

Section A: The Network Approach

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist 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 Specialist Children's Cardiology Centres where appropriate. 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 Specialist ACHD Centres where appropriate. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.
A24 SS apart from (a) which is new	<p>Each Specialist Children's Cardiology Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for:</p> <ol style="list-style-type: none"> 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. Newborns with a murmur and otherwise clinically well 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. New referrals from GPs 		<p>Each Specialist ACHD Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for:</p> <ol style="list-style-type: none"> New referrals from GPs, cardiologists and local hospitals Ongoing care of patients diagnosed with congenital heart defects

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	<p>and paediatricians</p> <p>Local hospitals will refer children/young people to a Specialist Children's Cardiology Centre/Local Children's Cardiology Centre, as appropriate, for the following categories of 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>		

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A1 New	<p>Specialist Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:</p> <ul 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 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; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how paediatric cardiologists and PECs will work across the network, including at the Specialist Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres according to local circumstances; f. ensure that when a Specialist Children's Cardiology Centre cannot admit a patient for whatever reason it takes responsibility for sourcing an appropriate bed at another Specialist Children's Surgical or Cardiology 	A1	<p>Specialist ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:</p> <ul 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 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; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how specialist ACHD cardiologists will work across the network, including at Specialist ACHD Surgical Centres and Local ACHD Centres, according to local circumstances; f. ensure that when a Specialist ACHD Centre cannot admit a patient for whatever reason it takes responsibility for sourcing an appropriate bed at another Specialist ACHD Surgical or Specialist ACHD Centre; g. address how Specialist ACHD Centres will communicate effectively with colleagues within the Congenital Heart Network (both Specialist ACHD Surgical Centre and Local ACHD Centres)

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	<p>Centre;</p> <p>g. 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>h. provide 24/7 cover by consultant paediatric cardiologists for specialist advice.</p>		<p>on the care of patients requiring non-cardiac interventions; and</p> <p>h. provide 24/7 advice via an on-call rota comprised predominantly of general consultant cardiologists who will have contact details for the on-call ACHD specialists in the network.</p>
A9 SS	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.		There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.
H22 New	<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>		<p>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.</p> <p>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.</p>
NEW	Cardiological Interventions		Cardiological Interventions
	<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</p>		<p>Specialist ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways of care that will:</p>

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	<p>therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre; and</p> <p>b. ensure that emergency balloon atrial septostomy and 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.</p>		<p>a. require all ACHD surgery and therapeutic interventions, including atrial septal defect closure, and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre (see appendix B for the definitions of ACHD surgery and intervention).</p>
	Non-Cardiac Surgery		Non-Cardiac Surgery
New	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.		Specialist 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.
NEW	External Relationships		External Relationships
D7.4	Each Specialist Children's Cardiology Centre must have a close network relationship with all maternity and fetal medicine services within their network and be able to demonstrate the operation of joint protocols.		Each Specialist ACHD Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.

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D7.1	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.		Each Specialist ACHD Centre must have a close network relationship with any paediatric CHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.
SS A2 Edit	Each Specialist Children's Cardiology Centre must demonstrate formal working relationships with: <ul style="list-style-type: none"> a. network Specialist Children's Surgical Centre and Local Children's Cardiology Centres; b. the paediatric cardiothoracic transplant centres; c. the national Pulmonary Hypertension Service; and d. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities. 	A2 and A3	Each Specialist ACHD Centre must demonstrate formal working relationships with: <ul style="list-style-type: none"> a. network Specialist ACHD Surgical Centre and Local ACHD Centres; b. a cardiothoracic transplant centre staffed by transplant surgeons with a congenital practice; c. the national Pulmonary Hypertension Service; and d. a cardiac pathologist with expertise in congenital cardiac abnormalities.
B15 NEW	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 patients with complex medical and social needs.		
	Telemedicine and IT		Telemedicine and IT
A4 NEW	Each Specialist Children's Cardiology Centre will have telemedicine facilities as required to link with designated	A5	Each Specialist ACHD Centre will have telemedicine facilities as required to link with designated hospitals in a network:

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Inc SS A16	<p>hospitals in a network:</p> <ul style="list-style-type: none"> a. the Specialist Children's Surgical Centre b. Local Children's Cardiology Centres <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. 		<ul style="list-style-type: none"> a. the Specialist ACHD Surgical Centre b. Local ACHD Centres <p>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:</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 ACHD services.
NEW	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.	C4	Each Specialist ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist ACHD Surgical Centre system, and enable immediate access to patient data. See Appendix C for detailed IT requirements.
NEW	Multidisciplinary Team (MDT)		Multidisciplinary Team (MDT)
NEW	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		Each Specialist ACHD 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

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	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.		Specialist ACHD Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.
NEW	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.		A designated cardiologist will attend (in person or by VC link) the weekly network MDT meeting, 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 meeting.
H21	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.		Staff from the Specialist 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.
A26 NEW	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).		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).
		A2	Specialist ACHD Centres will routinely refer patients to their primary network MDT meeting. Exceptions to this principle will include the exercise of patient choice and, when justified by a consideration of the clinical facts of the individual case, the exercise of referrer choice. In all cases when a patient is referred 'out of network' the Specialist ACHD Centre must inform the Specialist ACHD Surgical Centre in writing of the reasons for referral.

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	Network Leadership		Network Leadership
NEW	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 postholder 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.		Each Specialist ACHD 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 postholder must have specified time working in ACHD cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.

Section B: Staffing and skills

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist ACHD Centre
B1 New	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-led ward round will occur daily.	B9	Each Specialist ACHD Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, 7 days a week within legally compliant rotas. A consultant-led ward round will occur daily.
C1 SS	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	Medical		Medical
B3 New	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.	B3	Each Specialist ACHD Centre must be staffed by: <ul style="list-style-type: none"> a. one lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD; and b. at least one cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD. Each cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist.
New	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.	B1	Each Specialist ACHD Centre must have a dedicated consultant-led cardiology on-call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.

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	Paediatric		Adult
New	<p>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.</p> <p>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.</p>	B2	<p>Each Specialist ACHD Centre will have a formally nominated Clinical ACHD Lead with responsibility for the service at the Specialist ACHD Centre, who works across the network including outreach clinics, with precise duties determined locally..</p> <p>Each Specialist ACHD Centre will have separate clinical leads identified from the relevant specialties, including nursing, ICU, and anaesthesia who have a direct link and collaborative working partnership with the lead roles in the Specialist ACHD Surgical Centre.</p>
B4 New	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.		Cardiologists employed by the Specialist ACHD Centre and trained to the appropriate standards in interventional and diagnostic ACHD cardiology shall be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their specialist skills.
B5 New	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.	B5	Specialist ACHD Cardiologists based at the Specialist ACHD Centre who visit the Specialist ACHD Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year.
		B6	Electrophysiology will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre if specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network agreed governance arrangements.

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	Paediatric		Adult
B7 New	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.	B7	Each Specialist ACHD 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 MRI defined by Specialist Surgical Centre cardiologists and radiologists.
(B9) New	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, in line with Paediatric Intensive Care Society standards.		Intensive Care Unit consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.
New	Nursing		Nursing
New	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.		Specialist ACHD Centres must have locally designated registered nurses with a specialist interest in adult congenital heart disease, trained and educated in the assessment, treatment and care of patients with CHD.
New	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.		
New (B13)	Each Specialist Children's Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.		Each Specialist ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.

Section B: Staffing and skills

	Paediatric		Adult
New (B12)	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 the Specialist Children's Cardiology Centre (the number will depend on geography, population and the congenital heart network).	B8	Each Specialist ACHD Centre will employ a minimum of 2 WTE specialist ACHD nurses whose role will extend throughout the network. The precise number, above the minimum two, and location of these nurses will depend on geography, population and the configuration of the network.
New	Psychology		Psychology
New	Each Specialist Children's Cardiology Centre must have access to a clinical psychology service that is integrated with the ACHD team.	B12	Each Specialist ACHD Centre must have access to a clinical psychology service that is integrated with the ACHD team.
	Administrative		Administrative
New	Each Specialist Children's Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.		Each Specialist ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.
A21 ?SS	Each Specialist 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.	B11	Each Specialist ACHD Centre will provide onsite 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 patients, partners/family or carers in a timely fashion.
	Other		Other
New	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		Each Specialist ACHD 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

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	Paediatric		Adult
	served, and whether the service is integrated with ACHD echocardiography.		served, and whether the service is integrated with paediatric echocardiography.
B1.1 New	Each Specialist Children's Cardiology Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.		Each Specialist ACHD Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.
B(1.1) new	Each Specialist Children's Cardiology Centre will have a dedicated bereavement officer.		Each Specialist ACHD Centre will have a dedicated bereavement officer.

Section C: Facilities

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist ACHD Centre
C1.1 new	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.		There must be dedicated room space in which practitioner psychologists, cardiac nurse specialists and social work staff conduct therapeutic work.
C2 New	<p>There must be facilities in place to ensure 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) ability of 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>	C2	<p>There must be facilities in place to ensure convenient access for partners/family/carers. Facilities and support include:</p> <ul style="list-style-type: none"> a) accommodation for partners/family members to stay; b) access to refreshments; c) facilities suitable for the storage and preparation of simple meals; and d) an on-site quiet room completely separate from general facilities. <p>Family accommodation should be provided without charge</p>
New C3	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.	C3	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.

Section C: Facilities

	Paediatric		Adult
New	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.		Patients must have access to general resources including books, magazines and free wifi.
New C4.2	Specialist Children's Surgical Centres must have a hospital school with teachers. Children and young people must have access to education resources.		
New	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.		Patients/partners/family/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.
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.

Section D: Interdependencies

	Paediatric		Adult
	<p>The following specialties or facilities must be located on the same hospital site as Specialist Children's Cardiology Centres.</p> <p>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>		<p>The following specialties or facilities must be located on the same hospital site as Specialist ACHD Centres.</p> <p>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>
C12	Paediatric Cardiology.	D1	General adult cardiology services, including acute cardiac care unit.
C13	Paediatric Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).		Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).
C15	<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).</p> <p>Level 2 High Dependency beds staffed by medical and nursing teams experienced in managing paediatric cardiac patients.</p>	D1	<p>Level 3 Intensive Care Unit, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care.</p> <p>Level 2 High Dependency beds staffed by medical and nursing teams experienced in managing patients with ACHD.</p>
C1	<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 BP and pacemaker interrogation and follow up, as well as standard, transoesophageal</p>		<p>Each Specialist ACHD Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise.</p> <p>The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory BP and pacemaker follow-up and interrogation, as well as standard, contrast, transoesophageal and fetal echocardiography.</p> <p>Specialist ACHD Centres should be able to undertake cardio-pulmonary</p>

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	<p>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, 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>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> <p>These services must be available 24/7 where clinically indicated.</p>		<p>exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations.</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>Governance arrangements across the Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners are kept up to date.</p> <p>These services must be available 24/7.</p>

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	<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>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>		<p>The following specialties or facilities should ideally be located on the same hospital site as Specialist ACHD Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>
C14	Paediatric Surgery.	D2f	General Surgery.
C16	Paediatric anaesthetist with an interest in paediatric cardiac disease and working closely with specialist paediatric cardiac anaesthetists in the network.		Cardiac anaesthetist with an interest in congenital cardiac disease and working closely with specialist congenital cardiac anaesthetists in the network.
C20	Paediatric Nephrology.	D2p	Nephrology.
C27	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	D2o	Physiotherapy (service must be integrated with the ACHD team).
C33	Bereavement Support, including nurses trained in bereavement support.		Bereavement Support, including nurses trained in bereavement support.
S&S C56 D6	Multidisciplinary paediatric acute pain management service.		Acute pain management service.
	Paediatric Gastroenterology.	D2d	Gastroenterology.
		D2a	Clinical biochemistry.

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	<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>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>		<p>The following specialties or facilities should ideally be located on the same hospital site as Specialist ACHD Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>
		D2b	Clinical Haematology.
		D2c	Ear nose and throat.
		D2e	General medicine and provision for diabetes, endocrinology and rheumatology services.
		D2g	Gynaecology.
		D2h	Learning Disability Team.
		D2i	Level III neonatal unit (NICU).
		D2j	Microbiology and infectious diseases.
		D2k	Neurology.
		D2l	Neurosurgery.
		D2m	Obstetric Unit with Maternal Fetal Medicine Specialist/s.
		D2n	Orthopaedics.

Section D: Interdependencies

	Paediatric		Adult
	<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>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>		<p>The following specialties or facilities should ideally be located on the same hospital site as Specialist ACHD Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.</p>
		D2q	Respiratory medicine.
		D2r	Urology.

	Paediatric		Adult
	<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>		
C17	Paediatric Neurology.		
C18	Paediatric Respiratory Medicine.		
C19	Neonatology.		
C40	Paediatric Neurosurgery.		
C42	Child Psychiatry with dedicated sessions.		

Section D: Interdependencies

	Paediatric		Adult
	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.		
	Paediatric Endocrinology.		
	Paediatric Orthopaedics.		
	Plastic surgery.		
	Vascular surgery.		
C21	Clinical Haematology.		
C29	Infection control Nurse experienced in the needs of paediatric cardiac patients.		
C44	Clinical Biochemistry (including toxicology).		
C46	Pharmacy (24/7 on-call required for urgent supply and advice).		
	Microbiology and Infectious diseases.		
	Safeguarding team/social work (as per national standards).		

Section D: Interdependencies

	Paediatric		Adult
	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.		Advice and consultation must be available from the following services at least by the following working day. The services must be experienced in patients with congenital heart disease.
C13	Paediatric Ear, Nose and Throat.		
C24	General Paediatrics (seven day working week).		
C26	Psychology.		
C28	Paediatric Dietician.		
C34	Breast Feeding Support (seven day working week).		
C35	Social Work Services.		
C38	Obstetrics and Midwifery (seven day working week).		
C41	Clinical Genetics.	D3b	Clinical Genetics.
C43	Paediatric Dentistry.	D3d	Dentistry.
	Paediatric Immunology.	D3c	Clinical Immunology.
	Feto-maternal medicine.		
	Dermatology.	D3e	Dermatology.
	Sexual health.	D3k	Sexual Health.

Section D: Interdependencies

	Paediatric		Adult
	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.		Advice and consultation must be available from the following services at least by the following working day. The services must be experienced in patients with congenital heart disease.
	Paediatric Rheumatology.		
	Gynaecology.		
	Paediatric Urology.		
	Speech and language, including swallow assessment with access to video fluoroscopy.		
		D3a	Cardiac rehabilitation.
		D3f	Diabetes.
		D3g	Neurosurgery.
		D3h	Occupational Therapy
		D3i	Palliative Care.
		D3j	Psychiatry.
	Chronic pain services.		Chronic pain services.

Section D: Interdependencies

	Paediatric		Adult
	Specialist Children's Cardiology Centres must have a network relationship with the following services to provide a planned contribution to care in a timescale agreed between practitioners.		
D5	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.	D4	Each Specialist ACHD 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 patient and family. This should also include bereavement follow-up and referral on for on-going emotional support of the family.
D7	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 heart disease and to their families.	D6	Each Specialist ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of older people with congenital heart disease.
		D7	Each Specialist ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers and young people with congenital heart disease.
	Each Specialist Children's Cardiology Centre will provide access to a Psychology Service for children, and for parents and carers. It may provide this service directly or through a service level agreement with another Cardiology Service in the Network.		
	Each Specialist Children's Cardiology Centre will ensure that patients have access to a psychology appointment: <ul style="list-style-type: none"> a. by the next working day for inpatients in acute distress; 		

Section D: Interdependencies

	Paediatric		Adult
	Specialist Children's Cardiology Centres must have a network relationship with the following services to provide a planned contribution to care in a timescale agreed between practitioners.		
	b. within 10 working days for adjustment, adherence or decision making difficulties that interfere with medical care; and within six weeks for all other referrals.		
	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 cardiac psychologists closer to the child's home or other agencies.		

Section E: Training and Education

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist 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 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.		All members of the cardiac and ICU 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	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Surgical 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 Specialist Cardiology Centres must be offered allocated rotational time working in the Specialist Surgical Centre, to enhance development of clinical knowledge and skills enable professional development and career progression. A formal annual training plan should be in place.
E2 New	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.	E2	Each Specialist Cardiology Centre must demonstrate a commitment to the training and education of cardiology SpRs in ACHD and heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.

Section E: Training and Education

	Paediatric		Adult
A17 SS	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 children and young people with congenital heart problems.		Each Congenital Cardiology Network will have a formal annual training plan in place, which ensures on-going education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.
E1 New	<p>Clinical Nurse Educators must be provided across each Children's Heart Network, sufficient to deliver standardised training and competence 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 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.</p> <p>Skills in teaching, research, audit and management will also be part of the programme.</p>	E1	<p>Each Specialist Cardiology Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at Specialist Cardiology Centre. This individual will work with those at Specialist Surgical Centre to deliver standardised training and education competency-based programmes across the Congenital Heart Network. These programmes 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>

Section F: Organisation, governance and audit

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist ACHD Centre
F1 New	<p>Specialist Children's Cardiology Centres will operate within the Congenital Heart Network's clinical governance framework that includes:</p> <ul style="list-style-type: none"> 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. 	F1	<p>Specialist ACHD Centres will operate within the Congenital Heart Network's clinical governance framework that includes:</p> <ul style="list-style-type: none"> 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	<p>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 across the local and national Congenital Heart Networks.</p>	F2	<p>Each Specialist ACHD Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.</p>
F3 New	<p>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.</p>	F3	<p>Each Specialist ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.</p>
	<p>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 annually.</p>		<p>Each Specialist 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.</p>

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.
New	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.		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.
F4 New	Each Specialist Children's Cardiology Centre must participate in national programmes for audit and must submit data on any emergency procedures and endocarditis, to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	F4	Each Specialist ACHD Centre must participate in national programmes for audit and must submit data on 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.
New	Each Specialist Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.		Each Specialist ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.
F5 New	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 National Institute of Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	F5	Each Specialist ACHD Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Centres will follow mandatory National Institute of Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.
F6 New	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 6 weeks and according to clinical urgency.	F6	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.

Section G: Research

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

Section H: Communication with patients

	Paediatric		Adult
	Specialist Children's Cardiology Centre		Specialist ACHD Centre
SS E1 Edit H19 new	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.		Specialist ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision making at every stage in their care.
	Every patient must be given a detailed written care plan forming a patient care record, in plain English, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	H1	Every patient must be given a detailed written care plan forming a patient care record, in plain English, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.
H2 H16 new	<p>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.</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 should include any aspect of care that is relevant to their congenital heart condition, including</p> <ol style="list-style-type: none"> exercise and sports participation; sex, contraception, pregnancy; dental care and endocarditis prevention smoking, alcohol and drugs school and careers; 	H2 H16	<p>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.</p> <p>The psychological, social, cultural and spiritual factors impacting on the patient's understanding must be considered.</p> <p>Information should include any aspect of care that is relevant to their congenital heart condition, including</p> <ol style="list-style-type: none"> exercise and sports participation; sex, contraception, pregnancy; dental care and endocarditis prevention smoking, alcohol and drugs careers;

Section H: Communication with patients

	Paediatric		Adult
	<ul style="list-style-type: none"> f. travel; g. welfare benefits; h. social services; and i. community services. 		<ul style="list-style-type: none"> f. travel; g. welfare benefits; h. social services; and i. community services.
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	Specialist 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	Specialist 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	<p>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.</p> <p>Specialist 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.</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, parents and carers must be informed of the action taken following a complaint or suggestion made.</p> <p>Specialist Children's Cardiology Centres must demonstrate ongoing structured liaison with patient and parent groups</p>	H4	<p>Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service.</p> <p>Specialist 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.</p> <p>Specialist ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services.</p> <p>Patients must be informed of the action taken following a complaint or suggestion made.</p> <p>Specialist ACHD Centres must demonstrate on-going structured liaison with patients and groups, including evidence of how feedback is formally considered.</p>
H5 New	<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>	H5	<p>Each Specialist ACHD Centre must have booking systems that allow for long term follow up (up to 5 years).</p> <p>Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.</p>
H6 New	<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 parent, carer 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>	H6	<p>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/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist.</p> <p>ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.</p>

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	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
	guidance.		
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	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.	H12	Specialist 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, Specialist 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, Specialist 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	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

Section H: Communication with patients

	Paediatric		Adult
	their decisions so that they are able to give informed consent.		consent.
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	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.		A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients 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.
New	<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 family) will ensure continuity and consistency of information.</p> <p>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.</p>		<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 patient or their family) will ensure continuity and consistency of information.</p> <p>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.</p>

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 child-bearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	J4	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a nurse specialist with who have expertise in pregnancy in congenital heart disease.
J2 and J3 new	<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, 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>	J2	<p>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.</p> <p>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.</p> <p>The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.</p>
J7 new	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	J6	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.
J8	All male patients must have access to counselling and information	J7	All male patients must have access to counselling and information about

Section J: Pregnancy and contraception

	Paediatric		Adult
New (J5)	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.		contraception and recurrence risk by an ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.
	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.		
		J1	Each Specialist ACHD Centre must be staffed by Specialist ACHD cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.
		J5	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 3-4) risk, must receive joint pre-pregnancy counselling with the Cardiologist and a maternal medicine specialist (Consultant Obstetrician) with expertise in pregnancy in women with congenital heart disease.
		J8	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant.

Section J: Pregnancy and contraception

	Paediatric		Adult
			The plan 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.
		J9	Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at the obstetric unit co-located with the Specialist ACHD Surgical Centre during pregnancy, delivery and the puerperium.
		J10	<p>Women with moderate or high risk conditions, who are not at risk of requiring such intervention during pregnancy, may be managed at the obstetric unit co-located with the Specialist ACHD Centre, with network agreement.</p> <p>Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.</p>
		J11	Each Specialist ACHD Centre must be co-located, as defined by Appendix E, with a specialist tertiary maternity unit delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease, a maternal medicine specialist who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy.

Section J: Pregnancy and contraception

	Paediatric		Adult
		J12	The multidisciplinary team must include consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.
		J13	They will provide regular joint clinics with the Specialist ACHD Cardiologist with expertise in congenital heart disease in pregnancy, Specialist Obstetrician and with access to an Obstetric Anaesthetist. Regular specialist multidisciplinary team case conferences must take place across the network with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia, haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.

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	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.
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 Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.
SS B6 rev	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.
new	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.
New (H24 (1))	<p>A Children's Cardiac Nurse Specialist (CCNS) (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.</p> <p>The CCNS/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 CCNS/FCNS will act as the point of contact for the family throughout pregnancy for support and further information.</p>

Section K – Fetal diagnosis

	Paediatric
New	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.
B8 SS	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 rev	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.
SS B10 rev	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. 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, arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.

Section M: Dental

	Paediatric	Adult
	Specialist Children's Cardiology Centre	Specialist 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 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.	The Specialist 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. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	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 patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.
New M6	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.	Specialist 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.