NHS England

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

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Document Status

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- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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Contents

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 2 – Specialist ACHD 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 2 – Specialist ACHD Centres

Standard	Adult	Implementation timescale
A1(L2)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist ACHD Centres where appropriate.	Within 6 months
A2(L2)	Each Specialist ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	Each Specialist ACHD Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. New referrals from GPs, cardiologists and local hospitals; b. Ongoing care of patients diagnosed with congenital heart defects.	Within 6 months
A4(L2)	Specialist ACHD 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 delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, specialist ACHD cardiologists will work across the network, including at the Specialist ACHD Surgical Centres, the Specialist ACHD	Immediate

Standard	Adult	Implementation timescale
	Centres and Local ACHD Centres, according to local circumstances; f. address how Specialist ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. provide 24/7 advice via an on-call rota comprised predominantly of general consultant cardiologists who will have contact details for the on-call ACHD specialists in the network.	
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Within 6 months
A6(L2)	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.	Immediate
Cardiological Interventions		
A7(L2)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will 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]. Interventional closures of ASDs will usually be undertaken at a Specialist ACHD Surgical Centre, but ASD closures may be undertaken at a Specialist ACHD Centre providing certain conditions are met: • All interventional ASD closures must only be undertaken under network agreed	Within 6 months

Standard	Adult	Implementation timescale
	governance arrangements including oversight by the network lead congenital interventionist. • All cases of ASD must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT where the intervention should be performed and by whom. • ASD closure may be undertaken at a Specialist ACHD Centre only for patients with an adult diagnosis of CHD, with an ASD without additional complicating features. • All procedures must be reported to the NICOR congenital audit. • ASD closures may only to be undertaken at sites where vascular surgeons and cardiac surgeons are available to provide back-up and surgical retrieval of devices • All interventionists must undertake a minimum volume of procedures as required by standard B7(L2). Diagnostic catheterisation will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre providing certain conditions are met: • All diagnostic catheterisation must only be undertaken under network agreed governance arrangements. • All diagnostic catheterisation must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT as to whether diagnostic catheterisation is appropriate, and if so where the catheterisation should be performed and by whom.	
Non-Cardiac Surgery		
A8(L2)	Specialist ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate

Standard	Adult	Implementation timescale
External Relationships		
A9(L2)	Each Specialist ACHD Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist ACHD Centre must have a close network relationship with any paediatric CHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist ACHD Centre must demonstrate formal working relationships with: a. network Specialist ACHD Surgical Centres and Local ACHD Centres, according to local circumstances; b. the cardiothoracic transplant centres, including one staffed by transplant surgeons with a congenital practice; c. the national Pulmonary Hypertension Service; and d. a cardiac pathologist with expertise in congenital cardiac abnormalities.	Within 6 months
A12(L2)	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		
A13(L2)	Each Congenital Heart Network will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Surgical Centres and Local Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to:	Within 3 years

Standard	Adult	Implementation timescale
	a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services; and d. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate.	
A14(L2)	Each Specialist ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist ACHD Surgical Centre system, and enable immediate access to patient data.	Immediate
Multidisciplinary Team (MDT)		
A15(L2)	Each Specialist ACHD Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist ACHD Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT meeting, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT meeting.	Within 1 year
A17(L2)	Staff from the Specialist Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate

Standard	Adult	Implementation timescale
A18(L2)	The composition of the MDT will be pathway driven, and adjusted according to the needs of different aspects of the service (for example: assessment, post-operative care, clinic, pathological and audit meetings).	Immediate
A19(L2)	Specialist ACHD Centres will routinely refer patients to their primary network MDT meeting. Exceptions to this principle will include the exercise of patient choice and, when justified by a consideration of the clinical facts of the individual case, the exercise of referrer choice. In all cases when a patient is referred 'out of network' the Specialist ACHD Centre must inform the Specialist ACHD Surgical Centre in writing of the reasons for referral.	Immediate
Network Leadership		
A20(L2)	Each Specialist ACHD Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the network. The post holder must have specified time working in ACHD cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

Standard	Adult	Implementation timescale
B1(L2)	Each Specialist ACHD Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, 7 days a week within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	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
Medical		
B3(L2)	Each Specialist ACHD Centre must be staffed by: a. one lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD; and b. at least one cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD. Each cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist.	Within 3 years
B4(L2)	Each Specialist ACHD Centre must provide a dedicated consultant-led cardiology on-call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.	Immediate
B5(L2)	Each Specialist ACHD Centre will have a formally nominated Clinical ACHD Lead with responsibility for the service at the Specialist ACHD Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist ACHD Centre will have separate clinical leads identified from the relevant specialties, including nursing, ICU, and anaesthesia who have a direct link and collaborative working partnership with the lead roles in the Specialist ACHD Surgical Centre.	Within 6 months

Standard	Adult	Implementation timescale
B6(L2)	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.	Within 6 months
B7(L2)	Specialist ACHD Cardiologists performing therapeutic catheterisation in adults with CHD must be the primary operator in a minimum of 50 such procedures per year (while not normally within the definition of CHD, for these purposes, PFO closure is included as a countable procedure), averaged over a three-year period.	Immediate
B8(L2)	Electrophysiology will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre if specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network agreed governance arrangements.	Immediate
B9(L2)	Each Specialist ACHD Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B10(L2)	Intensive Care Unit consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
Nursing		
B11(L2)	Specialist ACHD Centres must have locally designated registered nurses with a specialist interest in adult congenital heart disease, trained and educated in the assessment, treatment and care of patients with CHD.	Immediate
B12(L2)	Each Specialist ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate

Standard	Adult	Implementation timescale
B13(L2)	Each Specialist ACHD Centre will employ a minimum of 2 WTE specialist ACHD nurses whose role will extend throughout the network. The precise number, above the minimum two, and location of these nurses will depend on geography, population and the configuration of the network.	Within 1 year
Psychology		
B14(L2)	Each Specialist ACHD Centre must have access to a clinical psychology service that is integrated with the ACHD team. The Network Children's Cardiac Psychologist will support the Specialist ACHD Centre. An appropriate number of ACHD Psychology sessions will be based at the Specialist ACHD Centre (the number will depend on geography, population and the congenital heart network).	Immediate
Administrative		
B15(L2)	Each Specialist ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist ACHD 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, partners/family or carers in a timely fashion.	Immediate
Other		
B17(L2)	Each Specialist ACHD Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	Immediate
B18(L2)	Each Specialist ACHD Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable	Immediate

Standard	Adult	Implementation timescale
	adults.	
B19(L2)	Each Specialist ACHD Centre will have a dedicated bereavement officer.	Immediate

Standard	Adult	Implementation timescale
C1(L2)	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
C2(L2)	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
C3(L2)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C4(L2)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C5(L2)	Patients and their partners/family/carers must be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate

Standard	Adult	Implementation timescale
C6(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C7(L2)	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 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(L2)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L2)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L2)	Intensive Care Unit: Level 3, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L2)	Each Specialist ACHD Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. 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, transesophageal and fetal echocardiography. Specialist ACHD 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. 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. These services must be available 24/7.	Immediate

Standard	Adult	Implementation timescale
D5(L2)	Adult cardiac surgery (required if interventional ASD closure is undertaken).	Immediate
D6(L2)	Vascular services including surgery and interventional radiology (required if interventional ASD closure is undertaken).	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD 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.		
D7(L2)	General Surgery.	Immediate
D8(L2)	Cardiac anaesthetist who works closely with specialist congenital cardiac anaesthetists in the network.	Immediate
D9(L2)	Nephrology.	Immediate
D10(L2)	Physiotherapy (service must be integrated with the ACHD team).	Immediate
D11(L2)	Bereavement Support, including nurses trained in bereavement support.	Immediate
D12(L2)	Pain management service.	Immediate
D13(L2)	Gastroenterology.	Immediate
D14(L2)	Clinical biochemistry.	Immediate
D15(L2)	Clinical Haematology.	Immediate
D16(L2)	Ear nose and throat.	Immediate
D17(L2)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Immediate
D18(L2)	Gynaecology.	Immediate

Standard	Adult	Implementation timescale
D19(L2)	Neonatal Intensive Care Unit (NICU): Level 3 – for new-borns of mothers with CHD	Immediate
D20(L2)	Microbiology and infectious diseases.	Immediate
D21(L2)	Obstetric Unit with Maternal Fetal Medicine Specialist/s.	Immediate
D22(L2)	Orthopaedics.	Immediate
D23(L2)	Respiratory medicine.	Immediate
D24(L2)	Urology.	Immediate
D25(L2)	Acute stroke services	Immediate

Standard	Adult	Implementation timescale
The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD 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.		
D26(L2)	Learning Disability Team.	Immediate
D27(L2)	Neurology.	Immediate
D28(L2)	Neurosurgery.	Immediate
D29(L2)	Psychiatry.	Immediate

Standard	Adult	Implementation timescale
	Advice and consultation must be available from the following services at least by the following working day. The services must be experienced in patients with congenital heart disease.	
D30(L2)	Clinical Genetics.	Immediate
D31(L2)	Dentistry.	Immediate
D32(L2)	Clinical Immunology.	Immediate
D33(L2)	Dermatology.	Immediate
D34(L2)	Sexual Health.	Immediate
D35(L2)	Cardiac rehabilitation.	Immediate
D36(L2)	Diabetes.	Immediate
D37(L2)	Occupational Therapy.	Immediate
D38(L2)	Palliative Care.	Immediate

Standard	Adult	Implementation timescale
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, working with adults with learning disability, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and ICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	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(L2)	Each Specialist Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in in ACHD cardiology and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.	Within 6 months

Standard	Adult	Implementation timescale
E6(L2)	Each Specialist ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Specialist ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre 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(L2)	Each Specialist ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	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
F3(L2)	Each Specialist ACHD Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L2)	Each Specialist ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate

Standard	Adult	Implementation timescale
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year
F8(L2)	Each Specialist ACHD Centre must participate in national programmes for audit and must submit data on electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F9(L2)	Each Specialist ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist ACHD Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist ACHD 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.	Immediate
F13(L2)	Each Specialist ACHD 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

Standard	Adult	Implementation timescale
F14(L2)	Each Specialist ACHD 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
F15(L2)	Each Specialist ACHD 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(L2)	Each Specialist ACHD Centre must participate in research.	Immediate
G2(L2)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

Standard	Adult	Implementation timescale
H1(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place that allows patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L2)	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(L2)	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 provided should include any aspect of life 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(L2)	Information must be made available to patients, partners, family or carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate
H5(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H6(L2)	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
H7(L2)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD 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 Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and partners/family /carers must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Centres must demonstrate ongoing structured liaison with patients and patient	Immediate

Standard	Adult	Implementation timescale
	groups, including evidence of how feedback is formally considered.	
H8(L2)	Each Specialist ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L2)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Immediate
H10(L2)	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 relevant literature.	Immediate
H11(L2)	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
H12(L2)	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
H13(L2)	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

Standard	Adult	Implementation timescale
H14(L2)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H16(L2)	Patients, partners, family and carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L2)	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
H21(L2)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible	Immediate

Standard	Adult	Implementation timescale
	consequences of their decisions so that they are able to give informed consent.	
H22(L2)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H23(L2)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H24(L2)	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 1 year
H25(L2)	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 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(L2)	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(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L2)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I4(L2)	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(L2)	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(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate

Standard	Adult	Implementation timescale
I7(L2)	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(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L2)	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(L2)	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(L2)	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(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by an ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate
Pregnancy and Planning Pregnancy		
J6(L2)	Each Specialist ACHD Centre must be staffed by Specialist ACHD cardiologists with expertise in	Immediate

Standard	Adult	Implementation timescale
	pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	
J7(L2)	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(L2)	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(L2)	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
J10(L2)	Women with moderate or high risk conditions, who are not at risk of requiring such 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

Standard	Adult	Implementation timescale
J11(L2)	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(L2)	Each Specialist ACHD 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. Consultants 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 or 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(L2)	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(L2)	Each Specialist ACHD Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and 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(L2)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	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(L2)	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(L2)	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(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members	Immediate

Standard	Adult	Implementation timescale
	(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.	
L7(L2)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L2)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L2)	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(L2)	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(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	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(L2)	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(L2)	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(L2)	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(L2)	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(L2)	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(L2)	Patients will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L2)	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(L2)	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(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the 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(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
Ongoing support after the death of a patient		
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the 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(L2)	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(L2)	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(L2)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate