

## Section A: The Network Approach

	Paediatric		Adult
	Specialist Children's Surgical Centres		Specialist ACHD Surgical Centres
SS A2 edit	<p>Specialist Children's Surgical Centres in partnership with the Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of children and young people with congenital heart disease. The model of care will ensure that all congenital cardiac care is carried out only by congenital cardiac specialists (including investigation, cardiology and surgery).</p> <p>The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist Children's Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.</p>		<p>Specialist ACHD Surgical Centres in partnership with the Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of patients with congenital heart disease throughout their life. The model of care will ensure that all congenital cardiac care is carried out only by congenital cardiac specialists (including investigation, cardiology and surgery).</p> <p>The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist ACHD Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.</p>
New A6	Pathways must involve prenatal diagnosis, maternity and obstetric services, transition to adult congenital cardiac services and palliative care. Congenital Heart Networks should be aligned with networks for fetal services; the transition from fetus → child, child → adolescent, and adolescent → adult requires a joined-up approach with treatment continuity.		Pathways must involve transition from paediatric congenital cardiac services and appropriate links with other adult specialties including obstetrics and palliative care. Congenital Heart Networks should be aligned with networks for fetal services; the transition from adolescent → adult requires a joined-up approach with treatment continuity.
New A1	<p>Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:</p> <ol style="list-style-type: none"> <li>achieve high quality of care at all stages of a seamless pathway in accordance with the model of care;</li> <li>facilitate the development of as much non-surgical care and</li> </ol>	A1	<p>Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:</p> <ol style="list-style-type: none"> <li>achieve high quality of care at all stages of a seamless pathway in accordance with the model of care;</li> <li>facilitate the development of as much non-surgical care and</li> </ol>

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	<p>treatment as close as possible to home;</p> <ul style="list-style-type: none"> <li>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;</li> <li>d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); and</li> <li>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 (if present) and Local Children's Cardiology Centres, according to local circumstances.</li> </ul>		<p>treatment as close as possible to home;</p> <ul style="list-style-type: none"> <li>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;</li> <li>d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); and</li> <li>e. address how specialist ACHD cardiologists will work across the network, including at the Specialist ACHD Surgical Centre, the Specialist ACHD Centres and Local ACHD Centres, according to local circumstances.</li> </ul>
SS C68	<p>There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following:</p> <ul style="list-style-type: none"> <li>a. Clinical transfers must be arranged in a timely manner according to patient need.</li> <li>b. Critically ill children must be transferred/retrieved in accordance with the standards set out within the designation standards for Paediatric Intensive Care services.</li> <li>c. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.</li> </ul>		
SS A9	<p>There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.</p>		<p>There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.</p>

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New H22	<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 be 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>
SS A12	Specialist Children's Surgical Centres will develop and implement a nationally consistent system of 'patient-held records'.		Specialist ACHD Surgical Centres will develop and implement a nationally consistent system of 'patient-held records'.
	Cardiological Interventions		Cardiological Interventions
New (derived from Fro m S&S A29 A30, A31, B9)	<ol style="list-style-type: none"> <li>Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's 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;</li> <li>allow neonates with <i>patent ductus arteriosus</i> to receive surgical ligation in the referring neonatal intensive care unit (level 3) provided that the visiting surgical team is despatched from a designated Specialist Children's Surgical Centre and is suitably equipped in terms of staff and equipment (this is the sole exception to the requirement that heart surgery must be performed in a designated Specialist Children's Surgical Centre). It will be for each Congenital Heart Network to determine whether this arrangement is optimal (rather than transferring the neonate to the Specialist</li> </ol>		<p>Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:</p> <ol style="list-style-type: none"> <li>require all ACHD surgery, 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 definition of ACHD Surgery and Interventions;</li> <li>enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist ACHD Surgical Centre or in another Specialist ACHD Surgical Centre, if the need arises; and</li> <li>ensure that if a Specialist ACHD Surgical Centre cannot admit a patient for whatever reason it takes responsibility for sourcing an appropriate bed at another Specialist ACHD Surgical or Cardiology</li> </ol>

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	<p>Children's Surgical Centre) according to local circumstances, including a consideration of clinical governance and local transport issues;</p> <ul style="list-style-type: none"> <li>c. ensure that emergency balloon atrial septostomy and temporary pacing, if undertaken outside of a Specialist Children's Surgical Centre, can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process;</li> <li>d. ensure that patients requiring electrophysiology must be treated in dedicated paediatric services, with paediatric cardiac surgical support not adult services;</li> <li>e. enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist Children's Surgical Centre or in another Specialist Children's Surgical Centre, if the need arises; and</li> <li>f. ensure that if a Specialist Children's Surgical Centre cannot admit a patient for whatever reason, it takes responsibility for sourcing an appropriate bed at another Specialist Children's Surgical or Cardiology Centre.</li> </ul>		Centre.
	Non-Cardiac Surgery		Non-Cardiac Surgery
New	Specialist Children's Surgical Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment by a Congenital Heart team including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, the most appropriate location for that surgery or		Specialist ACHD Surgical Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, the most appropriate location for surgery and advice to non-ACHD cardiologists

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	investigation, and advice to paediatricians across the in congenital network.		across the congenital network.
	<b>External Relationships</b>		<b>External Relationships</b>
D7.4	Each Specialist Children's Surgical 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.	D7.4	Each Specialist ACHD Surgical Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.
D7.1	Each Specialist Children's Surgical Centre must have a close network relationship with any ACHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.		Each Specialist ACHD Surgical 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.
New A2 inc SS C45	Each Specialist Children's Surgical Centre must demonstrate formal working relationships with: <ul style="list-style-type: none"> <li>a. network Specialist Children's Cardiology Centres (if present) and Local Children's Cardiology Centres;</li> <li>b. the paediatric cardiothoracic transplant centres;</li> <li>c. the national Pulmonary Hypertension Service; and</li> <li>d. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities.</li> </ul>	A2	Each Specialist ACHD Surgical Centre must demonstrate formal working relationships with: <ul style="list-style-type: none"> <li>a. network Specialist Cardiology Centres and Local Cardiology Centres;</li> <li>b. a cardiothoracic transplant centre staffed by transplant surgeons with a congenital practice;</li> <li>c. the national Pulmonary Hypertension Service; and</li> <li>d. a cardiac pathologist with expertise in congenital cardiac abnormalities.</li> </ul>
SS	Children and young people who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a designated paediatric cardiothoracic transplant centre. The designated transplant centre is		Patients who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a cardiothoracic transplant centre. The designated transplant centre is responsible for managing and developing referral, care, treatment

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C10	responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.		and transfer pathways, policies, protocols, and procedures in respect of transplant patients.
New B15	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
New A4 And new C5	<p>Each Specialist Children's Surgical Centre will have telemedicine facilities as required to link with designated hospitals in a network:</p> <ul style="list-style-type: none"> <li>a. Specialist Children's Cardiology Centres (if present)</li> <li>b. Local Children's Cardiology Centres</li> </ul> <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"> <li>a. undertake initial assessments of echocardiograms;</li> <li>b. support participation in multi-site VC MDT meetings;</li> <li>c. handle emergency referrals; and</li> <li>d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric cardiac services.</li> </ul>	A4 and C5	<p>Each Specialist ACHD Surgical Centre will have telemedicine facilities as required to link with designated hospitals in a network:</p> <ul style="list-style-type: none"> <li>a. Specialist ACHD Centres</li> <li>b. Local ACHD Centres</li> </ul> <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"> <li>a. undertake initial assessments of echocardiograms;</li> <li>b. support participation in multi-site VC MDT meetings;</li> <li>c. handle emergency referrals; and</li> <li>d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.</li> </ul>

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New C4	Each Specialist Children's Surgical Centre must cooperate to allow visiting paediatric cardiologists and PECs from the network to gain remote access to the Specialist Children's Cardiology Centre system, and enable immediate access to patient data. See Appendix C for detailed IT requirements.	C4	Each Specialist ACHD Surgical Centre must cooperate to allow visiting specialist ACHD cardiologists from Specialist ACHD Centres to gain remote access to the Specialist ACHD Centre system, and enable immediate access to patient data. See Appendix C for detailed IT requirements.
	Multidisciplinary Team (MDT)		Multidisciplinary Team (MDT)
New	Each Specialist Children's Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	B11	Each Specialist ACHD Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.
New H21	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.		Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.
SS A26	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).
SS A3	The Specialist Children's Surgical Centres and services within the Congenital Heart Network will hold regular multidisciplinary team meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.		The Specialist ACHD Surgical Centres and services within the Congenital Heart Network will hold regular multidisciplinary team meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.

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	Network Leadership		Network Leadership
New B2	<p>Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by separate clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia.</p> <p>The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.</p>		<p>Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by separate clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia.</p> <p>The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.</p>
New B3.1	<p>Each Specialist Children's Surgical Centre will have a lead cardiologist who supports the Network Clinical Director, and works across the network including outreach clinics, with precise duties determined locally.</p>	B2	<p>Each Specialist ACHD Surgical Centre will have a formally nominated Clinical Lead with responsibility for the service overall, who supports the Network Clinical Director, and works across the network including outreach clinics, with precise duties determined locally.</p> <p>The clinical lead will be supported by designated clinical leads for surgery, cardiac intervention, anaesthesia and critical care.</p>
New B(2)	<p>Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.</p>		<p>Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.</p> <p>Each Specialist ACHD Surgical Centre must have a formally nominated Lead Nurse who is an expert in the field of ACHD providing professional and clinical leadership and support to the team of nurse specialists across the network.</p>



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	Specialist Children's Surgical Centre		Specialist ACHD Surgical Centre
SS C9 Edit	Each Specialist Children's Surgical Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including 24/7 paediatric surgery and interventional cardiology cover. A consultant-led ward round will occur daily.		Each Specialist ACHD Surgical Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including 24/7 surgery and interventional cardiology cover. A consultant-led ward round will occur daily.
New	<p>Consultant interventional paediatric cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either:</p> <ol style="list-style-type: none"> <li>the support of a competent second operator/interventionist must be obtained from within the network or another Specialist Children's Surgical Centre; or</li> <li>the patient must be referred to an alternative Specialist Children's Surgical Centre where a surgeon/interventionist has the appropriate skills.</li> </ol>		<p>Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either:</p> <ol style="list-style-type: none"> <li>the support of a competent second operator/interventionist must be obtained from within the network or another Specialist ACHD Surgical Centre; or</li> <li>the patient must be referred to an alternative Specialist ACHD Surgical Centre where a surgeon/interventionist has the appropriate skills.</li> </ol>
C5	Arrangements must be in place in each Specialist Children's Surgical Centre both for consultant interventional paediatric cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.		Arrangements must be in place in each Specialist ACHD Surgical Centre both for consultant interventional specialist ACHD cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.

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New E(3.1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.		Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.
New	Specialist Children's Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.		Specialist ACHD Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.
C1	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.
	Surgery		Surgery
SS C2 Edit	All paediatric cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in paediatric cardiac disease.		All adult congenital cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in adult congenital heart disease.

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	<p>Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. In centres with three surgeons, there will be the potential for commissioners to agree a 1 in 3 rota for a defined period while working towards a 1 in 4 rota.</p> <p>Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence.</p> <p>The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.</p>		<p>Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. In centres with three surgeons, there will be the potential for commissioners to agree a 1 in 3 rota for a defined period while working towards a 1 in 4 rota.</p> <p>Each Specialist ACHD Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence.</p> <p>The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.</p>
New B8	Congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).	B8	Congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).
	Cardiology		Cardiology
SS C2	All paediatric congenital cardiology must be carried out by specialist paediatric cardiologists.		All adult congenital cardiology must be carried out by specialist ACHD cardiologists.

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New	Each Specialist Children's Surgical Centre must be staffed by a minimum of one consultant paediatric cardiologist per half million population served by the network, working flexibly across the network.	New	Each Specialist ACHD Surgical Centre must be staffed by a minimum of 4 WTE consultant specialist ACHD cardiologists. Each ACHD Cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist. (See Appendix A for the British Congenital Cardiac Association definition of a Specialist ACHD Cardiologist.)
New Inc New B (10.1)	<p>Each Specialist Children's Surgical Centre must deliver 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover for the Specialist Children's Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4.</p> <p>The rota may deliver care for both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.</p>	B1	<p>Each Specialist ACHD Surgical Centre must deliver 24/7 elective and emergency care, including consultant specialist ACHD cardiology on-call cover for the Specialist ACHD Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4.</p> <p>The rota may deliver care for both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.</p>
New	<p>Consultant interventional cardiology cover must be provided by consultant interventional paediatric cardiologists providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. This could include interventional cardiologists based at a Specialist Children's Surgical Centre or a Specialist Children's Cardiology Centre.</p> <p>Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for interventionists only to undertake procedures for which they have the appropriate competence.</p> <p>The rota will deliver care for both children and adults. If this means that the interventionist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.</p>	B4	Each Specialist ACHD Surgical Centre must be staffed by at least two interventional specialist cardiologists (ACHD or paediatrics), who may be included in the number referred to in standard B1

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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.
New B5	Cardiologists performing therapeutic catheterisation in children and young people with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year; the Lead Cardiologist must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	B5	Cardiologists performing therapeutic catheterisation in patients with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year; the Lead Cardiologist must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.
New	Each Specialist Children's Surgical Centre must be staffed by a minimum of one electrophysiologist experienced in paediatric cardiac disease.	B6	Each Specialist ACHD Surgical Centre must be staffed by an electrophysiologist experienced in ACHD.
New B6	Paediatric electrophysiology procedures must only be undertaken by an electrophysiologist experienced in the management of paediatric arrhythmias.		ACHD electrophysiology procedures must only be undertaken by an electrophysiologist experienced in the management of arrhythmias with congenital heart disease.
New	<p>The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely:</p> <ul style="list-style-type: none"> <li>a. dedicated and appropriately trained cardiac physiologists;</li> <li>b. a radiographer;</li> <li>c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and</li> </ul>		<p>The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely:</p> <ul style="list-style-type: none"> <li>a. dedicated and appropriately trained cardiac physiologists;</li> <li>b. a radiographer;</li> <li>c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital</li> </ul>

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	d. a nurse with experience of paediatric cardiac catheterisation.		interventional catheterisation; and d. a nurse with experience of congenital cardiac catheterisation.
New B7	Each Specialist Children's Surgical Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases.  There will be shared protocols for cross-sectional imaging across the network.	B7	Each Specialist ACHD Surgical Centre must be staffed by a congenital cardiac imaging specialist who may be a cardiologist or a radiologist, expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases.  There will be shared protocols for cross-sectional imaging across the network.
SS C16b Edit	Each Specialist Children's Surgical Centre will have a continuous, immediate and documented availability of specialised cardiac paediatric anaesthetists with full training (in accordance with the Royal College of Anaesthetists' Guidelines and Paediatric Intensive Care Society Standards) and competence in managing paediatric cardiac cases including a specialist paediatric cardiac on-call rota which is separate from the intensive care rota.		Each Specialist ACHD Surgical Centre will have 24/7 anaesthetic support by consultants experienced in the management of ACHD patients.
New	At each Specialist Children's Surgical Centre a paediatric cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.		At each Specialist ACHD Surgical Centre an ACHD cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.
New	Each Specialist Children's Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity, who spends at least		Each Specialist ACHD Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity, who spends at least

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	half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.		half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.
	Intensive Care		Intensive Care
SS C11 Edit	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.		Intensive Care Unit (ICU) consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.
C66	Paediatric Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Children and young people must be cared for by children's nurses with appropriate training and competencies in paediatric cardiac critical care.		Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Patients must be cared for by nurses with appropriate training and competencies in adult congenital cardiac critical care.
	Nursing		Nursing
SS C3	Nursing care must be provided by a dedicated team of nursing staff trained in the care of children and young people who have received cardiac surgery.  The paediatric cardiac inpatient nursing team will be led by a senior children's nurse with specialist knowledge and experience in the care of children and young people and in paediatric cardiology and cardiac surgery.		Nursing care must be provided by a dedicated team of nursing staff trained in the care of young people and adults who have received cardiac surgery.  The ACHD inpatient nursing team will be led by a senior nurse with specialist knowledge, experience and understanding of congenital cardiology and cardiac surgery.
SS F4 Edit Inc	Each Congenital Heart Network must have a minimum of 7 WTE children's cardiac specialist nurses, employed by the Specialist Children's Surgical Centre, whose role will extend throughout the Children's Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided.	B9 edit (inc 15)	Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses, employed by the Specialist ACHD Surgical Centre, whose role will extend throughout the network ensuring that both an in-hospital and outreach service is provided. The precise number, above the

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	Paediatric		Adult
B12.4 And SS F3	<p>The precise number, above the minimum seven, and location of these nurses will depend on geography, population and the configuration of the network. Networks must demonstrate that the role of each Children's Cardiac Nurse Specialist meets the minimum requirements of the Royal College of Nursing role description.</p> <p>Each patient must have access to a Children's Cardiac Specialist Nurse and complex patients will have a named CCSN responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and parents/carers.</p>		<p>minimum five, and location of these nurses will depend on geography, population and the configuration of the network. See Appendix D for the role of the Specialist ACHD Nurse.</p> <p>Each patient must have a named Specialist ACHD Nurse responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and partner/family or carers.</p>
New	Each Congenital Heart Network will ensure that there is at least 1 WTE Fetal Cardiac Nurse Specialist, shared with the fetal network, to provide expert information and on-going support to parents who have a fetal diagnosis of congenital heart disease.		
SS D3	Each Congenital Heart Network must have a minimum of 1 WTE designated Children's Cardiac Transition Nurse, employed by the Specialist Children's Surgical Centre, (in addition to the network's seven children's cardiac specialist nurses) to coordinate the transition process across the network.		The ACHD nurse specialists will work closely with the Children's Cardiac Transition Nurse to coordinate the transfer process for each patient.
	Psychology		Psychology
New B(14.4)	<p>Each Specialist Children's Surgical Centre must employ a minimum of 1 WTE practitioner psychologist (with experience of working with CHD) per 400 children and young people undergoing cardiac surgery each year.</p> <p>In addition, each Congenital Heart Network must have 1 WTE practitioner psychologist, employed by the Specialist Children's Surgical Centre, per 5,000 children and young people with CHD.</p>		Practitioner psychologists employed by the Specialist Children's Surgical Centre will provide advice to adult patients as required.



## Section B: Staffing and skills

	Paediatric		Adult
	The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network.		
	<b>Administrative Staffing</b>		<b>Administrative Staffing</b>
New B12	Each Specialist Children's Surgical 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.	B12	Each Specialist ACHD Surgical 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 and partners/family or carers in a timely fashion.
SS G8 edit	Each Specialist Children's Surgical Centre must have a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1 WTE assistant, responsible for timely audit and database submissions in accordance with necessary timescales.	B13	Each Specialist ACHD Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.
	<b>Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)</b>		<b>Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)</b>
New B1.1	Each Specialist Children's Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.		Each Specialist ACHD Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.
New B(1.1)	Each Specialist Children's Surgical Centre will have an identified bereavement officer.		Each Specialist ACHD Surgical Centre will have an identified bereavement officer.
New	Each Specialist Children's Surgical Centre must have a minimum of 2 WTE dedicated play specialists.		

## Section C: Facilities

	Paediatric		Adult
	Specialist Children's Surgical Centre		Specialist ACHD Surgical Centre
New C2	<p>There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include:</p> <ul style="list-style-type: none"> <li>a) accommodation for at least two family members to stay;</li> <li>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);</li> <li>c) access to refreshments;</li> <li>d) facilities suitable for the storage and preparation of simple meals;</li> <li>e) ability of parents/carers to play and interact with their child (and their other children); and</li> <li>f) an on-site quiet room completely separate from general family facilities.</li> </ul> <p>Family accommodation should be provided without charge.</p>	C2	<p>There must be facilities in place to ensure easy and convenient access for partners/family/carers. Facilities and support include:</p> <ul style="list-style-type: none"> <li>a) accommodation for partners/family members to stay;</li> <li>b) access to refreshments;</li> <li>c) facilities suitable for the storage and preparation of simple meals; and</li> <li>d) an on-site quiet room completely separate from general facilities</li> </ul> <p>Family accommodation should be provided without charge.</p>
New C3	<p>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.</p>	C3	<p>All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, ideally within a dedicated ACHD ward space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.</p>
SS F9	<p>Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by dedicated play specialist teams.</p>		<p>Patients must have access to general resources including books, magazines and free wifi.</p>

## Section C: Facilities

	Paediatric		Adult
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.		
F8	There must be facilities, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.		There must be facilities, including access to maternity staff, that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breast feeding and the emotional health of the mother and baby.
SS F10	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/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.
New C5.2	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.
New 1.1	There must be dedicated room space in which practitioner psychologists, children's cardiac nurse specialists and social work staff conduct therapeutic work.		There must be dedicated room space in which practitioner psychologists, ACHD nurse specialists and social work staff conduct therapeutic work.
New	Specialist Children's Surgical Centres should ideally have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.		

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within <b>30 minutes</b> ).		Specialist ACHD Surgical Centres must be co-located on the same hospital site as the following specialties or facilities.
C12	Paediatric Cardiology.	D2a	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	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).  Level 2 High Dependency beds staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	D2c	Level 3 Intensive Care Unit, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care.  Level 2 High Dependency beds staffed by medical and nursing teams experienced in managing patients with ACHD.
C16	Specialised paediatric cardiac anaesthesia.	D2e	Specialised congenital cardiac anaesthesia.
C54	Post-operative extra corporeal life (Non nationally designated extracorporeal membrane oxygenation (ECMO)).		Post-operative extra corporeal life support (Non nationally designated extracorporeal membrane oxygenation (ECMO)).
		D2b	Adult cardiac surgery.
		D2d	Vascular services including surgery and Interventional Radiology.

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within <b>30 minutes</b> ).		Specialist ACHD Surgical Centres must be co-located on the same hospital site as the following specialties or facilities.
C1	<p>Each Specialist Children's Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise.</p> <p>The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, standard exercise testing, ambulatory BP and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transoesophageal and fetal echocardiography.</p> <p>There must be a 24/7 congenital echocardiography service with access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes, with facilities for advanced techniques including 3D and speckle tracking.</p> <p>Specialist Children's Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents; if not provided on site they must have access to these investigations.</p> <p>Specialist Children's Surgical Centres must have access to Isotope Imaging.</p> <p>Radiological and echocardiographic images must be stored digitally</p>		<p>Each Specialist ACHD Surgical 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, intraoperative, transoesophageal and fetal echocardiography.</p> <p>Specialist ACHD Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations.</p> <p>Specialist ACHD Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network.</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>Specialist ACHD Surgical Centres must offer invasive diagnostic investigation and treatment, including:</p>

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within <b>30 minutes</b> ).		Specialist ACHD Surgical Centres must be co-located on the same hospital site as the following specialties or facilities.
	<p>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 undertaking paediatric echocardiograms are kept up to date.</p> <p>Specialist Children's Surgical Centres must offer invasive diagnostic investigation and treatment, including:</p> <ul style="list-style-type: none"> <li>a. catheter intervention;</li> <li>b. electrophysiological intervention;</li> <li>c. pacemaker insertion and extraction; and</li> <li>d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment where clinically indicated).</li> </ul> <p>These services must be available 24/7.</p>		<ul style="list-style-type: none"> <li>a. catheter intervention;</li> <li>b. electrophysiological intervention;</li> <li>c. pacemaker insertion and extraction; and</li> <li>d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment where clinically indicated).</li> </ul> <p>These services must be available 24/7.</p>

## Section D: Interdependencies

	Paediatric		Adult
	<p>The following specialties or facilities should <b>ideally</b> be located on the same hospital site as Specialist Children's Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7.</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>		<p>The following specialties or facilities <b>should ideally</b> be located on the same hospital site as Specialist ACHD Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>
	Specialist Adult Congenital Heart Surgery and Intervention [This standard recognises shared staffing and out of hours cover]	D1	Specialist Paediatric Congenital Cardiac Surgery and Intervention. [This standard recognises shared staffing and out of hours cover]
C14	Paediatric Surgery.	D3f	General Surgery.
C20	Paediatric Nephrology/Renal Replacement Therapy.	D3p	Nephrology/Renal Replacement Therapy.
	Vascular Surgery.		
	Adult cardiology interventionist (to provide thrombolysis, clot removal and back-up for catheter lab emergencies including acute dissection).		
	Paediatric Gastroenterology (to provide emergency endoscopy).	D3d	Gastroenterology.
C27	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	D3o	Physiotherapy (service must be integrated with the ACHD team).

## Section D: Interdependencies

	Paediatric		Adult
	<p>The following specialties or facilities should <b>ideally</b> be located on the same hospital site as Specialist Children's Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7.</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>		<p>The following specialties or facilities <b>should ideally</b> be located on the same hospital site as Specialist ACHD Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>
		D3a	Clinical biochemistry.
		D3b	Clinical haematology.
		D3c	Ear nose and throat.
		D3e	General medicine and provision for diabetes, endocrinology and rheumatology services.
		D3g	Gynaecology.
		D3h	Learning disability team.
		D3i	Level 3 neonatal unit (NICU).
		D3j	Microbiology and infectious diseases.
		D3k	Neurology.



## Section D: Interdependencies

	Paediatric		Adult
	<p>The following specialties or facilities should <b>ideally</b> be located on the same hospital site as Specialist Children's Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7.</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>		<p>The following specialties or facilities <b>should ideally</b> be located on the same hospital site as Specialist ACHD Surgical Centres.</p> <p>They must function as part of the extended multidisciplinary team.</p> <p>Consultants from the following services <b>must</b> be able to provide emergency bedside care (call to bedside within <b>30 minutes</b>) 24/7</p> <p>Specialist Surgical Centres (SSC) must ensure that facilities are available to allow emergency intervention by these specialties at the SSC if clinically indicated (ie. without transfer).</p>
		D3l	Neurosurgery.
		D3m	Obstetric unit with maternal fetal medicine specialist(s).
		D3n	Orthopaedics.
		D3q	Respiratory medicine.
		D3r	Urology.
S&S C56 D6	Multidisciplinary paediatric acute pain management service.		Acute pain management service.
C33	Bereavement Support, including nurses trained in bereavement support.		Bereavement Support, including nurses trained in bereavement support.

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities <b>should ideally</b> be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within <b>30 minutes</b> ) and a visit or transfer of care within <b>four hours</b> if needed. The services must be experienced in caring for patients with congenital heart disease.		
C17	Paediatric Neurology.		
C18	Paediatric Respiratory Medicine.		
C19	Neonatology.		
C21	Clinical Haematology.		
C29	Infection control team experienced in the needs of paediatric cardiac surgery patients.		
C40	Paediatric Neurosurgery.		
C42	Child Psychiatry (with dedicated sessions and 24/7 on call).		
C44	Clinical biochemistry (including toxicology).		
C46	Pharmacy (with dedicated sessions for CHD and 24/7 on-call for urgent supply and advice).		
	Paediatric Endocrinology.		
	Paediatric Orthopaedics.		
	Plastic surgery.		

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities <b>should ideally</b> be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within <b>30 minutes</b> ) and a visit or transfer of care within <b>four hours</b> if needed. The services must be experienced in caring for patients with congenital heart disease.		
	Microbiology and Infectious diseases.		
	Safeguarding team/social work (as per national standards).		

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be able to provide <b>advice and consultation at least by the next working day</b> . The services must be experienced in caring for patients with congenital heart disease.		The following specialties or facilities must be able to provide <b>advice and consultation at least by the following working day</b> . The services must be experienced in patients with congenital heart disease.
C13	Paediatric Ear, Nose and Throat (seven day working week).		
C24	General Paediatrics (seven day working week).		
C34	Breast Feeding Support (seven day working week).		
C38	Obstetrics and Midwifery (seven day working week).		
C26	Psychology, with dedicated sessions for CHD.		Psychology.
C28	Paediatric Dietician with dedicated sessions for CHD	D4f	Dietician.
C35	Social Work Services.		
C41	Clinical Genetics.	D4b	Clinical Genetics.
C43	Paediatric Dentistry.	D4d	Dentistry.
	Paediatric Immunology.	D4c	Clinical Immunology.
	Dermatology.	D4e	Dermatology.
	Sexual health.	D4i	Sexual health.

## Section D: Interdependencies

	Paediatric		Adult
	The following specialties or facilities must be able to provide <b>advice and consultation at least by the next working day</b> . The services must be experienced in caring for patients with congenital heart disease.		The following specialties or facilities must be able to provide <b>advice and consultation at least by the following working day</b> . The services must be experienced in patients with congenital heart disease.
		D4a	Cardiac rehabilitation.
		D4g	Occupational therapy.
		D4h	Psychiatry.
	Feto-maternal medicine.		
	Paediatric Rheumatology.		
	Gynaecology.		
	Paediatric Urology.		
	Speech and language, with dedicated sessions for CHD, including swallow assessment with access to video fluoroscopy.		
	Chronic pain services.		Chronic pain services.

## Section E: Training and Education

	Paediatric		Adult
	Specialist Children's Surgical Centre		Specialist ACHD Surgical Centre
New E(1.1)	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 level 1 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 level two to four training.		All members of the cardiac and ICU medical and nursing team will complete mandatory level 1 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 level two to four training.
New E2	Each Specialist Children's Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology and paediatric cardiac surgery (according to the latest Joint Royal Colleges of Physicians' Training Board curriculum) and to the training of Paediatricians with expertise in cardiology.	E2	Each Specialist ACHD Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level cardiology SpRs in ACHD and heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.
New E3	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 children and young people with congenital heart problems.  Specialist Children's Surgical Centres must provide resources sufficient to support these educational needs across the network.		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.  Specialist ACHD Surgical Centres must provide resources sufficient to support these educational needs across the network.

## Section E: Training and Education

	Paediatric		Adult
New E1	<p>Specialist Children's Surgical Centres must provide Cardiac Clinical Nurse Educators sufficient 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>	E1	<p>Each Specialist ACHD Surgical Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and 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
SS G1	Each Specialist Children's Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.		Each Specialist ACHD Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.
New F1	<p>All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:</p> <ul style="list-style-type: none"> <li>a. clinical audit;</li> <li>b. regular network multidisciplinary team meetings, to discuss patient care pathways, guidelines and protocols;</li> <li>c. regular network meetings, whose role extends to reflecting on mortality, morbidity and adverse incidents; and</li> <li>d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.</li> </ul>	F1	<p>All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:</p> <ul style="list-style-type: none"> <li>a. clinical audit;</li> <li>b. regular network multidisciplinary team meetings to discuss patient care pathways, guidelines and protocols;</li> <li>c. regular network meetings whose role extends to reflecting on mortality, morbidity and adverse incidents; and</li> <li>d. regular audit days that will include discussion of adverse incidents and resultant action plans from all units.</li> </ul>
SS G5	Each Specialist Children's Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Surgical Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.	F2	Each Specialist ACHD Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Surgical Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.
SS G6	Each Specialist Children's Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). Audit of clinical practice should be considered where recognised standards exist or improvements can	F3	Each Specialist ACHD Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). Audit of clinical practice should be considered where recognised



## Section F: Organisation, governance and audit

	Paediatric		Adult
	<p>be made.</p> <p>At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.</p>		<p>standards exist or improvements can be made.</p> <p>At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.</p>
New F(3.1)	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 F(3.2)	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.
SS G9	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.		Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.
New F4	Each Specialist Children's Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	F4	Each Specialist ACHD Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.
New F(4.1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.		Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.

**Section F: Organisation, governance and audit**

	<b>Paediatric</b>		<b>Adult</b>
G10	Each Specialist Children's Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	F5	Each Specialist ACHD Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Surgical 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.
New F6	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner.  Cases 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.	F6	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner.  Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.
SS C60	Admission for planned surgery will be booked for a specific date.		Admission for planned surgery will be booked for a specific date.
SS C62	All children/young people who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	F7	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.
New F(7.1)	Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be informed of any relevant cancellations and the new date offered.		Specialist ACHD Centres and Local ACHD Centres must be informed of any relevant cancellations and the new date offered.
NEW	Same-day cancellations must be recorded and discussed at the multidisciplinary team meeting.		Same-day cancellations must be recorded and discussed at the multidisciplinary team meeting.

**Section F: Organisation, governance and audit**

	<b>Paediatric</b>		<b>Adult</b>
New F8	<p>If a child/young person needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the child/young person or parents/carers wish(es).</p> <p>Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be involved in any relevant discussions.</p>	F8	<p>If a patient needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the patient wishes.</p> <p>Specialist ACHD Centres and Local ACHD Centres must be involved in any relevant discussions.</p>
SS C64	<p>When a Specialist Children's Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre.</p>	B10	<p>When a Specialist ACHD Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist ACHD Surgical Centre.</p>
C67	<p>A children's cardiac nurse specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.</p>		<p>An ACHD nurse specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.</p>
New	<p>Each Specialist Children's Surgical Centre must implement a pain control policy that includes advice on pain management at home.</p>		<p>Each Specialist ACHD Surgical Centre must implement a pain control policy that includes advice on pain management at home.</p>
S&S C58 C59	<p>Advice must be taken from the acute pain team for all children/young people who have uncontrolled severe pain. Particular attention must be given to children/young people who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.</p>		<p>Advice must be taken from the acute pain team for all patients who have uncontrolled severe pain. Particular attention must be given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.</p>
D7	<p>Each Specialist Children's Surgical Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent</p>	D7	<p>Each Specialist ACHD Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of</p>

## Section F: Organisation, governance and audit

	Paediatric		Adult
	patients with heart disease and to their families/carers.		teenagers, young people and older people with congenital heart disease.
D7.2	<p>Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment:</p> <ul style="list-style-type: none"> <li>a. by the next working day for inpatients in acute distress;</li> <li>b. within 10 working days for adjustment, adherence or decision making difficulties that interfere with medical care; or</li> <li>c. within six weeks for all other referrals.</li> </ul>		<p>Each Specialist ACHD Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment:</p> <ul style="list-style-type: none"> <li>a. by the next working day for inpatients in acute distress;</li> <li>b. within 10 working days for adjustment, adherence or decision making difficulties that interfere with medical care; or</li> <li>c. within six weeks for all other referrals.</li> </ul>
New B(14.3)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.		Each Specialist ACHD Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient's home or other agencies.

## Section G: Research

	Paediatric		Adult
SS G11	Each Specialist Children's Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every five years.	A3	Each Specialist ACHD Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every five years.
SS G12 Edit	Each Congenital Heart Network must have, and regularly update a research strategy and programme that documents current and planned research activity in the field of paediatric cardiac disease and the resource needed to support the activity and objectives for development.. This must include a commitment to working in partnership with other Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of children and young people with CHD and their families.	G1	Each Congenital Heart Network must have, and regularly update a research strategy and programme that documents current and planned research activity in the field of ACHD and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist ACHD Surgical Centres and Specialist ACHD Centres in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.
SS G13 Edit	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	G2	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.

## Section H: Communication with patients

	Paediatric		Adult
SS E1	Specialist Children's Surgical Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to participate in decision making at every stage in their child's care.		Specialist Surgical Centres must demonstrate that arrangements are in place that allow patients to 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.

## Section H: Communication with patients

	Paediatric		Adult
New H2 New H16	<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, parents' and carers' understanding must be considered.</p> <p>Information provided should include any aspect of life that is relevant to their congenital heart condition, including:</p> <ul style="list-style-type: none"> <li>• exercise and sports participation;</li> <li>• sex, pregnancy and contraception;</li> <li>• dental care and endocarditis prevention</li> <li>• smoking, alcohol and drugs</li> <li>• school and careers;</li> <li>• travel;</li> <li>• welfare benefits;</li> <li>• social services; and</li> <li>• community services.</li> </ul>	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> <ul style="list-style-type: none"> <li>• exercise and sports participation;</li> <li>• sex, contraception, pregnancy;</li> <li>• dental care and endocarditis prevention</li> <li>• smoking, alcohol and drugs</li> <li>• careers;</li> <li>• travel;</li> <li>• welfare benefits;</li> <li>• social services; and</li> <li>• community services.</li> </ul>
New	When referring patients for further investigation, surgery or cardiological interventional patient care plans, will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that parents, carers, children and young		When referring patients for further investigation, surgery or cardiological intervention patient care plans, will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that patients are advised of any appropriate

## Section H: Communication with patients

	Paediatric		Adult
	people are advised of any appropriate choices available as well as the reasons for any recommendations.		choices available as well as the reasons for any recommendations
New Includes part of SS E14	<p>Sufficient information must be provided to allow informed decisions to be made, including supporting parents, carers and young people in interpreting publicly available data that support choice. The following should also be described:</p> <ul style="list-style-type: none"> <li>a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities;</li> <li>b. accessibility of alternative units;</li> <li>c. patient facilities offered by alternative units; and</li> <li>d. consideration of the closest unit to the patient's home.</li> </ul>		<p>Sufficient information must be provided to allow the patient to make informed decisions, including supporting patients, partners, family or carers in interpreting publicly available data that support choice. The following should also be described:</p> <ul style="list-style-type: none"> <li>a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities;</li> <li>b. accessibility of alternative units;</li> <li>c. patient facilities offered by alternative units; and</li> <li>d. consideration of the closest unit to the patient's home.</li> </ul>
New H12	Specialist Children's Surgical Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another Specialist Children's Surgical Centre	H12	Specialist Surgical Centres must demonstrate that patients, partners, family or carers are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.
SS E6 Edit	<p>Information must be made available to parents and carers in a wide range of formats and on more than one occasion.</p> <p>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 interpreted or transcribed as necessary.</p>	H15	<p>Comprehensive information must be made available in plain English, in all clinical areas, to patients, partners, family or carers in a wide range of formats and on more than one occasion.</p> <p>It must take into account special needs as appropriate. When given verbally, information must be interpreted or transcribed as necessary.</p>



## Section H: Communication with patients

	Paediatric		Adult
SS E13 Edit	Specialist Children's Surgical Centres must demonstrate that arrangements are in place for parents and carers, children and young people to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	H3	Specialist Surgical 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	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.	H18	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.
New H4	<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 Surgical Centres must make this feedback openly available, to children, young people, parents / carers and the general public, together with outcome of relevant local and national audits.</p> <p>Specialist Children's Surgical 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 Surgical Centres must demonstrate on-going structured liaison with patients and patient groups, including evidence of how feedback is formally considered.</p>	H4	<p>Patients, partners, family or carers must be encouraged to provide feedback on the quality of care and their experience of the service.</p> <p>Specialist Surgical 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 Surgical 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 Surgical Centres must demonstrate on-going structured liaison with patients and patient groups, including evidence of how feedback is formally considered.</p>

## Section H: Communication with patients

	Paediatric		Adult
New H5	<p>Each Specialist Children's Surgical 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 Surgical 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>
New H6	<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 person throughout their care. Children 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/carer 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>
SS E3 Edit	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain diagnosis and management of the child's condition, and to provide relevant literature.	H7	An ACHD Specialist Nurse must be available at all outpatient clinics to be available to help explain the diagnosis and management of the patient's condition and to provide literature
New H(7.1)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child's condition, and providing psychosocial support to promote parental (and child'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.

## Section H: Communication with patients

	Paediatric		Adult
New H8	<p>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.</p> <p>Support for people with learning disabilities must be provided from an appropriate specialist or agency.</p>	H8	<p>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.</p> <p>Support for people with learning disabilities must be provided from an appropriate specialist or agency.</p>
New H9	<p>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.</p>	H9	<p>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.</p>
New C6	<p>There must be access (for patients and family members) to support services including faith support and interpreters.</p>		<p>There must be access for patients to support services including faith support and interpreters.</p>
New H10	<p>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.</p>	H10	<p>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.</p>
SS E10 Edit	<p>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</p>	H11	<p>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. 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.</p>

## Section H: Communication with patients

	Paediatric		Adult
	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.
SS E7	Where surgery or intervention is planned, the child and their parents or carers must have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team, including the Children's Congenital Specialist Nurse, 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, patients and carers will have the opportunity to visit the Specialist Surgical Centre well in advance of admission to meet the team, including the ACHD Specialist Nurse that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.
New	Children/young people and their parents must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Preliminary consent may be taken by any member of the medical team, at a pre admission clinic or visit. Final consent will be taken by the operating consultant.		Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Preliminary consent may be taken by any member of the medical team, at a pre admission clinic or visit. Final consent will be taken by the operating consultant

## Section H: Communication with patients

	Paediatric		Adult
SS E9	A Children's Cardiac Nurse Specialist must be available to support parents and children/young people throughout the consent process. When considering treatment options, parents, carers (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	H14	An ACHD Specialist Nurse must be available to support patients and 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.
SS E12	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	H17	Patients and carers must be given details of available local and national support groups at the earliest opportunity.
New H23	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.
New H24	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	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		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

## Section H: Communication with patients

	Paediatric		Adult
	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.		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 I: Transition

	Paediatric		Adult
New SS D1	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.  'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.		Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.  'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.
SS D2	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.		
SS D7	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.		All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.
New I2	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.  Transfer will normally be completed by age 18.	I2	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.  Transfer will normally be completed by age 18.
New I3	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports	I3	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future

## Section I: Transition

	Paediatric		Adult
	must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long term follow up.		management in a clearly specified setting, unless the patient's care plan indicates that they do not require long term follow up.
New 14	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	14	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.
New 15.1	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.		
New 16	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	16	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.
New 17	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice.  Their attention must be drawn to sources of information and support groups.	17	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice.  Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition,



## Section I: Transition

	Paediatric		Adult
			contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.
New I8	The particular needs of young people with learning disabilities and their parents/carers must be considered.	I8	The particular needs of young people with learning disabilities and their parents/carers must be considered.
SS D6	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.		Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.

## Section J: Pregnancy and Contraception

	Paediatric		Adult
	Contraception and Advice		Contraception and Advice
J5	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	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 expertise in pregnancy in congenital heart disease.
J2 and J3	<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. 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	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.

## Section J: Pregnancy and Contraception

	Paediatric		Adult
J8 (J5)	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.	J7	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.
	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.
	<b>Pregnancy and Planning Pregnancy</b>		<b>Pregnancy and Planning Pregnancy</b>
J6	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 Surgical 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.

## Section J: Pregnancy and Contraception

	Paediatric		Adult
		J8	<p>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.</p> <p>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.</p>
		J9	<p>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.</p>
		J10	<p>Women with moderate or high risk conditions, who are not at risk of requiring such emergency surgery or intervention during pregnancy, may be managed at an obstetric unit outside the specialist surgical centre with specific network agreement and advice from the specialist centre.</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>

## Section J: Pregnancy and Contraception

	Paediatric		Adult
		J11	Each Specialist ACHD Surgical 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.
		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	Obstetric services caring for patients with congenital heart disease must offer fetal cardiac diagnosis and management protocols as an integral part of the service offered to patients with congenital heart disease.
New K1	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 B3 Edit	Each Specialist Children's Surgical Centre will agree and establish protocols with obstetric, fetomaternal medicine units, tertiary neonatal units, local neonatal units and paediatrics teams in their Congenital Heart Network for the care and treatment of pregnant women whose fetus has been diagnosed with a major heart condition. The protocols must meet the relevant NHS Fetal Anomaly Screening Programme Standards.
SS B4 Edit	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.
New K2	<p>Congenital Heart Networks must establish protocols (in line with British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards) to ensure that all women with a suspected or confirmed fetal cardiac anomaly are seen by:</p> <ol style="list-style-type: none"> <li>1. an obstetric ultrasound specialist within three working days of the referral being made; and</li> <li>2. a fetal cardiology specialist within five working days of referral and preferably within two working days if possible.</li> </ol> <p>If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist.</p>
SS B6 Edit	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.

## Section K – Fetal diagnosis

	Paediatric
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 H(24.1)	<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>
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.
SS B8	At diagnosis, a plan must be agreed between 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 Edit	<p>In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents.</p> <p>Appropriate contact must be maintained with the local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.</p>

## Section K – Fetal diagnosis

	Paediatric
SS B10 Edit	<p>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.</p> <p>A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.</p>



## Section L: Palliative Care and Bereavement

	Paediatric		Adult
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.		Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.
D5	Each Specialist Children's Surgical Centre and Specialist Children's Cardiology Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.  Each Local Children's Cardiology Centre must have a palliative care service or have access to the service at the Specialist Children's Surgical or Specialist Children's Cardiology Centre.	D5	Each Specialist ACHD Surgical Centre and 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 partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.  Each Local ACHD Centre must have a palliative care service or have access to the service at the Specialist ACHD Surgical or Specialist ACHD Centre.
D5.1	Clinicians should use nationally approved paediatric palliative medicine pathways to plan palliative care from the point of diagnosis.		Clinicians should use nationally approved palliative medicine pathways to plan palliative care from the point of diagnosis.
New H27	When a child or young person is entering a palliative or end-of-life pathway, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.		When a patient is entering a palliative or end-of-life pathway, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.
	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.		The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.

## Section L: Palliative Care and Bereavement

	Paediatric		Adult
	<p>An individualised end-of-life pathway, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family).</p> <p>The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.</p>		<p>An individualised end-of-life pathway, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family).</p> <p>The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.</p>
New H28	The lead doctor, with the named nurse, will ensure that the agreed end-of-life pathway is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.		The lead doctor, with the named nurse, will ensure that the agreed end-of-life pathway is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.
New H25	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.		Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.
New H29	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.		The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.
New H31	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.		For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.

## Section L: Palliative Care and Bereavement

	Paediatric		Adult
	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.		The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.
New H35	All members of the clinical team must be familiar with the bereavement services available in their hospital.		All members of the clinical team must be familiar with the bereavement services available in their hospital.
H37	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.		Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.
	<b>Discharge and out-of-hospital care</b>		<b>Discharge and out-of-hospital care</b>
New H30	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.		Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.
	The lead doctor, with the named nurse, will ensure that the end-of-life pathway and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community paediatric nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care pathways must be provided for all members of the team.  All equipment needed in the home must be available prior to discharge.		The lead doctor, with the named nurse, will ensure that the end-of-life pathway and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care pathways must be provided for all members of the team.  All equipment needed in the home must be available prior to discharge.

## Section L: Palliative Care and Bereavement

	Paediatric		Adult
New H34	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.		Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.
	<b>Management of a Death (whether expected or unexpected)</b>		<b>Management of a Death (whether expected or unexpected)</b>
New H32	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.		The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.
H36	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.		If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.
H38	Young people, parents and carers will be offered an opportunity to discuss the donation of organs with the <i>Donor</i> team.		Patients will be offered an opportunity to discuss the donation of organs with the <i>Donor</i> team.
H39	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.		The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.

**Section L: Palliative Care and Bereavement**

	Paediatric		Adult
C40	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.		Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.
C41	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.		When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death and the organisation of a funeral will be offered.
New	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.		Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.
	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.		Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.
C44	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.		Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.

## Section L: Palliative Care and Bereavement

	Paediatric		Adult
	Ongoing support after the death of a child/young person		Ongoing support after the death of a patient
C45	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.		Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.
C46	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This may be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment pathway, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.		Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This may be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment pathway, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.
	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.		When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.
C47	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.		If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.

## Section M: Dental

	Paediatric	Adult
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 (CHD) diagnosis by the cardiologist or nurse.	
New M3	All children and young people with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	All patients with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.
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.	
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 Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist led dental treatment under general anaesthetic for children and young people with congenital heart disease.	Specialist ACHD Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist led dental treatment under general anaesthetic for patients with congenital heart disease.