

Review of Adult Congenital Heart Disease Services

Engagement on Proposed Model of Care and Draft Designation Standards

11 April – 10 May 2013



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Prepared by the ACHD Advisory Group (Chaired by Professor John Deanfield)

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Foreword

The population of adults with congenital heart disease (ACHD) is increasing, and those living with the condition need specialist advice, support and care. Services for ACHD have not always developed in a systematic way, and in some areas of the country excellent service provision is not always available.

We want to improve services for adults with congenital heart disease by ensuring that quality services are available regardless of where a person lives, with all services working to the same high quality standards. NHS England is leading the review, working closely with a multi-disciplinary expert Advisory Group to create a model of care and designation standards that will ensure all ACHD patients are able to access the right level of care dependent on their condition.

Thank you to everyone who commented on the proposed model of care and draft designation standards for ACHD services during last year's period of engagement. The ACHD Advisory Group has spent the last six months working to revise and improve the proposals in light of the feedback they received during engagement. A number of changes have been made, and we want to know what you think about the revised proposed model of care and draft designation standards.

This document asks some questions on specific standards but we welcome your comments on any of the standards and any aspect of the model of care.

A report on comments received, together with full responses, will be considered by the ACHD Advisory Group on 30 May 2013. The final version of the standards will be used to designate some hospitals in England for the care for adults with congenital heart disease. Proposals will be issued for public consultation by NHS England before any decisions are made.

Changes and retentions made to the draft standards include, but are not limited to:

- We have retained the requirement for Specialist Surgical Centres to be staffed by a minimum of four consultant congenital cardiac surgeons **(Standard B8)**
- We have proposed a new requirement for Specialist Surgical Centres to be co-located with a designated Specialist Paediatric Congenital Cardiac Surgical Centre **(Standard D1)** and we have proposed a definition of co-location in **Appendix E**

- We propose that all Atrial Septal Defect (ASD) closures to be undertaken within a Specialist Surgical Centre; Patent Foramen Ovale (PFO) closures may be undertaken in a non-congenital centre (**Appendix B**)
- We have proposed a number of interdependent services that must be co-located with the Specialist Surgical Centre (**Standards D2-D7**) and with the Specialist Cardiology Centre (**Standards D1-D6**)
- We have revised the standards that relate to the provision of specialist congenital nursing within Specialist Surgical Centres (**Standard B9**) and within Specialist Cardiology Centres (**Standard B8**)
- We have changed our previous proposal so that there is no expectation that Specialist Cardiology Centres will provide 24/7 congenital cardiology cover, but we do propose that they must provide a 1:4 rota comprising congenital and non-congenital cardiologists (**Standard B1**)
- We have more closely defined the proposed requirements for cardiology cover at all centres: Specialist Surgical Centre (**Standard B3**); Specialist Cardiology Centre (**Standard B3**) and Local ACHD Centre (**Standard B2**)
- We have included a new section of proposed standards dedicated to pregnancy and contraception for Specialist Surgical Centres (**Standards J1-J15**); Specialist Cardiology Centres (**Standards J1-J15**); and Local ACHD Centres (**Standards G1 – G2**)
- We have increased the emphasis on providing appropriate information and access to nurses across all centres; see for example **Standards C3, D5, H6, H16, I7, J3**

We want to hear your views on what you think of the proposed model of care and draft designation standards for ACHD services in England. A number of specific questions have been identified within the standards, but we are interested in feedback on all the proposals.

Comments should be submitted by 10 May 2013 to Hannah Weaver:

Letter: Hannah Weaver
NHS England
Southside
105 Victoria Street
London
SW1E 6QT

Email: Hannah.Weaver@nhs.net

If you have any questions on the process please contact Hannah on 020 7932 9128.

Further information about the review and the previous engagement phase can be found on our website at: <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

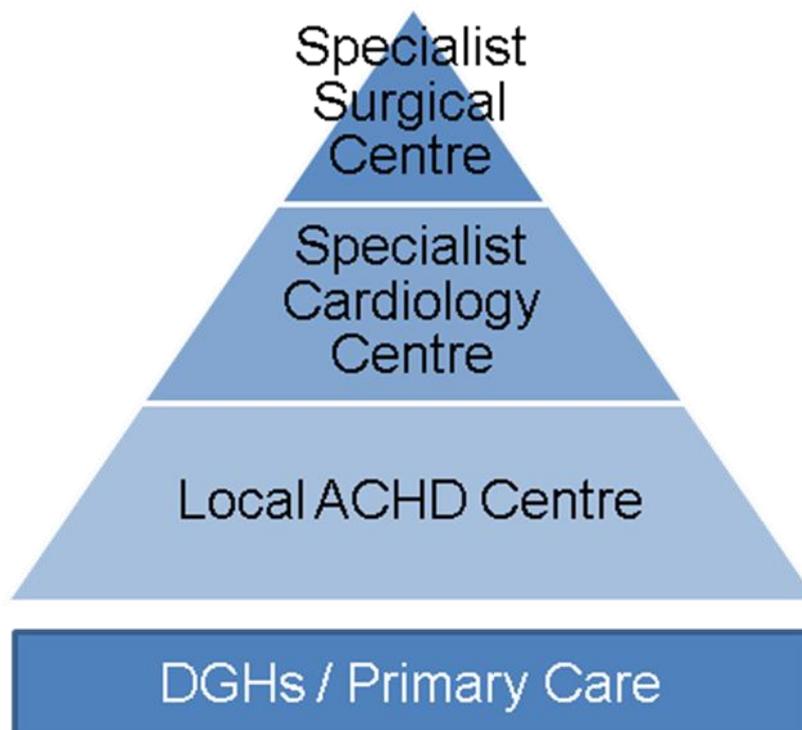
The Proposed ACHD Model of Care

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 Surgical Centres, Specialist Cardiology Centres and Local ACHD Centres – on a network basis and is a more sophisticated version of the hub and spoke model usually followed.

Patients would not necessarily follow a linear path through the three levels of care, depending upon circumstances, and would be able to move from a Specialist Surgical Centre to a Local ACHD Centre and back again without needing to access care at a Specialist Cardiology Centre. Some networks may function adequately without a Specialist Cardiology Centre, depending on local issues and geography.

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 15](#).

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 ACHD Centres, Specialist Cardiology Centres or Specialist Surgical Centres – with patients moving between the levels as required. Patients would not necessarily move in a linear manner between care settings.
- c) The Specialist Surgical Centre would provide leadership and clinical support to a geographically cohesive network of Local ACHD Centres, and may also include one or more Specialist Cardiology Centres depending on geography and other local factors.
- d) Within a framework of commissioning consistent with the NHS England, 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 and as appropriate.
- f) Specialist Surgical 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.
- g) It is recognised that occasionally a non-ACHD cardiac surgeon may discover an incidental congenital defect that is within their capability to address and that it is not possible to develop a model of care that covers every eventuality.
- h) All Specialist Surgical, Specialist Cardiology and Local ACHD Centres must be an integral part of a formally defined and established ACHD network.

- i) Specialist Cardiology Centres would deliver the same quality of care to those with ACHD as the Specialist Surgical Centres, whilst focusing on diagnosis and on-going management of patients.
- j) 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.
- k) 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.
- l) Strong working links would be formed between Specialist Surgical Centres and allied specialist services that may be required by ACHD patients, such as the National Pulmonary Hypertension Service and Obstetrics Cardiology.
- m) Existing patient self-referral would be built in to network policies and would be reflected in the requirements of ACHD standards.
- n) 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 Surgical Centres and Specialist Cardiology Centres.
- o) Cardiologists based at Specialist Surgical Centres and Specialist Cardiology Centres would work across the network, including at outreach clinics, according to local circumstances.
- p) 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.
- q) Specialist Surgical Centres and Specialist Cardiology Centres would provide rehabilitation appropriate to a patient's needs, palliative care, specialist dental care, and contraceptive and pregnancy advice. Local ACHD Centres would understand the need for these services and would refer patients to Specialist Surgical Centres or Specialist Cardiology Centres when necessary.

¹ As defined by British Congenital Cardiac Association guidelines.
Model of Care

- r) 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.

- s) 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. This does not preclude PFO closure from being performed in ACHD services within the congenital heart network.

ACHD Specialist Surgical Centre

All Specialist Surgical Centres must be co-located with a formally designated Specialist Paediatric Congenital Cardiac Surgical Centre and must have 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 BCCA guidelines
- Access to 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 Specialist Cardiology Centres 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 congenital transplantation services, 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 Specialist Cardiology Centres and Local ACHD Centres

ACHD Specialist Cardiology Centre

Services delivered in this setting:

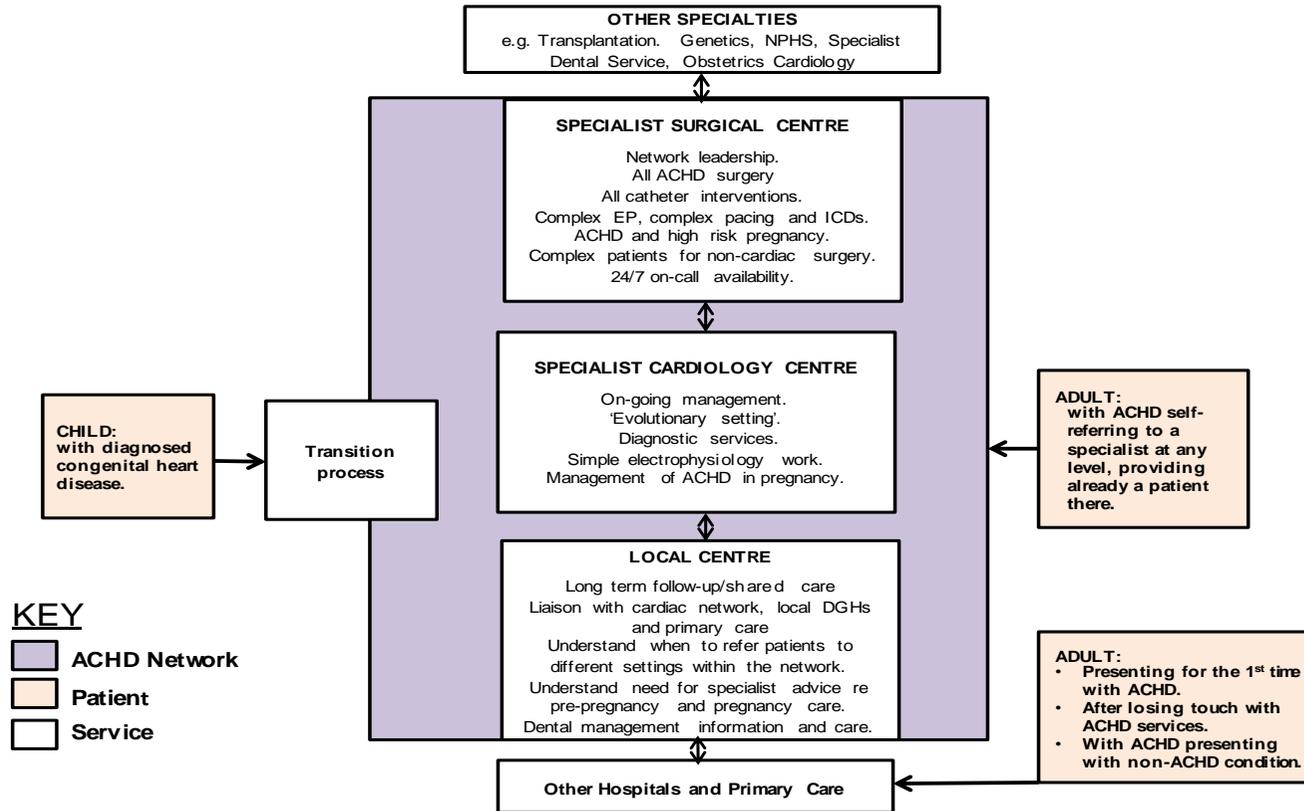
- Specialist Cardiology Centres will not perform any surgical procedures or catheter interventions. (Closure of PFO is not considered an ACHD procedure and may be delivered in this setting)
- A Specialist ACHD Cardiologist and a cardiologist committed to ACHD would be based there and would also work across the network, including at Specialist Surgical Centres and Local ACHD Centres, according to local circumstances
- 1:4 rota comprising congenital and non-congenital cardiologists
- ACHD Specialist Nurses will be based there
- On-going ACHD patient management
- Broad range of diagnostic services, including non-invasive imaging, delivered at the same quality to those in Specialist Surgical Centres
- 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 Specialist Surgical Centres in high risk cases
- Also delivers any service provided at Local ACHD Centres

ACHD Local ACHD Centre

Services delivered in this setting:

- The Local ACHD Centre will be staffed by one cardiologist with an interest in ACHD who will be supported by others who visit on an outreach basis from Specialist Surgical Centres or Specialist Cardiology Centres
- The cardiologist with an interest in ACHD would liaise with primary care and other local DGHs, forming a link between them and the ACHD network
- The cardiologist with an interest in ACHD would also have a formal liaison role between the ACHD network and the local adult cardiac network
- The cardiologist with an 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
- Management of low risk pregnancies
- Advice on lifestyle issues

Proposed Adult Congenital Heart Disease (ACHD) Model of Care



Specialist Surgical Centre Standards

	The Network Approach	Evidence of Compliance	Questions for Engagement	
A1	<p>Specialist Surgical Centres will agree with their Congenital Heart Networks clinical protocols and pathways to care that will:</p> <ul style="list-style-type: none"> • achieve high quality of care at all stages of a seamless pathway in accordance with the model of care • facilitate the development of as much non surgical care and treatment as close as possible to the patient's home • require all ACHD surgery and therapeutic interventions to take place within a Specialist Surgical Centre, see Appendix B for the definition of ACHD Surgery and Interventions • ensure a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, including a decision on the most appropriate location for surgery • address how Specialist ACHD Cardiologists will work across the network, including at Specialist Cardiology Centres and Local ACHD Centres, according to local circumstances • address how Specialist Surgical Centres will advise colleagues within the Congenital Heart Network on the care of patients requiring non-cardiac interventions, including the availability of specialist advice in emergency situations 24/7 • manage urgent self referrals to the Specialist Surgical Centres • enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate 	<p>Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital Heart Network.</p>		M

Specialist Surgical Centre

	facility either in the Specialist Surgical Centre or in another Specialist Surgical Centre, if the need arises			
A2	<p>Each Specialist Surgical Centre must demonstrate formal working relationships with:</p> <ul style="list-style-type: none"> • a cardiothoracic transplant centre staffed by transplant surgeons with a congenital practice • the national Pulmonary Hypertension Service • a cardiac pathologist with expertise in congenital cardiac abnormalities 	Written protocols		M
A3	Each Specialist Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every 5 years.	<p>Written protocols</p> <p>Terms of reference for, and outcome of, peer reviews</p>		M
A4	Each Specialist Surgical Centre will have telemedicine facilities as required to link with designated hospitals in a network. The level of telemedicine required will be agreed between network members. See Appendix C for more detail.	<p>Facilities in place</p> <p>Audit of use and effectiveness</p>		A

Specialist Surgical Centre

	Staffing in the Specialist Centre	Evidence of Compliance	Questions for Engagement	
B1	Each Specialist Surgical Centre must deliver 24/7 emergency care and inpatient admission facilities including a minimum rota of Specialist ACHD Cardiologists of 1:4. See Appendix A for the BCCA definition of a Specialist ACHD Cardiologist.	Named individuals Job descriptions Evidence of qualifications, experience and training		M
B2	Each Specialist Surgical Centre will have a formally nominated Clinical Lead with responsibility for the service overall, who will be supported by designated clinical leads for surgery, cardiac intervention, anaesthesia and critical care. Each Specialist Surgical Centre must have a formally nominated Lead Nurse who is an expert in the field of ACHD providing professional and clinical leadership and support to the team of nurse specialists across the network.	Named individuals Job descriptions		M
B3	Each Specialist Surgical Centre must be staffed by a minimum of 4 WTE Specialist ACHD Cardiologists with an indicative maximum patient workload of 1,500 per WTE cardiologist.	Named individuals Job descriptions Evidence of qualifications, experience and training		M
B4	Each Specialist Surgical Centre must be staffed by at least 2 interventional Specialist ACHD Cardiologists, who may be included in the number referred to in standard B3, or who may be paediatric cardiologists.	Named individuals Job descriptions		M

Specialist Surgical Centre

B5	<p>Cardiologists performing therapeutic catheterisation must perform at least 50 such procedures per year; the Lead Cardiologist must perform at least 100 such procedures per year.</p>	<p>Posts in place</p> <p>Audit of catheter logs</p> <p>Submission of data to the national congenital database in the National Institute for Cardiovascular Outcomes Research</p>	M
B6	<p>Each Specialist Surgical Centre must be staffed by an Electrophysiologist experienced in ACHD.</p>	<p>Named individuals</p> <p>Job Descriptions</p>	M
B7	<p>Each Specialist Surgical Centre must be staffed by a congenital cardiac imaging specialist who may be a cardiologist or a radiologist.</p>	<p>Named individuals</p> <p>Job Descriptions</p>	M
B8	<p>Each Specialist Surgical Centre must be staffed by Congenital Cardiac Surgeons who are each the primary operator in a minimum of 125 congenital heart operations per year (in adults and / or children).</p> <p>Consultant cover for patients undergoing congenital cardiac surgery must be provided by Consultant Congenital Cardiac Surgeons. A Consultant Congenital Cardiac Surgeon must not partake in an on-call rota more frequent than 1:4 (requiring a minimum of 4 surgeons). The rota must be comprised solely of Consultant Congenital Cardiac Surgeons. At the same time as providing cover for ACHD patients, a Consultant Congenital</p>	<p>Named individuals</p> <p>Job Descriptions</p> <p>Audit of Surgical Logs</p> <p>Submission of data to CCAD</p>	M

Specialist Surgical Centre

	Cardiac Surgeon may also provide cover for paediatric congenital cardiac patients.			
B9	Each Specialist Surgical Centre will employ a minimum of 5 whole time equivalent ACHD Specialist Nurses whose role will extend throughout the network. The precise number, above the minimum 5, and location of these nurses will depend on geography, population and the configuration of the network. See Appendix D for the role of the Specialist Nurse.	Staff records Role descriptions	Is this the right number of nurses? See also standard B8 for the Specialist Cardiology Centre	M
B10	Sufficient staff and facilities will be available at the Specialist Surgical Centre to meet the demand for in-patient beds, critical care beds, theatre capacity and service provision as generated by the Congenital Heart Network. When a Specialist Surgical Centre cannot admit a patient for whatever reason it has a responsibility to source a bed at another Specialist Surgical Centre.	Staff rotas Audit of refusals and onward referrals (including reports from other Specialist Surgical Centres)		M
B11	Each Specialist Surgical Centre will have a dedicated specialist multi-disciplinary team to consider case management. Patients undergoing complex interventions or any surgical interventions should be discussed in an appropriate MDT as defined by the local network.	MDT register of attendance and activities		M
B12	Each Specialist Surgical Centre must have onsite administrative support sufficient to provide continuous daytime cover and to respond to patient enquiries.	Job Descriptions		M

Specialist Surgical Centre

B13	Each Specialist Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager responsible for timely audit and database submissions in accordance with necessary timescales.	Job Descriptions		M
	Clinical Facilities	Evidence of Compliance	Questions for Engagement	
C1	Each Specialist Surgical Centre must possess the full range of diagnostic imaging capabilities including CT and MRI scanning, bi-plane catheter lab, contrast and transoesophageal echocardiography and suitable trained radiological or cardiological expertise; CPEX and the 6-minute walk test.	Description of services available		M
C2	Accommodation should be provided for carers where appropriate.	Description of services available		A
C3	Adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, within a dedicated ACHD ward space, and offered cultural and age appropriate cardiac rehabilitation as appropriate, taking into account any learning or physical disability.	Description of services available	Is it feasible to have dedicated ward space for ACHD patients?	M
C4	Each Specialist Surgical Centre must cooperate to allow visiting Specialist ACHD Cardiologists from Specialist Cardiology Centres to gain remote access their own Specialist Cardiology Centre desktop, thus enabling immediate access to patient data. See Appendix C for detailed IT requirements.	Written protocols		M

Specialist Surgical Centre

C5	Each Specialist Surgical Centre must demonstrate the existence of an IT infrastructure that allows a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services in the network.	Description of services available Written protocols		M
Services experienced with patients with congenital heart disease that must be co-located with Specialist Surgical Centres		Evidence of Compliance	Questions for Engagement	
D1	Specialist Surgical Centres must be co-located with a formally designated Specialist Paediatric Congenital Cardiac Surgical Centre. The definition of co-location in this regard is set out in Appendix E.	Description of services available and physical evidence of co-location		M
D2	<p>Specialist Surgical Centres must be co-located on the same hospital site as the following specialties or facilities:</p> <ul style="list-style-type: none"> a. General adult cardiology services, including acute cardiac care unit b. Adult cardiothoracic surgery c. Level 3 Intensive Care Unit, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care. Level 2 High Dependency beds staffed by medical and nursing teams experienced in managing patients with ACHD d. Vascular services including surgery and Interventional Radiology 	Description of services available and physical evidence of co-location		M

Specialist Surgical Centre

	<p>e. Specialised anaesthesia providing 24/7 anaesthetic support by consultants experienced in the management of ACHD patients</p>			
D3	<p>Specialist Surgical Centres must be co-located with the following services. The definition of co-location in this regard is set out in Appendix E.</p> <ul style="list-style-type: none"> a. Clinical haematology b. Ear nose throat c. Gastroenterology d. General medicine e. General Surgery f. Gynaecology g. Hepatology h. Infectious diseases i. Learning Disability Team j. Level III neonatal unit k. Microbiology l. Nephrology m. Neurology n. Neurosurgery o. Obstetric Unit with Maternal Fetal Medicine Specialist/s p. Orthopaedics q. Physiotherapy (service must be integrated with the ACHD team) r. Psychiatry s. Renal medicine t. Respiratory medicine u. Urology 	<p>Description of services available and physical evidence of co-location</p>	<p>Are there any other relevant services?</p>	M

Specialist Surgical Centre

D4	<p>Where co-location (as defined in Appendix E) is not achievable, it is required that advice and consultation must be available by the following working day. The services must be experienced in patients with congenital heart disease.</p> <ul style="list-style-type: none"> a. Cardiac rehabilitation b. Clinical biochemistry c. Clinical genetics d. Clinical immunology e. Clinical psychology (service must be integrated with the ACHD team) f. Dentistry g. Dermatology h. Diabetes i. Dietician j. Endocrinology k. Maxillo-facial surgery l. Occupational therapy m. Palliative care n. Rheumatology o. Sexual health 	Description of services available	Are there any other relevant services?	M
D5	<p>Each Specialist Surgical Centre must have a palliative care service able to provide end-of-life care in hospital and shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and family. This should also include bereavement follow-up and referral on for ongoing emotional support of the family.</p>	Description of services available		M

Specialist Surgical Centre

D6	Each Specialist Surgical Centre will provide 24-hour access to an acute pain management service which will ensure that particular attention is given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, illness or disability. Specialist Surgical Centres will provide access to chronic pain services.	Description of services available		M
D7	Each Specialist Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of older people with congenital heart disease.	Description of services available	Are the standards sufficient for the needs of older people?	M
Training and Education		Evidence of Compliance	Questions for Engagement	
E1	Each Specialist Surgical Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver standardised training and education competency-based programmes across the Congenital Heart Network. These programmes must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	<p>Named individuals</p> <p>Job Descriptions</p> <p>Training register and training records</p> <p>Staff appraisal documentation</p> <p>Written outcomes of reviews of training programmes</p>		M
E2	Each Specialist Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level cardiology SpRs in ACHD and heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training	Training register and training records		M

Specialist Surgical Centre

	Board curriculum.			
	Governance and Audit	Evidence of Compliance	Questions for Engagement	
F1	Each Specialist Surgical Centre must demonstrate that all clinical teams are operating within a robust and documented clinical governance framework, including regular Multi-Disciplinary Team Meetings whose role extends to reflecting on adverse incidents.	Written protocols MDT register of attendance and activities		M
F2	Each Specialist Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements Specialist Surgical Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks.	Reported adverse health care events, including reports from other Specialist Surgical Centres. Evidence of implementation of action plans.		M
F3	Each Specialist Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). Audit of clinical practice should be considered where recognised standards exist or improvements can be made. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance should be undertaken annually.	Data entry Evidence of audits		M
F4	Each Specialist Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery and electrophysiology procedures to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for	Submission of data to the national congenital database in the National Institute for Cardiovascular Outcomes Research		M

Specialist Surgical Centre

	morbidity audit.			
F5	Each Specialist Surgical Centre 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.	New Treatment Review Committee NICE procedures credentialing		M
F6	Where cases are referred to the specialist MDT for decision on management, they must be considered and responded to within a maximum of 6 weeks.	MDT register of attendance and activities	Is a maximum of 6 weeks an appropriate amount of time?	M
F7	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Audit of cancellations and evidence of re-scheduling		M
F8	If waiting lists dictate that a patient can expect to wait longer than 3 months for any surgical or interventional procedure, all reasonable steps must be taken to offer a range of alternative providers, if the patient agrees.	Written protocols Access audit		A
	Academic Research	Evidence of Compliance	Questions for Engagement	
G1	Each Specialist Surgical Centre must have, and regularly update, a research strategy and research programme that documents current and planned research activity in the field of ACHD; 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 Specialist Surgical Centres and Specialist Cardiology Centres in research activity which aims to address research issues that are important for the further	Research Strategy Register of grant applications Register of research activity		M

Specialist Surgical Centre

	development and improvement of clinical practice, for the benefit of ACHD patients.			
G2	Each Specialist Surgical Centre must demonstrate close links with one or more academic departments in Higher Education Institutions.	<p>Research Strategy</p> <p>Register of grant applications</p> <p>Register of research activity</p>		M
	Communication with Patients	Evidence of Compliance	Questions for Engagement	
H1	Every patient must be seen by a Specialist ACHD Cardiologist (BCCA definition) at least once and given a detailed written care plan forming a patient care record, in language they understand/jargon free, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	<p>Written protocols</p> <p>Patient/carer literature</p>		M
H2	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.	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaires</p>		M
H3	Specialist Surgical Centres 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.	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaires</p>		M

Specialist Surgical Centre

H4	<p>Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service, and Specialist Surgical Centres must demonstrate ongoing structured liaison with patients and groups, including evidence of how feedback is formally considered. Specialist Surgical Centres should make this feedback openly available to patients, parents / carers and the general public, together with outcome of relevant local and national audits.</p>	<p>Written protocols</p> <p>Written records of complaints or feedback</p> <p>Written records of how feedback was considered and acted upon</p> <p>Patient / carer literature</p> <p>Patient / carer questionnaires</p>		M
H5	<p>Each Specialist Surgical Centre should have booking systems that allow for long term follow up (up to 5 years).</p>	<p>Written protocols</p> <p>Facilities in place</p>		M
H6	<p>Each patient must be given a single ongoing point of contact, who acts as care coordinator for that patient's care across the network. These contact details will be given to each patient when they attend the outpatient clinic and will also be available on the department letter head.</p>	<p>Written protocols and audit of compliance</p> <p>Job descriptions</p>		M
H7	<p>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.</p>	<p>Role description</p> <p>Patient/carer literature</p> <p>Audit of attendance</p> <p>Patient/carer questionnaires</p>		A

Specialist Surgical Centre

H8	Support for people with learning disabilities should be provided from an appropriate specialist or agency.	Written protocols and audit of compliance	Are the standards sufficient for the needs of people with learning disabilities?	M
H9	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 practical or use of alternative arrangements such as Language Line and learning disability 'passports' which define their communication needs.	Written protocols and audit of compliance		M
H10	Copies of all correspondence for GP and local centres should be copied to the patient in language they understand/jargon free to retain in the patient's personal record in accordance with national guidance.	Written protocols and audit of compliance		M
H11	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.	Written protocols Patient/carer literature Audit of out of hours advice given Patient/carer questionnaires		M
H12	Patients and carers should be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data.	Written protocols Patient/carer literature		A

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		Audit of onward referrals Patient/carer questionnaires		
H13	Where surgery or intervention is planned, patients and carers should have the opportunity to visit the Specialist Surgical Centre well in advance of admission to meet the team and ACHD Specialist Nurse that will be responsible for their care, including the surgeon or interventionist where possible.	Written protocols Pre-admission process Patient/carer literature Patient/carer questionnaires		A
H14	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.	Job descriptions Written protocols Patient/carer literature Access audit Patient/carer questionnaires		M
H15	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.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M

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H16	Information should include any aspect of care, including contraception, pregnancy, dental care and lifestyle issues, that is relevant to their congenital heart condition. Information on welfare benefits and social services should also be provided.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M
H17	Patients and carers must be given details of available local and national support groups (e.g. The Somerville Foundation, previously known as GUCHPA) at the earliest opportunity.	Written protocols Patient/carer literature Patient/carer questionnaires		A
H18	The patient's management plan should be reviewed at each consultation – in all services that comprise the local Congenital Heart Network.	Written protocols Audit of patient records		M
	Transition	Evidence of Compliance	Questions for Engagement	
I1	Transition and transfer arrangements must be in place between the relevant paediatric congenital cardiac unit(s), the ACHD Specialist Surgical Centre, ACHD Specialist Cardiology Centre or Local ACHD Centres as an integral part of the Congenital Heart Network arrangements.	Written protocols		M
I2	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	Written protocols		M

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	special needs. Transfer is usually around 16 years of age and will normally be completed by age 18.			
13	All patients undergoing transition should be seen at least once for consultation by a specialist with ACHD expertise and an ACHD Specialist Nurse, in a specialist MDT transfer clinic or equivalent. Clear care plans must be 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.	Written protocols Audit of patient records		M
14	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.	Written protocols Patient/carer literature Patient/carer questionnaire		M
15	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.	Role descriptions Written protocols		A
16	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Written protocols		A
17	Young people undergoing transition must be supported by age appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim	Written protocols Patient/carer literature		M

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	to ensure that they are fully confident in managing their own condition and health care. In the clinic they will see a Clinical Nurse Specialist, who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle. The cardiologist will discuss the treatment plan with the young person and discuss it with their family when appropriate. The young person will have some independent time to talk with their cardiologist and nurse specialist.	Patient/carer questionnaire		
I8	The particular needs of young people with learning disabilities and their carers must be considered.	Written protocols Patient/carer literature Patient/carer questionnaire		M
	Pregnancy and Contraception	Evidence of Compliance	Questions for Engagement	
J1	Each Specialist Surgical Centre must be staffed by a cardiologist with special expertise in pregnancy in heart disease, with arrangements for cover within the centre.	Named individuals Job Descriptions		M
J2	All female patients of childbearing age should have access to a specialist service that provides contraceptive advice and counselling by a consultant cardiologist and nurse specialist with expertise in pregnancy and contraception in congenital heart disease. They should have ready access to appropriate contraception.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J3	Age appropriate discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture,	Written protocols		M

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	psychological and cognitive ability level and taking into account any personal/cultural expectations for the future.	Patient/carer literature Patient/carer questionnaire		
J4	All female patients of childbearing age should be given the opportunity to discuss their child-bearing potential with a consultant cardiologist and a nurse specialist with special expertise in pregnancy in heart disease.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J5	All female patients of childbearing age should be offered personalised pre-pregnancy counselling by a consultant cardiologist and a nurse specialist both of whom must have special expertise in pregnancy in congenital heart disease.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J6	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 3-4) risk* should receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with special expertise in pregnancy in women with congenital heart disease. *See: Thorne SA, MacGregor AE, Nelson Piercy C. Risk of Contraception and Pregnancy in Heart Disease. Education in Heart 2006; 92 1520-1525.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J7	Specialist genetic counselling should be available for those with heritable conditions.	Written protocols Patient/carer literature Patient/carer questionnaire		M

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J8	All male patients should have access to counselling and information about contraception and recurrence risk by a consultant cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J9	Women with congenital heart disease must be discussed with the Specialist ACHD Cardiologist with specialist expertise in pregnancy in heart disease at a Specialist Surgical Centre or Specialist Cardiology Centre immediately once they are pregnant to plan their care. This must include access to contraception and termination. The individualised care plan must cover the ante-natal, intra-partum and post-natal 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.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J10	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, should be managed at the Specialist Surgical Centre during pregnancy, delivery and the puerperium.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J11	Women with moderate or high risk conditions, who are not at risk of requiring such intervention during pregnancy, may be managed at an ACHD Specialist Cardiology Centre, with network agreement.	Written protocols Patient/carer literature Patient/carer questionnaire		M

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J12	Each Specialist Surgical Centre must be co-located, as defined by Appendix E, with a specialist tertiary maternity unit delivered within a dedicated multidisciplinary service staffed by a consultant cardiologist with expertise in pregnancy in congenital heart disease, a maternal medicine specialist who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy.	Description of services available and physical evidence of co-location	M
J13	The multidisciplinary team must include consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Written protocols MDT register of attendance and activities	M
J14	These specialised maternity services must have sufficient activity to maintain expertise, ensure best practice, training opportunities and for the organizational infrastructure, staffing, facilities and equipment to be clinically and economically efficient. They should have robust risk management and performance monitoring processes.	Written protocols	M
J15	They will provide regular joint clinics with the cardiologist with expertise in congenital heart disease in pregnancy, specialist obstetrician and with access to an obstetric anaesthetist. Regular specialist MDT case conferences should 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.	Written protocols MDT register of attendance and activities	M

Specialist Surgical Centre

Key:

M = Mandatory

A = Agreed plans in place post designation

Specialist Cardiology Centre Standards

	The Network Approach	Evidence of Compliance	Questions for Engagement	
A1	<p>Specialist Cardiology Centres will agree with their Congenital Heart Networks clinical protocols and pathways to care that will:</p> <ul style="list-style-type: none"> • achieve high quality of care at all stages of a seamless pathway in accordance with the model of care • facilitate the development of as much non surgical care and treatment as close as possible to the patient’s home • require all ACHD surgery and therapeutic interventions to take place within a Specialist Surgical Centre; Specialist Cardiology Centres may not undertake any ACHD surgeries or interventions; see Appendix B for the definition of ACHD Surgery and Interventions • address how Specialist ACHD Cardiologists will work across the network, including at Specialist Surgical Centres and Local ACHD Centres, according to local circumstances • address how Specialist Cardiology Centres will adequately communicate with colleagues within the Congenital Heart Network (both Specialist Surgical Centre and Local ACHD Centres) on the care of patients requiring non-cardiac interventions • 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 	<p>Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital Heart Network.</p>		M

Specialist Cardiology Centre

	<ul style="list-style-type: none"> manage urgent self referrals to both the Specialist Cardiology Centres and the Specialist Surgical Centres 			
A2	Each Specialist Cardiology Centre must demonstrate formal protocols with a Specialist Surgical Centre. Specialist Cardiology Centres will routinely refer patients to their primary network MDT. 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 Cardiology Centre must inform the Specialist Surgical Centre in writing of the reasons for referral.	Written protocols		M
A3	Each Specialist Cardiology Centre must demonstrate formal working relationship with the national Pulmonary Hypertension Service.	Written protocols		M
A4	Each Specialist Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners at a clinical, audit, research and administrative level, including formal inter-unit peer review every 5 years.	Written protocols Terms of reference for, and outcome of, peer reviews		M
A5	Specialist Cardiology Centres will have telemedicine facilities as required to link with the ACHD Specialist Surgical Centre. The level of telemedicine required will be agreed between network members. See Appendix C for more detail. The ACHD cardiologist will attend (in person or by VC link) the weekly Specialist Surgical Centre MDT.	Facilities in place Audit of use and effectiveness		A

Specialist Cardiology Centre

	Staffing in the Specialist Centre	Evidence of Compliance	Questions for Engagement	
B1	<p>Network provision of on call advice (or request for transfer) for any admitting cardiologist at Specialist Cardiology Centres will be available from the on call Specialist ACHD Cardiologist at the Specialist Surgical Centre. Each Specialist Cardiology Centre must have a dedicated consultant led cardiology on-call rota of 1:4 cardiologists comprising congenital and non-congenital cardiologists.</p> <p>It is desirable that there is a subspecialty rota for rhythm management (HRS definition).</p>	<p>Named individuals</p> <p>Job descriptions</p> <p>Evidence of qualifications, experience and training</p>		M
B2	<p>Each Specialist Cardiology Centre will have a formally nominated Clinical ACHD lead with responsibility for the service at the Specialist Cardiology Centre as well as development within the network under the overall direction of the Clinical Lead of the Specialist Surgical Centre.</p> <p>Each Specialist Cardiology Centre must 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 Surgical Centre.</p>	<p>Named individuals</p> <p>Job descriptions</p>		M
B3	<p>Each Specialist Cardiology Centre must be staffed by 1 lead cardiologist who is an ACHD Specialist spending at least 0.8 WTE clinical time on ACHD.</p>	<p>Named individuals</p> <p>Job descriptions</p>		M

Specialist Cardiology Centre

	<p>AND</p> <p>At least 1 cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD.</p> <p>Each cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist.</p>			
B4	Diagnostic catheter procedures may be undertaken at a Specialist Cardiology Centre, within an agreed Managed Clinical Network protocol.	Managed Clinical Network protocols		M
B5	A Specialist ACHD Cardiologist who visits the Specialist Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year.	<p>Audit of catheter logs</p> <p>Submission of data to the national congenital database in the National Institute for Cardiovascular Outcomes Research</p>		M
B6	Electrophysiology will usually be undertaken at a Specialist Surgical Centre, but it may be undertaken at a Specialist Cardiology Centre if the network decides this is appropriate according to local circumstances and governance arrangements.	Network protocols		M
B7	<p>Each Specialist Cardiology Centre must be staffed by a cardiologist or radiologist who has undertaken formal training in congenital cardiac imaging (echo, MRI and CT).</p> <p>The centre will be undertaking >500 cardiac MRI/yr (as included in</p>	<p>Named individuals</p> <p>Job Descriptions</p> <p>Evidence of qualifications,</p>		M

Specialist Cardiology Centre

	the standards for inherited cardiac diseases) with joint reporting (ACHD cardiologist and radiologist) and dedicated MDT review. There will be shared protocols for MRI defined by Specialist Surgical Centre cardiologists and radiologists. There must be image exchange portal (IEP) technology to allow rapid transfer of images between Specialist Cardiology Centres and Specialist Surgical Centres.	experience and training		
B8	Each Specialist Cardiology Centre will employ a minimum of 2 whole time equivalent ACHD Specialist Nurses whose role will extend throughout the network. The precise number, above the minimum 2, and location of these nurses will depend on geography, population and the configuration of the network.	Staff records Role descriptions	Is this the right number of nurses? See also standard B9 for the Specialist Surgical Centre	M
B9	Sufficient staff and facilities will be available at the Specialist Cardiology Centre to meet the demand for in-patient beds. When a Specialist Cardiology Centre cannot admit a patient for whatever reason it has a responsibility to source a bed at another Specialist Surgical Centre or Specialist Cardiology Centre.	Staff rotas Audit of refusals and onward referrals (including reports from other Specialist Surgical Centres)		M
B10	Each Specialist Cardiology Centre will have a dedicated specialist multi-disciplinary team to consider case management. Patients to be considered for cardiac interventions or cardiac surgery (to be undertaken only at the Specialist Surgical Centre) should be discussed in the appropriate MDT with Specialist Surgical Centre as defined by the local network.	MDT register of attendance and activities		M

Specialist Cardiology Centre

B11	Each Specialist Cardiology Centre must have onsite administrative support sufficient to provide continuous daytime cover and to respond to patient enquiries.	Job Descriptions		M
	Clinical Facilities	Evidence of Compliance	Questions for Engagement	
C1	<p>Each Specialist Cardiology Centre must possess the full range of diagnostic imaging capabilities including CT and MRI scanning with suitably trained radiological or cardiological expertise, contrast and transoesophageal echocardiography; CPEX and the 6-minute walk test.</p> <p>Patients undergoing investigations at the Specialist Cardiology Centre must receive the same level of care as that received at a Specialist Surgical Centre (excluding specific haemodynamic assessment for which follow on intervention may be deemed necessary).</p>	Description of services available		M
C2	Accommodation should be provided for carers where appropriate.	Description of services available		A
C3	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 as appropriate, taking into account any learning or physical disability.	Description of services available		M

Specialist Cardiology Centre

C4	Each Specialist Cardiology Centre must cooperate to allow visiting Specialist ACHD Cardiologists from Specialist Surgical Centres to gain remote access their own Specialist Surgical Centre desktop, thus enabling immediate access to patient data. See Appendix C for detailed IT requirements.	Written protocols		M
C5	Each Specialist Cardiology Centre must demonstrate the existence of an IT infrastructure that allows a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services in the network.	Description of services available Written protocols		M
Services experienced with patients with congenital heart disease that must be co-located with Specialist Cardiology Centres		Evidence of Compliance	Questions for Engagement	
D1	Specialist Cardiology Centres must be co-located on the same hospital site as the following specialties or facilities: <ul style="list-style-type: none"> • General adult cardiology services, including acute cardiac care unit • Level 3 Intensive Care Unit • Level 2 High Dependency beds • Vascular services including surgery • Interventional Radiology 	Description of services available and physical evidence of co-location		M
D2	Specialist Cardiology Centres must be co-located with the following services. The definition of co-location in this regard is set out in Appendix E. <p>a. Clinical haematology</p>	Description of services available and physical evidence of co-location	Are there any other relevant services?	M

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	<ul style="list-style-type: none"> b. Ear nose throat c. Gastroenterology d. General medicine e. General Surgery f. Gynaecology g. Hepatology h. Infectious diseases i. Learning Disability Team j. Level III neonatal unit k. Microbiology l. Nephrology m. Neurology n. Neurosurgery o. Obstetric Unit with Maternal Fetal Medicine Specialist/s p. Orthopaedics q. Physiotherapy (service must be integrated with the ACHD team) r. Psychiatry s. Renal medicine t. Respiratory medicine u. Urology 			
D3	<p>Where co-location (as defined in Appendix E) is not achievable, it is required that advice and consultation must be available by the following working day. The services must be experienced in patients with congenital heart disease.</p> <ul style="list-style-type: none"> a. Cardiac rehabilitation b. Clinical biochemistry c. Clinical genetics 	Description of services available	Are there any other relevant services?	M

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	<ul style="list-style-type: none"> d. Clinical immunology e. Clinical psychology (service must be integrated with the ACHD team) f. Dentistry g. Dermatology h. Diabetes i. Dietician j. Endocrinology k. Maxillo-facial surgery l. Occupational therapy m. Palliative care n. Rheumatology o. Sexual health 			
D4	<p>Each Specialist Cardiology Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and family. This should also include bereavement follow-up and referral on for ongoing emotional support of the family.</p>	Description of services available		M
D5	<p>Each Specialist Cardiology Centre will provide 24-hour access to an acute pain management service which will ensure that particular attention is given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, illness or disability. Specialist Cardiology Centres will provide access to chronic pain services.</p>	Description of services available		M

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D6	Each Specialist Cardiology Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of older people with congenital heart disease.	Description of services available	Are the standards sufficient for the needs of older people?	M
	Training and Education	Evidence of Compliance	Questions for Engagement	
E1	Each Specialist Cardiology Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at Specialist Cardiology Centre. This individual will work with those at Specialist Surgical Centre 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.	<p>Named individuals</p> <p>Job Descriptions</p> <p>Training register and training records</p> <p>Staff appraisal documentation</p> <p>Written outcomes of reviews of training programmes</p>		M
E2	Each Specialist Cardiology Centre must demonstrate a commitment to the training and education of cardiology SpRs in ACHD and heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Training register and training records		M

Specialist Cardiology Centre

	Governance and Audit	Evidence of Compliance	Questions for Engagement	
F1	Each Specialist Cardiology Centre must demonstrate that all clinical teams are operating within a robust and documented clinical governance framework, including regular Network Multi-Disciplinary Team Meetings with Specialist Surgical Centres, whose role extends to reflecting on adverse incidents.	Written protocols MDT register of attendance and activities		M
F2	Each Specialist Cardiology Centre will report on adverse incidents and action plans at the Network audit day held regularly.	Reported adverse health care events, including reports from other Specialist Surgical Centres. Evidence of implementation of action plans.		M
F3	Each Specialist Cardiology Centre will have a robust internal database. 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.	Data entry Evidence of audits		M
F4	Each Specialist Cardiology Centre must participate in national programmes for audit and must submit data on electrophysiology procedures to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Submission of data to the national congenital database in the National Institute for Cardiovascular Outcomes Research		M

Specialist Cardiology Centre

F5	Each Specialist Cardiology Centre 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.	New Treatment Review Committee NICE procedures credentialing		M
F6	Where cases are referred to the specialist MDT for decision on management, they must be considered and responded to within a maximum of 6 weeks.	MDT register of attendance and activities	Is a maximum of 6 weeks an appropriate amount of time?	M
	Academic Research	Evidence of Compliance	Questions for Engagement	
G1	Each Specialist Cardiology Centre must have, and regularly update, a research strategy and research programme that documents current and planned research activity in the field of ACHD; 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 Specialist Surgical Centres and Specialist Cardiology Centres 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.	Research Strategy Register of grant applications Register of research activity		M
G2	Each Specialist Cardiology Centre should demonstrate close links with one or more academic departments in Higher Education Institutions.	Research Strategy Register of grant applications Register of research activity		M

Specialist Cardiology Centre

	Communication with Patients	Evidence of Compliance	Questions for Engagement	
H1	Every patient must be seen by a Specialist ACHD Cardiologist (BCCA definition) at least once and given a detailed written care plan forming a patient care record, in language they understand/jargon free, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Written protocols Patient/carer literature		M
H2	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.	Written protocols Patient/carer literature Patient/carer questionnaires		M
H3	Specialist Cardiology Centres 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.	Written protocols Patient/carer literature Patient/carer questionnaires		M
H4	Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service, and Specialist Cardiology Centres must demonstrate ongoing structured liaison with patients and groups, including evidence of how feedback is formally considered. Specialist Cardiology Centres should make this feedback openly available to patients, parents / carers and the general public, together with outcome of relevant local and national audits.	Written protocols Written records of complaints or feedback Written records of how feedback was considered and acted upon		M

Specialist Cardiology Centre

		<p>Patient / carer literature</p> <p>Patient / carer questionnaires</p>		
H5	Each Specialist Cardiology Centre should have booking systems that allow for long term follow up (up to 5 years).	<p>Written protocols</p> <p>Facilities in place</p>		M
H6	Each patient must be given a single ongoing point of contact, who acts as care coordinator for that patient's care across the network. These contact details will be given to each patient when they attend the outpatient clinic and will also be available on the department letter head.	<p>Written protocols and audit of compliance</p> <p>Job descriptions</p>		M
H7	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.	<p>Role description</p> <p>Patient/carer literature</p> <p>Audit of attendance</p> <p>Patient/carer questionnaires</p>		A
H8	Support for people with learning disabilities should be provided from an appropriate specialist or agency.	<p>Written protocols and audit of compliance</p>	<p>Are the standards sufficient for the needs of people with learning disabilities?</p>	M

Specialist Cardiology Centre

H9	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.	Written protocols and audit of compliance	M
H10	Copies of all correspondence for GP and local centres should be copied to the patient in language they understand/jargon free to retain in the patient's personal record in accordance with national guidance.	Written protocols and audit of compliance	M
H11	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.	Written protocols Patient/carer literature Audit of out of hours advice given Patient/carer questionnaires	M
H12	Patients and carers should be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data.	Written protocols Patient/carer literature Audit of onward referrals Patient/carer questionnaires	A

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H13	Specialist Cardiology Centres should facilitate the ability for patients and carers to be able to visit the Specialist Surgical Centre well in advance of any planned surgery or intervention to meet the team and ACHD Specialist Nurse that will be responsible for their care, including the surgeon or interventionist where possible.	Written protocols Patient/carer literature Patient/carer questionnaires		A
H14	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.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M
H15	Information should include any aspect of care including contraception, pregnancy, dental care and lifestyle issues that is relevant to their congenital heart condition. Information on welfare benefits and social services should also be provided.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M
H16	Patients and carers must be given details of available local and national support groups (e.g. The Somerville Foundation, previously known as GUCHPA) at the earliest opportunity.	Written protocols Patient/carer literature Patient/carer questionnaires		A

Specialist Cardiology Centre

H17	The patient's management plan should be reviewed at each consultation – in all services that comprise the local Congenital Heart Network.	Written protocols Audit of patient records		M
	Transition	Evidence of Compliance	Questions for Engagement	
I1	Transition and transfer arrangements must be in place between the relevant paediatric congenital cardiac unit(s), the ACHD Specialist Surgical Centre, ACHD Specialist Cardiology Centre or Local ACHD Centres as an integral part of the Congenital Heart Network arrangements.	Written protocols		M
I2	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.	Written protocols		M
I3	All patients undergoing transition should be seen at least once for consultation by a specialist with ACHD expertise and an ACHD Specialist Nurse, in a specialist MDT transfer clinic or equivalent. Clear care plans must be 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.	Written protocols Audit of patient records		M
I4	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	Written protocols Patient/carers literature		M

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	offered the opportunity to discuss matters in private away from their parents/carers if they wish.	Patient/carer questionnaire		
15	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.	Role descriptions Written protocols		A
16	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Written protocols		A
17	Young people undergoing transition must be supported by age appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic they will see a Clinical Nurse Specialist, who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle. The cardiologist will discuss the treatment plan with the young person and discuss it with their family when appropriate. The young person will have some independent time to talk with their cardiologist and nurse specialist.	Written protocols Patient/carer literature Patient/carer questionnaire		M
18	The particular needs of young people with learning disabilities and their carers must be considered.	Written protocols Patient/carer literature		M

Specialist Cardiology Centre

		Patient/carer questionnaire		
	Pregnancy and Contraception	Evidence of Compliance	Questions for Engagement	
J1	Each Specialist Cardiology Centre must be staffed by a cardiologist with special expertise in pregnancy in heart disease, with arrangements for cover within the centre.	Named individuals Job Descriptions		M
J2	All female patients of childbearing age should have access to a specialist service that provides contraceptive advice and counselling by a consultant cardiologist and nurse specialist with expertise in pregnancy and contraception in congenital heart disease. They should have ready access to appropriate contraception.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J3	Age appropriate discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, psychological and cognitive ability level and taking into account any personal/cultural expectations for the future.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J4	All female patients of childbearing age should be given the opportunity to discuss their child-bearing potential with a consultant cardiologist and a nurse specialist with special expertise in pregnancy in heart disease.	Written protocols Patient/carer literature Patient/carer questionnaire		M

Specialist Cardiology Centre

J5	All female patients of childbearing age should be offered personalised pre-pregnancy counselling by a consultant cardiologist and a nurse specialist both of whom must have special expertise in pregnancy in congenital heart disease.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J6	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 3-4) risk* should receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with special expertise in pregnancy in women with congenital heart disease. *See: Thorne SA, MacGregor AE, Nelson Piercy C. Risk of Contraception and Pregnancy in Heart Disease. Education in <i>Heart</i> 2006; 92 1520-1525.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J7	Specialist genetic counselling should be available for those with heritable conditions.	Written protocols Patient/carer literature Patient/carer questionnaire		M
J8	All male patients should have access to counselling and information about contraception and recurrence risk by a consultant cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Written protocols Patient/carer literature Patient/carer questionnaire		M

Specialist Cardiology Centre

J9	<p>Women with congenital heart disease must be discussed with the Specialist ACHD Cardiologist with specialist expertise in pregnancy in heart disease at a Specialist Surgical Centre or Specialist Cardiology Centre immediately once they are pregnant to plan their care. This must include access to contraception and termination. The individualised care plan must cover the ante natal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery.</p>	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaire</p>		M
J10	<p>Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, should be managed at the Specialist Surgical Centre during pregnancy, delivery and the puerperium.</p>	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaire</p>		M
J11	<p>Women with moderate or high risk conditions, who are not at risk of requiring such intervention during pregnancy, may be managed at an ACHD Specialist Cardiology Centre, with network agreement.</p>	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaire</p>		M
J12	<p>Each Specialist Cardiology Centre must be co-located , as defined by Appendix E, with a specialist tertiary maternity unit delivered within a dedicated multidisciplinary service staffed by a consultant cardiologist with expertise in pregnancy in congenital heart disease, a maternal medicine specialist who has undergone training in pregnancy in congenital heart disease, and a supporting</p>	<p>Description of services available and physical evidence of co-location</p>		M

Specialist Cardiology Centre

	multidisciplinary team with experience of managing congenital heart disease in pregnancy.			
J13	The multidisciplinary team must include consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Written protocols MDT register of attendance and activities		M
J14	These specialised maternity services must have sufficient activity to maintain expertise, ensure best practice, training opportunities and for the organizational infrastructure, staffing, facilities and equipment to be clinically and economically efficient. They should have robust risk management and performance monitoring processes.	Written protocols		M
J15	They will provide regular joint clinics with the cardiologist with expertise in congenital heart disease in pregnancy, specialist obstetrician and with access to an obstetric anaesthetist. Regular specialist MDT case conferences should 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.	Written protocols MDT register of attendance and activities		M

Key:

M = Mandatory

A = Agreed plans in place post designation

Local ACHD Centre Standards

	The Network Approach	Evidence of Compliance	Questions for Engagement	
A1	<p>Local ACHD Centres will agree with their Congenital Heart Networks clinical protocols and pathways to care that will:</p> <ul style="list-style-type: none"> • achieve high quality of care at all stages of a seamless pathway in accordance with the model of care • facilitate the development of as much non surgical care and treatment as close as possible to the patient's home • require all ACHD surgery and therapeutic interventions to take place within a Specialist Surgical Centre; Local ACHD Centres may not undertake any ACHD surgeries or interventions • address how Local ACHD Centres will adequately communicate with colleagues within the Congenital Heart Network (both Specialist Surgical Centre and Specialist Cardiology Centre) on the care of patients requiring non-cardiac interventions • deliver joint clinics between a Specialist ACHD Cardiologist and a cardiologist with an interest in ACHD in a Local ACHD Centre 	Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital Heart Network.		M
A2	Local ACHD Centres 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.	Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital		M

Local ACHD Centre

		Heart Network.		
A3	The cardiologist with an interest in ACHD will liaise with other local DGHS, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Written protocols		M
A4	Where cases are referred to the specialist MDT for decision on management, they must be considered and responded to within a maximum of 6 weeks.	MDT register of attendance and activities	Is a maximum of 6 weeks an appropriate amount of time?	M
	Staffing in the Local ACHD Centre	Evidence of Compliance	Questions for Engagement	
B1	The Local ACHD Centre will provide: <ul style="list-style-type: none"> • An ACHD designated cardiac clinic • Access to advice and support from a designated Cardiac Specialist Nurse with an interest in ACHD • Access to a dental team • Palliative care team 	Description of services available	Are there any other relevant services?	M
B2	The Local ACHD Centre must be staffed by at least one consultant cardiologist with an interest in ACHD.	Named individuals Job descriptions	Should the standards stipulate a specific amount of time dedicated by the cardiologist to ACHD?	M
B3	The Local ACHD Centre cardiologist with an interest in ACHD should regularly participate, at least 6 times per year, in specialist MDT meetings led by the Specialist Surgical Centre, either in	Written protocols Facilities in place		M

Local ACHD Centre

	person or via tele-medicine facilities. The Local ACHD Centre cardiologist must also attend the annual network meeting.			
B4	ACHD Specialist Nurses from the Specialist Surgical Centre or Specialist Cardiology Centre will provide support, education and a link to the Network outpatient and ward nursing staff caring for ACHD patients at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.	Named individuals Job descriptions		M
	Clinical Facilities	Evidence of Compliance	Questions for Engagement	
C1	Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: <ul style="list-style-type: none"> • Blood Testing • ECG available 24/7 • Transthoracic Echo • Chest X ray • Exercise Testing/6 minute walk test • 24 hour tapes, event recorders • Ambulatory blood pressure monitoring 	Description of services available		M
C2	Local ACHD Centres must be co-located on the same hospital site as general adult cardiology services, including acute cardiac care unit.	Description of services available and physical evidence of co-location	Should Local ACHD Centres be co-located with any other services?	M

Local ACHD Centre

C3	Diagnostic catheter procedures, EP procedures and TOE's should not be undertaken outside Specialist Surgical Centres or Specialist Cardiology Centres unless agreed by the responsible specialist ACHD Cardiologist within an agreed Managed Clinical Network protocol.	Managed Clinical Network protocols		M
C4	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 as appropriate, taking into account any learning or physical disability.	Description of services available Written protocols		M
C5	Each Local ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of older people with congenital heart disease.	Description of services available Written protocols	Are the standards sufficient for the needs of older people?	M
C6	Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and MDTs to gain remote access their own SSC desktop, thus enabling immediate access to patient data.	Description of services available Written protocols		M
C7	Each Local ACHD Centre must demonstrate the existence of an IT infrastructure that allows a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services in the network.	Description of services available Written protocols		M

Local ACHD Centre

	Training and Education	Evidence of Compliance	Questions for Engagement	
D1	Each Local ACHD Centre must assist the Specialist Surgical Centre in providing core curriculum level training as per the JRCPTB curricula to all adult cardiology trainees within their network catchment area.	Written protocols Training register and training records		M
	Communication with Patients	Evidence of Compliance	Questions for Engagement	
E1	Each Local ACHD Centre must demonstrate arrangements within the network that ensures that every patient is seen by a Specialist 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.	Written protocols Patient/carer literature		M
E2	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.	Written protocols Patient/carer literature Patient/carer questionnaires		M
E3	Each patient must be given a single ongoing point of contact, who acts as care coordinator for that patient's care across the network. These contact details will be given to each patient when they attend the outpatient clinic and will also be available on the department letter head.	Written protocols and audit of compliance Job descriptions		M

Local ACHD Centre

E4	A nurse with a specialist interest in ACHD should be present at all outpatient clinics to help explain the diagnosis and management of the patient's condition and to provide literature and general support to the patient.	<p>Role description</p> <p>Patient/carer literature</p> <p>Audit of attendance</p> <p>Patient/carer questionnaires</p>		A
E5	Support for people with learning disabilities should be provided from an appropriate specialist or agency.	Written protocols and audit of compliance	Are the standards sufficient for the needs of people with learning disabilities?	M
E6	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.	Written protocols and audit of compliance		M
E7	Copies of all correspondence for GP and local centres must be copied to the patient to retain in the patient's personal record in accordance with national guidance.	Written protocols and audit of compliance		M
E8	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	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Audit of out of hours advice</p>		M

Local ACHD Centre

	advice in the case of emergency should be in place.	given Patient/carer questionnaires		
E9	Patients and carers should be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data.	Written protocols Patient/carer literature Audit of onward referrals Patient/carer questionnaires		A
E10	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.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M
E11	Advice from the clinical team should include any aspect of care, including contraception, pregnancy, dental care and lifestyle issues, that is relevant to their congenital heart condition. Written information on welfare benefits and social services should also be provided.	Written protocols Patient/carer literature Patient/carer questionnaires Evidence of methods of communication with patients		M

Local ACHD Centre

E12	Patients and carers must be given details of available local and national support groups (e.g. The Somerville Foundation, previously known as GUCHPA) at the earliest opportunity.	Written protocols Patient/carer literature Patient/carer questionnaires		A
E13	The patient's management plan should be reviewed at each consultation – in all services that comprise the local Congenital Heart Network.	Written protocols Audit of patient records		M
E14	Each Local ACHD Centre must offer booking systems that allow for long term follow up (up to 5 years)	Audit of patient records IT software		M
	Transition	Evidence of Compliance	Questions for Engagement	
F1	Transition and transfer arrangements must be in place between the relevant paediatric congenital cardiac unit(s), the ACHD Specialist Surgical Centre, ACHD Specialist Cardiology Centre or Local ACHD Centres as an integral part of the Congenital Heart Network arrangements.	Written protocols		M
F2	Patients with moderate or simple conditions may have their transition arrangements in place to transfer to a Local ACHD Centre or DGH as long as a specialist ACHD Cardiologist has approved the arrangement and there is an agreed network protocol in place.	Written protocols		M

Local ACHD Centre

F3	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.	Written protocols		M
F4	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. Clear care plans must be 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.	Written protocols Audit of patient records		M
F5	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.	Written protocols Patient/carer literature Patient/carer questionnaire		M
F6	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. This named ACHD Specialist Nurse may be located at the Specialist Surgical Centre or the Specialist Cardiology Centre, depending on local circumstances.	Role descriptions Written protocols		A

Local ACHD Centre

F7	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Written protocols	A
F8	<p>Young people undergoing transition must be supported by age appropriate information and lifestyle advice.</p> <p>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 a Clinical Nurse Specialist, who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle. The cardiologist will discuss the treatment plan with the young person and discuss it with their family when appropriate. The young person will have some independent time to talk with their cardiologist and nurse specialist.</p>	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaire</p>	M
F9	The particular needs of young people with learning disabilities and their carers must be considered.	<p>Written protocols</p> <p>Patient/carer literature</p> <p>Patient/carer questionnaire</p>	M

Local ACHD Centre

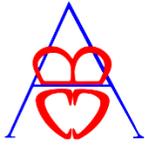
	Pregnancy and Contraception	Evidence of Compliance	Questions for Engagement	
G1	Women with congenital heart disease must have their cases discussed with the Specialist ACHD Cardiologist with specialist expertise in pregnancy in heart disease at a Specialist Surgical Centre or Specialist Cardiology Centre immediately once they are pregnant to plan their care. This must include access to contraception and termination. The individualised care plan must cover the ante natal, 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.	Written protocols Patient/carer literature Patient/carer questionnaire		
G2	The Local ACHD Centre may care for pregnant women with a low risk pregnancy, ensuring that there is appropriate liaison with specialist ACHD services and local obstetrics services.			

Key:

M = Mandatory

A = Agreed plans in place post designation

Appendix A: Definition of ACHD Cardiologists



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 $\geq 50\%$ of clinical time in GUCH.

If practising in adult cardiology, spend $\geq 75\%$ of clinical time in GUCH

- Be able to demonstrate close links with local GUCH centres
 - o joint clinics or case conference meetings
 - o 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.

Appendix B: A Definition of ACHD Surgery and Intervention

This is a definition of which Cardiac Surgical Operations should be carried out only by Cardiac Surgeons who are currently revalidated in Congenital Cardiac Surgery* and should be performed only in a designated ACHD Specialist Surgical Centre after approval by that unit's Multidisciplinary Team (MDT). These operations are termed "ACHD Surgery" and the outcomes of these operations will be audited by the UK Congenital Cardiac Audit Database. The referral route for these patients is via the Adult Congenital Cardiologist. Advice, as well as direct clinical care, will be available round the clock from designated ACHD Specialist Surgical Centre 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.**

This includes surgery for the residua or sequelae of interventional management of congenital cardiac lesions.

2. **Presents with a new primary diagnosis of Congenital Heart Disease.**

This includes Coarctation of the Aorta as well as structural cardiac lesions.

3. **Is a Woman of Child Bearing Age**

All these patients **MUST** be seen by an ACHD Cardiologist and **MUST** be discussed at an ACHD MDT prior to surgery or intervention.

Section B

ACHD surgery does not necessarily include:

1. **Situations in which the primary cardiac pathology is adult acquired disease.** Any secondary, minor congenital cardiac lesion should be discussed with the "Specialist" ACHD team prior to the decision to operate and a joint procedure (general adult cardiac surgeon and ACHD surgeon) should be considered where recommended by the MDT.

2. **Surgery for Aortopathy**, which should be carried out by a specialist Aortopathy team which may be a Specialist Surgical Centre 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. However, in view of the specific expertise of congenital cardiac surgery, careful consideration must be given to the need to refer to a Specialist Surgical Centre ACHD Team, in the following scenarios where a general cardiac surgeon should rarely operate.

- a. Patients less than 30 years of age.
- b. Patients requiring:
 - 1. Aortic Annulus Enlargement Procedures (Konno)
 - 2. Aortic Autograft Surgery (Ross)
 - 3. Aortic Valve Repair, especially for more complex congenital lesions.

If a patient needs such complex surgery on the aortic valve, then it should be performed by either the ACHD surgeon or general adult cardiac surgeon dependent on the decision of the ACHD MDT and the local arrangements for aortic surgery. Joint consultant (Congenital and General) operating is encouraged. Occasional practice in complex Aortic surgery by a surgeon 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 ACHD Specialist Surgical Centre should be balanced against the risks of delaying surgery, where time allows taking advice from the ACHD Specialist Surgical Centre. It is explicitly recognised that Cardiac teams must be supported to act in rare and demanding scenarios (e.g. dissection and endocarditis) where the individual patient is best served by “**Immediate Generalist**” rather than “**Delayed Specialist**” intervention.

** In addition, all Surgeons who achieved CCT in cardiothoracic surgery after 2014 will be required to appear on the GMC Sub-Specialty register of ‘Congenital Cardiac Surgery’.*

Atrial Septal Defect and Patent Foramen Ovale Closures

Atrial Septal Defect

Surgery for Atrial Septal Defects (ASD) should be undertaken by congenital surgeons within an ACHD Specialist Surgical Centre. The argument that this has historically been done by non-congenital surgeons is not relevant as:

- a) We are re-designing the service to achieve excellence of care now and in the future
- b) Morbidity etc. is a big issue in a low risk situation like ASD
- c) Essential for surgical numbers and training
- d) **The overall aim is to concentrate expertise**

As a key issue between surgery and catheter closure is decision making, catheter treatment should also be located in specialised ACHD centre to allow joined-up MDT planning. The advantages of this are around the number of interventional catheterisations, training of ACHD interventionists and facilitation of data collection for national audits within NICOR. **Within the ACHD model of care, ASD closure should only be undertaken in the Specialist Surgical Centre.** This ensures that congenital cardiac surgery co-location is available should it be needed. There should be flexibility within the network to enable cardiologists with skills from Specialist Cardiology Centres to continue to undertake interventional work in Specialist Surgical Centres by local planning.

Patent Foramen Ovale

Patent Foramen Ovale (PFO) normally presents or is detected in a broad clinical context (e.g. neurology, stroke etc). It is not normally associated with other structural heart diseases requiring other medical or surgical expertise. It is currently managed well in the medical community despite the uncertainty regarding appropriate treatments. **Closure of PFO is not 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.** Audit of PFO closure should be submitted to the BCIS registry.

This does not preclude PFO closure from being performed in ACHD services within the congenital heart network.

Appendix C: Network IT and Video Conferencing Requirements

All hospitals within the Congenital Heart Network must be able to communicate effectively with each other. This includes providing access for visiting staff from other hospitals as well as ensuring data and images are quickly and accurately transferred from one site to another. This appendix details the requirements for IT and Video Conferencing for all hospitals within the Congenital Heart Network.

1. IT leader within the network

Each network should have a designated Audit and IT Clinical Lead drawn from the consultant team in the network and a designated Audit and IT Managerial Lead with IT experience; they should be based at the Specialist Surgical Centre and would be responsible for the overall running and maintenance of the network. Specialist Cardiology Centres and Local ACHD Centres should also have an identified local IT lead who will liaise closely with the network IT lead at the Specialist Surgical Centre and assist in troubleshooting of potential IT problems. There should be a clearly identified network data entry individual who will be supported by the specialist nurses with physician input as required. A network Audit and IT group must exist and meet on a regular basis, with predominant clinical representation from throughout the Network. The standard of Network IT Access that it requests will be an obligatory requirement for the Trusts constituting the Network to meet.

2. Universal access to the data and technology

All hospitals within the Congenital Heart Network shall maintain an active database of all ACHD patients who at any stage have received care in the center. This should also include data regarding important events in the patient's medical journey (surgery / interventions / pregnancy / advanced PHT therapy) and integrated with the PAS system. The Specialist Surgical Centre shall also ensure that there is access to the database to identified Specialist Cardiology Centre and Local Center clinicians and specialist nurses, with appropriate protection for data access and a clear trail being available to such access. Such access should similarly be available to visiting network clinicians at Specialist Cardiology Centres and Local ACHD Centres. There should be facilities for access to relevant investigations performed in Specialist Cardiology Centres and Local Centers by the clinicians in the Specialist Surgical Centre via PACS and also for transfer of such images for ACHD MDT purposes.

A clinical, Audit and Research Database should be kept by the Specialist Surgical Centre for its Network. Each network should have a full time Database Manager or equivalent from the Network Centre's Management team. Secretarial, Clerical and Clinical Staff should be trained in data entry. The database should be available on a read and write basis to each clinician, medical, nurse and paramedical at the point of care and in office settings throughout the network.

Every patient under the care of the ACHD network should be clearly identified as an ACHD patient on the database so that Network, Team, and trust patient populations are clearly identified. There should be Network-wide point-of-care, office and clerical access to all clinical systems necessary for care on a read and write basis throughout the network' sites. All clinical systems required by the Audit and IT group for imaging, records, investigations care organisation such as listing and databases must be available at hospitals within the network. The network Audit and IT Managerial Lead has responsibility for ensuring that all firewalls and security measures permit this. A Single Password or similar integrated Log On system should be the norm.

3. National database

All Trusts within the network must submit data to the national congenital database, currently hosted by the National Institute for Cardiovascular Outcomes Research. Paediatric Networks and ACHD networks must have clear Database linkage to allow planning of ACHD transition on an individual and patient population basis so that individual and service transition needs can be planned and met.

4. Patient held records

Patient Held Records should be available electronically upon request, and offered to patients following changes to their management plan. There should be no difference in the information quality held on electronic and non-electronic patient records, and non-electronic options must always be available for patients. Electronic records must be operating system neutral to allow a maximum number of patients to use them as required.

5. Videoconferencing requirements for MDT's

All centres within the network must have the facilities to enable videoconference discussions for MDTs, unless geographical proximity allows all participants of the MDT to attend meetings in person. The technology must be "fast enough" to allow the hub and spoke to see imaging e.g. MRI, echo, CT, angiography.

Appendix D: The ACHD Specialist Nurse Role

ACHD Specialist Nurse will:

- Provide specialist nursing care, support and advice to adult patients with congenital heart disease. This will include support for patients undergoing cardiac surgery, cardiology interventions, complex pregnancy, heart failure and end of life care. They will provide advice and support for patients and health care professionals via the telephone advice line.
- Provide support to inpatients and out patients, discuss and facilitate implementation of the agreed plan of care.
- Support patients with learning difficulties, their carers and families particularly during Capacity Assessments and Best Interest meetings.
- Act as an advocate for teenagers, young adults and their families as they move to the adult service, educating and empowering them to begin to manage their own health care independently and recognising changes in their condition which require immediate specialist attention. Provide advice on how to access necessary support and information from the ACHD team.
- Act as an expert, clinical role model, leader and educator in adult congenital heart disease for all staff.
- Provide expert advice and support to the multidisciplinary team, community teams, specialist centre and regional network.

Appendix E: Requirements for co-location of services

Co-location of services means, in this context:

'Location on the same hospital site; or location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site'

Evidence of specialist opinion and intervention being "within the same parameters" includes:

- formal links such as consultant job plans and consultant on-call rotas
- the degree of mutual support offered by teams to each other across the hospital sites
- common governance structure and administration
- common rotas of different specialists across practice
- common IT platforms and record systems
- a single academic organisation covering relevant clinical activity
- an ability to reach each hospital site from the other site within 30 minutes, including compliance with the NHS national terms and conditions of employment that require a Consultant to reside within 30 minutes of the hospital (in this case, there will be stronger evidence of co-location if relevant Consultant staff reside within 30 minutes of both hospital sites)

