

***Safe and Sustainable***



***National Specialised  
Commissioning Group***

# Paediatric Congenital Cardiac Services in England

## Service Standards

March 2010

*'You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved organisation that meets required levels of safety and quality'*  
**Section 2a, NHS Constitution 2009**

## **INTRODUCTION**

*Safe and Sustainable* is about making sure that a child who has heart surgery in England has the best possible chance of survival and the best possible outcomes. We believe that these standards, if implemented in full, can reassure parents, professionals and NHS commissioners that the NHS in England has put in place a framework for excellent services, now and in the future.

These standards have been developed by a multi-disciplinary group of experts (Appendix A), which has itself received the benefit of views and contributions from an extensive range of professional and lay organisations, and from parents and patients. We have set out these standards with reference to seven key themes:

- A The Network
- B Prenatal Screening and Services
- C The Tertiary Centre
- D Age Appropriate Care
- E Information and Making Choices
- F The Family Experience
- G Ensuring Excellent Care

Surgery for children with congenital heart disease is increasingly complex and high risk. Our view, based on available evidence and professional consensus, is that larger teams deliver better outcomes. The result of our deliberations and engagement with stakeholders is therefore to recommend the concentration of specialist expertise – including surgery, cardiology, anaesthesia and nursing – into larger teams. This will ensure that a smaller number of institutions will treat a sufficient number of children to enable them to carry out these complex procedures safely and to become the true experts in their field. We are also conscious that

emergencies can happen at any time of day or night, and we have developed standards that will provide children and their families with a safe and accessible 24/7 service in every tertiary centre in England.

We have concluded that a minimum of 4 consultant congenital cardiac surgeons is necessary in each centre to safely deliver a 24/7 service that meets the need to cover theatre sessions, emergencies, ward rounds, outpatient clinics and other necessary activities such as research and education, and taking into account surgeons' planned and un-planned leave. There was broad support for a minimum of 4 surgeons at a national stakeholder event attended by clinicians, parents and NHS commissioners that we held in October 2009.

We have not recommended a minimum volume of surgical procedures for individual surgeons, but there is a need to ensure that occasional surgical practice is not present in any paediatric congenital cardiac service centre in England. We have therefore set out a minimum volume of 400 paediatric surgical procedures for each centre – with an ideal of 500 paediatric surgical procedures for each centre - sensibly distributed across the 4 consultant congenital cardiac surgeons.

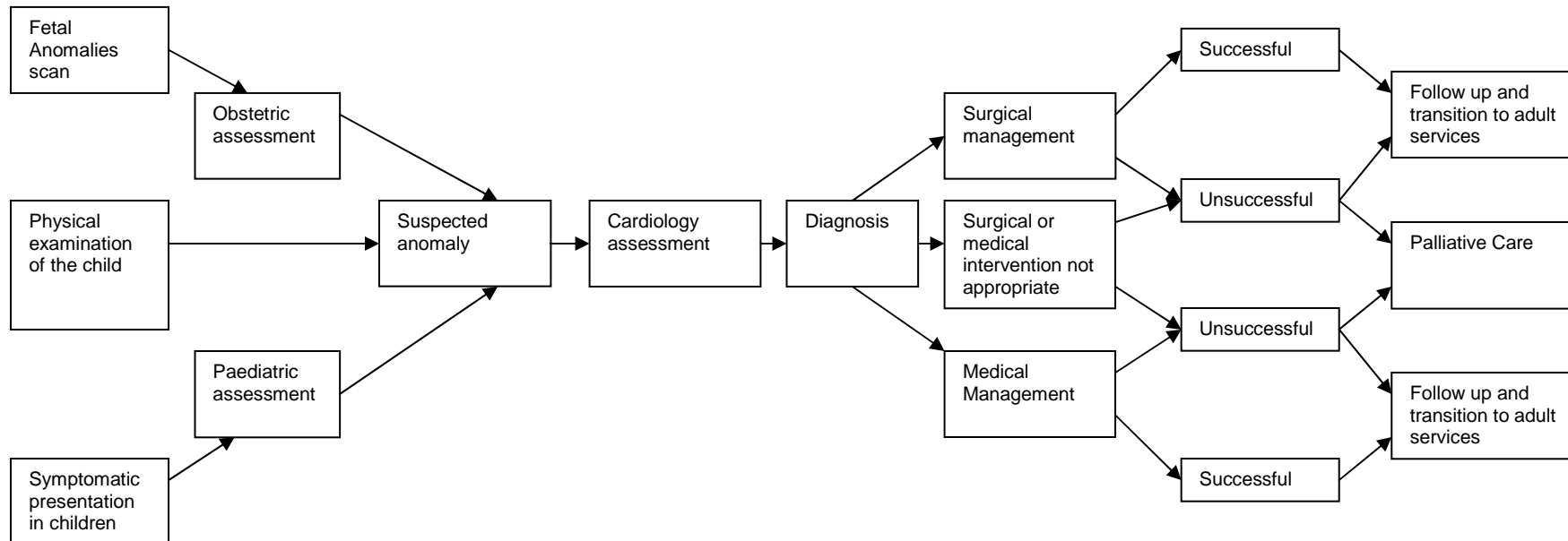
### **Incidence and activity projections for Congenital Heart Disease (CHD)**

Currently around 0.8 of every 1000 babies born will suffer from some form of Congenital Heart Disease. This level of incidence leads to around 3,600 paediatric surgical procedures being performed across England every year.

The paediatric workload has been relatively stable in previous years, and is not expected to rise significantly in the future other than in line with the projected birth rate for England (13.7% by 2025) and taking into account the impact of improved prenatal diagnostic services.

## The Congenital Heart Disease Pathway

The diagram below indicates the usual process a child's care will follow, from diagnosis, through to treatment and then to ongoing care.



## **The Network**

Surgery and interventional procedures are only two elements of a complex network of services for children with congenital heart disease that begins with prenatal screening and continues through to the transfer to adult services. While we have been mindful that issues of safety and clinical outcomes must be paramount in determining the location of children's heart surgery centres in the future – and that by their very nature these services can never be 'local' to most people in England - so too do we recognise that children and families are entitled to local access for as much other cardiac-related care as is safe and appropriate.

Within this standards document we have set out our vision for the development of local networks within which the surgical centres demonstrate clear and effective leadership, and which strengthen the planning and delivery of non-interventional care within local settings. This vision responds to comments that we have received from stakeholders over the past year, and is modelled on the approach set out by the British Congenital Cardiac Association. It has received widespread support from stakeholders. In setting out this vision we are clear that our purpose is to deliver a national template that *facilitates* the development of local networks, and that local networks by definition are best developed by local services with regard to local circumstances.

In this document we describe 'the network' through the relationship between three key services for children with congenital heart disease:

### **Tertiary Surgical Centre**

The Tertiary Surgical Centre (referred to as 'The Tertiary Centre' throughout the document) refers to the smaller number of centres that will be designated to perform surgical and interventional procedures on children. All children requiring a surgical or interventional procedure will be referred to a Tertiary Centre for this purpose. In addition to fetal diagnostic services, the Tertiary Centres will also provide the full range of diagnostic and follow-up care, reflecting the fact that for children who live close to the Tertiary Centre, this will also be their 'local' assessment and follow-up service.

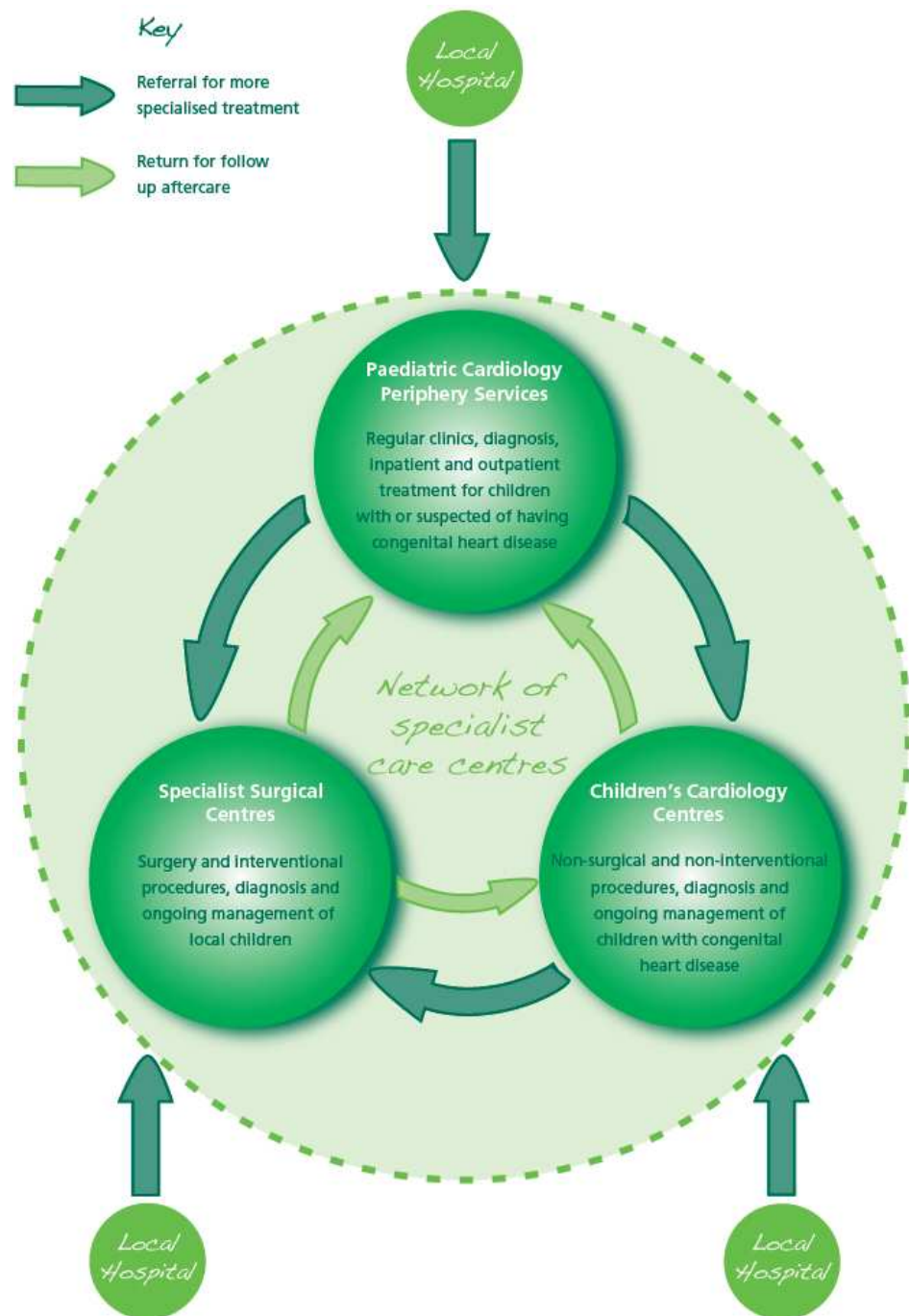
### **Children's Cardiology Centre (CCC)**

CCCs, as they are called in this document, refer to those centres that will have trained and experienced paediatric cardiologists. Their teams will be able to perform the full range of inpatient (including neonatal) and outpatient non-invasive diagnostic procedures and ongoing management of children with congenital heart disease. Children who need surgical or interventional procedures will be referred by the CCC to the Tertiary Centre. Regular combined clinics will be delivered by the Tertiary Centre and CCC. The role of CCCs has already been successfully developed by some NHS hospitals (Manchester, Cardiff and Edinburgh). As a result of *Safe and Sustainable* there will be some centres that are currently performing surgery and interventional procedures on children who will stop this in the future because they are not designated as a Tertiary Centre, and that will become a CCC.

## Paediatric Cardiology Periphery Services (PCPS)

PCPS will be delivered in some, but not all, local hospitals and they will have close working relationships with Tertiary Centre and CCCs and with other local hospitals in close proximity. The team will include a Consultant Paediatrician with expertise in cardiology, and there will be a named Consultant Paediatric Cardiologist from the Tertiary Centre or CCC so that combined paediatric cardiology clinics are held regularly at the PCPS. They will accept referrals for children suspected of having congenital heart disease from local hospitals, general practitioners, community paediatricians and others involved in primary care, and they will also perform inpatient (including neonatal) and outpatient non-invasive diagnostic procedures and ongoing management of children with congenital heart disease. If a prenatal diagnosis of congenital heart disease is made or is suspected, the mother will be referred to a Tertiary Centre or CCC so that the most appropriate care and treatment and an agreed plan of care after delivery can be determined.

The precise shape of each network will be determined by local need and local circumstances including population levels, geography and transport but we have set out in diagram form one possible network:



## **The Case for Change**

The current configuration of services in England is not satisfactory as not all centres can offer the same levels of service and expertise within their clinical teams. A detailed 'Case for Change' is set out in a separate document attached to these standards, but in summary:

- Surgical expertise is currently spread too thinly across the country
- This leads to some clinical teams not performing enough complex procedures regularly enough to avoid occasional practice
- There is too much variance in the size of the clinical teams; we believe that larger teams deliver a safer service with better outcomes
- Some centres are not adequately staffed in order to be able to provide appropriate 24/7 care
- Larger centres are best placed to recruit new surgeons and plan for the future, and there is current evidence to suggest that smaller centres are less able to attract and retain staff, leading to vulnerability

## **Aims and process for designation of specialised services**

These standards describe the vision for Paediatric Congenital Cardiac Services for the future. The standards will, in effect, be used for two purposes:

- 1) As a designation toolkit:

Designation is a formal process of ensuring that all specialised services meet quality and other standards and that services are able to meet demand (for example, there are enough units, beds and/or staff) and that they link together to provide accessible safe and effective services delivering the best possible outcomes for patients and good value for money.

National guidance has been written to support the designation process. The majority of services are designated through a process led by individual Specialised Commissioning Groups, applying a common set of standards agreed at national level,

across their own catchment area. However some services - including paediatric congenital surgery services - will be designated using standards agreed at national level through a nationally coordinated process.

A number of the individual standards are “core” for designation as a centre, and these core standards will be assessed as part of the formal assessment process. The core standards are described in more detail in the business case template that will be issued to each centre in March 2010. These core standards are not necessarily just the 'mandatory' standards – they represent those elements of the service that are critical for designation.

- 2) As a commissioning service specification:  
 Once centres are designated, they will be expected not only to have the core standards in place, but also to demonstrate to commissioners how they will achieve the standards, within timescales specified. The standards document will therefore be used as an ongoing commissioning service specification.

<b>Mandatory following designation</b>	<b>Mandatory Red</b>	<ul style="list-style-type: none"> <li>• Must be in place immediately once designated</li> <li>• Any failure or change in status would prompt immediate review of designation status</li> <li>• Following designation, robust plans/intentions must be in place to achieve all outstanding mandatory standards within a timescale agreed with NHS commissioners</li> <li>• Any failure or change in ability to meet the standard within the agreed timescale would prompt immediate review of designation status</li> </ul>
	<b>Mandatory* Amber</b>	
<b>Non-mandatory</b>	<b>Highly desirable Orange</b>	<b>Highly desirable</b> following designation.
	<b>Desirable Gold</b>	<b>Desirable</b> following designation
	<b>Value added Yellow</b>	<b>Value added</b> following designation.

	Designation standard	Measures	Compatible Evidence Base	Status
<b>A</b>	<b>A NETWORK FOR THE CHILD AND FAMILY</b>			
A1	<p>Tertiary Centres (in partnership with NHS commissioners) will provide active leadership in their clinical networks. This will include:</p> <ul style="list-style-type: none"> <li>○ Managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures</li> <li>○ Performance monitoring and audit, professional training and development</li> <li>○ Facilitating the development of as much care and treatment as possible close to the child's home and the transition to adult services</li> </ul>	<p>Written protocols and policies</p> <p>Documented pathways</p> <p>Outcome of audits</p>	<p>British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory Amber</b>
A2	Tertiary Centres in partnership with local services and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of children with paediatric congenital heart disease. The model of care will ensure that as much	Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the network.	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology	<b>Mandatory Amber</b>

	care and treatment should be provided as close as possible to the child's home and that the child and family travel to the Tertiary Centre only when essential, while ensuring timely access for interventional procedures and the best possible outcome for the child.		Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
A3	The Tertiary Centres and local services will hold regular multi-disciplinary meetings across the network for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every 6 months.	Meeting dates, evidence of attendance and minutes of meetings.	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as	<b>Mandatory</b>

			modified)	
A4	Each Tertiary Centre will have a formally nominated Clinical Lead with responsibility for the service overall, who will be supported by separate clinical leads for surgery, cardiac intervention and other areas.	Name of Lead  Job and role description	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory</b>
A5	Each Tertiary Centre will have a formally nominated Lead Nurse. The role of the Lead Nurse is set out in <u>Appendix B</u> .	Name of Lead  Job and role description	Advice from Royal College of Nursing (2010)  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory Amber</b>
A6	Pathways must involve prenatal diagnosis, maternity and obstetric services, transition to adult congenital cardiac services and palliative care. Networks should be aligned with networks for fetal services and adult congenital services; the transition from fetus → child and child → adolescent and adolescent → adult requires a joined up approach with treatment continuity.	Written protocols  Documented pathways	Standards for Providers of Services for Adults with Congenital Heart Disease (2010)  British Congenital Cardiac Association (2009) 'Requirements for Provision of	<b>Mandatory Amber</b>

			<p>Outreach Cardiology Service'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	
A7	<p>Tertiary Centres (in partnership with NHS commissioners) will collaborate to facilitate referrals to each other when necessary (reflecting that collectively they provide a national service) and to develop and embed best practice and benchmark performance.</p>	<p>Audit of referral and waiting time data</p> <p>Access data</p>	<p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>Department of Health Waiting Time Standards</p> <p>NHS Operational Framework</p>	<p><b>Mandatory Amber</b></p>

A8	Tertiary Centres will agree clinical protocols with their networks, based upon these and other national standards. The Tertiary Centres will be responsible for advising colleagues within the network on the care of children with cardiac conditions requiring associated non-cardiac interventions.	Written protocols	<p>British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p>	<b>Mandatory Amber</b>
A9	There will be specific protocols within each network for the transfer of children requiring interventional treatment.	Written protocols	<p>Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p>	<b>Mandatory</b>

A10	Interventional procedures must only be undertaken at a Tertiary Centre in view of the need for on-site surgical support.	Written protocols  Audit of interventions	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  British Paediatric Cardiac Association 'Recommendations for Therapeutic Cardiac Catheterisation in Congenital Heart Disease'	<b>Mandatory</b>
A11	All children transferring between services will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management or follow up plan.  Note: The health records summary will be a standard national template developed and agreed by the Tertiary Centres, representatives of the networks and NHS commissioners.	Audit of timeliness and completeness of information (about diagnosis and management) at time of transfer  Minimum Data Set	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young	<b>Mandatory Amber</b>

			People and Maternity Services (2003 and as modified)	
A12	Tertiary Centres will develop and implement a system of 'patient-held records'	Audit of use of 'Patient Held' records	Model for Obstetric Services in the NHS	<b>Highly Desirable</b>
A13	There will be written protocols covering communication between clinicians, and between clinicians and parents / carers and between clinicians and children / young people. The protocols will be developed and agreed with local referring paediatricians, paediatric cardiologists, Children's Cardiac Specialist Nurses, Clinical Psychologists and patient groups.	Written protocols	<p>British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>National Reference Group for Psychologists Working in Paediatric Cardiology (2010)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory Amber</b>

A14	The Tertiary Centre should have a paediatric palliative care service able to provide good quality end-of-life care in hospital and with well developed shared-care palliative services with the community.	Written protocols	National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory Amber</b>
<b>Children's Cardiology Centres and Periphery Services</b>				
A15	To ensure that children receive as much non-interventional treatment as close to their home as is safe, networks will be supported by specialised Children's Cardiology Centres (CCC) and Paediatric Cardiology Periphery Services (PCPS). The precise shape of each network should be determined by local need and local circumstances, including geography and transport.	Documented pathway  CCCs and PCPS established	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>
A16	Each CCC and PCPS will have telemedicine facilities to link with the Tertiary Centre. The level of telemedicine required will be agreed between network members.	Facilities in place  Audit of use and effectiveness	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>
A17	Each CCC and PCPS will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children with congenital heart problems.	The requirements for the training and education plan will be part of the contracts between commissioners and network members	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>
A18	Each PCPS will have a named Consultant Paediatric Cardiologist from the Tertiary Centre or CCC, and	Name of Consultant	British Congenital Cardiac Association	<b>Mandatory Amber</b>

	regular combined paediatric cardiology clinics should be held within the PCPS.	Job description and staff contracts	(2009) 'Requirements for Provision of Outreach Cardiology Service'	
A19	Each PCPS will have a named Consultant Paediatrician with expertise in paediatric cardiology who is closely involved in the organisation, running of and attendance in the PCPS and who has received training in accordance with the Royal College of Paediatrics and Child Health and Royal College of Physicians one-year joint curriculum in paediatric cardiology. The Consultant Paediatrician must be allocated time in the Tertiary Centre so that s/he may provide clinical continuity regarding the management of children under their care, enhance continued professional development and to ensure the Tertiary Centre is made aware of the views or concerns of patients.	Name of Consultant  Job description and staff contracts  Certificate of training	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Royal College of Physicians and Royal College of Paediatrics (2002): 'Curriculum for Paediatricians with Special Expertise in Paediatric Cardiology'	<b>Mandatory Amber</b>
A20	Each CCC and PCPS will provide all of the non-invasive investigations (including basic electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure monitoring, treadmill exercise testing and high quality echocardiography facilities).	Facilities in place	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>
A21	Each CCC and PCPS will provide outpatient administrative support to ensure availability of medical records, to organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow ups and	Staff names  Job descriptions and staff contracts	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology	<b>Mandatory Amber</b>

	respond to parents in a timely fashion.		Service'	
A22	Each CCC and PCPS will provide skilled nursing support with additional training in cardiology to undertake blood pressure and oxygen saturation monitoring.	Staff names  Job descriptions and staff contracts	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>
A23	Each CCC and PCPS will provide a Clinical Psychology Service for children, and for parents and carers.	Staff names  Job descriptions and staff contracts	National Reference Group for Psychologists working in Paediatric Cardiology (2010)  British Psychological Society (2003) 'Working with Children with Medical Conditions'	<b>Mandatory Amber</b>
A24	Each CCC and PCPS will provide pathways of care and management of congenital heart defects agreed with the Tertiary Centres  a) <i>Prenatally Diagnosed Congenital Heart Defects</i> If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be transferred to the Tertiary Centre or the CCC, as appropriate. Discussions will take place with the Tertiary Centre about the location of the delivery of the baby.	Written protocols  Audit of service activity	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory Amber</b>

<p>b) <i>Newborns with a murmur and otherwise clinically well</i></p> <p>c) <i>Neonates and infants diagnosed with congenital heart defects</i>  Each CCC and PCPS will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate.</p> <p>d) <i>New referrals of older infants and children from GPs and paediatricians</i>  Local hospitals will refer children to a CCC or PCPS, as appropriate, for the following categories of referrals:</p> <p>Murmurs  Cyanosis  Chest pain  Palpitations  Syncope or dizziness  Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes  Kawasaki disease</p> <p>e) <i>Ongoing care of children and young people diagnosed with congenital heart defects</i>  Local hospitals will refer children to the CCC or PCPS as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the</p>			
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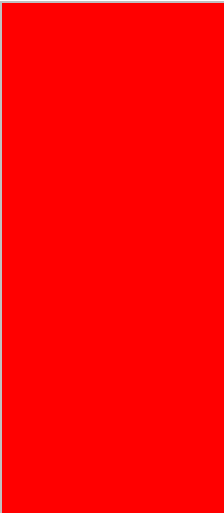
	adjustment of various cardiac drugs			
A25	The management of patients should be discussed and planned at combined cardiac surgery and cardiology Multi-Disciplinary Team (MDT) meetings at the Tertiary Centre to ensure the best possible care and outcomes.	MDT register of attendance and activities	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
A26	The composition of the MDT should be pathway driven, and adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinic-pathological and audit meetings).	MDT register of attendance and activities	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
A27	Staff from across the network should be encouraged by the Tertiary Centre to attend MDT meetings when, for example, an individual's care is complex or involves more than one specialty team. If physical	MDT register of attendance and activities	British Congenital Cardiac Association (2009) 'Requirements for Provision of	<b>Mandatory</b>

	attendance is not possible, it is essential that all staff from across the network are fully involved in the MDT process including by video / teleconferencing and in the decision making about their patient, where necessary.		Outreach Cardiology Service'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	
A28	The attendance and activities of the MDT should be maintained in a register.	MDT register of attendance and activities	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>

	<b>Designation standard</b>	<b>Measures</b>	<b>Compatible Evidence Base</b>	<b>Status</b>
<b>B</b>	<b>PRENATAL DIAGNOSIS</b>			
B1	Tertiary Centres and CCCs must meet the 'Fetal Cardiology Standards' developed by the British Congenital Cardiac Association.	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'	<b>Mandatory</b>
B2	CCCs and PCPS that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Tertiary Centre in their network in accordance with the 'Fetal Cardiology Standards' developed by the British Congenital Cardiac Association.	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'	<b>Mandatory Amber</b>
B3	Each Tertiary Centre will agree and establish protocols with fetomaternal medicine units and tertiary neonatal units in their networks for the care and treatment of pregnant women whose fetus has been diagnosed with a major heart condition. The protocols must meet the 'Fetal Cardiology Standards' developed by the British Congenital Cardiac Association and ensure that pregnant women are referred to the relevant specialists as early as possible, for diagnosis, further testing and counselling.	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory Amber</b>
B4	The timing of fetal cardiac scans for high risk mothers should be in line with the fetal cardiology standards of the British Congenital Cardiac Association.	Written protocols and audit of compliance	Fetal Anomaly Screening Programme, National Standards and Guidance for England (2010)	<b>Mandatory Amber</b>

			British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'	
B5	If the obstetric screening anomaly scan indicates that the fetus may have a heart problem, the mother should be offered a specialist fetal cardiology assessment within 1 week, and preferably within 48 hours.	Written protocols and audit of compliance	Fetal Anomaly Screening Programme, National Standards and Guidance for England (2010)  British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'	<b>Mandatory</b>
B6	Counselling for major congenital cardiac anomalies should be performed by fetal cardiology specialists with support from other members of the multi-disciplinary team. Support from a Clinical Psychologist or Nurse Counsellor or specialist nurse practitioner should be available at an early stage to work with families.	Written protocols and audit of compliance  Job descriptions	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'  National Reference Group for Psychologists working in Paediatric Cardiology (2010)	<b>Mandatory</b>
B7	A specialist nurse counsellor / specialist nurse practitioner / specialist practitioner will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information	Written protocols and audit of compliance  Job descriptions	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'	<b>Mandatory Amber</b>

	and support within 48 hours of diagnosis. Parents should also be given contact details for relevant local and national support groups at this point.			
B8	At diagnosis a plan should be agreed between the Tertiary Centre, the specialist feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan should be updated throughout pregnancy.	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'  British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory</b>
B9	In all cases where a baby is likely to require immediate post-natal intervention or surgery the parents must be given the choice of delivering the baby either at or close to the Tertiary Centre if necessary (for example, at a linked obstetric unit).	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'  British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	<b>Mandatory</b>
B10	If the plan is for the delivery of the baby at the local maternity unit this should include arrangements for the transfer of the mother and baby to the Tertiary	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Fetal	<b>Mandatory</b>

	<p>Centre if early intervention or assessment is required. A competent neonatologist should be present at the delivery and a neonatal team must be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment arrangements for early postnatal cardiac evaluation should be made after delivery.</p>		<p>Cardiology Standards'  British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p>	
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	Designation standard	Measures	Compatible Evidence Base	Status
<b>C</b>	<b>THE TERTIARY CENTRE</b>			
	<b>Professional Competence</b>			
C1	All children requiring investigation and treatment will receive care from staff trained in caring for children, including safeguarding standards, in accordance with the requirements of their profession and discipline.	<p>Posts in place</p> <p>Evidence of qualifications, experience and training</p>	<p>NHS Constitution 2009</p> <p>RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity</p>	<b>Mandatory</b>

			Services (2003 and as modified)	
C2	All paediatric cardiac surgical cases should be carried out by a dedicated paediatric cardiac surgical team.	Posts in place Audit of operating logs	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C3	Nursing care must be provided by a dedicated team of nursing staff trained in the care of children who have received cardiac surgery. The children's cardiac inpatient nursing team will be led by a senior children's nurse with specialist knowledge and experience in the care of children and in paediatric cardiac surgery.	Posts in place Named individuals Record of nurse staffing	RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'  RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
<b>Safe and Sustainable services</b>				
C4	Each Tertiary Centre must be staffed by a minimum of 4 full time consultant congenital cardiac surgeons. A 'consultant congenital cardiac surgeon' is defined as having the equivalent of two years dedicated training in a recognised congenital cardiac surgical centre.	Named individuals Job descriptions Evidence of qualifications, experience and training	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Consensus reached at	<b>Mandatory Amber</b>

			Safe and Sustainable national stakeholder event, October 2009	
C5	Arrangements must be in place in each Tertiary Centre for consultant congenital cardiac surgeons to operate together on complex or rare cases, within legally compliant rotas.	Written protocols and audit of compliance	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C6	Each Tertiary Centre <b>must</b> perform a minimum of 400 paediatric surgical procedures each year, sensibly distributed between all 4 of the consultant congenital cardiac surgeons to avoid occasional practice.  A 'paediatric surgical procedure' is defined as any open or closed cardiac surgical procedure i) performed on a child on or before the 16 <sup>th</sup> birthday ii) is the primary procedure in any one anaesthetic episode and iii) does not feature on the list of 'excluded' procedures as the sole intervention in any one episode (listed in <a href="#">Appendix C</a> ).	Submission of data to CCAD	This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons.  <a href="#">Appendix D</a> for relevant papers	<b>Mandatory Amber</b>
C7	Each Tertiary Centre <b>should</b> perform a minimum of 500 paediatric surgical procedures each year, sensibly distributed between all 4 of the consultant congenital cardiac surgeons to avoid occasional practice.  A 'paediatric surgical procedure' is defined as any open or closed cardiac surgical procedure i)	Submission of data to CCAD	This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons.	<b>Highly Desirable</b>

	performed on a child on or before the 16 <sup>th</sup> birthday ii) is the primary procedure in any one anaesthetic episode and iii) does not feature on the list of 'excluded' procedures as the sole intervention in any one episode (listed in <a href="#">Appendix C</a> ).		Appendix D for relevant papers	
C8	Each Tertiary Centre must be staffed by a minimum of 1 consultant paediatric cardiologist per half million population served.	Named individuals  Job descriptions	Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Highly Desirable</b>
C9	Each Tertiary Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24 hour emergency service, 7 days a week within legally compliant rotas, including 24/7 paediatric interventional cardiology cover. A consultant-led ward round will occur daily.	On call rota with defined contracts  Consultant contractual obligation	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'  RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People'	<b>Mandatory</b>
C10	Children who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a designated paediatric	Submission of data to CCAD  Submission of transplant	NSCAG / CTAG Cardiothoracic Transplant Standards	<b>Mandatory</b>

	cardiothoracic transplant centre. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	data to National Specialised Commissioning Team		<b>Mandatory</b>
C11	PICU consultants with appropriate skills in paediatric cardiac critical care should be available to the PICU on a 24/7 basis.	Posts in place Named individuals Record of staffing	Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'	
<b>Critical Interdependent Services: co-location as defined by the Framework of Critical Inter-Dependencies</b>				
C12	Paediatric Cardiology	Description of services available and physical evidence of co-location	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
C13	Paediatric Ear, Nose and Throat (Airway)	Description of services available and physical evidence of co-location	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
C14	Specialised Paediatric Surgery	Description of services available and physical evidence of co-location	Commissioning Safe and Sustainable Specialised Paediatric Services: A	<b>Mandatory</b>

			Framework of Critical Inter-Dependencies (2008)	
C15	Paediatric Intensive Care Unit: Level 3 / Level 4 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards)	<p>Description of services available and physical evidence of co-location</p> <p>Audit of compliance with national standards</p>	<p>Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'</p> <p>RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'</p> <p>RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People'</p> <p>Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)</p>	<b>Mandatory</b>
C16	Specialised Paediatric Anaesthesia (appropriately trained and experienced paediatric cardiac anaesthetists delivered in accordance with the Royal College of Anaesthetists' Guidelines and Paediatric Intensive Care Society Standards)	<p>Description of services available and physical evidence of co-location</p> <p>Audit of compliance with</p>	Guidelines under development by the Royal College of Anaesthetists, Association of	<b>Mandatory</b>

	Each Tertiary Centre will have a continuous and documented availability of trained and experienced paediatric cardiac anaesthetists who have experience and training in the peri-operative care of the paediatric cardiac patient in accordance with the guidelines being developed by the Royal College of Anaesthetists, Association of Paediatric Anaesthetists and Association of Cardiothoracic Anaesthetists, including a specialist on-call rota which is separate from the intensive care rota.	national standards	Paediatric Anaesthetists and Association of Cardiothoracic Anaesthetists.  Royal College of Anaesthetists (2009) 'Guidelines for the Provision of Anaesthetic Services'  Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	
<b>Other Critical Interdependencies</b>				
C17	Paediatric Neurology: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available  Audit of compliance with CID Framework	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
C18	Paediatric Respiratory Medicine: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available  Audit of compliance with	Commissioning Safe and Sustainable Specialised Paediatric Services: A	<b>Mandatory</b>

		CID Framework	Framework of Critical Inter-Dependencies (2008)	
C19	Neonatology: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available  Audit of compliance with CID Framework	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
C20	Paediatric Nephrology: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available  Audit of compliance with CID Framework	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
C21	Clinical Haematology: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available  Audit of compliance with CID Framework	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Mandatory</b>
	<b>Co-Location (as defined by the Framework for Critical Interdependent Services) with Core Clinical Services</b>			
C22	Adolescent Congenital Cardiac Surgery	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>

C23	Adolescent Congenital Cardiology	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C24	General Paediatrics	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C25	General Paediatric Surgery	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C26	Clinical Psychology	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Reference Group for Psychologists Working in Paediatric Cardiology (2010)  British Psychological Society (2003) 'Working with Children with Medical Conditions'	<b>Mandatory</b>

C27	Physiotherapy	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C28	Dietician	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C29	Infection control Nurse experienced in the needs of paediatric cardiac surgery patients	Description of services available  Evidence of qualifications, training and experience	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C30	Local facilities for transferring patients between airfields and helipads and the centre	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C31	Play room with facilities and Play Therapists	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C32	Hospital School with teachers	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C33	Bereavement Support	Description of services	Royal College of	<b>Mandatory</b>

		available	Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	
C34	Breast Feeding Support	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
C35	Social Work Services	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C36	Neonatal Intensive Care Unit	Description of services available	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter- Dependencies (2008)  Department of Health (2009) 'Toolkit for High Quality Neonatal	<b>Highly Desirable</b>

			Services'	
C37	Fetal Diagnostic Cardiology	Description of services available	British Congenital Cardiac Association (2010) 'Fetal Cardiology Standards'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>
C38	Obstetrics and Maternity	Description of services available	National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Highly Desirable</b>
C39	Landing facilities for helicopter	Description of services available	Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'	<b>Desirable</b>
C40	Paediatric Neurosurgery	Description of services available	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	<b>Desirable</b>
C41	Genetics	Description of services	National Service	<b>Desirable</b>

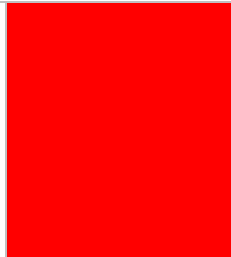
		available	Framework for Children, Young People and Maternity Services (2003 and as modified)	
C42	Child Psychiatry with dedicated sessions	Description of services available	National Service Framework for Children, Young People and Maternity Services  Diagnostic and Statistical Manual of Mental Disorders IV (1994)	<b>Desirable</b>
C43	Dental	Description of services available	National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Desirable</b>
<b>Co-Location with Non-Patient Contact Services</b>				
C44	Biochemistry	Description of services available		<b>Mandatory</b>
C45	Pathology: dedicated cardiac morphology (macroscopic and microscopic)	Description of services available		<b>Desirable</b>
C46	Pharmacy	Description of services available		<b>Mandatory</b>
<b>Equipment</b>				

C47	Electrophysiology	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C48	Echocardiography	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C49	Cardiac catheterisation laboratory	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C50	Intra-operative ECHO	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C51	Transoesophageal ECHO	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C52	MRI	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C53	CT	Description of equipment available and physical evidence of availability		<b>Mandatory</b>
C54	Post operative extra corporeal life support (Non nationally designated ECMO)	Description of equipment available and physical evidence of availability		<b>Mandatory Amber</b>

C55	Access to Isotope Imaging	Description of equipment available and physical evidence of availability		Highly Desirable
<b>Pain management</b>				
C56	Tertiary Centres must provide a co-located multi-disciplinary 24-hour pain management service.	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	Mandatory
C57	Tertiary Centres must implement a pain control policy that includes advice on pain management at home.	Written policy and description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	Mandatory
C58	A member of the acute pain team should attend the ward daily and all children who have had heart surgery or intervention should be assessed regularly.	Ward round records	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	Mandatory
C59	Particular attention should be given to children who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	Written description of arrangements for identifying such children	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	Mandatory
<b>Meeting Demand</b>				
C60	Admission for planned surgery will be booked for a specific date.	Evidence of planned admission policy and audit of records.		Mandatory
C61	Same-day cancellations for non-clinical reasons of elective cases shall not be more than 0.8%.	Records of delayed or cancelled admissions or operations		Highly Desirable

		Refused entry audit		
C62	All children 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	NHS Constitution 2009	<b>Mandatory</b>
C63	Unplanned readmission to PICU will only occur in less than 10% of admissions.	Emergency re-admission statistics (clinical indicator) for inpatient and re-admissions to HDU / PICU		<b>Mandatory Amber</b>
C64	Sufficient staff will be available at the Tertiary Centre to meet the demand for in-patient beds, critical care beds, theatre capacity and service provision as generated by the network. When a Tertiary Centre cannot admit a patient for whatever reason it is the responsibility of that centre to find another bed at another centre.	Staff rotas  Audit of refusals and onward referrals (including reports from other centres)		<b>Mandatory</b>
C65	Sufficient capacity will be available at the Tertiary Centre to ensure that the demands of emergency and elective surgery can be flexibly managed in daytime lists.	Theatre utilisation records		<b>Mandatory</b>
C66	Paediatric Intensive Care Units and High Dependency care will be staffed in accordance with national standards.	Record of nurse staffing  Record of night cover	Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'  RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'  RCN (2010) 'Health	<b>Mandatory</b>

			Care Service Standards in Caring for Neonates, Children and Young People'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
C67	A children's cardiac specialist nurse should be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Record of nurse staffing	RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services'  RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People'	<b>Mandatory</b>
<b>Retrieval and repatriation</b>				
C68	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: <ul style="list-style-type: none"> <li>o Clinical transfers should be arranged in a timely manner according to patient need</li> <li>o Critically ill children must be transferred/retrieved in accordance</li> </ul>	Refusal audit (including reports from other centres)  Record of delayed admissions  Record of precipitate discharges  Record of lengths of stay	Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class	<b>Mandatory</b>

	<p>with the standards set out within the designation standards for Paediatric Intensive Care services</p> <ul style="list-style-type: none"><li>○ Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.</li></ul>	<p>Audit data for paediatric cardiac surgery patients within acute cardiac surgical beds</p>	<p>Service'</p>	
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	Designation standard	Measures	Compatible Evidence Base	Status
<b>D</b>	<b>AGE APPROPRIATE CARE</b>			
D1	The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.	Written protocols	<p>Standards for Providers of Services for Adults with Congenital Heart Disease (2010)</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Department of Health (2006) 'Transition; Getting It Right For Young People'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory Amber</b>

D2	Children should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Written protocols	Standards for Providers of Services for Adults with Congenital Heart Disease (2010)  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Department of Health (2006) 'Transition; Getting It Right For Young People'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory Amber</b>
D3	Each network shall have designated transition nurses to facilitate effective and timely transition from children's to adult services ( <u>Appendix E</u> for role)	Named staff  Job descriptions	Advice from Royal College of Nursing (2010)	<b>Mandatory Amber</b>
D4	The patient's management plan should be reviewed at each consultation – in all services that comprise the local network - to make sure that it continues to be relevant to their particular stage of development.	Written protocols  Audit of patient records	Standards for Providers of Services for Adults with Congenital Heart Disease (2010)	<b>Mandatory Amber</b>

			<p>Department of Health (2006) 'Transition; Getting It Right For Young People'</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	
D5	Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present.	<p>Written protocols</p> <p>Patient / parent literature</p>	<p>General Medical Council '0-18 Years Guidance'</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory Amber</b>
D6	Young people must have the opportunity to be seen by a Clinical Psychologist on their own. Psychological support should also be offered to parents and carers.	<p>Written protocols</p> <p>Patient / parent literature</p>	<p>Standards for Providers of Services for Adults with Congenital Heart Disease (2010)</p> <p>National Reference Group for Psychologists Working in Paediatric</p>	<b>Mandatory Amber</b>

			<p>Cardiology (2010)</p> <p>Department of Health (2006) 'Transition; Getting It Right For Young People'</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p> <p>British Psychological Society (2003) 'Working with Children with Medical Conditions'</p>	
D7	<p>All services that comprise the local network should have appropriate arrangements in place with designated centres for adults with Congenital Heart Disease to ensure a seamless pathway of care, led jointly by paediatric and adult cardiologists. There should be access to beds and other facilities for adolescents.</p>	<p>Written protocols</p> <p>Services available with evidence of access arrangements</p>	<p>Standards for Providers of Services for Adults with Congenital Heart Disease (2010)</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Department of Health</p>	<p><b>Mandatory Amber</b></p>

			<p>(2006) 'Transition; Getting It Right For Young People'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory Amber</b>
D8	<p>There will not be a fixed point of transition between children's and adult services but the process of transition should be initiated no later than 14 years of age, taking into account individual circumstances and special needs. Children, parents and carers should be fully involved in discussions around the clinical issues. The views, opinions and feelings of the child should be fully heard and considered.</p>	<p>Written protocols</p> <p>Patient / parent literature</p>	<p>Standards for Providers of Services for Adults with Congenital Heart Disease (2010)</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Department of Health (2006) 'Transition; Getting It Right For Young People'</p>	

			National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
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	Designation standard	Measures	Compatible Evidence base	Status
<b>E</b>	<b>INFORMATION AND MAKING CHOICES</b>			
E1	Tertiary Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision making at every stage in their child's care, taking into account that young people can make decisions themselves at the age of 16 years.	Written protocols  Patient / parent literature  Parent / User questionnaires	NHS Constitution 2009  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
E2	Tertiary Centres must demonstrate that parents and carers are helped to understand their child's condition, the effect it may have on their child's health and future life and the treatment that they will receive.	Written protocols  Patient / parent literature  Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services	<b>Mandatory</b>

			Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
E3	A Children's Cardiac Specialist Nurse must be present at all outpatient appointments to help explain diagnosis and management of the child's condition, and to provide relevant literature.	Role description  Patient / parent literature  Audit of attendance  Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Advice from Royal College of Nursing (2010)	<b>Mandatory Amber</b>
E4	A Clinical Psychologist experienced in the care of paediatric cardiac patients must be available to support parents and children during the decision making process.	Named staff  Role description  Patient / parent literature  Access audit  Parent / User questionnaires	National Reference Group for Psychologists Working in Paediatric Cardiology (2010)  British Psychological Society (2003) 'Working with Children with Medical Conditions'	<b>Mandatory Amber</b>
E5	Parents, carers and children must have access to a health professional who can interpret and explain the data that is available from the public portal of the National Central Cardiac Audit Database.	Patient / parent literature  Access audit	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class	<b>Mandatory Amber</b>

		Parent / User questionnaires	Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
E6	Information must be made available to parents and carers in a wide range of formats and on more than one occasion. It should be clear, understandable, culturally sensitive, evidence based interpreted or transcribed and taking into account special needs as appropriate.. When given verbally, information should be precisely documented.	Patient / parent literature  Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
E7	Where surgery or intervention is planned, the child and their parents or carers should have the opportunity to visit the centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This should include the opportunity to meet the surgeon or interventionist who will be undertaking the	Written protocols  Patient / parent literature  Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the	<b>Mandatory Amber</b>

	procedure.		Paediatric Congenital Cardiac Services Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
E8	Consent for planned procedures should be sought by the Consultant in advance of the week of admission and the status of consent re-checked before the operation, reflecting that the process of consent is continuous.	Written protocols  Patient / parent literature  Audit of compliance  Parent / User questionnaires	Department of Health (2009) 'Reference Guide to Consent for Examination or Treatment'  Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
E9	A Children's Cardiac Specialist Nurse should be available to support parents throughout the consent process. When considering treatment options, parents and carers need to understand the potential	Role description  Written protocols	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class	<b>Mandatory Amber</b>

	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.	<p>Patient / parent literature</p> <p>Access audit</p> <p>Parent / User questionnaires</p>	<p>Service'</p> <p>Advice from Royal College of Nursing (2010)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	
E10	Parents, carers and all health professionals involved in the child'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 they should take. They should have immediate 24-hour access to a member of the clinical team for advice, information and support.	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Audit of 'out-of-hours' advice given</p> <p>Parent / User questionnaires</p>	<p>Royal College of Surgeons (2007)</p> <p>'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory</b>
E11	Tertiary Centres must demonstrate that parents and carers are offered support or cooperation in obtaining further opinions or referral to another	<p>Written protocols</p> <p>Patient / parent literature</p>	<p>Royal College of Surgeons (2007)</p> <p>'Surgery for Children:</p>	<b>Mandatory</b>

	Tertiary Centre.	Audit of onward referrals Parent / User questionnaires	Delivering a First Class Service' Report of the Paediatric Congenital Cardiac Services Review Group (2003) National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
E12	Parents and carers must be given details of available support groups at the earliest opportunity.	Patient / parent literature Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service' Report of the Paediatric Congenital Cardiac Services Review Group (2003) National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
E13	Tertiary Centres must demonstrate that arrangements are in place for parents and carers to	Written protocols	Royal College of Surgeons (2007)	<b>Mandatory Amber</b>

	<p>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>	<p>Parent / User questionnaires</p>	<p>'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	
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	Designation standard	Measures	Compatible Evidence Base	Status
<b>F</b>	<b>THE FAMILY EXPERIENCE</b>			
F1	There should be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support).	Facilities available	<p>Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'</p> <p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	<b>Mandatory</b>
F2	Each child should have a named Children's Cardiac Specialist Nurse who, working within a Cardiac Liaison Team, is responsible for coordinating their care, and who acts as a liaison between the clinical team and the parent, carer and child throughout their care.	<p>Role descriptions</p> <p>Written protocols</p>	Advice from Royal College of Nursing (2010)	<b>Mandatory</b>

F3	Tertiary Centres must demonstrate that the role of each Children's Cardiac Specialist Nurse meets the minimum requirements of the Royal College of Nurse role description ( <u>Appendix F</u> )..	Role descriptions	Advice from Royal College of Nursing (2010)	<b>Mandatory Amber</b>
F4	Each Tertiary Centre must have a minimum of 7 wte Children's Cardiac Specialist Nurses working within a functioning Cardiac Liaison Team. The number of required nurses will depend on geography, population and the network.	Staff records Role descriptions	Advice from Royal College of Nursing (2010)  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory Amber</b>
F5	Parents and carers must be offered access to a Clinical Psychologist who is integrated with the paediatric cardiac team to discuss their own concerns or problems.	Services available Parent / User literature Access audit	National Reference Group for Psychologists Working in Paediatric Cardiology (2010)  British Psychological Society (2003) 'Working with Children with Medical Conditions'	<b>Mandatory</b>
F6	There must be facilities in place to ensure easy and convenient access for parents and carers. Facilities and support include: <ul style="list-style-type: none"> <li>• accommodation for at least two family members to stay at the hospital</li> <li>• parents / carers to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate)</li> </ul>	Services available Parent / User literature Access audit Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for	<b>Mandatory</b>

	<ul style="list-style-type: none"> <li>• access to refreshments</li> <li>• ability of parents / carers to play and interact with their child (and their other children)</li> <li>• an on-site quiet room completely separate from general family facilities</li> </ul>		<p>Children, Young People and Maternity Services (2003 and as modified)</p> <p>Documented Parent / Carer Opinion</p>	
F7	Tertiary Centres must establish a patient hotel service.	Services available	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p> <p>Documented Parent / Carer Opinion</p>	<b>Mandatory Amber</b>
F8	There must be facilities, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breast feeding and the emotional health of the mother and baby.	<p>Service level agreements with maternity providers</p> <p>Access audit</p>	<p>Department of Health (2009) 'Toolkit for High Quality Neonatal Services'</p> <p>National Service Framework for</p>	<b>Mandatory</b>

			Children, Young People and Maternity Services (2003 and as modified)	
F9	Children should have access to general resources including toys, books, magazines, computers and other age appropriate activity coordinated by play therapy teams.	Facilities available Parent / User questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory</b>
F10	Parents and carers should be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Patient / Carer literature Parent / Carer questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
F11	Tertiary Centres must refund travel expenses to qualifying parents / carers at the time of each appointment in accordance with the 'Healthcare Travel Costs Scheme'.	Patient / Carer literature Parent / Carer questionnaires	Department of Health's 'Healthcare Travel Costs Scheme'	<b>Mandatory</b>

		Audit of compliance		
F12	Children, their parents and carers should be encouraged to provide feedback on the quality of care and their experience of the service, and Tertiary Centres must demonstrate ongoing structured liaison with parent and groups. They should be encouraged to participate in surveys of outcomes and/or experience. Tertiary Centres must make this feedback openly available, and they must demonstrate how they take this feedback into account when planning and delivering their services. Feedback should also be given to parents and carers on action taken following a complaint or suggestion made.	Written protocols  Written records of complaints or feedback  Written records of how feedback was considered and acted upon  Patient / Carer literature  Parent / Carer questionnaires	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
F13	Staff should receive training in communication with children, young people and parents, which shall include training in conveying unwelcome information.	Details of training provided	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
F14	There must be access (for patients and family members) to support services including faith support and interpreters.	Facilities available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory</b>

			National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	
F15	The outcome of relevant local and national audits will be made easily available to patients, parents / carers and the general public.	Publication of audits	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>

	Designation standard	Measures	Compatible Evidence Base	Status
<b>G</b>	<b>EXCELLENT CARE</b>			
G1	Each Tertiary Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Named professionals  Record of attendance and activities	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory</b>
G2	All healthcare professionals must take part in a programme of continuing professional development that is recorded in a training register. Training programmes will, where possible, submit to regular external review of content, facilities and results and will include the care of children, safeguarding, life support, pain management and infection control. Staff will have an annual appraisal, re-licensing and re-validation consistent with their appropriate professional registration. Tertiary Centres must provide resources to sufficient to support these educational needs.	Training register and training records  Staff appraisal documentation  Written outcome of reviews of training programmes	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
G3	Tertiary Centres must provide a number of cardiac	Staff records	Advice from Royal	<b>Mandatory</b>

	clinical nurse educators that is sufficient to deliver standardised training and education competency-based programmes across the network. These programmes must focus on the acquisition of knowledge and skills such as diagnosis and assessment and treatment, facilitating and evaluating care, evidence based practice and communication.	Training available	College of Nursing (2010)	<b>Amber</b>
G4	All clinical teams will operate within a robust and documented clinical governance framework that includes clinical audit, including in outreach centres.	Written protocols and guidelines.  Evidence of audits	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)  National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	<b>Mandatory</b>
G5	Each Tertiary Centre will report on adverse incidents In addition to contractual and national reporting requirements centres must demonstrate how details of adverse incidents are disseminated across the local and national network.	Reported adverse health care events, including reports from other centres	Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory</b>
G6	Each Tertiary Centre will have a robust internal database and outcome monitoring tool based on	Database entry	Royal College of Surgeons (2007)	<b>Mandatory</b>

	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.	Evidence of audits	'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	
G7	Tertiary Centres must participate in national programmes for audit and must contribute to the National Central Cardiac Audit Database and the national Paediatric Intensive Care Unit database.	CCAD National Annual Audit of Congenital Heart Disease  PICANET annual report	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)  Care Quality Commission 'Annual Health Check'	<b>Mandatory</b>
G8	Each Tertiary Centre must have a dedicated paediatric cardiac surgery / cardiology data collection manager responsible for timely audit and database submissions in accordance with necessary timescales.	Named individuals  Staff contracts  CCAD annual report PICANET annual report	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Care Quality	<b>Mandatory Amber</b>

			Commission 'Annual Health Check'	
G9	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Evidence of regular audit and outcome analysis and appropriate actions	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	<b>Mandatory Amber</b>
G10	Tertiary Centres must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. The centres will follow mandatory NICE guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	New Treatment Review Committee  NICE procedures credentialing	NICE Interventional Procedures Guidance  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Mandatory</b>
G11	Tertiary Centres must demonstrate that they have 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.	Written protocols  Terms of reference for, and outcome of, peer reviews	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	<b>Highly Desirable</b>
G12	Each Tertiary Centre must have, and regularly update, a research strategy and programme that documents current and planned research activity,	Research Strategy  Register of grant	Royal College of Surgeons (2007) 'Surgery for Children:	<b>Mandatory</b>

	the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other 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 children and their families.	applications Register of research activity	Delivering a First Class Service'  Report of the Paediatric Congenital Cardiac Services Review Group (2003)	
G13	Each Tertiary Centre must demonstrate close links with one or more academic departments in Higher Education Institutions.	Research Strategy  Register of grant applications  Register of research activity	Department of Health (2006) 'Best Research for Best Health'	<b>Mandatory</b>
G14	Tertiary Centres must demonstrate that support and supervision is available from a dedicated Clinical Psychologist for all healthcare professionals working within the paediatric cardiac team.	Services available  Staff literature  Access audit	National Reference Group for Psychologists Working in Paediatric Cardiology (2010)	<b>Mandatory Amber</b>

## APPENDIX A: MEMBERSHIP OF STANDARDS WORKING GROUP

<b>Name</b>	<b>Constituency</b>	<b>Role</b>
Mr William Brawn (Chair)	British Congenital Cardiac Association (Immediate Past President)	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust
Dr Martin Ashton-Key	Specialised Commissioning	National Specialised Commissioning Team
Dr Geoffrey Carroll	NHS in Wales	Medical Director, Health Commission Wales
Professor Martin Elliott	British Congenital Cardiac association	Consultant Congenital Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust
Jeremy Glyde	National Specialised Commissioning Team	Programme Director, NSC Team
Dr Kate Grebenik	Association of Cardiothoracic Anaesthetists	Consultant Anaesthetist, Oxford Radcliffe Hospitals NHS Trust
Mr Leslie Hamilton	Society for Cardiothoracic Surgery in Great Britain and Ireland	Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust
Dr Sue Hobbins	Royal College of Paediatrics and Child Health	Consultant Paediatrician, South London Healthcare NHS Trust
Dr Ian Jenkins	Paediatric Intensive Care Society (President)	Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust
Anne Keatley-Clarke	Patients and public	Chief Executive, Children's Heart Federation
Teresa Moss	National Specialised Commissioning	Director of National Specialised Commissioning
Dr Sally Nelson	Public Health	Medical Adviser, South Central SCG
Dr Shakeel Qureshi	British Congenital Cardiac Association (President)	Consultant Paediatric Cardiologist, Guy's and St Thomas' NHS Foundation Trust
Dr Tony Salmon	British Congenital Cardiac Association (President Elect)	Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust
Fiona Smith	Royal College of Nursing	Children's Adviser, Royal College of Nursing
Dr Graham Stuart	British Congenital Cardiac Association	Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust
Louise Tranmer	Specialised Commissioning	Director, South West SCG

## APPENDIX B

### Role of the Lead Nurse

#### **Purpose of the role**

The role of the Lead Nurse is to provide professional and clinical leadership and support to nursing staff within the Centre and across the network. As a senior member of the clinical team at the Tertiary Centre they will also contribute to the strategic development of the whole service across the network.

#### **Person specification**

Expert in the care of children and young people with cardiac conditions and has been educated to Masters level or equivalent.

#### **Core role**

##### **Responsible for:**

- advancing the development and practice of evidence-based children's cardiac nursing
- leading the development and delivery of child and family focused cardiac care and support
- developing and implementing effective communications across the network
- maintaining their own clinical practice which must be 20% of their time over the period of a month
- leading nursing Research & Development and for developing multi-disciplinary R&D working with the medical R&D lead

## APPENDIX C

<b>Procedures to be Excluded from Counts</b>
123200. Post-operative procedure
123206. Lung biopsy procedure
123280. Insertion of pleural tube drain
123351. Peripheral vascular procedure
123352. Non-cardiothoracic-vascular procedure
123713. Single lung transplant
123720. Double lung transplant
124003. Left thoracotomy
124006. Thoracoscopic approach (VATS)
124013. Minimally invasive procedure
124029. Median sternotomy: redo x 1-3
124118. Transverse bilateral thoracotomy: clamshell
126400. Bronchoscopy
126408. Bronchoscopic removal of foreign body
126420. Tracheal procedure
126421. Tracheostomy creation
126440. Tracheobronchial reconstruction procedure
126513. Pectus carinatum repair
126514. Pectus excavatum repair
126523. Anterior chest wall (pectus) repair
126545. Debridement of chest wall incision
126548. Sternal wire removal from previous sternotomy
126556. Sternotomy wound drainage
126560. Delayed closure of sternum
126582. Pleurodesis
126589. Pleural procedure
126600. Lung procedure

### Procedures to be Excluded from Counts

126601. Lung decortication
126602. Lung mass excision
126605. Lung lobectomy
126606. Pneumonectomy
126607. Lung sequestration repair
128000. Thoracic-mediastinal procedure
130021. Chest x-ray
130023. Computerised tomographic scan of chest
130024. Cardiovascular Magnetic Resonance Imaging (CMRI)
130100. Echocardiographic examination
130102. Transthoracic echocardiographic examination
130103. Transoesophageal echocardiographic examination
130103. Transoesophageal echocardiographic examination
130104. Epicardial echocardiographic examination
130501. Diagnostic cardiovascular catheterisation procedure
130512. Electrophysiological study (EPS)
130513. Catheterisation study for pulmonary hypertension evaluation
130514. Transcatheter procedure undertaken with x-ray guidance
130517. Electrophysiological study (EPS) with three dimensional mapping
150001. Cardiac arrest during procedure
150265. Postprocedural haemorrhage requiring reoperation
150300. Median sternotomy complication
150303. Infection of median sternotomy wound
150308. Dehiscence of median sternotomy wound
150330. Lateral thoracotomy complication
150350. Wound infection
150351. Wound dehiscence
153601. Postprocedural ascending aorta complication

<b>Procedures to be Excluded from Counts</b>
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154306. Unplanned reoperation during current admission
155000. Cardiac catheterisation complication
158052. Postprocedural left pleural effusion
158055. Postprocedural chylothorax
158061. Pleural effusion requiring drainage
158090. Intraprocedural phrenic nerve injury (paralysed diaphragm)
159001. Postprocedural complication
171002. Medical therapy for endocarditis

## APPENDIX D

### References

Ewart, H. (2009) The Relation Between Volume and Outcome in Paediatric Cardiac Surgery; Public Health Research Unit - A Literature Review for the National Specialised Commissioning Group

Calderone, C. and Al-Radi, O. (2008) 'The Limits of Confidence: At What Price a Baby's Life?' *Pediatric Cardiology*, 29, 704-705.

Daenen, W. and Lacour-Gayet, F. et al (2002) 'Optimal Structures of a Congenital Heart Surgery Department in Europe', *The EACTS Congenital Heart Surgery Committee*, 1-25.

Hamilton, J. (2001) 'Paediatric Cardiac Surgery: Potential Problems in Recruitment', 1-3.

Hannan, E. and Racz, M. et al (1998) 'Pediatric Cardiac Surgery: The Effect of Hospital and Surgeon Volume on In-hospital Mortality', *Pediatrics*, 101, 963-969.

'Heart surgery and interventional cardiology for children' (1993) *Report of a Committee of the Health Council of the Netherlands*, 20E The Hague, 11.

Hilton, C. and Hamilton, J et al (2005) 'Effects of 'Bristol' on surgical practice in the United Kingdom', *Interactive Cardiovascular and Thoracic Surgery*, 4, 197-199.

Hirsch, J. and Gurney, J. et al (2008) 'Hospital Mortality for Norwood and Arterial Switch Operations as a Function of Institutional Volume', *Pediatric Cardiology*, 29, 713-717.

Hudsmith, L. and Thorne, S. et al (2007) Transition of care from paediatric to adult services in cardiology, *British Medical Journal - Archives of Disease in Childhood*, 92, 927-930

Jenkins, K. and Newburger, J. et al (1995) 'In-Hospital Mortality for Surgical Repair of Congenital Heart Defects: Preliminary Observations of Variation by Hospital Caseload', *Pediatrics*, 95, 323-330.

Jenkins, K. and Gauvreau, K. et al (2002) 'Consensus-based method for risk adjustment for surgery for congenital heart disease', *The Journal of Thoracic and Cardiovascular Surgery*, 123, 110-118.

Lacour-Gayet, F. and Clarke, D. et al (2004) 'The Aristotle Score for Congenital Heart Surgery', *Paediatric Cardiac Surgery Annual of the Seminars in Thoracic and Cardiovascular Surgery*, 7, 185-191.

Lundström, N. and Berggren, H. et al (2000) Centralization of Pediatric Heart Surgery in Sweden, *Pediatric Cardiology*, 21, 353-357.

Ontario Ministry of Health and Long-Term Care (2002), 'Specialized Pediatric Services Review', *Report of the Minister's Advisory Committee*, 1-36.

Queensland Government - Queensland Health (2006) 'Report of the Taskforce on Paediatric Cardiac Services', 1-69.

Qureshi S, and Redington, A. et al (2000), Recommendations of the British Paediatric Cardiac Association for Therapeutic Cardiac Catheterisation in Congenital Heart Disease, *Cardiology in the Young*, 10, 649-667.

Reid, G. and Irvine, M. et al (2004) 'Prevalence and Correlates of Successful Transfer From Pediatric to Adult Health Care Among a Cohort of Young Adults With Complex Congenital Heart Defects', *Pediatrics*, 113, 197-205.

Sollano, J. and Gelijns, A. et al (1999) 'Volume-Outcome Relationships in Cardiovascular Operations: New York State, 1990-1995', *The Journal of Thoracic and Cardiovascular Surgery: Surgery for Adult Cardiovascular Disease*, 117, 419-430.

Spiegelhalter, D. (2002) 'Mortality and volume of cases in paediatric cardiac surgery: retrospective study based on routinely collected data', *The British Medical Journal*, 324, 261-264.

Stark, J. (1995) 'Quo vadis paediatric cardiac surgery?', *Annals of The Royal College of Surgeons of England*, 77, 217-221.

Stark, J. and Gallivan, S. et al (2000) 'Mortality rates after surgery for congenital heart defects in children and surgeons' performance', *The Lancet*, 355, 1004-1007

Stark, J. (1994) 'Predicting the unpredictable: Presidential address', *European Journal of Cardiothoracic Surgery*, 8, 1-6.

Stark, J. (1995) 'How to Choose a Cardiac Surgeon?', *W.W.L Glenn Lecture: American Heart Association Scientific Sessions*, 94 supplement II, II-1 – II-4.

Stark, J. and Gallivan, S. et al (2001) 'Assessment of Mortality Rates for Congenital Heart Defects and Surgeons' Performance', *The Annals of Thoracic Surgery*, 72, 169-175.

Welke, K. and Peterson, D. et al (2007) 'Comparison of Cardiac Surgery Volumes and Mortality Rates Between The Society of Thoracic Surgeons and Medicare Databases From 1993 Through 2001', *The Annals of Thoracic Surgery*, 84, 1538-1546.

Welke, K. and Diggs, B. et al (2008) 'The Relationship Between Hospital Surgical Case Volumes and Mortality Rates in Paediatric Cardiac Surgery: A National Sample'. *The Annals of Thoracic Surgery*, 86, 889-896.

## **Appendix E**

### **The 'Cardiac transition nurse' role**

- Facilitate transition from children's to adult services, engaging, educating and empowering young people to make decisions, manage their treatment regimes, to recognise any deterioration or acute episodes requiring immediate specialist attention and how to access the necessary support.
- Provide expert advice and support to members of the hospital and community teams
- Provide specialist nursing care, support and advice to congenital heart disease patients
- Act as an advocate for the young person and their family, giving expert support and advice based on best practice
- Act as an expert, clinical role model and leader in transitional care for all staff
- Collaborate with colleagues in adult centres to ensure transition process is effective

## Appendix F

### **The role of the Children's Cardiac Specialist Nurse within the Cardiac Liaison Team**

#### **Core role**

- Provide practical information, educational and emotional support to children, young people and their families
- Provide continuity between home, community and hospital cardiac care, ensuring continuity of care and effective communication across all boundaries throughout the child and young person's cardiac care pathway
- Assess the holistic needs of children, young people and their families
- Work in partnership with children, young people and their families to meet identified needs, planning, negotiating, implementing and evaluating an agreed plan of care
- Co-ordinate and facilitate out-of-hospital care delivery and provision of support for the child, young person and their family
- Act as an expert resource for the multidisciplinary team, providing specialist education and teaching to community and education colleagues