NHS England

Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres

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Contents

Contents 4
1 Document summary 5
2 Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres 6

1 Document summary

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

There are eight documents:

- Adult Congenital Heart Disease (ACHD) Specification
- Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres
- Adult Congenital Heart Disease Standards: Level 2 – Specialist ACHD Centres
- Adult Congenital Heart Disease Standards: Level 3 – Local ACHD Centres
- Paediatric Congenital Heart Disease Specification
- Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children's Surgical Centres
- Paediatric Congenital Heart Disease Standards: Level 2 – Specialist Children's Cardiology Centres
- Paediatric Congenital Heart Disease Standards: Level 3 – Local Children's Cardiology Centres

To encompass the whole patient pathway each set of standards is subdivided into categories A to M outlined below:

A – The Network Approach
B – Staffing and skills
C – Facilities
D – Interdependencies
E – Training and education
F – Organisation, governance and audit
G – Research
H – Communication with patients
I – Transition
J – Pregnancy and contraception
K – Fetal diagnosis
L – Palliative care and bereavement
M – Dental

2 Adult Congenital Heart Disease Standards: Level 1 – Specialist ACHD Surgical Centres

Standard	Adult	Implementation timeline
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network's host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network. Each network should develop a business plan.	Within 6 months
A2(L1)	Each Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of patients with congenital heart disease throughout their life. The model of care will ensure that all congenital cardiac care, including investigation, cardiology and surgery, is carried out only by congenital cardiac specialists (including cardiologists with an interest (BCCA definition)). [See Appendix A for definition of adult CHD surgery]. 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.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity and obstetric services, children's services, transition from paediatric congenital cardiac services, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist ACHD Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for adult cardiac, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.	Within 6 months

Standard	Adult	Implementation timeline
A4(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, specialist ACHD cardiologists and cardiologists with an interest will work across the network, including at the Specialist ACHD Surgical Centre, the Specialist ACHD Centres and Local ACHD Centres, according to local circumstances; and f. address how Specialist ACHD Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	Immediate
A5(L1)	There must be an appropriate mechanism for arranging transfer and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	Immediate
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of patients	Immediate

Standard	Adult	Implementation timeline
	requiring interventional treatment.	
A7(L1)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Within 6 months
A8(L1)	Congenital Heart Networks will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years
Cardiological Interventions		
A9(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all ACHD surgery, including atrial septal defect closure, to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]; b. require all therapeutic interventions, except atrial septal defect closure, and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]; and c. 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.	Within 6 months

Standard	Adult	Implementation timeline
Non-Cardiac Surgery		
A10(L1)	Each Congenital Heart Network will agree clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, the most appropriate location for that surgery and advice to non-ACHD cardiologists across the Congenital Heart Network.	Immediate
External Relationships		
A11(L1)	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.	Immediate
A12(L1)	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.	Immediate
A13(L1)	Each Congenital Heart Network must contain at least one Specialist ACHD Surgical Centre in a formal network relationship with the Specialist Children's Surgical service, Specialist ACHD Centres and Local ACHD Centres, evidenced by agreed joint referral and care protocols. Each Specialist ACHD Surgical Centre must have a formal network relationship with the following, evidenced by agreed joint referral and care protocols: a. the cardiothoracic transplant centres including one staffed by transplant surgeons with a congenital practice; b. the national Pulmonary Hypertension Service; and c. a cardiac pathologist with expertise in congenital cardiac abnormalities.	Immediate

Standard	Adult	Implementation timeline
A14(L1)	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 referring specialist is responsible for explaining to the patient the transplant pathway and the risks and benefits of referral and any alternative pathways, to inform patient choice. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	Immediate
A15(L1)	Each Specialist ACHD Surgical Centre must have a close relationship with all community adult services in their network, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
Telemedicine and IT		
A16(L1)	Each Congenital Heart Network will have telemedicine facilities as required to link designated hospitals in the network (Specialist ACHD Surgical Centres, Specialist Cardiology Centres and Local Cardiology Centres, according to local circumstances) and with other Congenital Heart Networks. The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the	Within 3 years

Standard	Adult	Implementation timeline
	various ACHD services; and e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate	
A17(L1)	Each congenital heart network must make arrangements for CHD clinicians (including cardiologists with an interest in congenital) within the network to be able to access patient records and imaging systems in all Specialist Surgical Centres and Specialist Cardiology Centres in the network.	Immediate
Multidisciplinary Team (MDT)		
A18(L1)	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 network. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will be pathway driven, and adjusted according to the needs of different aspects of the service (for example: assessment, post-operative care, clinic, pathological and audit meetings). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, an ACHD cardiologist and an intensivist.	Immediate

Standard	Adult	Implementation timeline
A21(L1)	Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months. Network patient representatives will be invited to participate in these meetings.	Immediate
Network Leadership		
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	Within 6 months
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months
A24(L1)	Each Congenital Heart Network will have a formally appointed Network Manager responsible for the management of the network, and the conduct of network business.	Within 6 months

Level 1 – Specialist ACHD Surgical Centres. Section B - Staffing and skills

Standard	Adult	Implementation timetable
B1(L1)	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 ward round will occur daily.	Within 6 months
B2(L1)	Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist ACHD Surgical Centre; or b. the patient must be referred to an alternative Specialist ACHD Surgical Centre where a surgeon/interventionist has the appropriate skills. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT.	Immediate
B3(L1)	Arrangements must be in place in each Specialist ACHD Surgical Centre both for consultant interventional specialist ACHD cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	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.	Immediate
B5(L1)	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.	Immediate
B6(L1)	Each Specialist ACHD Surgical Centre will have a formally nominated ACHD lead with	Within 6 months

Standard	Adult	Implementation timetable
	responsibility for the service at the Specialist ACHD Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	
B7(L1)	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.	Immediate
Surgery		
B8(L1)	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. [See Appendix A for the definition of what qualifies as ACHD surgery.]	Immediate
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist 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. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: 1 in 3 immediate; 1 in 4 within 5 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).	Teams of at least three: immediate Teams of at least four: within 5 years 125 operations:

Standard	Adult	Implementation timetable
		immediate
B11(L1)	Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland.	Immediate
Cardiology		
B12(L1)	All adult congenital cardiology must be carried out by specialist ACHD cardiologists (including cardiologists with a special interest in congenital (BCCA definition)).	Immediate
B13(L1)	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.	Within 3 years
B14(L1)	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. The on-call rota must ensure cover by appropriately trained specialists in care of both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B15(L1)	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 B13(L1).	Within 1 year
B16(L1)	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	Within 6 months

Standard	Adult	Implementation timetable
	develop their specialist skills.	
B17(L1)	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 Interventional Cardiologist in a team must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B18(L1)	Each Specialist ACHD Surgical Centre must be staffed by a minimum of one expert electrophysiologist experienced in ACHD. There must be appropriate arrangements for cover by a competent person.	Immediate
B19(L1)	ACHD electrophysiology procedures must only be undertaken by an expert electrophysiologist experienced in the management of arrhythmias with congenital heart disease.	Immediate
B20(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and d. a nurse with experience of congenital cardiac catheterisation.	Immediate
B21(L1)	Each Specialist Surgical Centre must be staffed by a congenital cardiac imaging specialist who may be a cardiologist or a radiologist, expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases.	Immediate

Standard	Adult	Implementation timetable
	There will be shared protocols for cross-sectional imaging across the network.	
B22(L1)	Each Specialist ACHD Surgical Centre will have 24/7 anaesthetic support by consultants experienced in the management of ACHD patients.	Immediate
B23(L1)	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.	Within 6 months
B24(L1)	Each Specialist Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	Within 1 year
Intensive Care		
B25(L1)	Intensive Care Unit (ICU) consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
B26(L1)	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.	Immediate

Level 1 – Specialist ACHD Surgical Centres. Section B - Staffing and skills

Standard	Adult	Implementation timetable
Nursing		
B27(L1)	Each Specialist ACHD Surgical Centre must have a formally nominated lead ACHD nurse with responsibility for the service at the Specialist ACHD Surgical Centre, providing professional and clinical leadership and support to the team of ACHD specialist nurses across the network.	Within 6 months
B28(L1)	Nursing care must be provided by a team of nursing staff trained in the care of young people and adults who have received cardiac surgery. The ACHD inpatient nursing team will be led by a senior nurse with specialist knowledge and experience of congenital cardiology and cardiac surgery.	Immediate
B29(L1)	Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum five, and location of these nurses will depend on geography, population and the configuration of the network. 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.	Within 3 years
B30(L1)	The ACHD nurse specialists will work closely with the Children's Cardiac Transition Nurse to coordinate the transfer process for each patient.	Within 6 months
Psychology		
B31(L1)	Each Specialist ACHD Surgical Centre must employ a minimum of 1 WTE practitioner psychologist (with experience of working with CHD). In addition, 1 WTE practitioner psychologist must be employed for each network.	Within 1 year

Standard	Adult	Implementation timetable
	The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network. The lead psychologist should provide training and mentorship to the other psychologists in the network.	
Administrative Staffing		
B32(L1)	Each Specialist Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients and partners/family or carers in a timely fashion.	Immediate
B33(L1)	Each Specialist Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.	Within 6 months
Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)		
B34(L1)	Each Specialist ACHD Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.	Immediate
B35(L1)	Each Specialist Surgical Centre will have an identified bereavement officer.	Immediate

Standard	Adult	Implementation timeline
C1(L1)	There must be facilities in place to ensure easy and convenient access for partners/family/carers. Facilities and support include: a. accommodation for partners/family members to stay; b. the ability for at least one parent/carer to stay with any patient with learning disabilities in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c. access to refreshments; d. facilities suitable for the storage and preparation of simple meals; and e. an on-site quiet room completely separate from general facilities Family accommodation should be provided without charge.	Within 6 months
C2(L1)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, within a dedicated ACHD ward space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability. Each Specialist Surgical Centre must provide a 24/7 emergency telephone advice service for patients with urgent concerns about deteriorating health.	Immediate
C3(L1)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C4(L1)	There must be facilities, including access to maternity staff, that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate

Level 1 – Specialist ACHD Surgical Centres. Section C - Facilities

Standard	Adult	Implementation timeline
C5(L1)	Patients and their 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.	Immediate
C6(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C7(L1)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C8(L1)	Specialist ACHD Surgical Centres must have local arrangements for transferring patients from airfields and helipads.	Immediate
C9(L1)	All patients should have access to cardiac rehabilitation facilities.	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities **must be located on the same hospital site** as **Specialist ACHD Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).		
D1(L1)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L1)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L1)	Intensive Care Unit: Level 3, capable of multi-organ failure support. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L1)	Specialised congenital cardiac anaesthesia.	Immediate
D5(L1)	Perioperative extracorporeal life support with or without ventricular assist programme. (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Adult cardiac surgery.	Immediate
D7(L1)	Vascular services including surgery and interventional radiology.	Immediate
D8(L1)	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. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography.	Within 6 months

Standard	Adult	Implementation timescale
	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. 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. Specialist ACHD Surgical Centres must offer invasive diagnostic investigation and treatment, including: a. catheter intervention; b. electrophysiological intervention; c. implantable cardioverter defibrillator (ICD) and pacemaker insertion and extraction (including Cardiac Resynchronization Therapy - CRT); and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment (where clinically indicated). These services must be available 24/7.	

Standard	Adult	Implementation timescale
The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).		
D9(L1)	Specialist Paediatric Congenital Cardiac Surgery and Intervention. [This standard recognises shared staffing and out-of-hours cover.]	Immediate
D10(L1)	General Surgery.	Immediate
D11(L1)	Nephrology/Renal Replacement Therapy.	Immediate
D12(L1)	Gastroenterology.	Immediate
D13(L1)	Physiotherapy (service must be integrated with the ACHD team).	Immediate
D14(L1)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Immediate
D15(L1)	Gynaecology.	Immediate
D16(L1)	Neonatal unit (NICU): Level 3.	Immediate
D17(L1)	Microbiology and infectious diseases.	Immediate
D18(L1)	Obstetric unit with maternal fetal medicine specialist(s).	Immediate
D19(L1)	Respiratory medicine.	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).		
D20(L1)	Urology.	Immediate
D21(L1)	Pain management service.	Immediate
D22(L1)	Bereavement Support, including nurses trained in bereavement support.	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.		
D23(L1)	Clinical Haematology.	Immediate
D24(L1)	Clinical biochemistry.	Immediate
D25(L1)	Orthopaedics.	Immediate
D26(L1)	Acute stroke services.	Immediate
D27(L1)	Neurology.	Immediate
D28(L1)	Neurosurgery.	Immediate
D29(L1)	Psychiatry (with dedicated sessions and 24/7 on call).	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in patients with congenital heart disease.		
D30(L1)	Ear, Nose and Throat.	Immediate
D31(L1)	Psychology.	Immediate
D32(L1)	Dietician.	Immediate
D33(L1)	Clinical Genetics.	Immediate
D34(L1)	Dentistry.	Immediate
D35(L1)	Clinical Immunology.	Immediate
D36(L1)	Dermatology.	Immediate
D37(L1)	Sexual health.	Immediate
D38(L1)	Cardiac rehabilitation.	Immediate
D39(L1)	Occupational therapy.	Immediate
D40(L1)	Social work services.	Immediate

Standard	Adult	Implementation timescale
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, working with adults with learning disability, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and ICU medical and nursing team will complete mandatory basic training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L1)	Nurses working within Specialist ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist ACHD Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in ACHD cardiology, ACHD surgery and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems. Specialist ACHD Surgical Centres must provide resources sufficient to support these educational needs across the network.	Within 6 months

Standard	Adult	Implementation timescale
E6(L1)	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 competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

Standard	Adult	Implementation timescale
F1(L1)	Each Specialist ACHD Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L1)	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.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F4(L1)	Each Specialist 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 locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist ACHD Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local ACHD Centres. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical	Within 6 months

Standard	Adult	Implementation timescale
	significance will be undertaken annually.	
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Within 6 months
F9(L1)	Each Specialist 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.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	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 ACHD Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and	Immediate

Standard	Adult	Implementation timescale
	according to clinical urgency.	
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist ACHD Centres and Local ACHD Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Last minute cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a 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. Specialist ACHD Centres and Local ACHD Centres must be involved in any relevant discussions.	Immediate
F18(L1)	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 or Specialist ACHD Centre, if appropriate.	Immediate
F19(L1)	An ACHD Nurse Specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate
F20(L1)	Each Specialist ACHD Surgical Centre must implement a pain control policy that includes advice on pain management at home.	Immediate
F21(L1)	Advice must be taken from the acute pain team for all patients who have uncontrolled severe pain.	Immediate

Standard	Adult	Implementation timescale
	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.	
F22(L1)	Each Specialist ACHD Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate
F23(L1)	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: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F24(L1)	Each Specialist 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.	Immediate

Standard	Adult	Implementation timescale
G1(L1)	Each Specialist ACHD Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of 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, and Local ACHD Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate
G4(L1)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

Standard	Adult	Implementation timescale
H1(L1)	Specialist ACHD Surgical Centres must demonstrate that arrangements are in place that allow patients to participate in decision-making at every stage in their care.	Immediate
H2(L1)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact, what signs and symptoms should be considered 'normal' for them, in order to be able to actively participate in decision-making at every stage in their care, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. careers; g. travel; h. welfare benefits;	Immediate

Standard	Adult	Implementation timescale
	i. social services; and j. community services.	
H4(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that patients are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate
H5(L1)	Sufficient information must be provided to allow 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: a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; d. outcomes at units under consideration; and e. consideration of the closest unit to the patient's home.	Immediate
H6(L1)	Specialist ACHD Surgical Centres must demonstrate that patients, partners, family and carers are offered support in obtaining further opinions or referral to another Specialist ACHD Surgical Centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H7(L1)	Information must be made available to patients, partners, family and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate

Standard	Adult	Implementation timescale
H8(L1)	Specialist ACHD 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.	Immediate
H9(L1)	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.	Immediate
H10(L1)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Surgical Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Specialist ACHD Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H11(L1)	Each Specialist ACHD Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H12(L1)	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	Immediate

Standard	Adult	Implementation timescale
	partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	
H13(L1)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide literature.	Within 6 months
H14(L1)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H15(L1)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H16(L1)	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.	Immediate
H17(L1)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H18(L1)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H19(L1)	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	Immediate

Standard	Adult	Implementation timescale
	provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	
H20(L1)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H21(L1)	Where surgery or intervention is planned, patients and carers must have the opportunity to visit the Specialist ACHD Surgical Centre well in advance of admission (as early as possible) 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.	Immediate
H22(L1)	Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Consent must be taken in line with GMC guidance.	Immediate
H23(L1)	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.	Immediate
H24(L1)	Patients and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H25(L1)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H26(L1)	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.	Within 6 months

Standard	Adult	Implementation timescale
H27(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

Standard	Adult	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L1)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L1)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I4(L1)	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 management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L1)	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.	Immediate
I6(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate

Standard	Adult	Implementation timescale
I7(L1)	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, 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.	Immediate
I8(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L1)	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.	Immediate

Standard	Adult	Implementation timescale
	Family Planning Advice	
J1(L1)	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.	Immediate
J2(L1)	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. Written advice about sexual and reproductive health and safe forms of contraception specific to their condition must be provided. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Immediate
J5(L1)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Within 1 year

Standard	Adult	Implementation timescale
Pregnancy and Planning Pregnancy		
J6(L1)	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.	Immediate
J7(L1)	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 2-4) 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.	Immediate
J8(L1)	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. 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. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	Immediate
J9(L1)	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 an obstetric unit at the Specialist ACHD Surgical Centre, or close by (for example at the network linked obstetric unit) during pregnancy, delivery and the puerperium.	Immediate

Standard	Adult	Implementation timescale
J10(L1)	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 ACHD Surgical Centre with specific network agreement and advice from the specialist centre.	Immediate
J11(L1)	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.	Immediate
J12(L1)	Each Specialist ACHD Surgical Centre must have a specialist tertiary maternity unit on the same hospital site or in a neighbouring hospital that functions as part of the extended multidisciplinary team. Consultant Obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease and an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The multidisciplinary team must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Immediate
J13(L1)	Regular joint clinics will be provided 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.	Immediate

Standard	Adult	Implementation timescale
Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.		
L1(L1)	Each Specialist ACHD Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the 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.	Immediate
L2(L1)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the 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). The potential for organ and tissue donation should be discussed. 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.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all	Immediate

Standard	Adult	Implementation timescale
	clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	
L7(L1)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L1)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L1)	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.	Immediate
L10(L1)	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.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
Discharge and out-of-hospital care		
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs,	Immediate

Standard	Adult	Implementation timescale
	community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	
L15(L1)	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.	Immediate
Management of a Death (whether expected or unexpected)		
L16(L1)	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.	Immediate
L17(L1)	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.	Immediate
L18(L1)	Patients will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a 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.	Immediate
L20(L1)	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.	Immediate

Standard	Adult	Implementation timescale
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
Ongoing support after the death of a patient		
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to offer the opportunity for the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, 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 plan, 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.	Immediate
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate

Standard	Adult	Implementation timescale
L28(L1)	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.	Immediate

Standard	Adult	Implementation timescale
M1(L1)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All 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.	Immediate
M3(L1)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	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.	Immediate