Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section A: The Network Approach

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
A15 SS	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local Children's Cardiology Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.		To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local ACHD Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.
A24 SS	Local Children's Cardiology Centres must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care as defined as part of network arrangements. Each Local Children's Cardiology Centre will provide pathways of care and management of congenital heart defects agreed with the Congenital Heart Network: a. Prenatally diagnosed congenital heart defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be referred to the network fetal cardiac service. Counselling will take place including discussion about the location of the delivery of the baby. b. Newborns with a murmur and otherwise clinically well Care may be provided at the Local Children's Cardiology Centre. c. Neonates and infants diagnosed with congenital heart defects Each Local Children's Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate.	A2	Local ACHD Centres must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care as defined as part of network arrangements. Each Local ACHD Centre will provide pathways of care and management of congenital heart defects agreed with the Congenital Heart Network: a. New referrals from GPs, cardiologists and local hospitals b. Ongoing care of patients diagnosed with congenital heart defects

Section A: The Network Approach

	Paediatric		Adult
	d. New referrals from GPs and paediatricians Following review by the Paediatrician with Expertise in Cardiology, children/ young people will be referred to a Specialist Surgical Centre or Children's Cardiology Centre, as appropriate, for the following: • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness • Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease e. Ongoing care of children and young people diagnosed with congenital heart defects Local hospitals will refer children/young people to the Local Children's Cardiology Centre as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.		
A1	Local Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care for:	A1	Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: :

Section A: The Network Approach

	Paediatric		Adult
New	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 the patient's home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services; e. address how Local Children's Cardiology Centres will communicate effectively with colleagues within the Congenital Heart Network (both Specialist Children's Surgical Centre and Specialist Children's Cardiology Centres (if present)) on the care of patients requiring non-cardiac interventions; f. deliver joint clinics between a paediatric cardiologist and a paediatrician with a expertise in cardiology (PEC) in a Local Children's Cardiology Centre; and g. Local Children's Cardiology Centres will provide weekday cover for CHD advice from a local network of PECs.		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 the patient's home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services; e. address how Local ACHD Centres will communicate effectively with colleagues within the Congenital Heart Network (both Specialist ACHD Surgical Centre and Specialist ACHD Centres) on the care of patients requiring non-cardiac interventions; f. deliver joint clinics between a specialist ACHD cardiologist and a cardiologist with an interest in ACHD in a Local ACHD Centre; and g. Local ACHD Centres will provide weekday cover for CHD advice from a local network of consultant cardiologists with expertise in CHD.

Section A: The Network Approach

	Paediatric		Adult
H22 New	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.		All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.
	Cardiological Interventions		**Cardiological Interventions**
New	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre. Local Children's Cardiology Centres may not undertake any paediatric cardiac surgeries, planned therapeutic interventions or diagnostic catheter procedures.		Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, therapeutic interventions and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre. Local ACHD Centres may not undertake any ACHD surgeries, therapeutic interventions or diagnostic catheter procedures; see Appendix B for the definition of ACHD Surgery and Interventions.
	Non-Cardiac Surgery		**Non-Cardiac Surgery**
New	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of pre-operative risk assessment by a Congenital Heart team including a paediatrician with expertise in cardiology and paediatric anaesthetists, in discussion with a paediatric cardiologist, for patients requiring non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.		Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for surgery.

Section A: The Network Approach

	Paediatric		Adult
	External Relationships		**External Relationships**
New	Each Local Children's Cardiology Centre must demonstrate formal working relationships with the network Specialist Children's Surgical Centre and Specialist Children's Cardiology Centres (if present). Other supraregional services will be accessed via the CHD network.		Each Local ACHD Centre must demonstrate formal working relationships with the network Specialist ACHD Surgical Centre and Specialist ACHD Centre (if present). Other supraregional services will be accessed via the CHD network.
B15 New	All Local Children's Cardiology Centres must have a close relationship with local community paediatric services, to ensure the provision of a full range of community paediatric support services particularly for patients with complex medical and social needs.		
New	**Telemedicine and IT**		**Telemedicine and IT**
A4 New	Each Local Children's Cardiology Centre will have telemedicine facilities as required to link with designated hospitals in a network: a. the Specialist Children's Surgical Centre b. Specialist Children's Cardiology Centres (if present) The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.		Each Local ACHD Centre will have telemedicine facilities as required to link with designated hospitals in a network: a. the Specialist ACHD Surgical Centre b. Specialist ACHD Centres The level of telemedicine required will be agreed between network members. See Appendix C for more detail. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.

Section A: The Network Approach

	Paediatric		Adult
	Each Local Children's Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to the Specialist Children's Surgical Centre/Specialist Children's Cardiology Centre system and enable immediate access to patient data.	C9	Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to their own Specialist ACHD Surgical Centre/Specialist ACHD Centre system and enable immediate access to patient data. See Appendix C for detailed IT requirements.
	Multidisciplinary Team (MDT)		**Multidisciplinary Team (MDT)**
H21 New	Staff from across the Local Children's Cardiology Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.		Staff from across the Local ACHD Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.
New B3	Each designated paediatrician with expertise in cardiology will attend (in person or by VC link) the weekly network MDT meeting at least six times per year, and must also attend the annual network meeting. This requirement will be reflected in job plans.	B3	Each Local ACHD Centre cardiologist with an interest in ACHD must participate (at least six times per year) in specialist MDT meetings led by the Specialist ACHD Surgical Centre, either in person or via telemedicine facilities, and must also attend the annual network meeting. This requirement will be reflected in job plans.
	Each designated paediatrician with expertise in cardiology will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	A3	Each cardiologist with an interest in ACHD will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.
New	Each Local Children's Cardiology Centre must have identified registered children's nurses with an interest and training in children's and young people's cardiology.		Each Local ACHD Centre must have identified registered nurses with an interest and training in ACHD.

Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section B: Staffing

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
New	Each Local Children's Cardiology Centre will have a named Consultant Paediatrician with expertise in cardiology (PEC) who is closely involved in the organisation, running of and attendance in the Local Children's Cardiology Centre. Each PEC must have received training in accordance with the Royal College of Paediatrics and Child Health and Royal College of Physicians one-year joint curriculum in paediatric cardiology (or gained equivalent competencies as agreed by the Network Clinical Director). Each PEC must spend a minimum 20% of his/her total job plan (including Supporting Professional Activities) in paediatric cardiology (in accordance with the British Congenital Cardiac Association definitions). Each PEC must be part of a Congenital Heart Network associated with a Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre. Each PEC must work with a link/named Consultant Paediatric Cardiologist from either the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre and take responsibility for the running of regular joint paediatric cardiology clinics with the visiting Consultant Paediatric Cardiologist. Each PEC will hold an honorary contract with the Specialist Children's Surgical Centre and/or the Specialist Children's Cardiology Centre and have the opportunity to attend clinical and educational opportunities in order to maintain expertise and facilitate good working relationships there as part of their job plan.	**B2**	The Local ACHD Centre must be staffed by at least one consultant cardiologist with an interest in ACHD.

Section B: Staffing

	Paediatric		Adult
S&S C3	Local Children's Cardiology Centres must have locally designated registered children's nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people		
(B13) New	Each Local Children's Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.		
(B12) New	Each Local Children's Cardiology Centre must have a locally designated 0.25 WTE registered children's nurse with a specialist interest to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice.		Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.
New	The Children's Cardiac Nurse Specialist Team from the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre will provide support, education and a link to the outpatient and ward nursing staff at the Local Children's Cardiology Centre. A local link nurse will be identified who can be a point of contact within the Local Children's Cardiology Centre.	B4	ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.
New	Each Local Children's Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.		Each Local ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.
B12 (B11) New	Each Local Children's Cardiology Centre will provide outpatient 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.		Each Local ACHD Centre will provide outpatient administrative support to ensure availability of medical records, to organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow ups and respond to patients and partners/family or carers in a timely fashion.

Section B: Staffing

	Paediatric		Adult
	Each Local Children's Cardiology Centre must have a cardiac physiologist with training in congenital echocardiography.	**C2**	Each Local ACHD Centre must have a cardiac physiologist with training in congenital echocardiography.
	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.		All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.
New	Each Local Children's Cardiology Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding children; and b. a dedicated bereavement officer.	**B1**	The Local ACHD Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding vulnerable adults; and b. a dedicated bereavement officer.

Section C: Facilities

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
	Each Local Children's Cardiology Centre must have the appropriate facilities and staff to undertake the following investigations: a) Electrocardiogram (ECG) available 24/7; b) Transthoracic Echocardiograph;; c) chest X-ray; d) exercise testing/six minute walk test; e) 24 hour tapes, event recorders; and f) ambulatory blood pressure monitoring.	**C1**	Each Local ACHD Cardiology Centre must have the appropriate facilities and staff to undertake the following investigations: a) Electrocardiogram (ECG); b) Transthoracic Echocardiograph; c) chest X-ray; d) exercise testing/six minute walk test; e) 24 hour tapes, event recorders; and f) ambulatory blood pressure monitoring.
	There must be dedicated room space in which practitioner psychologists, cardiac nurse specialists and social work staff conduct therapeutic work.		There must be dedicated room space in which practitioner psychologists, cardiac nurse specialists and social work staff conduct therapeutic work.
New	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;		There must be facilities in place to ensure easy and convenient access for partners/family/carers. Should this reflect the text in the paediatric standards?

Section C: Facilities

	Paediatric		Adult
	e) ability for parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation must be provided without charge.		
	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.	C5	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.
	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.		
New	Children and young people must have access to education resources.		
New	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.		Patients/partners/family/ and carers will 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.
New	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.		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.

Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be located **on the same hospital site** as **Local Children's Cardiology Centres.**		The following specialties or facilities must be located **on the same hospital site** as **Local ACHD Centres.**
D8	In and Outpatient Paediatric and Adolescent Services.		
D9	Prenatal diagnostic services, obstetrics, midwifery and breast-feeding support and neonatal services.		
D10	Adult cardiological services.	C2	Local ACHD Centres must be co-located on the same hospital site as general adult cardiology services, including acute cardiac care unit.
C1	Each Local Children's Cardiology Centre must provide standard non-invasive diagnostic imaging capabilities, with access, across the network, to CT and MRI scanning. The exact range of equipment and investigations will be agreed with the Network. The range of cardiac physiological investigations to which the Local Children's Cardiology Centre must have access include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory BP and pacemaker follow-up and interrogation, as well as standard, transoesophageal and fetal echocardiography. Local Children's Cardiology Centres must be able to access cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents. There must be 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a	C1	Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: a. blood testing; b. ECG available 24/7; c. Transthoracic Echo; d. chest X-ray; e. exercise testing/six minute walk test; f. 24 hour tapes, event recorders; and g. ambulatory blood pressure monitoring.

	selection of probes suitable for all age groups, including suitable fetal echo probes. There must be the facility to store and transfer digital recordings of radiological and echocardiographic images. Governance arrangements across the Children's Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.		
D12	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital Paediatric service – either from Specialist Cardiology Centres or from Specialist Surgical Centres in accordance with Network protocols**.**		Urgent advice 24/7 from any relevant services not on site or in the District General Hospital Paediatric service – either from Specialist Cardiology Centres or from Specialist Surgical Centres in accordance with Network protocols.
D7 / D13	Each Local Children's Cardiology Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with heart disease and to their families.	C5	Each Local ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young adults and older people with congenital heart disease.

Section E: Training and Education

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
New	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.		All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication
New	All members of the cardiac medical and nursing team will complete mandatory training on end of life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in depth training.		All members of the cardiac medical and nursing team will complete mandatory training on end of life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in depth training.
New E2	Each Local Children's Cardiology Centre must assist the Specialist Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all specialty doctors within their network catchment area.	D1	Each Local ACHD Centre must assist the Specialist Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all adult cardiology trainees within their network catchment area.
SS A17	Each Local Children's Cardiology Centre 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.		Each Congenital Cardiology Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.
New	Clinical Nurse Educators must be provided across each Children's Heart Network, sufficient to deliver standardised training and		Clinical Nurse Educators must be provided across each Congenital Heart Network, sufficient to deliver standardised training and

Section E: Training and Education

	Paediatric		Adult
E1	competence based education programmes. They will be responsible for ensuring the continuing professional development of nursing staff in the Local Children's Cardiology Centre. The competence based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence based practice and communication.		competence based education programmes. They will be responsible for ensuring the continuing professional development of nursing staff in the Local ACHD Centre. The competence based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence based practice and communication.
New	Nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Surgical Centre or Specialist Children's Cardiology Centre, to enhance development of clinical knowledge and skills enable professional development and career progression. A formal annual training plan should be in place.		Nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist Surgical Centre or Specialist ACHD Centre, to enhance development of clinical knowledge and skills enable professional development and career progression. A formal annual training plan should be in place.
New	PECs should have a named cardiologist within the Specialist Surgical Centre or Specialists Children's Cardiology Centre; this mentor would normally be the link cardiologist.		Cardiologists with an interest in ACHD should have a named cardiologist within the Specialist Surgical Centre or Specialist Cardiology Centre; this mentor would normally be the link cardiologist.

Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section F: Organisation, governance and audit

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
F1 New	Local Children's Cardiology Centres will operate within the Congenital Heart Network's clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.		Local ACHD Centres will operate within the Congenital Heart Network's clinical governance framework that includes: a. clinical audit; b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols; c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.
F2 New	Each Local Children's Cardiology Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local Children's Cardiology Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.		Each Local ACHD Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local ACHD Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.
F3 New	Each Local Children's Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children's Surgical Centre.		Each Local ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.
	Each Local Children's Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.		Each Local ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.

Section F: Organisation, governance and audit

	Paediatric		Adult
New	Audits must take into account or link with similar audits across the network, other networks and other related specialties.		Audits must take into account or link with similar audits across the network, other networks and other related specialties.
F4 New	Each Local Children's Cardiology Centre must participate in relevant national programmes for audit and must submit data to the Specialist Children's Surgical or Specialist Children's Cardiology Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.		Each Local ACHD Centre must participate in relevant national programmes for audit and must submit data to the Specialist ACHD Surgical or Specialist ACHD Cardiology Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.
New	Each Local Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.		Each Local ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.
F5 New	Each Local Children's Cardiology Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence guidance.		Each Local ACHD Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local ACHD Centres will follow mandatory National Institute for Health and Care Excellence guidance.
F6 New	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.		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.

Draft CHD Standards: Tier 3: Local (Children’s Cardiology/ACHD) Centres

Section G: Academic Research

	Paediatric		Adult
	Local Children’s Cardiology Centre		**Local ACHD Centre**
New G1	Each Local Children’s Cardiology Centre must demonstrate a robust policy for collaboration with the network Specialist Children’s Surgical Centre, any Specialist Children’s Cardiology Centres, other Local Children’s Cardiology Centres and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every five years.		Each Local ACHD Centre must demonstrate a robust policy for collaboration with the network Specialist ACHD Surgical Centre, any Specialist ACHD Centres, other Local ACHD Centres and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every five years.

Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section H: Communication with patients

	Paediatric		Adult
	Local Children's Cardiology Centre		**Local ACHD Centre**
SS E1 Edit H19 new	Local Children's Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision making at every stage.		Local ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision making at every stage in their care.
H2 H16 new	Children and young people, parents and carers must be helped to understand the patient's condition, the effect it may have on their health and future life and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child, young person's, parents' and carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention d. smoking, alcohol and drugs e. school and careers; f. travel; g. welfare benefits; h. social services; and i. community services.	H2 H16	Patients and partners, family or carers must be helped to understand the patient's condition and its impact in order to be able to actively participate in decision making at every stage in their care including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention d. smoking, alcohol and drugs e. careers; f. travel; g. welfare benefits; h. social services; and i. community services.

Section H: Communication with patients

	Paediatric		Adult
H15 new	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, 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.	E6	Information must be made available to patients, partners, family or carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.
H3 new	Local Children's Cardiology Centres must demonstrate that arrangements are in place for parents/carers 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.	H3	Local ACHD Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.
D4 SS	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network to make sure that it continues to be relevant to their particular stage of development.	H17	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network to make sure that it continues to be relevant to their particular stage of development.

Section H: Communication with patients

	Paediatric		Adult
H4 new New	Children and young people, their parents and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local Children's Cardiology Centres must make this feedback openly available, to patients, parents / carers and the general public, together with outcome of relevant local and national audits. Local Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, parents and carers must be informed of the action taken following a complaint or suggestion made. Local Children's Cardiology Centres must demonstrate ongoing structured liaison with patient and parent groups	H4	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local ACHD Centres must make this feedback openly available to patients, parents / carers and the general public, together with outcome of relevant local and national audits. Local ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. Local ACHD Centres must demonstrate on-going structured liaison with patients and groups, including evidence of how feedback is formally considered.
H5 New	Each Local Children's Cardiology Centre must have booking systems that allow for long term follow up (up to 5 years) Patients and their parents / carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	H5	Each Local ACHD Centre must have booking systems that allow for long term follow up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.
H6 New	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 parent, carer and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	H6	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carer throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.

Section H: Communication with patients

	Paediatric		Adult
H7 new	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.	H7	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide literature.
	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child's /young person's condition, and providing psychosocial support to promote parental (and child's/young person's) adaption and adjustment.		The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan, and providing psychosocial support to promote adaption and adjustment.
H8 New	The Children's Congenital Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	H8	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.
H9 New	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 practicable or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	H9	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.
C6 New	There must be access (for patients and family members) to support services including faith support and interpreters.		There must be access (for patients, partners, family members and carers) to support services including faith support and interpreters.
H10 New	Copies of all correspondence for GP and local centres must be copied to the parent / carer / young person (as appropriate), in plain English to retain in the patient's personal record in accordance with national guidance.	H10	Copies of all correspondence for GP and local centres must be copied to the patient in plain English to retain in the patient's personal record in accordance with national guidance.

Section H: Communication with patients

	Paediatric		Adult
H11 New	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.	H11	Patients, partners, family or carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.
New	Parents and carers should be offered resuscitation training when appropriate.		Partners/family/carers should be offered resuscitation training when appropriate.
H12 New	Local Children's Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	H12	Local ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data.
H13 new	Where surgery or intervention is planned, Local Children's Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist 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.	H13	Where surgery or intervention is planned, Local ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist 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.
H14 new	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.	H14	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.

Section H: Communication with patients

	Paediatric		Adult
H17 new	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	H17	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.
H23 new	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.		Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.
H24 new	Each Local Children's Cardiology Centre must ensure that children and young people can access a Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support parents and children / young people at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.		Each Local ACHD Centre must ensure that children and young people can access a Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support parents and children / young people at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist ACHD Centre.
New	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 family) will ensure continuity and consistency of information. A clear plan of on-going 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 on-going opportunity for the patient and parents to discuss concerns about treatment must be offered.		When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family) will ensure continuity and consistency of information. A clear plan of on-going treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An on-going opportunity for the patient to discuss concerns about treatment must be offered.

Section J: Pregnancy and Contraception

	Paediatric		Adult
	Contraception and Advice		**Contraception and Advice**
J5 New	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant cardiologist or paediatrician with expertise in cardiology and a nurse specialist with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.		All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist or cardiologist with special interest in congenital heart disease who have expertise in pregnancy in congenital heart disease. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.
J2 New	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, 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.		All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy. Written advice about sexual and reproductive health, safe forms of contraception, specific to their condition must be provided. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.

Section J: Pregnancy and Contraception

	Paediatric		Adult
J7 New	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.		Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.
J8 New (J5)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant cardiologist or paediatrician with expertise in cardiology and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.		All male patients must have access to counselling and information about contraception and recurrence risk by a consultant cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.
New	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.		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.
	Pregnancy and Planning Pregnancy		**Pregnancy and Planning Pregnancy**
J6 New	For patients planning pregnancy or who are pregnant, refer to adult standards, section J: Pregnancy and Contraception for further relevant standards.		
		G1	Women with congenital heart disease must be discussed with the Specialist ACHD Cardiologist with specialist expertise in pregnancy in heart disease at a Specialist ACHD Surgical Centre or Specialist ACHD Centre immediately once they are pregnant to plan their care. The plan

Section J: Pregnancy and Contraception

	Paediatric		Adult
			must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery.
		G2	The Local ACHD Centre may care for pregnant women with ACHD in whom pregnancy presents a low maternal risk at the onset of pregnancy. It should be acknowledged that as pregnancy proceeds, complications such as severe pre-eclampsia may alter this risk assessment.

Draft CHD Standards: Tier 3: Local (Children’s Cardiology/ACHD) Centres

Item 8

Section K – Fetal diagnosis

	Paediatric
New	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.
SS B2 Edit	Local Children’s Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children’s Surgical Centre in their Congenital Heart Network.
SS B4	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenial Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.
SS B6 Edit	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.
	A Children’s Cardiac Nurse Specialist (who has been appropriately trained in counselling for fetal CHD) will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support within 48 hours of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The CCNS/Fetal Cardiac Nurse Specialist (FCNS) must work in collaboration with the Cardiologist and fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The CCNS/FCNS will act as the point of contact for the family throughout pregnancy for support and further information.
SS B8	At diagnosis a plan must be agreed with the Specialist Children’s Surgical Centre, the specialist feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.
SS B9	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Children’s Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with their local obstetric unit which will continue to be the mother’s first port of call in an emergency or in case of preterm delivery.

Section K – Fetal diagnosis

	Paediatric
SS B10	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children’s Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.

Draft CHD Standards: Tier 3: Local (Children's Cardiology/ACHD) Centres

Item 8

Section M: Dental

	Paediatric	Adult
	Local Children's Cardiology Centre	**Local ACHD Centre**
New M1	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.	
New M3	The Local Children's Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	The Local ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.
New M4	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.	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.
New M5	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.	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.
New M6	Local Children's Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children's Surgical Centre.	Local ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.