

National Specialised
Commissioning Group

Safe and Sustainable
Paediatric Cardiac Surgery Services



Children's heart surgery centres in England

Draft service specification standards

September 2009



Contents

- i. Welcome from the Chair of the working group
- ii. Background to the *Safe and Sustainable* programme
- iii. Draft service specification standards
- iv. Related standards
- v. Appendix A: Membership of the working group
- vi. Appendix B: List of children's heart surgery centres in England
- vii. Glossary (words in **bold** throughout this document appear in the glossary)
- viii. How to make your views known

Welcome



In 2006, a national workshop attended by children's heart surgeons and cardiologists, other NHS staff and patient representatives concluded that the current configuration of children's heart surgery services in England was not sustainable. In response to this view the NHS Medical Director, Professor Sir Bruce Keogh, asked the **National Specialised Commissioning Group** to deliver recommendations that will ensure a safe and sustainable children's heart surgery service in England. This is called the *Safe and Sustainable* programme, and its motivation is to deliver the best possible care for children and their families into the future.

The *Safe and Sustainable* programme is overseen by a steering group chaired by Dr Patricia Hamilton, Director of Medical Education for England and Immediate Past President of the Royal College of Paediatrics and Child Health.

The steering group has asked me to chair a working group that has been tasked with developing a framework of service standards to inform and guide the process for future service configuration and future service delivery. Members of the working group are listed in this document. I would like to acknowledge the contribution of members of previous reviews of children's heart surgery services. Our work builds upon their previous recommendations, most notably the report of the Paediatric and Congenital Cardiac Services Review Group in 2003¹.

The standards working group will:

- examine existing standards, including international standards
- develop standards that will ensure that children's heart surgery centres are of the highest quality, responsive and *sustainable*.

We will also identify the available evidence base for our recommendations and describe how centres will be measured on their compliance against standards in the future, though in this draft working document we wish to emphasise the standards we aspire to achieve.

My vision for children that need heart operations is nothing less than a world-class service and the very best possible outcomes. And to deliver this vision we need the surgeons who operate on these children and the teams who support them to be working to world-class standards. The draft standards in this document envisage a model of care that delivers as much care and treatment as close as possible to where children and their families live. This requires the surgical centres, local services and patients and their families, to work together to answer the question:

How do we achieve the very best, world class service?

This working document offers a first draft of these standards and we now invite all those with an interest in children's heart surgery services to give us their views on this draft by **10 November 2009**. You can find out how to do this at the back of this document.

I look forward to hearing your views.



Mr William Brawn

Consultant Paediatric Cardiac Surgeon
Chair of the Standards Working Group for the *Safe and Sustainable* Paediatric Cardiac Surgery Service Programme

¹ Report of the Paediatric and Congenital Cardiac Services Review Group, 2003, Department of Health; gateway ref: 1981

Background to the *Safe and Sustainable* Programme

On behalf of the **NHS Management Board**, the NHS Medical Director has asked the National Specialised Commissioning Group to undertake a review of the provision of children's heart surgical services in England with a view to reconfiguration. This is called the *Safe and Sustainable Paediatric Cardiac Surgery Programme*.

The programme is led by a steering group that includes representation from the following:

- Children's Heart Federation and lay representation
- British Congenital Cardiac Association
- Society for Cardiothoracic Surgery in Great Britain and Ireland
- Association of Cardiothoracic Anaesthetists
- Royal College of Paediatrics and Child Health
- Paediatric Intensive Care Society
- **NHS commissioners**
- NHS public health doctors
- **NHS Strategic Health Authorities**
- NHS in Scotland
- Health Commission Wales
- Department of Health.

There are currently 11 children's heart surgery centres in England. The centres are shown in Appendix B.

The programme aims to deliver robust proposals that will ensure that children's heart surgery services are world class into the future. We believe that children and their families will benefit from:

- a model of care that plans and delivers services around the needs of the child and which takes account of the transition to adult services
- improved communication and planning between specialised surgical centres and local hospitals that links care in an effective "**hub-and-spoke**" model
- a network of specialist surgical centres that collaborate with each other in the interests of clinical care, audit and research
- an NHS workforce that is highly trained and expert in the care and treatment of children and young people.

The draft standards that are set out in this working document form the quality framework that we envisage the centres will be working to in order to deliver a high quality, world class service. We welcome your views on the draft standards and we encourage you to make your views known.

The working group recommends that all of the draft standards in this document, if agreed, should be mandatory in all designated surgical centres, though it may be appropriate for some standards to become mandatory over a period of time.

The draft standards in this document do not apply to services for Grown-Ups with **Congenital Heart Disease** (GUCH services) as the NHS is developing a separate set of standards for GUCH services². However, we have included draft standards that address the transition from child to GUCH services so that both sets of standards join-up in the interests of the patient.

No decisions have yet been made on the future shape of the children's heart surgery service in England, but the proposals may recommend that some existing centres stop performing surgery and interventional procedures in the interests of achieving the best possible clinical outcomes. The proposals will be developed in 2010 by **NHS commissioners** working in consultation with local stakeholders.

Once the proposals have been considered by the steering group we will hold a formal public consultation in 2010 so that all stakeholders have the opportunity to comment.

Further information on the *Safe and Sustainable* programme including terms of reference and minutes of meetings can be found on our website www.specialisedcommissioning.nhs.uk or by contacting us (our contact details are given at the back of this document).

Throughout this document, the term 'centres' refers to a number of NHS hospitals that will be designated in 2010 as specialised providers of children's heart surgery services.

² Designation of Specialist Service Providers for Grown-Ups with Congenital Heart Disease (GUCH)/ Adults with Congenital Heart Disease (ACHD)", East of England Specialised Commissioning Group, 2009

Draft service specification standards

Standard A – The network approach

We believe that care for children who need heart surgery is improved when all of the NHS services that treat them work together, and communicate with each other.

A1 Centres will agree pathways of care with their local services that reflect the principle that as much care and treatment should be provided as close as possible to the child's home, while ensuring the best possible outcome for the child.

A2 Centres should provide comprehensive care which is linked to local services as well as other tertiary centres. The centres are the hub of the clinical network providing the full range of surgery and interventional cardiology for all **congenital heart conditions**, and coordinating the care for children in their catchment area.

A3 Centres will collaborate with each other to manage demand (reflecting that collectively they provide a national service) and to develop and embed best practice and benchmark performance.

A4 Centres will establish models of care and service pathway mapping that will ensure quality care along the entire patient pathway.

A5 The centres will agree policies for referral criteria and discharge criteria between **primary, secondary and tertiary care**.

A6 There will be written guidelines for the centres covering communication between clinicians, and between clinicians and parents / carers. The guidelines will be agreed with local referring **paediatricians**, paediatric **cardiologists** and patient groups.

A7 There will be specific guidelines within each network for the transfer of children requiring heart surgery.

A8 Centres will provide active leadership and participation in their clinical networks in order to:

- manage and develop further referral, care and treatment pathways, policies, procedures, performance monitoring and audit, professional training and development
- facilitate the development of as much care and treatment as possible close to the child's home.

A9 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 when appropriate.

A10 Children who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) will be referred to a designated paediatric cardiothoracic transplant centre.

A11 The centres will agree clinical guidelines with their local networks, based upon nationally established standards. They will be responsible for advising colleagues within the network on the care for patients requiring associated non-cardiac interventions.



Standard B – Prenatal screening

We believe that babies with heart conditions and their mothers are best served by a specialised patient pathway that begins care before birth.

B1 Centres will agree and establish protocols with maternity and **neonatal** units in their catchment area for the care and treatment of pregnant women whose fetus has been diagnosed with a heart condition. The protocols must ensure that pregnant women are referred to the relevant specialist as early as possible, and that accurate diagnosis is made promptly.

B2 If the standard prenatal scan indicates that the fetus may have a heart problem, the mother should be offered a specialist heart scan as soon as possible, and in any event within 1 week.

B3 If the heart scan suggests that the fetus has a **cardiac lesion**, there should be a full medical assessment as soon as possible, and in any event within 1 week of the heart scan.

B4 All high-risk mothers (for example, where there is a history of congenital heart disease in the mother, father or previous child) should be offered a specialist heart scan at 18 -20 weeks.

B5 Parents who have been told that their expected child has a heart condition should have access to non-directive counselling and support to help them interpret the diagnosis and possible outcomes. Parents should also be given contact details for relevant local and national support groups at this point.

B6 A paediatric heart surgeon or paediatric cardiologist will be available for antenatal counselling for congenital cardiac anomalies.

B7 At diagnosis, a plan should be agreed between the centre, the maternity unit, the neonatal team and the parents about arrangements for the delivery of the baby.

B8 If the plan is for the delivery of the baby at the local maternity unit this should include arrangements for the transfer of the baby to the centre. An experienced paediatrician should be present at the delivery and a neonatal team must be available to care for the baby whilst awaiting transfer. There should be a facility to deliver the baby close to the centre if necessary (for example, at a linked obstetric unit).

Standard C – Making choices

We believe that NHS services should fully support parents and carers in making decisions about their child's treatment.

- C1 Centres should encourage parents and carers to actively participate at every stage in their child's care.
- C2 Parents and carers should be 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.
- C3 Information should be made available to parents and carers in a wide range of formats and on more than one occasion. It should be clear, understandable, and culturally sensitive and evidence based. When given verbally, information given should be precisely documented.
- C4 When considering treatment options, parents and carers need to understand the potential risks as well as the benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.
- C5 Where surgery is planned, the child and their parents or carers should have the opportunity to visit the centre and to meet the clinicians who will be responsible for their care, including an opportunity to discuss the planned operation with a consultant paediatric heart surgeon who will obtain consent for the procedure.

C6 Parents, carers and their General Practitioners should be given details of all who they can contact in the clinical team should they have any questions or concerns. They should have immediate, 24-hour access to a member of the clinical team for advice, information and support.

C7 Parents and carers should receive support and cooperation in obtaining further opinions.

C8 Parents and carers whose first language is not English must be provided with appropriate interpreting and translation services.

C9 Parents and carers should be given details of available support groups. Involvement of these groups should be available early in the assessment process.

C10 Parents and carers should be given an agreed, written care plan that includes notes of discussions with the clinical team, the treatment options agreed and written record of consents.

Standard D – The patient and family experience

We believe that in addition to the best possible treatment, children and their families should have the best possible experience of their hospital.

D1 Each child should have a named cardiac liaison nurse who is responsible for coordinating their care, and who acts as a liaison between the clinical team and the child throughout their care.

D2 There must be facilities in place to ensure easy and convenient access for parents and carers. Facilities and support include accommodation for the whole family to stay at the hospital and for parents to stay with their child in the ward 24 hours a day when appropriate, access to refreshments, and to be able to play and interact with their child (and their other children). There should be a quiet room available on the ward or centre completely separate from general family facilities.

D3 There must be facilities, including access to maternity staff, that allow the mothers of new-born 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.

D4 There should be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support).

D5 Children should have access to general resources including toys, books, magazines, computers and other age appropriate activity coordinated by play therapy teams.

D6 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.

D7 Children, their parents and carers should be encouraged to provide feedback on the quality of care and their experience of the service, and they should be encouraged to participate in national Patient Reported Outcome Measures (PROMS) surveys. Centres must make this feedback openly available, and they must demonstrate how they take this feedback into account when planning and delivering their services.

D8 Staff in the multi-disciplinary team should have training and be supported in using communication skills. Staff should be trained in breaking bad news.

D9 There must be access to culturally appropriate support services including faith support, social workers, interpreters, clinical psychologists and bereavement counsellors. These should be made available at the specialist centre and links to facilitate this at a local level should also be developed.

D10 Parents, carers and support groups will be regularly updated with appropriate information on issues of clinical governance and the results of local and national audits.

D11 There should be formal arrangements for addressing complaints and other comments made by children, parents and carers.

Standard E – Access to services

We believe that heart surgery services should be planned and delivered around the needs of the child.

- E1 There will be 24 hour, 7 day a week access to paediatric cardiac surgical advice and care. The consultant on duty will be available by phone for urgent advice and able to attend their own centre within 30 minutes.
- E2 Each centre will provide a full 24 hour emergency service, sufficient to meet the needs of its catchment population.
- E3 Each centre will provide interventional cardiology. This should not be undertaken without on-site surgical back up.
- E4 Each cardiology team will have a lead interventionist who is responsible for assuring the quality of the cardiology team's work overall, including involvement in the planning of procedures and the audit of activity; taking steps to eliminate occasional practice; and ensuring that interventionists have received training and are competent in the procedures that they undertake.
- E5 Each centre will be co-located with **anaesthetists** trained in paediatric cardiac anaesthesia.
- E6 Each centre will be co-located with paediatric critical care services.
- E7 All children requiring investigation and treatment will receive that care from staff trained in looking after children and trained specifically according to the requirements of their profession or discipline.
- E8 There must be sufficient 24 hour access to the complete range of supportive paediatric medical and surgical services and other resources required for end to end management of the child's needs for the whole patient journey including Paediatric Intensive Care Units (PICU), accredited diagnostic laboratory services (Clinical Pathology Accreditation UK) and blood transfusion.

- E9 Centres will have on-site access to:
- Experienced paediatric **Intensivists**
 - Experienced PICU and High Dependency Unit (HDU) nurses
 - **Extracorporeal mechanical support** (for support post-cardiac surgery)
 - **Transoesophageal Echocardiography (TOE)**
 - **Computed Tomography and Magnetic Resonance Imaging (+/- GA)**
 - Paediatric competent **radiologist**
 - Infection control nurse experienced in the needs of paediatric cardiac surgery patients
 - Paediatric pain control nurse cover
 - Paediatric pharmacist cover
 - Paediatric physiotherapy
 - Play therapy staff
 - Paediatric dietician
 - Paediatric social worker
 - Hospital / school teacher
 - Child and adolescent mental health professionals with dedicated sessions in congenital heart disease (for patients and staff).

- E10 Centres must be able to provide (in accordance with the Framework of Critical Inter-Dependencies³):
- Specialised Paediatric Surgery: a transfer to, or visit from, a paediatric surgical specialist within 4 hours; it is desirable that this service is co-located but may not be practical in all configurations
 - Paediatric Ear, Nose and Throat (Airway): a transfer to, or visit from, a paediatric ENT specialist by the next working day
 - Paediatric Neurology: a transfer to, or visit from, a paediatric neurology specialist by the next working day
 - Paediatric Respiratory Medicine: a transfer to, or visit from, a paediatric respiratory specialist by the next working day
 - Neonatology: a transfer to, or visit from, a neonatal specialist by the next working day
 - Nephrology: a transfer to, or visit from, a nephrology specialist by the next working day
 - Clinical Haematology: a transfer to, or visit from, a clinical haematology specialist by the next working day

E11 Admission for planned surgery will be booked for a specific date rather than from a waiting list.

E12 Same-day cancellations for non-clinical reasons of elective cases shall not be more than 0.8 per cent. There shall not be more than 0.8 per cent of patients who are not offered a binding date for operation within 28 days of the cancellation.

E13 Transfers in and out of the centres should be dictated by individual patient need.

E14 Un-planned readmission to Paediatric Intensive Care Unit (PICU) should only occur in less than 10 per cent of admissions.

E15 All paediatric cardiac surgical cases should be carried out on theatre lists with appropriately trained staff.

E16 Nursing staff numbers will be sufficient to allow HDU nursing and one to one PICU nursing.

E17 Sufficient staff will be available to provide in-patient beds, critical care beds, theatre capacity and service provision.

a) There must be sufficient access to on-site beds (suitably staffed) to guarantee 100 per cent acceptance rates for emergency referrals

b) There must be sufficient access to formal cardiac surgery beds (suitably staffed) to guarantee 100 per cent acceptance rates

When a centre cannot admit a patient for whatever reason it is the responsibility of that centre to find another bed (suitably staffed) at another centre.

E18 There must be an appropriate mechanism for arranging retrieval and back transfer of patients which takes into account the following:

- clinical transfers should be arranged in a timely manner according to patient need
- critically ill children must be transferred/retrieved in accordance with the standards set out within the designation standards for Paediatric Intensive Care services⁴.

E19 Sufficient capacity will be available to allow urgent cases to be accommodated in daytime lists by providing a dedicated paediatric cardiac surgery operating theatre with access for emergency cases.

E20 There should be arrangements for accepting patients transferred by incoming helicopter and fixed wing aircraft. It is not mandatory for centres to have on-site landing facilities, though this is desirable.

E21 There must be an appropriate network of care to facilitate repatriation in a timely fashion. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.

³ "Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies" Department of Health, 2006, Gateway Ref: 10044

⁴ Currently draft with a Paediatric Intensive Care Society working party for consultation



Standard F – Age appropriate care

We believe that children and adolescents should receive care that is appropriate to their age and which facilitates the transition to adult services.

- F1 Centres should make the patient aware and responsible for their condition from an appropriate age.
- F2 The patient's management plan should be reviewed at each consultation to make sure that it continues to be relevant to their particular stage of development.
- F3 When the patient begins school or moves to a new school the cardiac liaison service should be available to provide information or visit the school in person at the parent's request, in order to help teachers and other staff understand the patient's condition.
- F4 Centres should provide the patient with information on relevant life-style issues at an appropriate stage and in a way that is accessible. Parents should be involved in decisions over timing of this information.
- F5 Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present.
- F6 Appropriate "transition clinic" arrangements should be in place with designated centres for Grown-Ups with Congenital Heart Disease to ensure a seamless pathway of care, led jointly by paediatric and adult cardiologists. There should be access to adolescent beds for the care and treatment of adolescents and young people. These adolescent beds may be on site or off site or part of a broad adolescent unit.
- F7 There will not be a fixed point of transition between children's and adult services but the process should be initiated no later than 14 years of age. 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.

Standard G – Excellent Care

We believe that children are entitled to the best possible care and treatment, delivered by exceptional clinical and nursing staff.

G1 All clinicians and nursing staff will take part in a programme of continuing professional development.

G2 All clinical teams will operate within a robust and documented clinical governance framework that includes undertaking clinical audit.

G3 All members of the Multi-Disciplinary Team (MDT) will take part in continuing education and continuing professional development. Training Programmes will where possible submit to regular external review of content, facilities and results. Staff will have an annual appraisal and re-licensing and re-validation consistent with their appropriate professional registration. There must be appropriate resources to support educational needs (such as seminar rooms and technical equipment).

G4 Each centre will have a robust internal database and outcome monitoring tool, with standardised coding. All aspects of clinical practice where recognised standards exist, or improvements might be made, should be considered for audit. Individual and collective outcomes will be analysed, deficiencies identified and corrected by formal audit. At least one audit of clinical practice of demonstrable clinical significance should occur annually.

G5 The patient's outcome will be assessed with results monitored and compared against national and international outcome statistics.

G6 Centres will participate in national programmes for audit and contribute to national databases:

1. **National Central Cardiac Audit Database**
2. In-house computerised database

There must be a specific paediatric cardiac surgery/cardiology data collection manager responsible for timely audit and database submissions, no more than 3 months after patient is discharged.

G7 Systems will be in place to allow the managed introduction of new treatments and techniques into the centre. The centres will follow mandatory **NICE** guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance⁵.

G8 Centres will collaborate at a clinical, audit, research and administrative level, and will take part in formal inter-unit peer review.

G9 Each centre should have, and regularly up-date, a research strategy and programme which documents current and planned research activity, the resources needs to support the activity and objectives for development.

G10 The research strategy shall include a commitment to working in partnership with other centres in research activity which aims to address research issues which are important for the further development and improvement of clinical practice, for the benefits of children and their families.

G11 Each centre shall strive to continuously improve its research infrastructure, and such improvements will be monitored regularly.

G12 Each centre will have a dedicated management group for the internal management and coordination of service delivery. The group will comprise the different departments and disciplines delivering the service.

⁵ A summary of how NICE develops interventional procedures guidance is available at www.nice.org.uk/guidance

Standard H – Team delivered

We believe that the standard of care is at its highest when the skills and experience of the whole clinical team is brought to each case.

H1 The management of each patient should be discussed and planned at combined cardiac surgery and cardiology MDT meetings to ensure the best possible care and outcomes for children.

H2 Patients will be cared for by MDTs containing adequate numbers of specifically trained staff. The team shall include the following personnel:

- Clinicians directly responsible for patient care, including paediatric cardiac surgeons, paediatric cardiologists and paediatric anaesthetists / critical care specialists, together with junior staff in each of these specialties. All consultant clinicians are expected to have expertise in the management of patients with paediatric cardiac disease

- Paediatric cardiac liaison nurses

- Dietician, pharmacist, physiotherapist, social worker

- Clinicians involved in specialist diagnostic services, including paediatric cardiac radiology, histopathology and microbiology

The composition of the MDT can be adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinico-pathological and audit meetings).

H3 Centres must provide appropriately trained and experienced medical staff sufficient to provide 24 hour, 7 day cover within legally compliant rotas.

H4 The attendance and activities of the MDT should be maintained in a register.

H5 There must be a 24 hour, seven day a week cover by paediatric cardiology consultants who should do ward rounds on all paediatric cardiology patients on a daily basis. There must also be 7 day access to interventional cardiology medical cover on an emergency or elective basis.

H6 The paediatric intensive care unit should be staffed on a 24 hr basis by PICU consultants with appropriate skills in paediatric cardiac critical care.
Consultant allocation to paediatric cardiology/surgery care will allow adequate clinical cover of the centre including on-call responsibility, management, audit, teaching, retrieval, follow up, research and development.

H7 Each centre will have a continuous and documented availability of formally trained paediatric cardiac anaesthetists including a specialist on-call rota which is separate from the intensive care rota. Cardiac anaesthetists involved in cardiac surgical services should have experience and training in the peri-operative care of the paediatric cardiac patient.

H8 There will be sufficient recovery staff with experience in paediatric cardiac surgery to allow a constant throughput of paediatric cardiac patients. Full monitoring of the paediatric cardiac surgical patient should be available in the immediate post-operative period.

H9 There must be an appropriate number of paediatric cardiac liaison nurses within each centre. The Steering Group will make a recommendation on the minimum number of cardiac liaison nurses.

Standard I – Safe and Sustainable

We believe that children’s heart surgery services must be *safe and sustainable* into the future, taking account of the need to avoid occasional surgical practice.

I1	Each centre must perform a minimum number of surgical procedures each year.	Evidence suggests that centres that perform a higher number of surgical procedures have better clinical outcomes. A summary of the evidence that relates specifically to children’s heart surgery is available on our website www.specialisedcommissioning.nhs.uk To avoid occasional practice the Steering Group will make a recommendation on the minimum number of annual surgical procedures per centre.
I2	All children requiring heart surgery will be managed by consultant paediatric surgeons.	
I3	Each centre must have a minimum number of paediatric surgeons. a) Paediatric cardiac surgeon is defined as having two years dedicated training in a designated paediatric heart surgical centre. b) No new appointments without the equivalent of a formal two year fellowship training.	To ensure that centres are able to implement a legally compliant rota and to ensure that centres can deliver the range of surgical procedures the Steering Group will make a recommendation on the minimum number of surgeons within each centre.

Related standards

Centres must also meet these related standards and best practice guidance in full:

National Standards for the Care of Critically Ill Children	2009, Paediatric Intensive Care Society; (currently draft)
Improving Services for Children in Hospital	2007, Commission for Healthcare, Audit and Inspection
“Transition: Getting It Right For Young People”	2006, Department of Health; product number 271558; gateway ref: 5914
The National Service Framework for Children, Young People and Maternity Services	2004, Department of Health, and Department of Education and Skills; product number: 40496; gateway ref: 3779
Recommendations of the British Paediatric Cardiac Association for Therapeutic Cardiac Catheterisation in Congenital Heart Disease	2002, British Cardiac Society

Centres must take these standards and best practice guidance into account:

“Designation of Specialist Service Providers for Grown-Ups with Congenital Heart Disease (GUCH)/ Adults with Congenital Heart Disease (ACHD)”	2009, East of England Specialised Commissioning Group
National Heart and Lung Transplant Standards	2006, National Specialist Commissioning Advisory Group
National Service Framework for Long Term Conditions	2005, Department of Health; product number 265109; gateway ref: 2005

Appendix

Appendix A: Membership of the Standards Working Group

Name	Constituency	Role
Mr William Brawn (Chair)	British Congenital Cardiac Association (President)	Consultant Paediatric Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust
Dr Martin Ashton-Key	Specialised Commissioning / Public Health	Medical Adviser, National Specialised Commissioning Team
Dr Geoffrey Carroll	NHS in Wales	Medical Director, Health Commission Wales
Steve Collins	National Specialised Commissioning Team	Deputy Director Policy and Coordination, NSC Team
Michaela Dixon	Nursing	University Hospitals Bristol NHS Foundation Trust
Professor Martin Elliott	British Congenital Cardiac Association	Consultant Paediatric Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust
Jeremy Glyde	National Specialised Commissioning Team	Programme Manager, 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 (President)	Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust
Dr Sue Hobbins	Royal College of Paediatrics & 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
Dr Shakeel Qureshi	British Congenital Cardiac Association (President Elect)	Consultant Paediatric Cardiologist, Guy's and St Thomas' NHS Foundation Trust
Peter Ripley	Ambulance NHS Trust	Assistant Director of Operations, East Midlands Ambulance Service NHS Trust
Dr Graham Stuart	British Congenital Cardiac Association	Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust

Appendix B: Children's heart surgery centres in England

- Freeman Hospital, Newcastle
- Leeds Teaching Hospital
- Alder Hey Children's Hospital, Liverpool
- Glenfield Hospital, Leicester
- Birmingham Children's Hospital
- Oxford John Radcliffe Hospital
- Bristol Royal Hospital for Children
- Great Ormond Street Hospital for Children, London
- Royal Brompton Hospital, London
- Evelina Children's Hospital, London
- Southampton General Hospital

Glossary

- Page 04 **National Specialised Commissioning Group:** The group that oversees specialised commissioning in the NHS in England.
- Page 06 **NHS Management Board:** The group that supports the NHS Chief Executive in managing NHS performance and shaping policy and strategy in the NHS.
- Page 06 **NHS strategic health authorities:** There are 10 strategic health authorities in England, responsible for the local management of the NHS in their regions.
- Page 06 **'Hub and spoke':** A model of care that has a specialist centre (the hub) working very closely with a number of local centres that each provide the non-specialist element of care (the spokes).
- Page 06 **NHS commissioners:** NHS commissioners ensure that health services effectively meet the needs of the population. Commissioners assess the health needs of the population, develop a strategic plan, procure health services from health providers and manage their performance in the delivery of services.
- Page 07 **congenital heart disease:** An abnormality of the heart present since birth.
- Page 08 **primary care:** Health services provided in the local community, such as General Practitioners and dentists.
- Page 08 **secondary care:** Health services provided in hospitals, either on a planned or emergency basis.
- Page 08 **tertiary care:** Health services that are provided on a specialised basis in hospitals, for rare and complex conditions.
- Page 08 **Paediatrician:** A medically qualified doctor who specialises in the diagnosis and treatment of children.
- Page 08 **Cardiologist:** A medically qualified doctor who specialises in the investigation, diagnosis and treatment of heart disease. Cardiologists do not perform surgery, but may undertake interventional cardiology.
- Page 11 **neonatal:** refers to new born infants.
- Page 11 **cardiac lesion:** An abnormality of the heart.
- Page 16 **Anaesthetist:** A medically qualified doctor who induces sleep during surgical procedures.
- Page 17 **Intensivist:** A medically qualified doctor who specialises in treatment in intensive care units.
- Page 17 **Extracorporeal mechanical support:** A device that removes blood from the patient's body, introduces oxygen into the blood, and then pumps the oxygenated blood back into the patient's body.
- Page 17 **Transoesophageal Echocardiography:** A specialised means of taking ultrasound images of the heart.
- Page 17 **Computed Tomography and Magnetic Resonance Imaging:** Specialised methods of taking images of the internal body.
- Page 17 **Radiologist:** Medically qualified doctors who specialise in the use of imaging techniques to diagnose and treat conditions.
- Page 22 **National Central Cardiac Audit Database:** A database available to the public that provides information on every children's heart surgical centre in the United Kingdom, including the number and range of procedures they carry out and survival rates for the most common types of treatment.
- Page 23 **National Institute for Health and Clinical Excellence (NICE):** An independent organisation responsible for providing national guidance on promoting good health, and preventing and treating ill health.

How to make your views known

We value the opinions of everyone concerned and are keen for you to contribute to the development of these draft standards. You can do so in the following ways:

- write to Jeremy Glyde, Programme Manager, National Specialised Commissioning Team, 2nd floor, Southside, 105 Victoria Street, London SW1E 6QT
- call Jeremy on 020 7932 3958
- e-mail ChildHeart@nsscgs.nhs.uk

Visit our website www.specialisedcommissioning.nhs.uk





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