

Adult Congenital Heart Disease Review - Engagement

Improving everyday life for adults with congenital heart disease
A review into NHS services – we want your views

This document contains the Proposed Model of Care (pages 2-8) and the Draft Designation Standards (pages 10-20). This document should be read alongside the *Adults living with congenital heart disease* publication.

To find out more about the review or to download the *Adults living with congenital heart disease* publication, go to: <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

We want to hear your views on:

Q: What do you think of our proposed model of organising care into networks of specialist centres, intermediate centres and local centres with links to non-cardiac care?

Q: Do you have any comments on the draft national designation standards?

Q: What other improvements can be made to the way the NHS organises care for people with ACHD?

You can submit your views by:

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In person: We are holding a number of regional workshops for patients and people working with adults with congenital heart disease. If you would like to attend please contact the communications team on 020 7025 7520 for more details.

Please provide your comments by Friday 27 July 2012.

THE PROPOSED ADULT CONGENITAL HEART DISEASE MODEL OF CARE

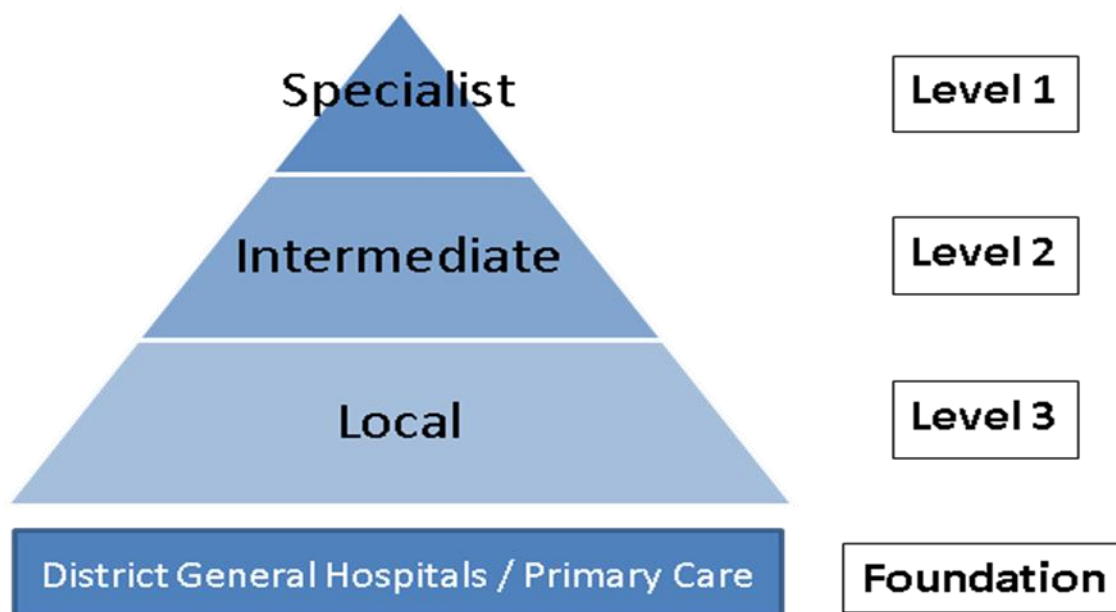
GENERAL FEATURES

The proposed model of care shown in diagrammatic form below is based on an overarching principle of hierarchical service delivery on 3 levels – Specialist, Intermediate and Local – on a network basis and is a more sophisticated version of the hub and spoke model usually followed.

Within each congenital cardiac network, Level 1 is used to refer to the Specialist level, Level 2 Intermediate and Level 3 Local level.

Patients would not necessarily follow a linear path through the three levels of care, depending upon circumstances, and would be able to move from Levels 1 to 3 and back again without needing to access care at Level 2.

In common with most other types of healthcare provided by the NHS, patients would be likely to enter the ACHD model of care via a general hospital or primary care, unless diagnosed during antenatal or post-birth care.



BASIC PRINCIPLES

The latest iteration of the proposed model of care is set out on [page 8](#).

The following basic principles have been applied when revising this model:

- a) The proposed model relates to care provided to adults with congenital heart disease who are, by definition, aged 16 years and over (recognising that the process of transition to adult services may not be completed until the age of 18 years).
- b) ACHD care would be provided at one of three levels – Local, Intermediate or Specialist – with patients moving between the levels as required. Patients would not necessarily move in a linear manner between care settings.

- c) The ACHD Specialist Centre would provide leadership and clinical support to a geographically cohesive network of ACHD Local Centres, and may also include an ACHD Intermediate Centre depending on geography.
- d) Within a framework of commissioning consistent with the NHS Commissioning Board, each network would adopt policies and guidelines agreed across the network relating to patient management, pathways and each Centre's role.
- e) The vertical levels in the model provide potential for service development in this rapidly evolving field. They provide the flexibility to move services around the levels as they evolve.
- f) Although the development of Intermediate Centres would be assumed to comprise any de-designated specialised centres in the first instance, there would be the possibility to create more of these centres if activity flows in future justify this.
- g) Specialist Centres would manage all patients with highly complex congenital heart disease and all cardiac surgical procedures and all therapeutic catheter interventions would take place in this setting.
- h) It is recognised that occasionally a non-ACHD cardiac surgeon may discover an incidental congenital defect that it is within their capability to address and that it is not possible to develop a model of care that covers every eventuality.
- i) All Specialist, Intermediate and Local Centres must be an integral part of a formally defined and established ACHD network.
- j) Intermediate Centres would deliver the same quality of care to those with ACHD as the Specialist Centres, whilst focussing on diagnosis and on-going management of patients.
- k) Care would be provided at any of the three levels, as appropriate to the patient's condition, or in a non-ACHD hospital's cardiology service, or as shared care with primary care if that is considered appropriate following specialist assessment.
- l) A certain degree of flexibility should be applied throughout the model where possible. There is no intent to impose a rigid location of care that does not take into account level of complexity, geographic location and the patients' wishes.
- m) The future location of care for patients emerging from transition should be agreed by a specialist ACHD cardiologist in a specialist MDT transfer clinic or equivalent.
- n) All adult patients newly diagnosed with ACHD, or those previously diagnosed re-entering the system in adulthood, would be assessed initially by a Specialist ACHD Cardiologist.
- o) Strong working links would be formed between Specialist Centres and allied specialist services that may be required by ACHD patients, such as the National Pulmonary Hypertension Service and Obstetrics Cardiology.
- p) Existing patient self-referral would be built in to network policies and would be reflected in the requirements of ACHD standards.

- q) The Specialist ACHD Cardiologist¹ (as per BCCA Definitions guidance at [Appendix A](#), note that terminology regarding centres to be revised) would play a central role in establishing joint working, communication and cohesive patient flows across Specialist and Intermediate Centres (Levels 1 and 2).
- r) The Cardiologist with a Special Interest in ACHD² would likely be based in a Level 2 Centre, working alongside the substantive or visiting Specialist ACHD Cardiologist and would also work on an outreach basis at Level 3 supporting cardiologists who are managing patients with ACHD, or at Level 1 maintaining intervention skills.
- s) ACHD Specialist Nurses would work at locations across the network and would be an integral part of the service. There is increasing specialist activity that can be delivered by these roles.
- t) All Centres would provide rehabilitation appropriate to a patient's needs, palliative care, specialist dental care, and contraceptive and pregnancy advice. Local Centres would understand the need for these services and refer appropriately where they cannot deliver them.
- u) All Centres, at all three levels in the model, would participate in multi-disciplinary team meetings and would submit ACHD procedure data to national audit.
- v) The ACHD Advisory Group has advised that closure of patent foramen ovale (PFO) should no longer be considered a part of the spectrum of conditions covered by the term ACHD and the management of PFOs is therefore not covered by this model.
- w) A series of standards, for designation of services and on-going commissioning, will be established which reflect the recommended model of care and will underpin delivery where service elements are in development.

¹ As defined by current British Congenital Cardiac Association guidelines.

² As defined by current British Congenital Cardiac Association guidelines.

ACHD SPECIALIST CENTRE - LEVEL 1

Would not necessarily be located in one building but is managed within one network and has formal links to an academic institution.

Services delivered in this setting:

- ACHD network management – pathways and policies will be established at this level, in partnership with constituent organisations in the network, and delivery of consistent services in line with these is overseen by the centre.
- Proactively lead training, development and research around ACHD across the network.
- All ACHD surgery, to be delivered only by trained congenital cardiac surgeons with anaesthetic cover provided by those with appropriate ACHD training.
- All ACHD catheter interventions, compliant with emerging BCCA guidelines.
- Hybrid procedures – combined ACHD surgical / ACHD cardiology working.
- Joint surgical procedures - combined ACHD surgical / general cardiothoracic surgical working.
- Joint cardiology procedures – combined ACHD cardiology / general cardiology working.
- Complex electrophysiology. Simple procedures could be carried out at Level 2 but only following MDT consideration of individual cases.
- Complex pacing and ICD procedures.
- Invasive and non-invasive imaging (including echo).
- Transition and transfer clinics
- 24 hour on-call availability, 7 days per week.
- In-reach working by cardiologists from the Specialist Cardiology Centre.
- Working links to other specialist specialties such as transplantation service, genetics, National Pulmonary Hypertension Service.
- Very complex patients requiring non-cardiac surgery to be managed in this setting in order to have access to anaesthetists with ACHD experience.
- Joint management of ACHD patients with high risk pregnancy.
- Also delivers any service provided at Levels 2 and 3.

ACHD INTERMEDIATE CENTRE - LEVEL 2

Initially likely to apply to de-designated specialist centres.

Network leads would be able to develop further Intermediate Centres over time where Local Centres (Level 3) are geographically located in an area of ACHD need and have reached a level of development which means they can meet national standards for ICs.

This intermediate tier offers an opportunity for diagnostic and some treatment procedures to be relocated over time along the hierarchical model, from Specialist Centres, as they become more embedded in mainstream ACHD provision.

Services delivered in this setting:

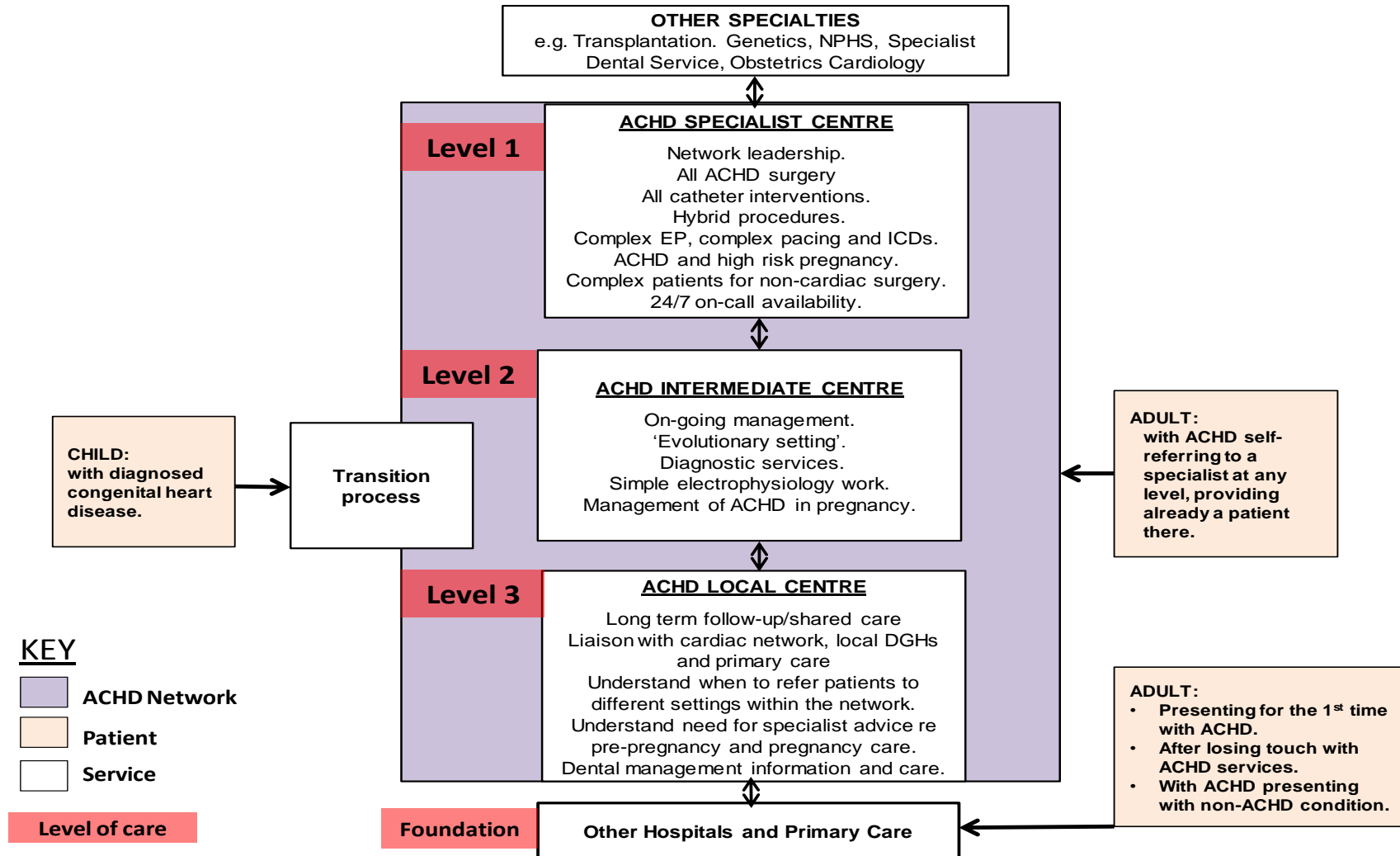
- This Centre will not perform any surgical procedures or catheter interventions. (Closure of PFO is not considered an ACHD procedure and may be delivered in this setting).
- A Specialist ACHD Cardiologist would be based there or would hold sessions there on a regular basis.
- Cardiologists with a special interest in ACHD would be based there and would have the opportunity to outreach to the Specialist Centre to maintain skills.
- Cardiologists with a special interest in ACHD would also outreach to support cardiologists with an interest in ACHD in Local Centres.
- On-going ACHD patient management.
- Broad range of diagnostic services, including non-invasive imaging, delivered at the same quality to those in Level 1.
- Simple electrophysiology work – only if agreed as part of network wide arrangements and following MDT consideration.
- On-going management of pacing.
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to Level 1 in high risk cases.
- The services of an ACHD Specialist Nurse are available and/or a nurse specialist with an interest in ACHD.
- Also delivers any service provided at Level 3.

ACHD LOCAL CENTRE - LEVEL 3

Services delivered in this setting:

- The centre will be developing at least one cardiologist with a special interest in ACHD who is based and who will be supported by others who visit on an outreach basis from Level 1 or Level 2.
- The emerging cardiologist with a special interest in ACHD would liaise with primary care and other local DGHs, forming a link between them and the ACHD network.
- The emerging cardiologist with a special interest in ACHD would also have a formal liaison role between the ACHD network and the local adult cardiac network.
- The emerging cardiologist with a special interest in ACHD would be supported by specialist MDT sessions, via video conferencing if geography precludes attendance in person.
- Delivery of shared care under protocols established within the network.
- Ensure the delivery of long term follow-up as appropriate to need.
- Understand when to refer the patient to different network settings to meet changing clinical need.
- Basic cardiac diagnostic services.
- Dental management, information and care.
- Monitoring of anticoagulation and blood chemistry.
- Joint working with palliative care.
- Meet the need for specialist advice regarding contraception, pre-pregnancy and pregnancy care and refer on as appropriate.

Proposed Adult Congenital Heart Disease (ACHD) MODEL OF CARE



A Draft Definition of ACHD Surgery

This is a definition, by the Society for Cardiothoracic Surgery, of which Cardiac Surgical Operations should be carried out only by Cardiac Surgeons on the General Medical Councils “Congenital Heart Surgery” Subspecialist register in a designated Level 1 “Specialist” Adult Congenital Unit. These operations are termed “ACHD Surgery” and the outcomes of these operations will be audited by the UK Congenital Cardiac Audit Database.

Advice, as well as direct clinical care, will always be available from designated Level 1 ACHD teams.

Section A

ACHD surgery includes all cardiac surgery in an adult who:

1. Has had cardiac disease diagnosed, operated or intervened on in childhood.
2. Presents with a new primary diagnosis of Congenital Heart Disease.
3. Requires heart surgery for the failures or complications of interventional management of congenital cardiac lesions.

Section B

ACHD surgery does not necessarily include:

1. Secondly significant congenital cardiac lesions where the primary cardiac pathology is adult acquired disease. If discovered preoperatively, which should be the norm, these must be discussed with the “Specialist” ACHD team prior to deciding to operate.
2. Surgery for Aortopathy, which should be carried out by a specialist Aortopathy team which may be a Level 1 ACHD team depending on local arrangements.
3. Surgery of the Aortic Valve, including the Bicuspid Aortic Valve, the overwhelming majority of which will be undertaken by general adult cardiac surgeons. Careful consideration must be given to the need to refer to a Level 1 ACHD Team, or an alternative Specialist Aortic Valve Surgery Team in the following scenarios.
 - a. Patients less than 30 years of age.
 - b. Women of child bearing age.
 - c. Patients with aortic valve disease who should be assessed for, and must have access to, the following procedures
 1. Major Aortic Annulus Enlargement Procedures (Konno)
 2. Aortic Autograft Surgery (Ross)
 3. Aortic Valve Repair, especially for more complex congenital lesions.

Any alternative teams to the ACHD team must have adequate expertise, experience and volumes in both multidisciplinary assessment and operative surgical practice specific to the clinical scenario concerned. They must also have adequate numbers of surgeons to offer constant expert consultant subspecialist cover and mutual support. Occasional practice by small numbers of surgeons without appropriately experienced multidisciplinary support is not acceptable.

Section C

Surgery for immediately life threatening presentations of congenital heart disease, which, in less urgent scenarios, would qualify as ACHD surgery.

The risks of transfer to a distant Level 1 ACHD Centre should be balanced against the risks of delaying surgery, where time allows taking advice from the Level 1 Centre.

It is explicitly recognised that Cardiac teams must be supported to act in rare and demanding scenarios where the individual patient is best served by “Immediate Generalist” rather than “Delayed Specialist” intervention.

DRAFT ACHD STANDARDS

A	<u>LEVEL 1 CARE - SPECIALIST CENTRES (SCs)</u> SCs must also observe the network, transition and patient standards as set out in Sections C, D and E.	
A1	Specialist Centres (SCs), in partnership with the Congenital Heart Network and NHS commissioners, must adapt the advised model of care that delivers all aspects of the care and treatment of patients with adult congenital heart disease to local circumstances. Where the same quality of care can be achieved, the adapted model of care will ensure that as much care and treatment should be provided as close as possible to the patient's home. The patient, and carer, should need to travel to the SC only when essential, or if the patient wishes to, whilst ensuring timely access for interventional procedures and the best possible outcome for the patient.	A
A2	SCs must agree clinical protocols and pathways to care with their Congenital Heart Networks, based upon these and other national standards.	A
A3	SCs must be responsible for advising colleagues within the Congenital Heart Network on the care of patients with cardiac conditions requiring non-cardiac interventions, and where emergency non- cardiac conditions are concerned on a 24/7 basis.	M
A4	Each SC must deliver emergency care and inpatient admission facilities 24 hours, 7 days week with access to a specialist ACHD Cardiologist on this basis.	M
A5	Each SC should be staffed by the following, with specific experience and expertise in ACHD: a) A MINIMUM of 4 WTE ACHD specialists with at least 2 ACHD interventional (who may be included in this number or be predominantly paediatric) cardiologists, with an indicative maximum patient workload of 1,500 per cardiologist. b) An electrophysiologist experienced in ACHD, a congenital cardiac imaging specialist who may be a cardiologist or a radiologist, and a cardiologist with a specialist interest in pregnancy. c) The dominant priority is that each individual Congenital Cardiac Surgeon should be the primary operator in a minimum of 125 Congenital Heart Operations per year, in adults and/or children, in order to maintain a safe individual operative volume. Consultant cover for patients undergoing cardiac surgery in a Level 1 ACHD unit must be provided by congenital cardiac surgeons. A congenital cardiac surgeon must not partake in an on-call rota more frequent than 1 in 4 (4 or more surgeons). The rota must be comprised solely of congenital cardiac surgeons. At the same time as providing cover for ACHD cardiac surgical cases a consultant congenital cardiac surgeon can/may also provide cover for paediatric cardiac surgical cases. <u>Question: During the engagement exercise we seek views on the extent to which the physical separation of two units will affect the appropriateness of the provision of such simultaneous cover.</u> d) Specialised cardiac anaesthetists who are trained to, or regularly, anaesthetise patients with CHD. On-call cover arrangements must ensure that such expertise is available 24/7.	M
A6	Each SC must have a formally nominated Lead Nurse who is an ACHD Nurse Specialist, providing professional and clinical leadership and support to staff across the network, and	

	<p>a MINIMUM of 3 WTE specialist ACHD nurses. Nursing care must be provided by a designated team of nursing staff trained in the care of ACHD patients.</p> <p>(See also Standard D8 - these 3 nurses are the same minimum 3 that each network should have upon establishment.)</p>	M
A7	<p>Each SC should have access to the following staff:</p> <ul style="list-style-type: none"> Cardiac Physiologists Echocardiographers Psychologist Physiotherapist Dietician Administrative support Database administrator 	M
A8	<p>Each SC should carry out the recommended minimum number of therapeutic catheterisations per year in line with BCCA guidance, currently as follows:</p> <ul style="list-style-type: none"> a) All clinicians performing these procedures to carry out at least 40 therapeutic catheterisations per year. b) A minimum of 2 such clinicians to be employed within the SC. c) The lead clinician to perform at least 80 therapeutic catheterisations per year. d) Cardiac surgery and vascular surgery expertise must be available to provide emergency care if required during therapeutic catheterisations. 	M
A9	<p>Referrals to the SC must be accepted from GPs, DGH medical staff, Local ACHD Centre or other medical professionals.</p>	M
A10	<p>Urgent existing patient self referral to specialist ACHD clinicians at the SC is possible.</p>	A
A11	<p>Each SC will have a formally nominated Clinical Lead with responsibility for the service overall, who will be supported by separate clinical leads for surgery, cardiac intervention, anaesthesia, ITU and other areas.</p>	A
A12	<p>Sufficient staff and facilities will be available at the SC to meet the demand for in-patient beds, critical care beds, theatre capacity and service provision as generated by the Congenital Heart Network. When an SC cannot admit a patient for whatever reason it has a responsibility to help find another bed at another SC.</p>	A
A13	<p>Each SC must have policies in place covering access and working links to:</p> <ul style="list-style-type: none"> a) At least one transplant centre with surgeons familiar with congenital cardiac malformations. b) A dental service and specialist dentistry. c) The National Pulmonary Hypertension Service. d) Cardiac pathologist with interest in congenital cardiac malformations. e) Genetics service. 	M
A14	<p>Each SC must have a full range of diagnostic imaging capabilities including CT and MRI scanning, bi-plane catheter lab, contrast and transoesophageal echocardiography, and suitable trained radiological expertise. Other diagnostic modalities should include CPEX and 6 min walk test.</p>	M
A15	<p>Each SC to have the ability to perform hybrid procedures.</p>	A
A16	<p>Each SC will have a dedicated specialist multidisciplinary team to consider case management. Adult patients undergoing complex interventions or any surgical interventions should be discussed in an appropriate specialist MDT as defined by the local network.</p>	M

A17	Each SC will have access to specialist antenatal/obstetric care to include: a) Obstetric unit and delivery suite b) Fetal medicine c) Fetal echocardiography d) Level III neonatal intensive care e) Regular joint clinics with the cardiologist and specialist obstetrician, with access to specialist anaesthetic advice. f) Regular specialist MDT case conferences with input from high-risk obstetrics, cardiac and obstetric anaesthesia, haematology, neonatal and foetal medicine, contraception and pre-pregnancy care.	M
A18	Each SC will have access to specialised cardiac and obstetric anaesthetists who regularly anaesthetise patients with ACHD.	M
A19	Each SC must: a) Provide 24-hour access to an acute post-op pain management service. b) Implement a pain control policy that includes advice on pain management at home. c) Ensure particular attention is given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	M
A20	SCs should have a palliative care service able to provide good quality end-of-life care in hospital and with well developed shared-care palliative services with the community.	M
A21	Each SC and services within its Congenital Heart Network will hold regular stakeholder meetings for issues such as agreement of protocols, review of audit data and monitoring of performance, as follows: a) Meetings will be held at least every 6 months to ensure the best possible care and outcomes. b) The composition of the stakeholder group should 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). c) Staff from across the Congenital Heart Network must be encouraged by the SC to attend. If physical attendance is not possible, it is essential that all staff from across the Congenital Heart Network are fully involved in the process including by video / teleconferencing and in the decision making about their patients, where necessary.	M
A22	SCs must demonstrate that arrangements are in place for patients and carers to be given an agreed, written care plan that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	M
A23	A pre-operative risk assessment for patients requiring non-cardiac surgery should be undertaken by a specialist ACHD cardiologist prior to any surgery and the location of surgery designated by the ACHD cardiologist. All cardiac surgery should be carried out at the SC. Non-cardiac surgery in patients known or judged to be at high risk should be carried out at an SC.	M
A24	An ACHD Specialist Nurse should be available to provide education, advice and support to nursing staff within intensive care, high dependency care and inpatient wards, and the outpatient department.	M
A25	All healthcare professionals must take part in a programme of continuing professional development that includes appraisal, re-licensing and re-validation consistent with their appropriate professional registration.	M
A26	Each SC must demonstrate a commitment to the training and education of both core and subspecialty level cardiology SpRs in ACHD and heart disease in pregnancy, according to the latest JRCPTB (Joint Royal Colleges of Physicians' Training Board).	A

A27	Each SC must have one individual who is responsible for ensuring continuing professional development in nursing staff delivering ACHD care, and to deliver standardised training and education competency-based programmes across the Congenital Heart Network. These programmes must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	A
A28	Each SC will report on adverse incidents. In addition to contractual and national reporting requirements SCs must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.	M
A29	Each SC will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). Audit of clinical practice should be considered where recognised standards exist or improvements can be made. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance should be undertaken annually.	M
A30	Each SC MUST participate in national programmes for audit and MUST submit data on all interventions, surgery and EP procedures to the national Central Cardiac Audit Database (CCAD), including any emerging data requirements for morbidity audit.	M
A31	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	M
A32	Each SC must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners, and to comply with any mandatory guidelines.	A
A33	Each SC must demonstrate a robust policy for collaboration with each other and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every 5-7 years.	A
A34	Each SC must have, and regularly update, a research strategy and programme that documents current and planned research activity, the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other designated SCs in research activity which aims to address research issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.	A
A35	Each SC must demonstrate close links with one or more academic departments in Higher Education Institutions.	M
A36	Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service, and SCs must demonstrate ongoing structured liaison with patients and groups. SCs should make this feedback openly available to patients, parents / carers and the general public, together with outcome of relevant local and national audits.	A
A37	Each SC should have booking systems that allow for long term follow up (up to 5 years).	A
A38	Each SC should have access to the full range of medical and surgical specialties in an appropriate timeframe to deal with emergency situations.	M

B	<p>LEVEL 2 CARE – INTERMEDIATE CENTRES (ICs)</p> <p>ICs must deliver the requirements of the standards set out in Section A for Level 1 Centres, except where highlighted in B1 below.</p> <p>Standards B2 – B9 specifically apply to ICs.</p> <p>ICs must also observe the standards as set out at C5-C14 inclusive and the network, transition and patient standards in Sections D, E and F.</p>	
B1	<p>The IC must deliver the requirements of the standards set out in Section A for specialist centres (Level 1), with the exception of the following standards which are specific to the specialist centres: A1, A2, A3, A4, A5, A6, A8, A11, A12, A13, A15, A17, A19.</p> <p>The status of remaining individual standards in Section A (e.g. mandatory, desirable) should be observed by ICs.</p>	M
B2	<p>The IC must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care, as defined within network arrangements.</p>	M
B3	<p>The IC will not perform any cardiac surgery and catheter interventions will be limited to procedures for PFOs only. All cardiac surgery cases and those requiring catheter interventions other than for PFO will be referred to the SC at Level 1.</p>	M
B4	<p>Diagnostic catheter procedures, EP procedures and TOE's should not be undertaken outside Specialist Centres unless agreed by the responsible specialist ACHD Cardiologist within an agreed Managed Clinical Network protocol.</p>	M
B5	<p>The IC must deliver emergency care and inpatient admission facilities on a 24hours, 7 days per week basis, with access to advice from a specialist ACHD cardiologist according to network protocols.</p>	M
B6	<p>Each IC must have at least one full-time ACHD specialist based there or one full-time cardiologist with a special interest in ACHD, supported by a visiting ACHD specialist from the SC. (Posts in accordance with BCCA definitions and with evidence of a commitment to continuing professional development in ACHD).</p>	M
B7	<p>Each IC and its ACHD patients must have access to advice and support from an ACHD Nurse Specialist, designated 0.5 WTE registered nurse with a specialist interest. They will participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice as part of the network wide arrangements.</p>	M
B8	<p>The quality of any diagnostic and therapeutic procedures will meet the quality expected for the same procedure in an SC setting.</p>	M
B9	<p>ACHD staff will take part in MDT meetings as required by the network leadership, which may be of a virtual nature and facilitated by communication technology.</p>	M

C	LEVEL 3 CARE - LOCAL CENTRES (LCs) Local Centres (LCs) must also observe the network, transition and patient standards as set out in Sections D, E and F.	
C1	LCs must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care as defined as part of network arrangements.	M
C2	The LC will not perform any ACHD surgery or any catheter interventions, patients requiring this type of care will be referred along network pathways to Level 1.	M
C3	Diagnostic catheter procedures, EP procedures and TOE's should not be undertaken outside Specialist Centres unless agreed by the responsible specialist ACHD Cardiologist within an agreed Managed Clinical Network protocol.	A
C4	The LC must be developing at least one cardiologist with a specialist interest in ACHD in accordance with the BCCA definitions, who is based there and who will be supported by others who visit on an outreach basis from Level 1 or Level 2.	M
C5	The following investigations will be available: a) Blood Testing b) ECG c) Transthoracic Echo d) Chest X ray e) Exercise Testing/6 minute walk test f) 24 hour tapes, event recorders g) Ambulatory blood pressure monitoring	M
C6	The LC will provide: a) Access to advice and support from a designated Cardiac Specialist Nurse with an interest in ACHD. b) A clinical psychology service for patients and carers. c) Booking systems that allow for long term follow up (up to 5 years) d) Access to a dental team e) Palliative care team	A
C7	Patients with moderate or simple conditions may have their transition arrangements in place to transfer to an LC or DGH as long as a specialist ACHD Cardiologist has approved the arrangement and here is an agreed network protocol in place.	M
C8	Each LC should 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.	A
C9	Copies of all correspondence for GP, DGH and SC are copied to the patient to retain in the patient's personal record.	M
C10	Each LC must assist the SC in providing core curriculum level training as per the JRCPTB curricula to all adult cardiology trainees with their network catchment area.	A
C11	LC should regularly participate in specialist MDT meetings led by SC (in person or via tele-communications).	M
C12	The emerging cardiologist with a special interest in ACHD will liaise with other local DGHs, Primary Care and the local cardiac network, forming a link between them and the ACHD network.	M

C13	LC will work collaboratively with SCs to ensure national audit and participation in any research programmes as required.	M
C14 a) b) c) d) e) f) g)	Where patients with ACHD are receiving local antenatal care there should be: Agreement by the ACHD specialist that care is appropriate in that setting for an individual. A care plan provided by the ACHD specialist, disseminated to all physicians involved, the GP and patient. The care plan to state the level of care required and frequency of cardiology review. A plan should be provided for labour and delivery which includes the level of monitoring required. Access to information for patients on any aspect of care including throughout pregnancy and for contraception. Joint clinics between the cardiologist, obstetrician and anaesthetist as appropriate. Pregnancy care for low risk pregnancies subject to specialist maternal medicine.	A
C15	Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service, and LCs must demonstrate ongoing structured liaison with patients and groups. LCs should make this feedback openly available to patients, parents / carers and the general public, together with outcome of relevant local and national audits.	A

D	NETWORK STANDARDS	
D1	<p>Each SC (in partnership with NHS commissioners) must provide active leadership in the Congenital Heart Networks. This will include:</p> <ul style="list-style-type: none"> a) Managing and developing referral, care, treatment and transfer pathways, policies, protocols and procedures. b) Performance monitoring and audit, professional training and development. c) Facilitating the development of as much care and treatment as possible close to the patient's home and the transition to adult services. d) Succession planning throughout the network. 	A
D2	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place with designated centres for adults with Congenital Heart Disease to ensure a seamless pathway of care, led jointly by paediatric and adult cardiologists.	M
D3	All newly diagnosed patients should be seen at least once by an expert ACHD cardiologist and clear care plans agreed for on-going management within the network. All patients with complex conditions should be managed by an SC. The SCs should have shared care arrangements in place with local centres for the treatment and management of non-complex patients.	M
D4	Each patient must be given a single ongoing point of contact, preferably an ACHD Specialist Nurse, who acts as care coordinator for that patient's care across the network.	M
D5	Clear arrangements for advice in the case of emergency, for patients, carers and other professionals, should be established for centres throughout the network and widely disseminated.	A
D6	Pathways must involve transition to adult congenital cardiac services and to other services as appropriate.	M
D7	Each setting in a network will have telemedicine facilities as required to link with the ACHD SC. The level of telemedicine required will be agreed between network members.	A
D8	Each Congenital Heart Network should aspire to provide an indicative 7 whole time equivalent ACHD Specialist Nurses working within a functioning ACHD network, with a minimum of 3 upon creation of the network. The precise number and location of these nurses will depend on geography, population and the configuration of the network.	A
D9	The patient's management plan should be reviewed at each consultation – in all services that comprise the local Congenital Heart Network.	M
D10	Where cases are referred to the specialist MDT for decision on management, they must be considered and responded to within a 3 month maximum, with an aim to respond within a maximum 2 months of referral.	M
D11	ACHD service provision within the Congenital Heart Network will be subject to governance arrangements as set out by the SCs and commissioners (See Section A).	M
D12	All centres in the network will submit data to national audit (CCAD) and local audit as required.	M
D13	All centres will submit data to emerging national audit processes around morbidity measures as required.	M

E	TRANSITION	
E1	Transition and transfer arrangements must be in place between the paediatric cardiac unit(s), the SC, intermediate or local centre as an integral part of the Congenital Heart Network arrangements.	M
E2	SCs will manage all patients with complex conditions and will have in place shared care arrangements for the treatment and management non-complex lesions. These will vary depending on the development of centres within the local congenital heart networks.	M
E3	There will not be a fixed point of transition between children's and adult services but the process of transition should begin around the age of 12 years, taking into account individual circumstances and special needs. Transfer is usually around 16 years of age and will normally be completed by age 18.	M
E4	All patients undergoing transition should be seen at least once for consultation by a specialist with ACHD expertise, in a specialist MDT transfer clinic or equivalent, where clear care plans are agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they are ready to be discharged from the service.	M
E5	Patients, parents and carers should 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 should be fully heard and considered, and the patient should be offered the opportunity to discuss matters in private away from their parents/carers if they wish.	M
E6	Each patient must have a named ACHD Specialist Nurse who, working within a Cardiac Team, is responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and carer.	A
E7	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	A
E8	Adolescents undergoing transition must be supported by age appropriate information and lifestyle advice.	M
E9	The particular needs of young people with learning disabilities and their carers must be considered.	M

F	PATIENT FOCUSED STANDARDS	
F1	Every patient must be seen by a specialist GUCH/ACHD cardiologist (BCCA definition) at least once and given a detailed written care plan forming a patient care record, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	M
F2	Patients and carers must be helped to understand the patient's condition and its impact in order to be able to actively participate in decision making at every stage in their care.	M
F3	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 age appropriate cardiac rehabilitation where required.	M
F4	An ACHD Specialist Nurse should be present at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide literature and general support to the patient.	A
F5	Support for people with learning disabilities should be provided from an appropriate specialist or agency.	M
F6	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 advocates / interpreters where practicable or use of alternative arrangements such as Language Line and learning disability 'passports' which define their communication needs.	M
F7	Copies of all correspondence for GP and local centres should be copied to the patient to retain in the patient's personal record.	M
F8	Patients, carers and all health professionals involved in the patient's care should 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. Clear arrangements for advice in the case of emergency should be in place.	M
F9	Patients and carers should be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publically available ACHD data.	A
F10	Where surgery or intervention is planned, patients and carers should have the opportunity to visit the SC well in advance of admission to meet the team that will be responsible for their care, including the surgeon or interventionist where possible.	A
F11	Admission for planned surgery should be booked for a specific date where possible, with same day cancellation rate no higher than 0.8%.	A
F12	Consent for planned procedures should be sought by the consultant in advance of the week of admission and the status of consent re-checked before the operation.	M
F13	An ACHD Specialist Nurse should be available to support patients and carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	M
F14	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	M

Specialised Services

F15	Accommodation should be provided for carers where appropriate.	A
F16	If waiting lists dictate that a patient can expect to wait longer than 3 months for any surgical or interventional procedure, efforts should be made to place that patient in another centre with shorter waiting times, if the patient agrees.	A
F16	Comprehensive information must be made available in plain English, in all clinical areas, to patients and carers in a wide range of formats and on more than one occasion.	M
F17	Information should include any aspect of care including contraception, pregnancy and dental care that is relevant to their congenital heart condition.	M
F18	Patients and carers must be given details of available local and national support groups (e.g. GUCHPA) at the earliest opportunity.	A

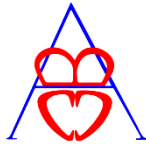
KEY



Mandatory



Agreed plans
in place for
post designation



BRITISH CONGENITAL CARDIAC ASSOCIATION

Definitions of GUCH (Adult Congenital Heart Disease) Specialists and Cardiologists with a Special Interest in GUCH

Notes

- (i) References
 - DH GUCH Guide 2006
 - Bethesda Conference 2001 for definitions of severity
- (ii) These recommendations are based on the hub and spoke model of care (DH Guide p11), where the 'hub' is the specialist (GUCH surgical) centre and the 'spoke' a local (non surgical) centre.
- (iii) All patients should have the opportunity to be seen at least once by a Specialist, regardless of complexity, since medical complexity does not predict a patient's perception of the influence of their heart disease on their quality of life.

Definitions

1. **Specialist GUCH centre** ('hub') defined by DH document p25-26
2. **Local GUCH centre** ('spoke') defined by DH document p27
3. Both a **specialist GUCH cardiologist** and a **cardiologist with a special interest in GUCH** should:
 - Be able to demonstrate ongoing commitment to GUCH CME
 - Be able to demonstrate GUCH clinical workload:
 - frequency of GUCH clinics
 - total number of GUCH patients seen per annum
 - proportion with moderate or complex disease (32nd Bethesda Conference)
4. A **specialist GUCH cardiologist**: one working in a specialist centre ('hub') may have an adult or paediatric background and should:
 - If CCT gained in last 3 years, have trained according to the current GUCH curriculum on the JRCTB website
 - If longer standing consultant, have trained in GUCH and have worked as a GUCH specialist for at least 3 years
 - If all of clinical practice is within congenital cardiology, spend ≥50% of clinical time in GUCH.
If practising in adult cardiology, spend ≥ 75% of clinical time in GUCH
 - Be able to demonstrate close links with local GUCH centres
 - joint clinics or case conference meetings
 - clear referral pathway for GUCH interventions and cardiac surgery

5. A **cardiologist with a special interest in GUCH** may have an adult or paediatric background and work

Either: in a specialist centre ('hub') as part of a GUCH team that includes at least 1 specialist GUCH cardiologist. Thus, for example, a specialist paediatric cardiologist may have a special interest in GUCH and work as part of a specialist GUCH team.

Or: in a local centre ('spoke')

They should:

- If CCT gained in last 3 years, have trained according to the current GUCH curriculum on the JRCTB website
- If longer standing consultant, have trained in GUCH and have worked as a consultant cardiologist with a special interest in GUCH for at least 3 years
- Spend $\geq 10\%$ of clinical time in GUCH.
- For those in a local centre, be able to demonstrate close links with specialist GUCH centre
 - o joint clinics with visiting GUCH specialist, or case conference meetings
 - o clear referral pathway for GUCH interventions and cardiac surgery
- For those in a specialist centre, be able to demonstrate a close links with the specialist GUCH cardiologists within the centre.