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Adult Congenital Heart Disease Standards: Level 3 – Local ACHD Centres

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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 3 – Local 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 3 – Local ACHD Centres

Standard	Adult	Implementation timescale
A1(L3)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local ACHD Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Immediate
A2(L3)	Each Local ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L3)	Local ACHD Centres 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	Immediate
A4(L3)	Local 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 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, and with clear links to 24/7 specialist services; 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, paediatric cardiologists and paediatricians with	Within 1 year

Standard	Adult	Implementation timescale
	expertise in cardiology (PECs) will work across the network, including at the Specialised Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; f. address how Local ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. deliver joint clinics between a specialist ACHD cardiologist and a cardiologist with an interest in ACHD in a Local ACHD Centre. Local ACHD Centres will provide weekday cover for CHD advice from a local network of consultant cardiologists with expertise in CHD.	
A5(L3)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Within 6 months
A6(L3)	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(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, therapeutic interventions and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre. Local ACHD Centres may not undertake any ACHD surgeries, planned interventional catheter procedures or diagnostic catheter procedures as part of their investigation into congenital heart disease. [See Appendix A for the definition of ACHD Surgery and Interventions.]	Immediate

Standard	Adult	Implementation timescale
Non-Cardiac Surgery		
A8(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate
Emergency Care		
A9(L3)	When patients with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local ACHD Centres will seek advice from the local cardiologist with expertise in CHD or an ACHD cardiologist at a specialist centre on appropriate care and management.	Immediate
	External Relationships	
A10(L3)	Each Local ACHD Centre must demonstrate formal working relationships with the network Specialist ACHD Surgical Centres and Specialist ACHD Centre, according to local circumstances. Other supra-regional services will be accessed via the CHD network.	Immediate
A11(L3)	Local ACHD Centres must have a close relationship with local community adult services, 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		
A12(L3)	Each Local ACHD Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Surgical Centres and Specialist ACHD 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 multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	
A13(L3)	Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to their own Specialist ACHD Surgical Centre or Specialist ACHD Centre system and enable immediate access to patient data.	Within 6 months
	Multidisciplinary Team (MDT)	
A14(L3)	Staff from across the Local ACHD Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.	Immediate
A15(L3)	Each Local ACHD Centre cardiologist with an interest in ACHD must participate (at least six times per year) in specialist MDT meetings led by the Specialist ACHD Surgical Centre, either in person or via telemedicine facilities, and must also attend the annual network meeting. This requirement will be reflected in job plans.	Within 1 year
A16(L3)	Each cardiologist with an interest in ACHD will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Within 1 year
A17(L3)	Each Local ACHD Centre must have identified registered nurses with an interest and training in ACHD.	Within 1 year

Standard	Adult	Implementation timescale
B1(L3)	The Local ACHD Centre must be staffed by at least one consultant cardiologist with an interest in ACHD.	Within 1 year
B2(L3)	Each Local ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
B3(L3)	Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
B4(L3)	ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.	Immediate
B5(L3)	Each Local ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Within 6 months
B6(L3)	Each Local ACHD Centre will provide administrative support to ensure availability of medical records, to organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients, partners/family or carers in a timely fashion.	Immediate
B7(L3)	Each Local ACHD Centre must have a cardiac physiologist with training in congenital echocardiography.	Within 1 year
B8(L3)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding	Immediate

Standard	Adult	Implementation timescale
	standards, in accordance with the requirements of their profession and discipline.	
B9(L3)	The Local ACHD Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding vulnerable adults; and b. a dedicated bereavement officer.	Immediate

Standard	Adult	Implementation timescale
C1(L3)	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(L3)	There must be facilities in place to ensure easy and convenient access for partners/family/carers.	Within 6 months
C3(L3)	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(L3)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C5(L3)	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
C6(L3)	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(L3)	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 **Local ACHD Centres.**		
D1(L3)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L3)	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital– either from Specialist ACHD Centres or from Specialist ACHD Surgical Centres in accordance with network protocols.	Immediate
D3(L3)	Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: a. blood testing; b. electrocardiogram (ECG) available 24/7; c. transthoracic echocardiogram; d. chest X-ray; e. exercise testing/six-minute walk test; f. 24 hour tapes, event recorders; and g. ambulatory blood pressure monitoring.	Immediate

Standard	Adult	Implementation timescale
E1(L3)	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(L3)	All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L3)	Each Local ACHD Centre must assist the Specialist ACHD Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all adult cardiology trainees within their network catchment area.	Immediate
E4(L3)	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 1 year
E5(L3)	Each Local ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Local 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 will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
E6(L3)	Nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, to enhance development of clinical	Within 1 year

Standard	Adult	Implementation timescale
	knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.	
E7(L3)	Cardiologists with an interest in ACHD should have a named cardiologist within the Specialist ACHD Surgical Centre or Specialist ACHD Centre who acts as a mentor; this mentor would normally be the link cardiologist.	Immediate

Standard	Adult	Implementation timescale
F1(L3)	Each Local 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(L3)	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(L3)	Each Local ACHD Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L3)	Each Local ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L3)	Each Local ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L3)	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(L3)	Each Local ACHD Centre must participate in relevant national programmes for audit and must submit data to the Specialist ACHD Surgical or Specialist ACHD Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F8(L3)	Each Local ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Within 1 year
F9(L3)	Each Local ACHD Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local ACHD Centres will follow mandatory National Institute for Health and Care Excellence guidance.	Immediate
F10(L3)	Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F11(L3)	Each Local 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**
G1(L3)	Each Local ACHD Centre should participate in research.	Immediate
G2(L3)	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(L3)	Local ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L3)	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(L3)	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 their 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; i. social services; and	Immediate

Standard	Adult	Implementation timescale
	j. community services.	
H4(L3)	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
H5(L3)	Local ACHD Centres must demonstrate that arrangements are in place for patients, partners, family and 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(L3)	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(L3)	Patients, partners, families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Local ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and their partners/families/carers must be informed of the action taken following a complaint or suggestion made. Local ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate

Standard	Adult	Implementation timescale
H8(L3)	Each Local ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L3)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carer throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Within 6 months
H10(L3)	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.	Within 1 year
H11(L3)	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(L3)	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(L3)	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(L3)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L3)	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(L3)	Patients, partners, family or carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L3)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L3)	Local ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L3)	Where surgery or intervention is planned, Local ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist 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(L3)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate

Standard	Adult	Implementation timescale
H21(L3)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L3)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L3)	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. Where this service is not available locally the patient should be referred to the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Within 1 year
H24(L3)	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(L3)	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(L3)	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(L3)	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(L3)	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(L3)	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(L3)	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
I7(L3)	Young people undergoing transition must be supported by age-appropriate information and	Immediate

Standard	Adult	Implementation timescale
	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.	
I8(L3)	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(L3)	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.	Within 1 year

Standard	Adult	Implementation timescale
Family Planning Advice		
J1(L3)	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist or cardiologist with special interest in congenital heart disease with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
J2(L3)	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(L3)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L3)	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. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate

Standard	Adult	Implementation timescale
J5(L3)	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(L3)	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 at a Specialist ACHD Surgical Centre or Specialist ACHD Centre immediately once 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
J7(L3)	The Local ACHD Centre may care for pregnant women with ACHD in whom pregnancy presents a low maternal risk at the onset of pregnancy. It should be acknowledged that as pregnancy proceeds, complications such as severe pre-eclampsia may alter this risk assessment.	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(L3)	Each Local 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. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service at the Specialist ACHD Surgical or Specialist ACHD Centre.	Immediate
L2(L3)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L3)	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(L3)	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(L3)	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	Immediate

Standard	Adult	Implementation timescale
	doctor.	
L6(L3)	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 clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L3)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L3)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L3)	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(L3)	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(L3)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L3)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate

Standard	Adult	Implementation timescale
	Discharge and out-of-hospital care	
L13(L3)	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(L3)	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, 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.	Immediate
L15(L3)	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(L3)	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(L3)	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(L3)	Patients will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate

Standard	Adult	Implementation timescale
L19(L3)	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(L3)	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
L21(L3)	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(L3)	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(L3)	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(L3)	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(L3)	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

Standard	Adult	Implementation timescale
L26(L3)	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(L3)	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
L28(L3)	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(L3)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L3)	Each Local ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L3)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L3)	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(L3)	Local ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate