients.	Immediate
D23(L2)	Clinical Biochemistry (including toxicology).	Immediate

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Standard	Paediatric	Implementation timescale
D24(L2)	Pharmacy (24/7 on-call required for urgent supply and advice).	Immediate
D25(L2)	Microbiology and Infectious diseases.	Immediate
D26(L2)	Learning Disability Team.	Immediate
D27(L2)	Safeguarding team/social work (as per national standards).	Immediate

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

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Standard	Paediatric	Implementation timescale
D41(L2)	Paediatric Rheumatology.	Immediate
D42(L2)	Gynaecology.	Immediate
D43(L2)	Paediatric Urology.	Immediate
D44(L2)	Speech and language, with dedicated sessions for CHD, including swallow assessment with timely access to video fluoroscopy.	Immediate

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Level 2 – Specialist Children’s Cardiology Centres. Section E – Training and education

Standard	Paediatric	Implementation timescale
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, working with children with learning disabilities, life support, pain management, infection control, end-of-life care, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and PICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	Nurses working within Specialist Children’s Cardiology Centres must be offered allocated rotational time working in the Specialist Children’s Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children’s Cardiology Centres must be offered allocated rotational time working in the Specialist Children’s Surgical Centre or Specialist Children’s Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L2)	Each Specialist Children’s Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology according to the latest Joint Royal Colleges of Physicians’ Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.	Within 6 months

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Standard	Paediatric	Implementation timescale
E6(L2)	<p>Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. Each Specialist Children’s Cardiology Centre must have one clinical educator who is responsible for ensuring the continuing professional development of nursing staff in the Specialist Children’s Cardiology Centre. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.</p> <p>Skills in teaching, research, audit and management will also be part of the programme.</p>	Within 6 months
E7(L2)	<p>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.</p>	Within 6 months

Standard	Paediatric	Implementation timescale
F1(L2)	Each Specialist Children’s Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	<p>All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:</p> <ul style="list-style-type: none"> 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(L2)	Each Specialist Children’s Cardiology Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children’s Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist Children’s Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children’s Surgical Centre.	Within 6 months
F5(L2)	Each Specialist Children’s Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken	Immediate

Standard	Paediatric	Implementation timescale
	annually.	
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year
F8(L2)	Each Specialist Children’s Cardiology Centre must participate in national programmes for audit and must submit data on any emergency procedures, electrophysiology procedures and endocarditis, to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F9(L2)	Each Specialist Children’s Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist Children’s Cardiology Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children’s Cardiology Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist Children’s Cardiology Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children’s Surgical Centre or Specialist Children’s Cardiology Centre.	Immediate

Standard	Paediatric	Implementation timescale
F13(L2)	Each Specialist 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
F14(L2)	<p>Each Specialist Children’s Cardiology Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment:</p> <ul style="list-style-type: none"> a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals. 	Immediate
F15(L2)	Each Specialist Children’s Cardiology 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

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section G – Research

Standard	Paediatric	Implementation timescale
G1(L2)	Each Specialist Children’s Cardiology Centre must participate in research.	Immediate
G2(L2)	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(L2)	Specialist Children’s Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L2)	Every family/carer (and young person as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient’s GP.	Immediate
H3(L2)	<p>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.</p> <p>The psychological, social, cultural and spiritual factors impacting on the child/young person’s, parents’ and carers’ understanding must be considered.</p> <p>Information provided should include any aspect of life that is relevant to their congenital heart condition, including</p> <ul style="list-style-type: none"> 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
	<ul style="list-style-type: none"> h. welfare benefits; i. social services; and j. community services. 	
H4(L2)	Information must be made available to parents, carers, children and young people in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L2)	Specialist Children’s Cardiology Centres must demonstrate that arrangements are in place for parents/carers and children and young people 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(L2)	The child/young person’s management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L2)	<p>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.</p> <p>Specialist Children’s Cardiology Centres must make this feedback openly available to patients, families/carers and the general public, together with outcome of relevant local and national audits.</p> <p>Specialist Children’s Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services.</p> <p>Children, young people, families and carers must be informed of the action taken following a</p>	Immediate

Standard	Paediatric	Implementation timescale
	<p>complaint or suggestion made.</p> <p>Specialist Children’s Cardiology Centres must demonstrate ongoing structured liaison with patient and patient groups, including evidence of how feedback is formally considered.</p>	
H8(L2)	<p>Each Specialist Children’s Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years).</p> <p>Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.</p>	Immediate
H9(L2)	<p>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.</p> <p>CCNS contact details will be given at each attendance at the outpatient clinic.</p>	Immediate
H10(L2)	<p>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.</p>	Immediate
H11(L2)	<p>The Children’s Cardiac Nurse Specialist will support parents/carers by explaining the diagnosis and management plan of the child/young person’s condition, and providing psychosocial support to promote parental (and child/young person’s) adaptation and adjustment.</p>	Immediate
H12(L2)	<p>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.</p> <p>Support for people with learning disabilities must be provided from an appropriate specialist or agency.</p>	Immediate

Standard	Paediatric	Implementation timescale
H13(L2)	Where patients, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	Immediate
H14(L2)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate), in plain language to retain in the patient’s personal record in accordance with national guidance.	Immediate
H16(L2)	Parents, carers and all health professionals involved in the child’s care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist Children’s Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist Children’s Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist Children’s Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate

Classification: Official
 Level 2 – Specialist Children’s Cardiology Centres. Section H – Communication with patients

Standard	Paediatric	Implementation timescale
H20(L2)	A Children’s Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H21(L2)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L2)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L2)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care.	Within 1 year
H24(L2)	<p>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.</p> <p>Identification of a lead doctor and nurse (as agreed by the young person if appropriate or their family) will ensure continuity and consistency of information.</p> <p>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.</p>	Immediate

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section I - Transition

Standard	Paediatric	Implementation timescale
I1(L2)	<p>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.</p> <p>‘Lost to follow-up’ rates must be recorded and discussed at the network multidisciplinary team meeting.</p>	Within 1 year
I2(L2)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L2)	There will not be a fixed age of transition from children’s to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I5(L2)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient’s care plan indicates that they do not need long-term follow-up.	Immediate
I6(L2)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in	Immediate

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section I - Transition

Standard	Paediatric	Implementation timescale
	private, away from their parents/carers if they wish.	
I7(L2)	The Children’s Cardiac Transition Nurse will work as a core member of the children’s Cardiac Team, liaising with young people, their parents/carers, the Children’s Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children’s to adult services.	Immediate
I8(L2)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I10(L2)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L2)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section J – Pregnancy and contraception

Standard	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L2)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L2)	<p>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.</p> <p>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.</p> <p>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.</p> <p>The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.</p>	Immediate
J3(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient	Immediate

Classification: Official
 Level 2 – Specialist Children’s Cardiology Centres. Section J – Pregnancy and contraception

Standard	Paediatric	Implementation timescale
	and their partner are concerned about attachment.	
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.	

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section K – Fetal diagnosis

Standard	Paediatric	Implementation timescale
K1(L2)	<p>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.</p> <p>There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.</p>	Immediate
K2(L2)	Specialist Children’s Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children’s Surgical Centre in their Congenital Heart Network.	Immediate
K3(L2)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K4(L2)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K5(L2)	<p>All women with a suspected or confirmed fetal cardiac anomaly must be seen by :</p> <ul style="list-style-type: none"> • 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. <p>If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist.</p> <p>(This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service</p>	Immediate

Classification: Official
 Level 2 – Specialist Children’s Cardiology Centres. Section K – Fetal diagnosis

Standard	Paediatric	Implementation timescale
	users.)	
K6(L2)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate
K7(L2)	<p>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.</p> <p>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.</p>	Immediate
K8(L2)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate
K9(L2)	At diagnosis, a plan must be agreed with the Specialist Children’s Surgical Centre, the specialist 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

Classification: Official
 Level 2 – Specialist Children’s Cardiology Centres. Section K – Fetal diagnosis

Standard	Paediatric	Implementation timescale
K10(L2)	<p>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.</p> <p>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.</p>	Immediate
K11(L2)	<p>When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including a timetable, for the transfer of the mother and baby to the Specialist Children’s Surgical Centre if early intervention or assessment is required.</p> <p>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.</p>	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(L2)	Each Specialist Children’s Cardiology Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L2)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L2)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L2)	<p>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.</p> <p>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.</p>	Immediate

Standard	Paediatric	Implementation timescale
L6(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L2)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L2)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L2)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L2)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
Discharge and out-of-hospital care		
L13(L2)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate

Standard	Paediatric	Implementation timescale
L14(L2)	<p>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.</p> <p>All equipment needed in the home must be available prior to discharge.</p>	Immediate
L15(L2)	<p>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.</p>	Immediate
Management of a Death (whether expected or unexpected)		
L16(L2)	<p>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.</p>	Immediate
L17(L2)	<p>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.</p>	Immediate
L18(L2)	<p>Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the <i>Donor</i> team.</p>	Immediate
L19(L2)	<p>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.</p>	Immediate
L20(L2)	<p>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</p>	Immediate

Standard	Paediatric	Implementation timescale
	opportunity to collect memories of their child.	
L21(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family’s pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person’s family/carers at the time they leave hospital.	Immediate
L24(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
Ongoing support after the death of a child/young person		
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child’s death. This should, where possible, be timed to follow the results of a post-mortem or coroner’s investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate

Classification: Official
 Level 2 – Specialist Children’s Cardiology Centres. Section L – Palliative care and bereavement

Standard	Paediatric	Implementation timescale
L27(L2)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L2)	If families/carers are seeking more formal ongoing support, the identified Children’s Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

Classification: Official
Level 2 – Specialist Children’s Cardiology Centres. Section M - Dental

Standard	Paediatric	Implementation timescale
M1(L2)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist Children’s Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist Children’s Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children’s Surgical Centre.	Immediate
M6(L2)	Specialist Children’s Cardiology Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate