



Specialised Services

SAFE AND SUSTAINABLE

REVIEW OF CHILDREN'S CONGENITAL CARDIAC SERVICES IN ENGLAND

PRE-CONSULTATION BUSINESS CASE

16 February 2011

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EXECUTIVE SUMMARY

This document sets out recommendations for a superior congenital heart service for the children of England and Wales - a service that is *SAFE AND SUSTAINABLE*.

The recommendations are the outcome of a robust review process that has been clinically led and supported by the relevant professional associations and national parent groups. There is an overwhelming feeling that the time for change is long overdue.

The recommendations are:

- Development of Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services
- Implementation of new clinical standards that must be met by all NHS hospitals designated to provide heart surgery for children
- Implementation of new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with Congenital Heart Disease

- A reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence
- The options for the number and location of hospitals that provide children's heart surgical services in the future are:

Option A (option 2 in analysis below)

Seven surgical centres at:

- Freeman Hospital, Newcastle
- Alder Hey Children's Hospital, Liverpool
- Glenfield Hospital, Leicester
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- 2 centres in London

Option B (option 14 in analysis below)

Seven surgical centres at:

- Freeman Hospital, Newcastle
- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- Southampton General Hospital
- 2 centres in London

Option C (option 6 in analysis below)

Six surgical centres at:

- Freeman Hospital, Newcastle
- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- 2 centres in London

Option D (option 8 in analysis below)

Six surgical centres at:

- Leeds General Infirmary
- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- 2 centres in London

London

The preferred two London centres in the four options are:

- Evelina Children's Hospital
- Great Ormond Street Hospital for Children.

If endorsed by the Joint Committee of Primary Care Trusts, these recommendations will be the subject of a formal public consultation between 28 February and 1 July 2011.

INTRODUCTION TO THE PRE-CONSULTATION BUSINESS CASE

This pre-consultation business case supports and enables formal public consultation on options for change between February 2011 and July 2011

This document sets out potential viable options for the reconfiguration of services for children up to 16 years with Congenital Heart Disease.

It provides the Joint Committee of Primary Care Trusts with a robust evidence-based clinical case for change, a description of the clinical proposals for change and a framework for the planning and management of the proposed reconfiguration of services. The document uses information available at the time of writing to analyse each potential viable option in terms of its suitability, the extent to which it will deliver a safe, high quality service within a proposed national model of care, its impact on children with Congenital Heart Disease and their families and its impact to local health economies.

Interdependent NHS services have been included in the review when considered critical to children's congenital cardiac services. This includes three very specialist services that require on-site paediatric cardiac surgical support (paediatric cardiothoracic transplantation, complex tracheal surgery and Extra Corporeal Membrane Oxygenation for children with severe respiratory failure, see Appendix A) as well as services delivered more widely such as paediatric intensive care services (Appendix B).

SAFE AND SUSTAINABLE is one element of a larger NHS review of congenital cardiac services in England. The scope of the *SAFE AND SUSTAINABLE* review excludes the designation of surgical services for adults with congenital heart disease

as this element of the review process is managed by individual Specialised Commissioning Groups.

However, the JCPCT is advised that the NHS in England will prioritise resolving any adult interdependencies immediately following the *SAFE AND SUSTAINABLE* review. Further information on the review of services for adults with CHD is set out in Appendix B.

The scope of *SAFE AND SUSTAINABLE* excludes the paediatric cardiac surgical services in Glasgow and Belfast, though representatives of the devolved administrations were invited to join the *SAFE AND SUSTAINABLE* steering group in order to identify relevant cross-border issues.

There are no paediatric cardiac surgical services in Wales, and the Director of the Welsh Health Specialised Services Committee was invited to join the JCPCT given the material use of the English service by the Welsh population. In the event the Welsh Assembly Government has determined that it will have observer status on the JCPCT.

BACKGROUND

National parent groups, NHS clinicians and their professional associations asked the NHS to review how it delivers congenital heart services to children in England and Wales

There have been long-standing concerns that smaller centres are not sustainable

Congenital Heart Disease is relatively rare. Around 8 of every 1000 babies born will have some form of Congenital Heart Disease¹. Services for children with Congenital Heart Disease are becoming increasingly complex. Surgical and cardiology interventions demand great technical skill and expertise from all of the professionals in the cardiac teams.

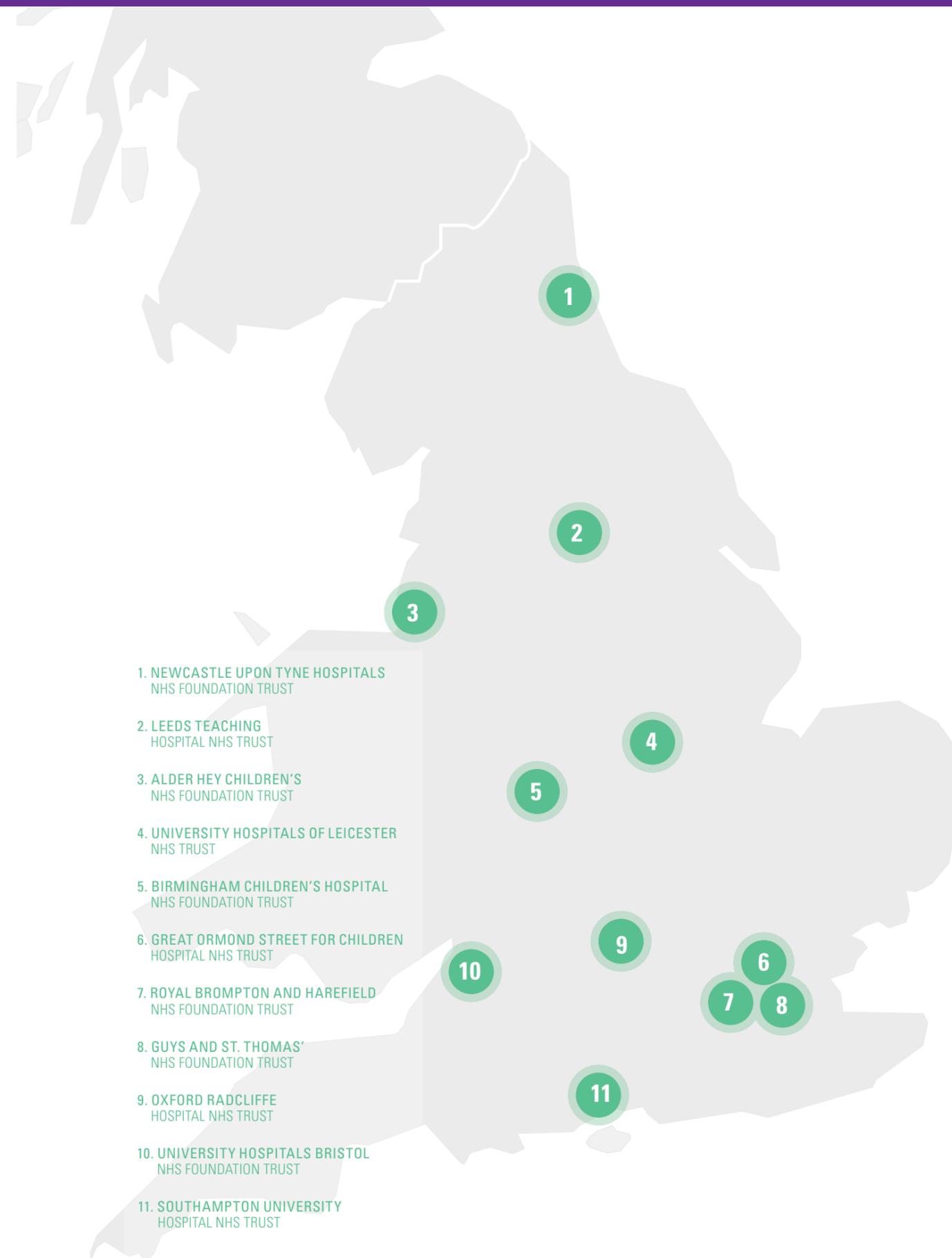
At the request of national parent groups, NHS clinicians and their professional associations the National Specialised Commissioning Team has reviewed how the NHS in England delivers congenital heart services to children in England and Wales through the **SAFE AND SUSTAINABLE** review.

The **SAFE AND SUSTAINABLE** review was instigated in response to long standing concerns that some congenital heart services for children are too small to be able to deliver a **SAFE AND SUSTAINABLE** 24/7 service. There are also concerns that the NHS in England is over-reliant on foreign countries for the training of its next generation of surgeons.

The aim of the review is to make recommendations to the Joint Committee of Primary Care Trusts (JCPCT) for design and delivery of a national service that has improved clinical outcomes with fewer deaths and complications following surgery, and a trained clinical workforce expert in the care and treatment of children and young people with congenital heart disease.

The review was managed by NHS Specialised Services on behalf of the 10 Specialised Commissioning Groups in England and their constituent Primary Care Trusts. At the time the review began there were 31 consultant congenital cardiac surgeons in England spread across 11 NHS hospitals

SEE MAP ON THE OPPOSITE PAGE



¹ Various studies suggest that the incidence of CHD is around 6 to 8 per 1000 births. See J Hoffman and S Kaplan, *Journal American College of Cardiology* Vol. 39, No. 12, 2002 'The Incidence of Congenital Heart Disease' June 19, 2002:1890-900

There have been long-standing concerns that medical expertise is spread too thinly across England to be able to deliver the highest quality service around the clock in every centre. In 2010 a review panel visited each of the 11 hospitals to meet clinical and management staff, and while (as would be expected) there were differing opinions on the preferred outcome of the review there was widespread support for the aims of the review based on a belief that smaller paediatric cardiac teams – sometimes staffed by only one or two surgeons – are sub-optimal and have no place in the modern NHS. This view has developed over many years amongst experts in the field, and there is an almost overwhelming feeling that in 2010 the time for change is overdue.

The review is supported by:

- The Children's Heart Federation
- The British Heart Foundation
- The Royal College of Surgeons of England
- The Royal College of Paediatrics and Child Health
- The Royal College of Nursing
- The Society for Cardiothoracic Surgery in Great Britain and Ireland
- The British Congenital Cardiac Association
- The Paediatric Intensive Care Society and
- The Specialised Healthcare Alliance

The SAFE AND SUSTAINABLE review began in January 2009 and has involved:

- Extensive stakeholder engagement across the country
- Proposed new standards that children's congenital cardiac centres must meet in the

future, including minimum surgical volumes and minimum surgeon numbers

- The assessment of each of the current centres against the standards by an independent expert panel, chaired by Professor Sir Ian Kennedy
- A consideration of a number of potential configuration options against other important criteria including access, travel times, deliverability and sustainability

The review has been guided by five key principles:

- **The welfare of the child is paramount in all considerations.** A principle enshrined in legislation by the Children Act 1989².
- **Quality** – all children in England and Wales with Congenital Heart Disease must receive the very highest standard of care in the NHS and
- **Equity** – the same high quality of service must be available to each child regardless of where they live or which hospital provides their care. One of the recommendations of Sir Ian Kennedy in his 2001 report was that national quality standards should be implemented by the NHS in order that all hospitals across England that provide services for children with Congenital Heart Disease are working to the same high standards of care.
- **The NHS must plan and deliver care that is based around the needs of the child.** "Children are not just little adults" – a phrase made repeatedly by The Royal College of Paediatrics and Child Health in various guidance and by children's agencies

around the world. Services and facilities for children must be designed and delivered around their specific needs.

- **Local where possible** – other than surgery and interventional procedures, all cardiac-related treatment should be provided by competent experts as close as possible to the child's home. Whilst the concentration of medical expertise in fewer, larger centres has broad support for specialist clinical interventions, such as children's heart surgery, there have been many calls for the development of Congenital Heart Networks that would result in better co-ordinated care and the delivery of assessment and ongoing care closer to the child's home.

Strategic context: the Kennedy recommendations (2001)

The findings and recommendations of SAFE AND SUSTAINABLE are the end-stage of a process that began as far back as 2001 when, following a public inquiry into children's heart surgery in the NHS, the Kennedy Report³ made a number of recommendations for delivering a safe, high quality service:

• National standards

'these should be developed, as a matter of priority, for all aspects of the care and treatment of children with congenital heart disease. The standards should address diagnosis, surgical and other

treatments, and continuing care. They should include standards for primary and social care, as well as for hospital care. The standards should also address the needs of those with CHD who grow into adulthood' (recommendation no. 192).

• Larger specialist centres

'the standards should stipulate the minimum number of procedures which must be performed in a hospital over a given period of time in order to have the best opportunity of achieving good outcomes for children. Heart surgery on children must not be undertaken in hospitals which do not meet the minimum number of procedures' (recommendation 193).

• Low volume equates to high risk

'an investigation should be conducted as a matter of urgency to ensure that heart surgery is not currently being carried out on children where the low volume of patients or other factors make it unsafe to perform such surgery' (recommendation 198).

In 2003 a previous review group⁴ published its findings and in line with the recommendations of the Kennedy Report called for the establishment of fewer, larger surgical centres in England in order to eradicate the risk of occasional practice of heart surgery on children.

² Children Act, Department of Health, 1989 <http://www.legislation.gov.uk/ukpga/1989/41/introduction>

³ Bristol Royal Infirmary Inquiry, Learning from Bristol: The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 -1995,(The Kennedy Report), HM Government, July 2001

⁴ Department of Health, Paediatric and Congenital Cardiac Services Review Group, January 2001 – December 2003.

In the absence of a robust commissioning framework for specialised services at the time these recommendations were not implemented.

Concerns persisted. In 2006 an extraordinary national meeting of surgeons and cardiologists from each of the 11 paediatric cardiac surgery centres, other NHS staff and national parent groups was jointly convened by the National Director for Heart Disease and Stroke and the National Clinical Director for Children, Young People and Maternity. There was unanimous consensus that the current configuration of children's heart surgery services in England was unsustainable, and the meeting called for the establishment of fewer, larger centres of expertise⁵.

This recommendation was echoed by the Royal College of Surgeons of England in an independent report⁶ in 2007 when it called for fewer, larger paediatric cardiac surgical centres, and repeatedly by the Children's Heart Federation, the country's leading support organisation for parents of children with congenital heart disease.

Strategic context: specialised children's services

SAFE AND SUSTAINABLE proceeds within an NHS commissioning framework that gives greater emphasis to the commissioning of specialised paediatric services⁷ as well as an increased awareness by the NHS that specialist centres of expertise for rare and complex conditions must

meet agreed minimum standards of care in order to ensure the best outcomes for patients. Restricting clinical expertise to a small number of specialist centres where this is desirable and appropriate in the interests of delivering the best clinical outcomes is well established in the NHS, either through national or regional specialised commissioning.

The aims and objectives of the review (and the clinical standards that have been developed) are concordant with relevant policy initiatives and best practice guidance for the planning and delivery of NHS and social care for children and families. This includes the Department of Health's 2010 report on 'Getting it Right for Children and Young People'⁸, the 'National Service Framework for Children'⁹ and the 'Children's Plan'¹⁰.

The **SAFE AND SUSTAINABLE** review also builds upon evidence of the benefits of developing managed network models of care¹¹. A network model of care requires specialist tertiary centres, regional specialist centres, local hospitals, primary care and NHS commissioners to plan, deliver and manage an entire pathway of care that delivers the best possible care for patients at every stage of treatment, including assessment, treatment and follow-up.

In some specialties, such as paediatric cardiac surgery, clinical practice has become so sophisticated and the technology has become so advanced those patients who would otherwise have died only 10 years ago can now be safely treated with confidence. However, an increasing trend for sub-specialisation in

these specialities presents challenges around the safety and sustainability of services in the future.

"The number of children with specialised conditions is relatively small, and services are increasingly sub-specialising. These factors will inevitably mean fewer, bigger centres. At the same time, we want to minimise the disruption to the lives of these children and young people, and their families, and to provide them with services as close to home as possible where appropriate. In addition, we are clear that planning the provision of specialised services must address other competing pressures – maximising efficiency in one service can compromise provision of key services for other children, and specialised commissioners must optimise outcomes and balance access."

Dr Sheila Shribman,
National Clinical Director for Children,
Young People and Maternity¹²

In 2008 an expert working group established by the Department of Health published the outcome of a comprehensive review and analysis of the critical inter-dependencies across specialised paediatric services: This document is called 'Commissioning **SAFE AND SUSTAINABLE** Specialised Paediatric Services: A Framework of Critical Inter-Dependencies'. This work produced, for the first time, a framework of inter-dependencies which identifies the various levels of co-dependency between 23 specialised paediatric services and sets out how these relationships need to be taken into account when commissioning services or when proposing changes to service delivery. The framework was endorsed by the relevant Royal Colleges and professional associations.

Strategic context: international experience

In recent years many countries have identified the same concerns around the safety and sustainability of their congenital cardiac services for children. Different health systems have sought to address these problems according to local requirements but common themes are clear: the unsustainable nature of fragmented models of care for children with

⁵ Department of Health, *Congenital Cardiac Services; Report of Workshop*, June 2006

⁶ The Royal College of Surgeons of England, *Surgery for children: Delivering a first class service*, London, July 2007

⁷ Department of Health, *Review of Commissioning Arrangements for Specialised Services*, May 2006,

⁸ Department of Health, *Getting it Right for Children and Young People*, September 2010

⁹ Department of Health, *National service framework for children, young people and maternity services*, September 2004

¹⁰ Department for Education, *The Children's Plan: Building Brighter Futures*, December 2007,

¹¹ For example, following the Calman/ Hine Report cancer networks were established to implement the Cancer Plan. These networks of cancer care were established, reaching from primary care to cancer units, treating the more common cancers and assessing and diagnosing rarer cancers, to cancer centres, treating the rarest cancers and providing highly specialised treatment such as radiotherapy and bone marrow transplantation. Department of Health, *The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales*, April 1995

¹² Foreword to, Department of Health, *'Commissioning SAFE AND SUSTAINABLE specialised paediatric services: a framework of critical inter-dependencies'*, September 2008

congenital heart disease (Australia, 2006¹³), the need for congenital heart services to comply with quality standards that set minimum staffing and activity requirements (Germany, 2010¹⁴ and the Netherlands, 2009¹⁵) and the relationship between cardiac surgical volumes and outcomes (Canada, 2002¹⁶ and Sweden, 2000¹⁷).

In the United Kingdom there are precedents for the centralisation of congenital cardiac services for children based on the need for centres of expertise to meet minimum activity thresholds. In the past 15 years the congenital cardiac services in Cardiff and Edinburgh have ceased performing heart surgery on children because the centres recognised that their surgical volumes were too low to remain sustainable.

¹³ Queensland Government - Queensland Health, *Report of the Taskforce on Paediatric Cardiac Services*, August 2006

¹⁴ Federal Ministry of Justice, *Proclamation of a resolution of the Federal Joint Committee regarding a guideline over quality assurance measures over cardiac surgery care for children and teenagers in accordance with 137 Paragraph 1 Number 2 of the fifth book of Social Security Statute Book (SGB V), Guidelines for paediatric cardiac surgery: First Edition*, February 2010. Document translated from German by London Translation

¹⁵ Commission for Paediatric Heart Interventions, *Concentration of congenital heart surgery and catheter interventions*, June 2009. Document translated from Dutch by Ubiquis, London

¹⁶ Ontario Ministry of Health and Long-Term Care, *Specialized Paediatric Services Review - Report of the Minister's Advisory Committee*, April 2002

¹⁷ Lundström, NR, Berggren, H, Björkhem, G, Jögi, P, Sunnegardh, J, *Centralization of Pediatric Heart Surgery in Sweden*, *Pediatric Cardiology*, 2000, 21:353-357

GOVERNANCE AND ASSURANCE

A Joint Committee of Primary Care Trusts has been established as the body with powers of consultation and decision making for this review

Independent scrutiny of *SAFE AND SUSTAINABLE* provides assurance about the rigour applied to the process of review

Governance and quality assurance

Specialised paediatric cardiology and cardiac surgery services are complex treatments that are defined as 'specialised services' by the National Specialised Services Definition Set¹⁸. These are regionally commissioned by Specialised Commissioning Groups. Given the interrelationship between the current 11 surgical centres it was clear that a review of children's congenital cardiac services warranted a national approach.

The *SAFE AND SUSTAINABLE* review was initiated in 2008 to 'undertake a review of the provision of paediatric cardiac surgical services in England with a view to reconfiguration'¹⁹. This request was made of the National Specialised Commissioning Group representing the 10 Specialised Commissioning Groups and their constituent Primary Care Trusts (the National Specialised Commissioning Team acts as the secretariat to the National Specialised Commissioning Group)²⁰.

With the endorsement of the NHS Operations Board and Secretary of State for Health when appropriate, NHS Specialised Services has established the following structures:

Specialised Commissioning Group Collaboratives

Initially in 2008 *SAFE AND SUSTAINABLE* proposed the establishment of SCG 'Collaboratives' to support the process for the development of reconfiguration proposals. Four geographical zones were proposed (i North of England; ii Midlands; iii South East England; iv South West England, South Central England and Wales). Proposed membership of the SCG collaboratives were the constituent SCGs from within the respective geographical zone, who it was proposed would identify from their own number a 'lead' SCG. The lead SCGs would be expected to manage the process for identifying options for reconfiguration within their own zones.

This model of governance was based on that applied in the recent national review of Burns Services. In the event in 2009 the

National Specialised Commissioning Group recommended that this model would not be optimum for the *SAFE AND SUSTAINABLE* review of children's congenital cardiac services and instead recommended the establishment of a Joint Committee of Primary Care Trusts to be the single body with delegated powers of consultation and decision making. The proposal for formal SCG collaboratives was therefore rescinded.

Joint Committee of Primary Care Trusts

The interrelationship between the current 11 surgical centres and the relatively low national caseload meant that the NHS had to undertake the review of options for reconfiguration of services at a national level. An attempt by SCGs to use their existing delegated powers to make a decision on a national reconfiguration would not withstand legal scrutiny.

Given the need for a single consultation on the options, based on a single model of care, with a decision made by a single commissioning body, a joint committee of Primary Care Trusts (JCPCT) was established with delegated powers for consultation and decision making²¹.

The JCPCT comprises the Chair of each of the 10 SCGs in England (or the nominated PCT) representative and the Director of National

Specialised Commissioning; it is chaired by the Chief Executive of the East of England Strategic Health Authority (Appendix C). The establishment of a JCPCT ensures that each region and each PCT in England is represented on the decision-making body via the relevant SCG Chair.

The Secretary of State for Health considered a number of options for consultation and decision making.

His view was that the establishment of a JCPCT is consistent with the principle of local decision-making, whilst being legally robust.

The JCPCT's terms of reference are (Appendix C):

- Approve the method and scope of the consultation on paediatric cardiac surgery services in England
- Approve the text of and issue the consultation document
- Act as the formal body in relation to the Joint Overview and Scrutiny Committees established for this Consultation by the relevant Local Authorities

¹⁸ Definition number 23; National Specialised Commissioning Team, Specialised Services National Definitions Set. Available at www.specialisedservices.nhs.uk/documents/index/document_category_id:26

¹⁹ National Specialised Commissioning Team, Letter from Professor Sir Bruce Keogh, NHS Medical Director, May 2008. Available at: <http://www.specialisedservices.nhs.uk/document/background-children-s-congenital-cardiac-services-1> Department of Health,

²⁰ *Review of Commissioning Arrangement for Specialised Services* (Carter Report), May 2006

²¹ The NHS (Functions of Strategic Health Authorities and Primary Care Trusts and Administrative Arrangements) (England Regulations 2002 SI 2002/2375) allocates certain of those functions to Primary Care Trusts and amongst other provisions authorises those Trusts to make arrangements for their functions to be exercisable jointly with other NHS bodies and permits the delegation of the exercise of those functions to committees or sub-committees including joint committees. If a body delegates its relevant functions to a joint committee and that committee reaches a decision the body will be bound by that decision.

Take decisions on issues which are the subject of the consultation.

SAFE AND SUSTAINABLE review team

Day-to-day management of the review has been led by the National Specialised Commissioning Team (NSC Team) on behalf of the 10 Specialised Commissioning Groups. The NSC Team established a review team managed by a dedicated **SAFE AND SUSTAINABLE** Programme Director, reporting to the Director of National Specialised Commissioning. The review team also comprised a medical adviser experienced in the commissioning of cardiothoracic services, and dedicated commissioning, finance and administrative support. External communications and analysis support was procured.

Advisory Expert Steering Group

The review team was supported by a steering group chaired by Dr Patricia Hamilton in her role as Immediate Past President of the Royal College of Paediatrics and Child Health. The steering group comprised a majority of clinical representatives of relevant professional bodies, patients associations and NHS commissioning bodies (Appendix D). Members were nominated or endorsed by their professional association.

The Steering Group has been kept apprised throughout the process. It has actively steered the review, has ensured that it complies with the quality assurance requirements (Gateway and National Clinical Advisory Team reviews), commented on and endorsed the proposed governance arrangements, timeline for the

programme and the plans for engagement with patients and the public. The Steering Group has also advised on the process of assessment including the process for the on-site assessments of each centre.

In summary the role of the steering group has been to:

- Develop and communicate the clinical 'Case for Change'²²
- Consider the available research evidence around the relationship between larger surgical centres and clinical outcomes
- Develop designation criteria that surgical centres must meet in the future
- Develop a proposed model of care for Congenital Heart Networks
- Oversee stakeholder engagement and communication
- Endorse the process for the assessment of the current surgical centres

Standards Working Group

A standards working group, chaired by the President (at the time) of the British Congenital Cardiac Association was established as a sub-group of the steering group. Its remit was to develop proposed standards against which the centres would be assessed for designation, and which designated centres would have to meet in the future (Appendix E for membership and Appendix F for the proposed standards).

The Standards Working Group has considered the available clinical evidence, as well as the best case examples of the services for children

with congenital heart disease from across the world. The standards are firmly rooted in relevant guidance. The list of clinical evidence and guidance considered can be found in Appendix G.

Networks Working Group

A separate working group was chaired by the Honorary Treasurer of the Royal College of Paediatrics and Child Health (for membership see Appendix H). The group's terms of reference were to describe how the proposed Congenital Heart Networks would function including governance and leadership across the network, the relationship between the three levels in a network and proposed patient pathways, including a description of the diagnostic, treatment, management and follow-up services that each of the levels will provide.

Financial Working Group

A Finance Working Group was established to:

- validate the 'finance data capture' returns supplied by the NHS Trusts subject to the review
- identify what further financial data is required to consider the affordability of potential configuration options
- identify relevant work streams which may need to be addressed in the implementation phase of **SAFE AND SUSTAINABLE**

The Group was chaired by the Interim Chief Operating Officer of East of England SCG and comprised representatives of the finance teams of each of the Specialised Commissioning Groups. (Appendix I)

Independent Assessment Panel (chaired by Sir Ian Kennedy)

An independent panel of experts, chaired by Professor Sir Ian Kennedy, was convened to assess the 11 centres against the proposed designation criteria (Appendix J for terms of reference and panel biographies).

Centres were assessed against written submissions in April 2010, followed by on-site visits in May and June 2010. The outcome of the assessment visits informed the development of options for configuration by the JCPCT, in addition to other criteria (see section 8).

Independent Assessment Panel (chaired by Mr James Pollock)

A separate panel of independent experts was convened in November 2010 to undertake a limited review of case notes relating to specific surgical procedures during specific time periods at three of the eleven centres. These limited reviews were in response to an analysis of mortality data that was received by the review team in September 2010 that suggested that these three centres had a higher than expected mortality. The findings and recommendations

²² Available at: http://www.specialisedservices.nhs.uk/library/30/Childrens_Heart_Surgery_in_England__The_Need_For_Change.pdf

of this panel, chaired by Mr James Pollock, a Consultant Congenital Cardiac Surgeon, were considered by Professor Sir Ian Kennedy and his panel in January 2011. Sir Ian Kennedy's panel did not find that there is cause to reconsider its previous findings for any of the three centres. The reports of Mr Pollock and Sir Ian Kennedy and the terms of reference for Mr Pollock's panel are set out at Appendices K1 and K2.

Independent Expert Panel (Nationally Commissioned Services)

An independent panel of experts was convened, chaired by Dr Patricia Hamilton, to provide the JCPCT with a report on the impact of potential configuration options to three very specialised services that are commissioned on a national basis and which require on-site paediatric cardiac surgical back-up:

- paediatric cardiothoracic transplantation (and mechanical device as a 'bridge' to transplant);
- complex tracheal surgery; and
- Extra Corporeal Membrane Oxygenation for children with severe respiratory failure.

Terms of reference, membership and recommendations of the panel are provided at Appendix A.

Health Impact Assessment (HIA) Steering Group

An independent steering group, accountable to the JCPCT, has been convened to steer the development of the HIA. The purpose of the

HIA is to produce a set of evidence-based practical recommendations that will inform decision-makers on how best they can promote and protect the health and well-being of local populations.

The HIA will answer two key questions:

- What are the positive and negative impacts of the proposed changes on communities within England and Wales, particularly in respect of (a) health; (b) health inequalities; (c); access (d) carbon footprint and (e), equalities taking specific regard, but not exclusively, to the groups defined in legislation?
- How can any adverse impacts be mitigated and positive impacts enhanced?

Terms of reference and membership are provided at Appendix L

Other sources of expertise that have been available to the JCPCT and *SAFE AND SUSTAINABLE* team:

- Central Cardiac Audit Database – The activity data relied upon by *SAFE AND SUSTAINABLE* has been validated by CCAD, which oversees a continuous process for the collection, validation and analysis of activity data submitted by each paediatric cardiac surgical unit in the United Kingdom. The CCAD information portal has been developed by 'The Information Centre' for health and social care in collaboration with the Society for Cardiothoracic Surgery in Great Britain and The British Congenital Cardiac Association.

Quality Assurance – the process for delivering recommendations under the *SAFE AND SUSTAINABLE* review has been quality assured by NHS London on behalf of the 10 Strategic Health Authorities in England.

Office of Government Commerce 'Gateway Review'

The 'Health Gateway Review' of *SAFE AND SUSTAINABLE* was carried out in September 2010. The primary purposes of a Health Gateway Review strategic assessment are to review the outcomes and objectives for the programme (and the way they fit together) and confirm that they make the necessary contribution to government, departmental, NHS or organisational overall strategy.

The Gateway Review concluded that *SAFE AND SUSTAINABLE* had made 'excellent progress'.

Positive indicators were:

- Excellent clinician, patient and key stakeholder engagement
- Production of a new set of standards
- Robust assessment process
- Breaking new governance ground which could help future projects
- An appropriately resourced programme
- Accolades for the National Specialised Commissioning Team in driving the review forward
- A supportive National Clinical Advisory Team review

National Clinical Advisory Team Review

The National Clinical Advisory Team (NCAT) is invited to conduct a clinical review whenever a major reconfiguration of service is required. The NCAT review of *SAFE AND SUSTAINABLE* was held in September 2010. It was agreed with the chair of NCAT that a desk top review was the appropriate means by which NCAT could carry out its review in view of the substantial work undertaken by the *SAFE AND SUSTAINABLE* team in collecting and reviewing evidence and visiting hospital sites.

The NCAT review concluded that there is a compelling case for providing children's heart surgical procedures in fewer, larger units. NCAT supports the clinical 'Case for Change' and endorses the minimum surgeon and activity levels for each surgical centre proposed by the *SAFE AND SUSTAINABLE* clinical standards. NCAT also supports the proposed network model of care and other proposed clinical standards.

The report is included as Appendix M.

THE NEED FOR CHANGE

- Congenital heart services for children have developed on an ad hoc basis
- Smaller centres are not sustainable
- Smaller centres struggle to provide safe 24/7 cover
- Smaller centres have problems with recruitment and retaining of surgeons and other key staff
- Many patients and carers have to travel long distances for routine follow-up care, as this is not always available closer to their homes

Services for children with Congenital Heart Disease are becoming increasingly complex and it is vital that those clinical teams responsible for ensuring the safety of these vulnerable and very sick children have the highest possible levels of competencies and expertise.

During the current assessment process I and my colleagues on the panel found many examples of commendably high commitment and dedication by talented NHS staff delivering congenital cardiac services. But we found exemplary practice to be the exception rather than the rule. Mediocrity must not be our benchmark for the future.'

Report of Professor Sir Ian Kennedy, 2010

There are currently eleven centres providing paediatric cardiac surgery in England. Of these eleven centres, only two had four paediatric surgeons as at June 2010²³. This creates challenges for on call rotas and means that in some centres there will be times when there is no surgeon available to deal with routine cases or with emergencies. Smaller centres struggle to provide safe 24/7 cover.

The minimum requirement of four surgeons per centre proposed by **SAFE AND SUSTAINABLE** is predicated on the minimum requirements to ensure safe 24/7 care. This ensures there are enough surgeons in each centre to meet the day-to-day demands of performing operations in theatre, being on call to respond to emergencies, undertaking ward rounds and holding outpatient clinics as well as other core activities.

Smaller centres with low volumes of activity tend to struggle to recruit and retain new surgeons, making it challenging for smaller centres to plan future staffing and activity levels. This is because smaller centres undertake a narrower range of procedures so junior surgeons are less likely to be exposed to the full range of surgical techniques necessary to deal with the complex and varied caseload of congenital heart disease. Furthermore, these centres are unable to provide the same opportunities for senior surgeons to mentor junior surgeons because smaller centres with fewer surgeons mean limited time and opportunities for team working and cross-cover.

There is also concern that the various NHS services that see children with Congenital Heart Disease could work better together. If the services across the child's pathway of

care were better coordinated, worked more collaboratively in the provision of care and research and communicated with each other more effectively, this would lead to a better quality, more accessible service for children and their families.

For example, not enough children are diagnosed with Congenital Heart Disease before birth even though there is evidence that antenatal diagnosis of major congenital heart disease improves results for children and can help to prevent serious morbidity such as brain damage.

Timely diagnosis can mean the difference between life and death in the most severe cases. Far too many babies are diagnosed after they are born (classic signs of Congenital Heart Disease in infants include fatigue, slow growth, fast breathing and bluish skin colour; older

²³ WTE based on centre's submissions to the National Specialised Commissioning Team, as at 30th June 2010

children may complain of heart palpitations and dizziness, have difficulty keeping up with playmates and get easily out of breath).

The graph²⁴ below shows that the percentages of children diagnosed before birth varies considerably across the United Kingdom. The quality of antenatal diagnosis relies largely on the effectiveness of foetal anomaly screening in obstetric units rather than the accuracy of diagnosis in the specialist cardiac centres. **SAFE AND SUSTAINABLE** proposes to address these problems by developing networks that would see greater collaboration between foetal screening services and children's heart services.

In summary:

- The different NHS services that care for children with Congenital Heart Disease could work together better
- Clinical expertise is spread too thinly over 11 surgical centres
- Some centres are reliant on small teams and cannot deliver a safe 24 hour emergency service
- Smaller centres are vulnerable to sudden and unplanned closure
- Current arrangements are inequitable to children and their families as there is too much variation in the expertise available from centres
- Fewer surgical centres are needed to ensure that surgical and medical teams are meeting the 'critical mass' of children to maintain and develop their specialist skills
- Available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes²⁵

- Having a larger and varied caseload means larger centres are best placed to recruit and retain new surgeons and plan for the future
- The delivery of non-surgical cardiology care for children in local hospitals is inconsistent; strong leadership is required from surgical centres to develop expertise through regional and local networks
- Increasing the national pool of surgeons is not the answer, as this would result in surgeons performing fewer surgical procedures and increase the risk of occasional surgical practice

- Better training for surgeons and their teams to ensure the sustainability of the service
- A trained workforce, expert in the care and treatment of children and young people with congenital heart disease
- Centres at the forefront of modern working practices and innovative technologies that are leaders in research and development

Evidence supporting the Case for Change

Relationship between volumes and outcomes

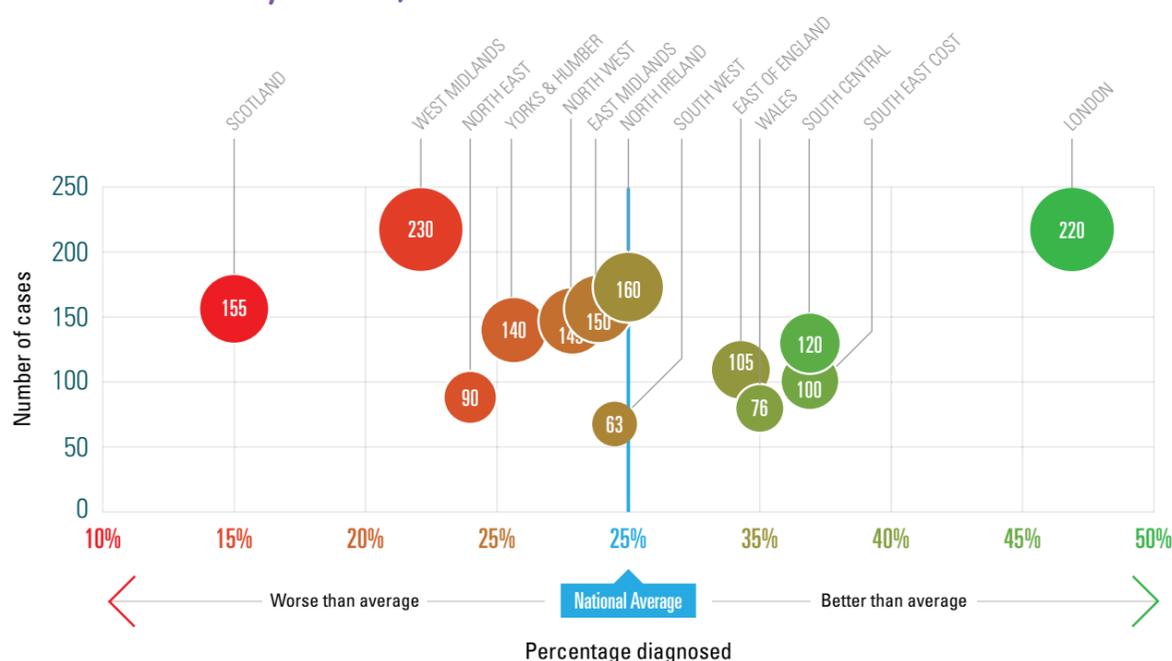
A recommendation for the concentration of medical and nursing expertise in smaller centres of excellence providing children's congenital cardiac services was made as far back as 2001 in the report of the public inquiry into paediatric cardiac surgical services at the Bristol Royal Infirmary²⁶. Subsequent working groups and reports have endorsed the recommendation, most recently by the Royal College of Surgeons in 2007²⁷.

The evidence base for ensuring a critical mass of surgical procedures per surgical unit is drawn from other examples in surgery which show that the more frequently a surgeon is performing a particular procedure, the better

What does the review aim to achieve?

- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network
- Better results in the surgical centres with fewer deaths and complications following surgery
- Better, more accessible diagnostic services and follow up treatment delivered within regional and local networks
- Reduced waiting times and fewer cancelled operations
- Improved communication for parents between all of the services in the network that support their child

Average percentage of cases where antenatal diagnosis has been made for children needing treatment in the first year of life, 2004-2008



²⁴ Source: CCAD

²⁵ Ewart, H. *The Relation Between Volume and Outcome in Paediatric Cardiac Surgery*; Public Health Research Unit - A Literature Review for the National Specialised Commissioning Group (2009). Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>

²⁶ Bristol Royal Infirmary Inquiry, *Learning from Bristol: The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995*, (The Kennedy Report), HM Government, July 2001

²⁷ The Royal College of Surgeons of England, *Surgery for children: Delivering a first class service*, London, July 2007

the outcomes in both morbidity and mortality²⁸. Studies also suggest cumulative phenomena within institutions, in that higher-volume surgical units have increasingly better outcomes over time²⁹.

In recent years many countries have identified concerns around safety and sustainability in their congenital cardiac services for children. A report from Canada states 'a recurring theme across jurisdictions is the positive relationship between volumes of procedures and favourable outcomes³⁰'.

The **SAFE AND SUSTAINABLE** review team asked the Public Health Resource Unit to carry out an independent review of the available literature around the relationship between volume and outcome in paediatric cardiac surgery³¹. The conclusion of this report was that there is an inverse relationship between volume and inpatient hospital mortality which increased with the complexity of the operation.

Two particular studies from that review are worth highlighting. The first was published in 2008 and was significant in that it was based on a study of a large number of operations of more than 55,000 over a period of 17 years³². This study concluded that large volume hospitals performed more complex operations and achieved superior results. A further study³³ based on over 32,000 patients found that for more difficult surgical procedures smaller surgical units performed significantly worse.

In 2010 the independent National Clinical Advisory Team (NCAT) undertook a review of the strength of the clinical case for change underpinning the **SAFE AND SUSTAINABLE**

review, including the evidence on which the review has relied. The NCAT report (Appendix M) concluded:

'...there is a good case for reducing the number of units, supported by the available clinical evidence and the need to create sustainable units ... NCAT can support the case for reconfiguring paediatric cardiac surgery, reducing the number of cardiac surgery centres'.

The **SAFE AND SUSTAINABLE** review team recommends to the JCPCT that there is clear evidence that higher volume surgical units deliver better clinical outcomes, and that the association between volume and outcome is evident in paediatric cardiac surgery. Relevant papers considered by the **SAFE AND SUSTAINABLE** steering group when considering the case for change and in developing the clinical standards and proposed model of care are listed as Appendix G.

SAFE AND SUSTAINABLE Recommendations around Minimum Staffing Levels

The proposed **SAFE AND SUSTAINABLE** standards (Appendix F), endorsed by the relevant professional associations, recommend that children's congenital cardiac units are staffed by a minimum of 4 consultant congenital cardiac surgeons.

In 2003 the report of the Paediatric and Congenital Cardiac Services Review Group³⁴ recommended a minimum of three surgeons in each surgical centre, based on professional consensus. However, in 2007 the Royal College

of Surgeons of England recommended 'four or five surgeons' in each centre³⁵ based on the need to concentrate expertise in the interests of quality.

When considering the available evidence the **SAFE AND SUSTAINABLE** steering group was mindful that their proposed clinical standards would go beyond the recommendations of the 2003 report by stipulating that:

'each surgical 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 rotas³⁶'.

The minimum of 4 surgeons per team can also be supported by looking at the job plans and available sessions of the surgeons. At all times

there should be a surgeon available to be in theatre; a surgeon on call for emergencies; a surgeon available for outpatient clinics; and a surgeon available to undertake ward rounds. In addition, given the average of 40 weeks at work per year (the remaining time being spent on annual leave, study leave or conducting research), there may only ever be 3 of the surgeons at work, available to cover all of the above positions at any one time.

This is thought to be a minimum staffing level to achieve the coverage listed above. In addition, this does not take account of the management duties some surgeons will have, training and mentoring, research interests and audit and governance responsibilities or unavoidable unplanned absence.

Consequently, the steering group's view was that four consultant congenital cardiac

²⁸ Halm EA, Lee C, Chassin MR. *Is volume related to outcome in health care? A systemic review and methodologic critique of the literature.* Ann Intern Med. 2002; 137:511-520.

²⁹ Chowdhury MM, Dagash H, Pierro A. *A systematic review of the impact of volume of surgery and specialization on patient outcome.* British Journal of Surgery 2007; 94:145-161.

³⁰ Ontario Ministry of Health and Long-Term Care (2002), 'Specialized Pediatric Services Review', Report of the Minister's Advisory Committee, 1-36.

³¹ Ewart, H. *The Relation Between Volume and Outcome in Paediatric Cardiac Surgery; Public Health Research Unit - A Literature Review for the National Specialised Commissioning Group* (2009). Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>

³² 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 1988-2005.* The Annals of Thoracic Surgery, 86, 889-896

³³ Welke, K. et al (2009), *the complex relationship between paediatric cardiac surgical case volumes and mortality rates in a national clinical database.* The Journal of Thoracic and Cardiovascular Surgery, 137, 1133-1140

³⁴ Department of Health, Paediatric and Congenital Cardiac Services Review Group, January 2001 – December 2003.

³⁵ The Royal College of Surgeons of England, *Surgery for children: Delivering a first class service*, London, July 2007

³⁶ Standard C9, National Specialised Commissioning Team, *SAFE AND SUSTAINABLE: Children's Congenital Cardiac Services in England Service Standards, March 2010.* Available at: http://www.specialisedservices.nhs.uk/library/30/Paediatric_Cardiac_Surgery_Standards.pdf

surgeons – rather than three - is the minimum number required in each centre to ensure safe 24/7 cover within a legally compliant rota. The steering group also considered that this number of surgeons would address concerns about appropriate surgical specialisation and succession planning in each centre.

There was broad support for a minimum of 4 surgeons at a **SAFE AND SUSTAINABLE** national stakeholder event attended by clinicians, parents and NHS commissioners in October 2009.

SAFE AND SUSTAINABLE recommendations around minimum activity levels

The **SAFE AND SUSTAINABLE** standards (Appendix F), endorsed by the relevant professional associations, recommend that children's congenital cardiac units must perform a minimum of 400 paediatric cardiac surgical procedures each year, with an optimum activity level of ideally 500 such procedures.

Whilst confirming an association between volume and outcome in paediatric cardiac surgery the scientific papers reviewed do not provide sufficient evidence to make firm recommendations regarding the cut-off point for minimum volume of activity for paediatric cardiac procedures overall, or for specific procedures at an institutional level.

The **SAFE AND SUSTAINABLE** standards are therefore based on the consensus of the professional societies, which in turn are based on the available evidence.

In developing a recommendation for the minimum or maximum number of surgical procedures that a surgical centre staffed with four surgeons must meet, the steering group considered the findings of the European Association for Cardio-Thoracic Surgery³⁷. Whilst acknowledging that the available research evidence does not identify an 'exact cut-off point between what is a too small, adequate or optimal a case load' it suggested a minimum caseload of 126 surgical procedures each year for a full time surgeon.

It is not stated that these 126 procedures per surgeon must all be in paediatric cardiac surgery; they could include procedures for adults with congenital heart disease. The **SAFE AND SUSTAINABLE** review has used 500 paediatric procedures per unit as the optimal figure and set the minimum number at 400 paediatric procedures per unit which would provide each of the four surgeons with 100 paediatric cardiac surgery procedures per year as a minimum (in addition to any adult congenital surgical caseload).

The steering group's recommendation of a minimum of 400 / 500 surgical procedures is therefore derived from a combination of the need to ensure a sufficient volume of paediatric surgery for four full-time consultant congenital cardiac surgeons in a unit, the need for 24/7 cover with a legally compliant surgical rota, the available evidence and professional consensus.

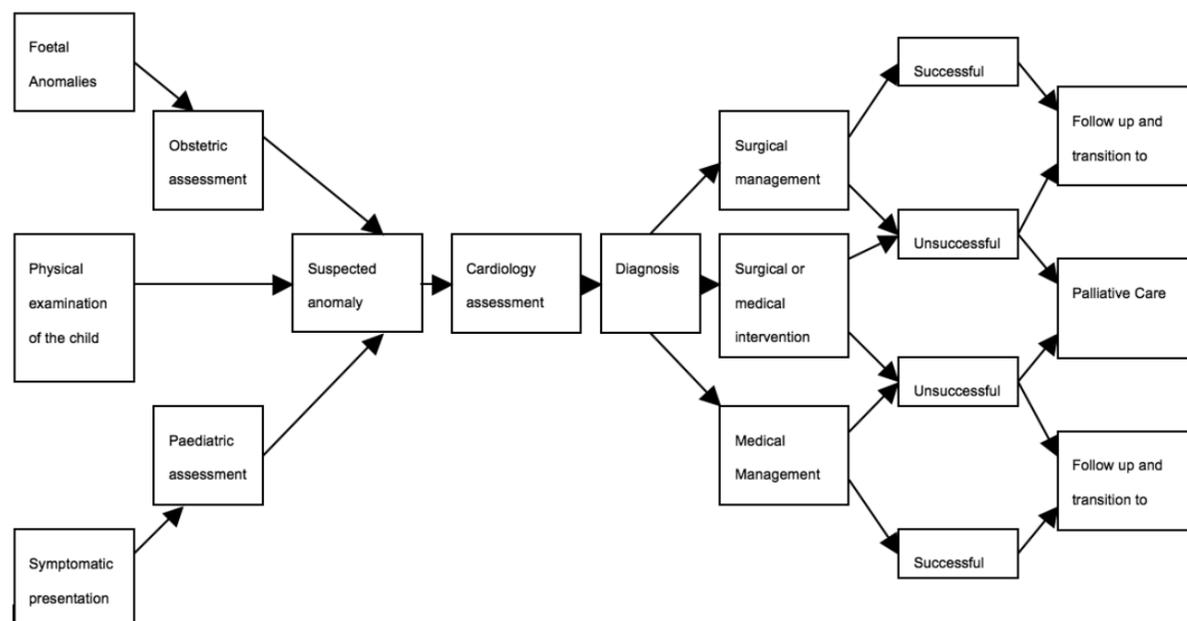
³⁷ 'Optimal Structure of a Congenital Heart Surgery Unit in Europe' Congenital Heart Surgery Committee on behalf of the European Association for Cardio-Thoracic Surgery, April 2003

MODEL OF CARE: CURRENT AND PROPOSED

Proposals for the future:

- Congenital Heart Networks across England and Wales that lead to better coordination of care
- Fewer, larger centres of excellence providing surgery and cardiology interventions
- Specialist assessment and follow-up care closer to home

CURRENT PATHWAY



Congenital Heart Networks

The current model of care is fragmented and the service that a child receives can depend on where s/he lives. For example, some children can receive their specialist cardiac assessment and follow-up care from a Consultant Paediatrician with Expertise in Cardiology at their local hospital. Some children however, do not have access to this service locally and have to travel longer distances to receive this care from a surgical unit. This is unsatisfactory because families have to travel longer distances unnecessarily and because surgical units have to provide more routine care that could be provided locally.

There is also concern that the various NHS services that see children with Congenital Heart Disease could work together better. If the services across the child's pathway of care were better coordinated, worked more collaboratively in the provision of care and research and communicated with each other more effectively, this would lead to a better quality, more accessible service for children and their families.

It is proposed that in the future services will be provided across regional networks of linked hospitals working together to pool expertise and experience to ensure the best results for children and young people. Managed clinical networks result in better coordinated care; information can be shared across the various NHS services that see children with Congenital Heart Disease more efficiently and agreed clinical protocols can improve access and timely interventions. Congenital Heart Networks would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening and maternity services through to the transition to services for adults with Congenital Heart Disease.

Better regional networks would also facilitate a national network of designated surgical units, working together to share learning, best practice and innovation.

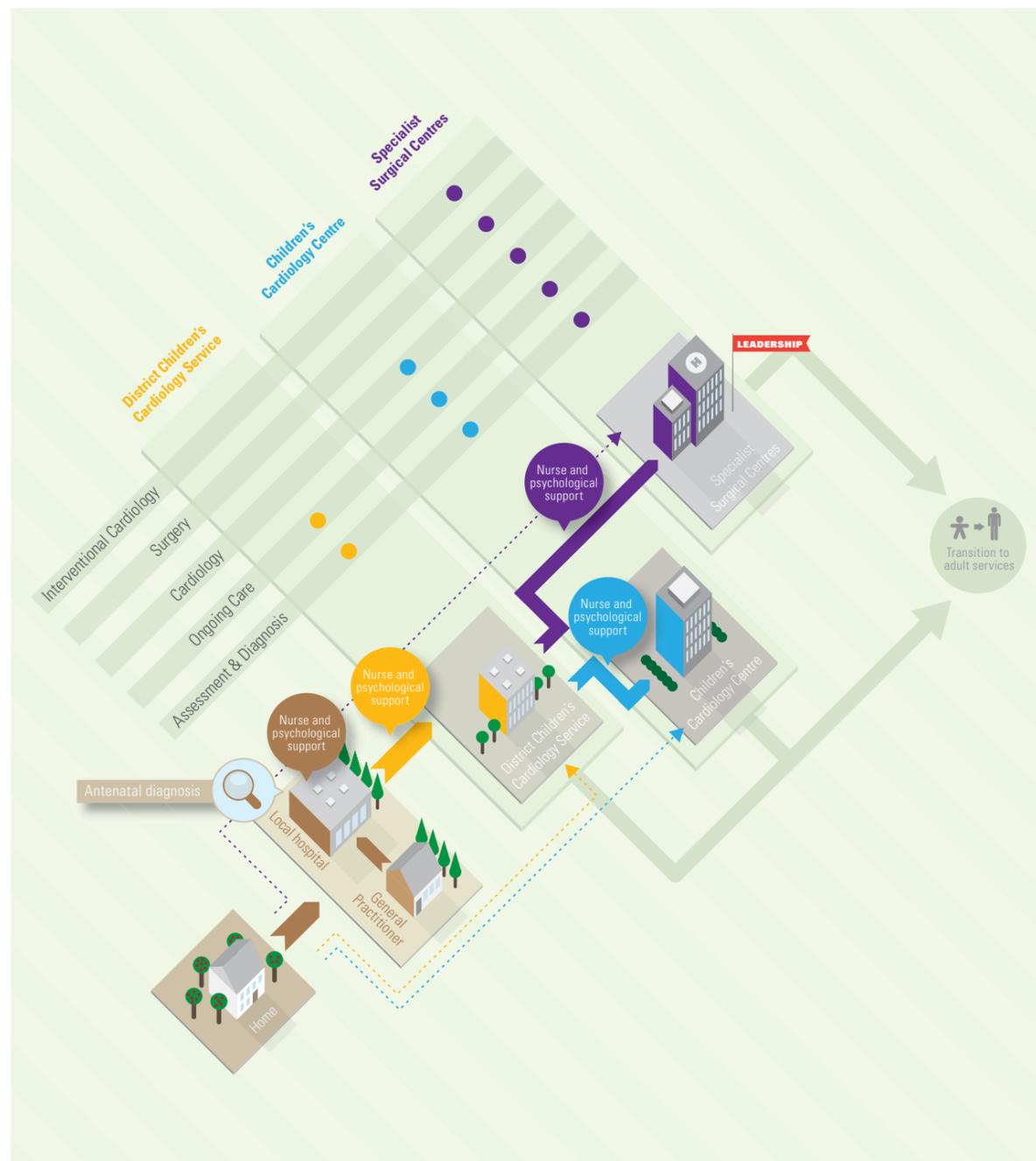
Although all children's heart surgical units in England currently work within clinical networks the **SAFE AND SUSTAINABLE** review recommends that there is much room for improvement, particularly in how surgical units are leading

'Too often centres seemed at a loss about the complex relationships that must be made and developed to make a network successful. There was perhaps a general feeling that networks are 'something that happen to you' rather than as an outcome of a well thought out and well managed strategy'

'Formal arrangements must address care pathways, sharing of data, training, governance and audit trails and working relationships between the various services in the network'

Report of Professor Sir Ian Kennedy, December 2010

NEW MODEL OF CARE



and managing their networks and in the development of formal protocols.

The precise shape of each network will be determined by local need and local circumstances including population levels, geography and transport; however a national template that facilitates the development of regional networks has been developed by the *SAFE AND SUSTAINABLE* review.

It is proposed that Congenital Heart Networks will comprise three main elements of service provision, though network groups (chaired by a senior clinician and comprising clinicians from across the network) will also ensure that other relevant services such as antenatal screening, child health services and GP services are encompassed:

District Children's Cardiology Services

Non interventional assessment and ongoing care staffed by Consultant Paediatricians with Expertise in Cardiology.

Children's Cardiology Centres

A tertiary specialist service led by Consultant Paediatric Cardiologists providing more complex non-interventional care.

Specialist Surgical Centres

A quaternary service comprising Consultant Congenital Cardiac Surgeons, Consultant

Paediatric Cardiologists and a specialist medical team providing surgery, interventional cardiology as well as assessment and ongoing care.

The recommendations of a working group established by the *SAFE AND SUSTAINABLE* steering group identified the following hallmarks of robust Congenital Heart Networks:

Care closer to home where possible

The provision of non-interventional assessment and ongoing care should be moved closer to home by increasing the number of local hospitals that have Consultant Paediatricians with Expertise in Cardiology and by increasing shared-care outreach clinics by Consultant Paediatric Cardiologists.

Leadership and Governance

Networks must be managed, and formal protocols must be in place. Specialist Surgical Centres must demonstrate leadership of the network, but there must be a collaborative approach to management with the various services that comprise the network. Networks should also have a relationship with General Practitioner Commissioning Consortia³⁸. It is proposed that Network Groups be established, chaired by a senior clinician and is comprised of clinicians from across the network (see section 13).

³⁸ Department of Health, Revision to the Operating Framework for the NHS in England 2010/11, June 2010

Clinical protocols

A successful implementation of a robust governance structure should result in agreed common clinical protocols to which all services adhere. It is proposed that each Children's Cardiology Centre has a 'primary relationship' with the designated Specialist Surgical Centre in its network. This would usually mean that under agreed protocols Children's Cardiology Centres would refer all children who require heart surgery or cardiology interventions to the designated Specialist Surgical Centre in its own network unless this was not clinically appropriate for a particular child. So too, District Children's Cardiology Services should be linked to specific Children's Cardiology Centres. The proposed networks would support the 'patient choice' agenda in that parents and patients would remain able to exercise choice regarding any of the services in the national network.

Network protocols and pathways should be managed, monitored, reviewed and updated within a continuous governance framework through the Network Group.

Communication

Telemedicine links should be developed across the services in networks, and formal protocols should address the sharing of data and the management of Information Technology systems. Regular Multi-Disciplinary Team meetings should be held, involving staff from across the network, including Children's Cardiac Specialist Nurses and Clinical Psychologists.

Research, Innovation and Education

Congenital Heart Networks should be formally linked to Academic Health Science Centres and Higher Education Institutions to further research and innovation. New treatments and techniques should be pioneered within appropriate governance frameworks. Opportunities for professional training and development across the network must ensure continuous professional development for all clinical staff in order to develop teams expert in the care of children with Congenital Heart Disease across the child's pathway. Specialist Surgical Centres should collaborate as a national network and develop better links to exploit the benefits of clinical sub-specialisation.

Outcomes

Networks should put in place systems that allow for the continuous collection, validation, analysis and reporting of clinical outcomes. This should include an analysis of morbidity and mortality data and processes for ensuring that serious untoward incidents are reported and actions learned across the network. Other indicators of an accessible, high quality service should also be identified and analysed, including those relating to support services offered to children and their families. A systematic process for the consideration of feedback from children and their families should also be integral.

Nursing Support

As part of the review process parents have expressed how greatly they value the role of Children's Cardiac Specialist Nurses. The

proposed *SAFE AND SUSTAINABLE* standards (Appendix F) and model of care envisage an enhanced role for Children's Cardiac Specialist Nurses across Congenital Heart Networks, including the introduction of standard minimum requirements for a job description developed by a Royal College of Nursing working party. The standards propose a minimum of 7 whole time equivalent CCSNs in each Congenital Heart Network, which would see an increase in the number of CCSNs nationally (more CCSNs may be required in an individual network depending on factors such as populations and geography). The standards also recommend that each child with Congenital Heart Disease has a named CCSN responsible for coordinating care across the network. In the future CCSNs could be employed by the Specialist Surgical Centre or the Children's Cardiology Centres.

The standards also propose the appointment of a Lead Nurse for the network based in the Specialist Surgical Centre with a standard role description developed by the Congenital Cardiac Nurses Association and the Royal College of Nursing, and for the appointment of a Transition Nurse to each network to facilitate the transition to adult services.

Parents greatly value the Children's Cardiac Specialist Nurse but few centres had sufficient nursing cover; there is too much variation in their role across the country and limited evidence of sharing best practice

Report of Professor Sir Ian Kennedy, 2010

Congenital Heart Networks would comprise three core elements of service provision:

District Children's Cardiology Services

It is proposed by the review team that a District Children's Cardiology Service will be based in local hospitals that have large maternity units, and after consulting with the professional associations, that those units have over 3,000 births a year (Appendix N) lists the units which currently have over 3,000 births a year). Larger units are preferred because of the need to ensure that specialised children's services are seeing enough children each year to maintain and develop specialist skills. The services would be led by Consultant Paediatricians with Expertise in Cardiology (PEC) who will work directly with a named Consultant Paediatric Cardiologist from the Surgical Centre or Children's Cardiology Centre including shared clinics.

A PEC is a Consultant Paediatrician who has developed additional expertise in the care of children with heart conditions. PECs will play an important role in the managed clinical networks envisaged by the *SAFE AND SUSTAINABLE* model of care and will continue to provide holistic care of the infant, child and young person. On average PECs could be expected to have two clinical sessions per week dedicated to their specialist cardiac work and their remaining time spent on general paediatric work.

PECs can provide all round non-interventional care for children with congenital heart disease in local hospitals, including the diagnosis of the presence of congenital heart defects and

the ongoing treatment and management of children with heart problems in liaison with the tertiary services in their networks. Being able to provide diagnostic and follow up care in local hospitals avoids unnecessary journeys to tertiary centres.

PECs are competent in electrocardiography and echocardiography and have an understanding and awareness of non-invasive imaging, cardiac catheterisation, interventional cardiology, electrophysiology and different surgical operations in congenital heart disease. PECs also play an important role in the education of other professionals who work in paediatric cardiology networks and in supporting paediatric colleagues in decision making around cardiac issues within a number of specialities as well as general paediatric and neonatal settings.

Commons aspects of a role description include³⁹:

- Paediatric inpatient and outpatient cardiology evaluation (neonates, children, adolescents)
- Ability to perform echocardiography
- Counselling parents with a foetus with CHD after diagnosis by a tertiary centre
- Outpatient clinics (general paediatrics and cardiac)
- Opinion on clinical measurements (ECG / 24hour monitoring / exercise test / CXR)
- Act as a resource on cardiac conditions and treatments for colleagues and trainees
- Liaison Paediatrician for all children and families with Congenital Heart Disease in catchment area

Although there are a number of PECs working in cardiology networks at the moment, the NHS has not previously sought to develop their work in a coordinated way. There is also a need to clarify roles and responsibilities within the networks because there are paediatricians who are working with cardiac patients with different levels of expertise who need support to develop competencies and skills. The Royal College of Paediatrics and Child Health and the British Congenital Cardiac Association have introduced a joint curriculum⁴⁰ that sets out training standards for paediatricians wishing to become PECs, and the *SAFE AND SUSTAINABLE* review has worked closely with both organisations to explore how best to strengthen the role of PECs in Congenital Heart Networks in the future.

Children's Cardiology Centres

It is proposed that centres that are currently providing children's heart surgery and are not designated as surgical units in the future would become Children's Cardiology Centres. The centres would act as tertiary referral units for a designated Surgical Centre and would work to the same standards to ensure a consistent service for children. These centres would also be linked to the District Children's Cardiology Services in their networks.

Children's Cardiology Centres would be led by trained and experienced Consultant Paediatric Cardiologists and would provide a specialist tertiary service, including outreach clinics. Their teams will perform the full range of non-interventional inpatient and outpatient care for children with congenital heart disease.

Children who need invasive surgical or other interventional procedures would be referred to a Specialist Surgical Centre.

Children's Cardiology Centres would provide a 24/7 service so that urgent care can be provided out of hours where necessary. It is proposed that the NHS develops national standards for these services in 2011 so that all centres are meeting minimum quality standards covering:

- Foetal diagnosis
- Assessment and diagnosis for babies
- Care for children between diagnosis and surgery
- Post-surgical care for recuperation and monitoring
- On-going care to support children's conditions
- Clinicians travelling to district hospitals to provide care such as outreach diagnosis
- Governance and monitoring of outcomes

Although there are precedents for this model of care (existing Children's Cardiology Centres at Manchester, Edinburgh and Cardiff support nearby surgical centres) one of the key challenges for the NHS in the implementation phase of *SAFE AND SUSTAINABLE* is how to manage the transition from surgical unit to non-surgical unit and the potential movement of key staff away from these centres. A further challenge for the leadership of the Congenital Heart Networks is to ensure that staff and patients of the Children's Cardiology Centres

do not consider these units to have been 'downgraded' in any way. This will be an immediate challenge, but also over time as new cohorts of children receive their operations at the newly designated surgical centres, the cohort of children previously operated on at the Children's Cardiology Centres mature and transition to adult services and local hospitals gradually shift their referral patterns for acutely ill children. The risk is that this perception could cause reluctance amongst clinical staff to care for complex cardiac patients, with a resulting reduction in the skill level and experience of clinical staff. However, the establishment of robust Congenital Heart Networks with good collaborative working across the services would mitigate against these risks.

³⁹ Paediatricians With Expertise In Cardiology Special Interest Group (PECSIG), *Paediatrician with Expertise in Cardiology: Job Plan Guidelines*. December 2009

⁴⁰ Curriculum for Paediatrician with Special expertise in Cardiology. Available at: www.rcpch.ac.uk/doc.aspx?id_Resource=1901

Specialist Surgical Centres

Paediatric cardiac surgery is currently provided in 11 centres across England (though the service at the John Radcliffe Hospital remains suspended following a separate review in 2010 by South Central Strategic Health Authority⁴¹).

These centres have between 1 and 4 surgeons employed by the Trust delivering paediatric cardiac surgery and there is significant variation in the number of paediatric surgical procedures each year at each centre. The table below does not include cover provided by locums.

Around 8 of every 1,000 babies born will suffer from some form of Congenital Heart Disease⁴⁴.

This level of incidence results in around 3,600 paediatric surgical procedures being performed in England each year. The number of children requiring heart surgery in England and Wales is not expected to increase significantly over the next 20 years. The growth assumptions relied upon by the *SAFE AND SUSTAINABLE* review are set out in Appendix O.

By their specialist nature, the location of children's heart surgery centres in the future cannot be 'local' to all people in England and Wales. Although fewer surgical centres in England will mean that some children and families will have to travel longer distances for surgery and cardiology interventions, this can be justified by the unsustainable nature

CENTRE	NUMBER OF SURGEONS (HEADS) ⁴²	NUMBER OF PROCEDURES UNDERTAKEN ⁴³
Alder Hey Children's Foundation Trust	3	400
University Hospitals Bristol NHS Foundation Trust	3	277
Birmingham Children's Hospital NHS Foundation Trust	3	555
Guys and St Thomas' Hospitals NHS Foundation Trust	3	337
Great Ormond Street Hospital for Children NHS Trust	4	541
Leeds Teaching Hospital NHS Trust	3	316
University Hospitals of Leicester NHS Trust	3	225
Newcastle Upon Tyne Hospitals NHS Foundation Trust	2	255
Oxford Radcliffe Hospitals NHS Trust	1	108
Royal Brompton and Harefield NHS Foundation Trust	4	353
Southampton University Hospitals NHS Trust	2	231

of the current national configuration and the need to ensure that all heart surgical services in England are safe and are able to provide outstanding care.

SAFE AND SUSTAINABLE recommends that the number of NHS centres in England providing heart surgery for children is reduced from 11 centres to 6 or 7 centres (see sections 8 and 11). These designated centres would also provide the full range of assessment and ongoing care for children who live in close proximity or who choose to receive their care in these centres.

Having weighed up the available evidence the *SAFE AND SUSTAINABLE* steering group has recommended that it is appropriate for children's heart surgical services to continue to be provided either in stand-alone children's hospitals or by integrated hospitals that provide treatment to adults and children (but by dedicated children's services). The steering group has not identified any evidence that suggests that either type of hospital produces better outcomes.

Interventional Cardiology

Under the proposed model of care interventional work would be undertaken at the Specialist Surgical Centres only. Interventional cardiology refers to diagnostic and therapeutic procedures that are invasive, such as when a catheter or

other device is inserted through the skin into the heart. Interventional cardiology procedures are becoming more sophisticated, so much so that for some congenital heart conditions interventional procedures are replacing surgical procedures as the primary form of treatment. Current activity indicated in Appendix B.

In order to provide interventional cardiology, the Consultant Paediatric Cardiologist needs the support of a skilled paediatric team that includes specialist nurses, anaesthetists, radiographers and cardiac technicians. The team performs interventional procedures in a specially designed and equipped 'catheterisation theatre'.

Interventional cardiology is becoming more complex and presents a degree of risk to the child as devices are inserted into the child's heart. If a complication were to arise, the Consultant Paediatric Cardiologist can usually address the problem. However, very occasionally in case of emergency, the cardiologist will require the assistance of a congenital cardiac surgeon.

It is for this reason that the *SAFE AND SUSTAINABLE* standards and the model of care propose that interventional procedures should only be undertaken in designated centres that can provide adequate on-site surgical back-up. It is recommended that only those centres that are designated as surgical centres may also provide interventional cardiology.

⁴¹ NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁴² Headcount based on centre's submissions to the National Specialised Commissioning Team, as at 30th June 2010 and panel visits.

⁴³ 2009/10 CCAD validated data, surgical procedures only

⁴⁴ Children's Heart Federation website. Available at: http://www.childrens-heart-fed.org.uk/how_we_help/information_service/heart_conditions

This would mean that children requiring any form of intervention, including diagnostic catheterisation, would have to travel to one of the designated surgical centres.

This recommendation builds on current professional guidelines⁴⁵ and aims to ensure that all children who receive interventional cardiology do so in the safest possible environment staffed by specialist clinical teams.

Model of Care: The Standards

Proposed standards have been developed by the *SAFE AND SUSTAINABLE* steering group and endorsed by relevant professional associations and national parent groups (Appendix F). The steering group recommends that implementation of these standards can reassure parents, clinical staff and NHS commissioners that the NHS in England has put in place a framework for excellent congenital heart services for children.

The standards are set out with reference to seven key themes:

- A** Congenital Heart Networks
- B** Prenatal screening and services
- C** Specialist Surgical Centres
- D** Age appropriate care
- E** Information and making choices
- F** Family experience
- G** Ensuring excellent care

As part of the process for delivering recommendations for reconfiguration all current providers of paediatric cardiac surgery in England were assessed against their ability to meet the proposed standards (see section 8).

There are 156 separate standards.

Core standards include:

- Specialist surgical centres will provide active leadership of their Congenital Heart Networks (standard A1)
- A Lead Nurse for each Congenital Heart Network with a standard role description (standard A5)
- Formal protocols will be implemented across networks (standard A8) including with foeto-maternal medicine units and tertiary neonatal units (standard B3)
- Interventional procedures must only be provided by designated Specialist Surgical Centres (standard A10)
- Each Specialist Surgical Centre must be staffed by a minimum of 4 full-time Consultant Congenital Cardiac Surgeons (standard C4)
- Each Specialist Surgical Centre must perform a minimum of 400 paediatric surgical procedures each year (standard C6) and should ideally perform a minimum of 500 paediatric surgical procedures each year (standard C7)
- Each Specialist Surgical Centre must provide sufficient staff to provide a full 24 hour emergency service (standard C9)

- Critical interdependent services to be co-located with paediatric cardiac surgical services as defined by the 'Framework of Critical Interdependencies' (standards C12 – C16)
- Appropriate and timely retrieval and repatriation of children (standard C68)
- Transition to adult services should be tailored to reflect individual circumstances (standard D1 and D8)
- Transition nurses should be present in each Congenital Heart Network (standard D3)
- Clinical Psychology support for children and young people (standard E4), their families (standard F5) and congenital heart professionals (standard G14)
- Clinical facilities should be developed around the needs of the child (standard F1)
- Each child should have a named Children's Cardiac Specialist Nurse working within a Cardiac Liaison Team across the Congenital Heart Network (standard F2)
- A minimum of 7 whole time equivalent Children's Cardiac Specialist Nurses in each Congenital Heart Network (standard F4)
- Appropriate accommodation and facilities for families (standard F6)
- Ongoing and continuous professional development for all staff involved in the care of children with Congenital Heart Disease (standard G1)
- Importance of academic research across networks (standard G12)

⁴⁵ British Paediatric Cardiac Association (BPCA), *Recommendations of the British Paediatric Cardiac Association for Therapeutic Cardiac Catheterisation in Congenital Heart Disease*, Cardiology in the Young 2000;10:649-667

STAKEHOLDER ENGAGEMENT

Details of key stakeholders:

SAFE AND SUSTAINABLE has been a transparent and inclusive process. Both the Office of Government Commerce 'Gateway' Review Team and National Clinical Advisory Team have commended the review for its transparency, objectivity and engagement and communication with stakeholders

Stakeholders have included:

- National professional associations
- NHS staff
- National parent and patient groups
- Local parent and patient groups
- NHS commissioners
- Scrutiny bodies (Health Overview Scrutiny Committees and LINKs)

What clinical, patient, public and other stakeholder engagement there has been and how it has influenced the scheme

Communication

Information about the review has been published on the **SAFE AND SUSTAINABLE** website since early 2009⁴⁶; this includes background documents, available evidence supporting the case for change, the clinical standards and minutes of meetings. In response to suggestions from stakeholders the website was revamped in 2010 to make information

more accessible. Specialised Commissioning Groups have also publicised the review on local websites.

Quarterly newsletters have been published between August 2009 and December 2010⁴⁷. Bundles of hard copies of the newsletters are shared with the surgical centres for placement in the hospitals, and electronic versions are emailed directly to stakeholders on the review team's database. Additionally the newsletters are placed on the **SAFE AND SUSTAINABLE** website, local NHS websites and those of relevant professional associations and parent and user groups.

SAFE AND SUSTAINABLE literature has encouraged stakeholders to have their say about the process for delivering recommendations at all stages of the review. Literature has included a contact postal address, email address and a telephone number. All emails and letters have received a personal response.

Parent and patient groups

The review team has worked closely with the Children's Heart Federation (CHF). The CHF is the country's leading organisation for parents of children with congenital heart disease, and is an umbrella organisation comprising 20 member group from across the United Kingdom and whose Chief Executive is a member of the **SAFE AND SUSTAINABLE** steering group.

The CHF has publicised the review widely via its website⁴⁸ and existing networks, and has urged parents to have their say as part of the process for delivering recommendations for reconfiguration. In order to disseminate knowledge about the review the CHF has established a **SAFE AND SUSTAINABLE** 'documents library' on its website.

In September 2009 the **SAFE AND SUSTAINABLE** review team gave a presentation at the CHF's annual conference, providing parents and patients present with the opportunity to learn more about the review's aims and processes. The **SAFE AND SUSTAINABLE** team also asked the CHF to canvass the views of parents across the country by commissioning focus groups and by undertaking a postal / online survey, the questions of which were set and analysed by an independent third party experienced in the field. Questionnaires were sent to over 5,000 parents, and over 1,000 responses were received and analysed.

The outcome of the analysis suggested support for the aims of the review, and also provided the review team with a list of concerns and priorities identified by parents:

- Accommodation for families, childcare, cost of travel and time off work were the four most important areas of concern identified by parents
- Survival and quality of life was the most important priority
- Travel distance was the least important priority

The **SAFE AND SUSTAINABLE** review team has also presented to other national and local parent groups at their invitation.

Local authorities (Health Overview Scrutiny Committees and LINKs)

With the assistance of the Centre for Public Scrutiny the review team has briefed Health and Overview Scrutiny Committees (HOSCs) and LINKs of the review's progress as part of a pre-consultation engagement strategy. Additionally all HOSCs and LINKs in England were contacted by the **SAFE AND SUSTAINABLE** team and invited to a national stakeholder event in October 2009 (see paragraph overleaf).

⁴⁶ National Specialised Commissioning Team, **SAFE AND SUSTAINABLE** website
Available at: http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services

⁴⁷ Newsletters, National Specialised Commissioning Team, **SAFE AND SUSTAINABLE** website.
Available at: <http://www.specialisedservices.nhs.uk/document/stakeholder-newsletters-cardiac>

⁴⁸ Children's Heart Federation website. Available at: <http://www.childrens-heart-fed.org.uk/>

In August 2010 and October 2010 the **SAFE AND SUSTAINABLE** review team wrote all HOSCs (via local SCGs) to provide them with briefings on the review and to seek early views on how HOSCs would wish to be consulted as part of the formal consultation that is planned for 2011. The Chief Executive of every local authority in England also received a briefing in November 2010.

National stakeholder event, October 2009

On 22 October 2009 the **SAFE AND SUSTAINABLE** review held a national event for all those – professionals and parents alike – that care about the future of children’s heart surgery service in England. The *“SAFE AND SUSTAINABLE children’s heart surgery services – how do we deliver a world class service for the future?”* event was designed to give stakeholders the opportunity to shape the work of the programme and discuss draft service standards. Around 200 people attended (See Appendix P for the minutes and delegate list).

Speakers at the event:

- Professor Sir Bruce Keogh, NHS Medical Director (by video)
- Bernard Stedman and Harrison Stedman (a child with CHD and his father)
- Dr Sheila Shribman, National Clinical Director for Children, Young People and Maternity
- Leslie Hamilton, President of the Cardiothoracic Society of Surgeons Great Britain
- Anne Keatley-Clarke, Chief Executive of the Children’s Heart Federation
- Jeremy Glyde, **SAFE AND SUSTAINABLE** Programme Director

- Mr William Brawn, President of British Congenital Cardiac Association
- Dr Patricia Hamilton, Chair of the **SAFE AND SUSTAINABLE** Steering Group

The aims of the day were to test the draft standards, seek advice on potential models of care and to test the strength of the case for change. The main achievements were feedback from participants that directly informed the development of the proposed network model of care and majority support by show of hands for the standard that proposes a minimum of 4 consultant congenital cardiac surgeons in each surgical centre in the future.

Through feedback forms after the event 97% of respondents found the event to be ‘informative’ and 87% agreed that ‘there were opportunities for discussion’.

Designation standards

The clinical standards were informed by contributions from a range of stakeholders following a period of extensive engagement between September 2009 and February 2010. The draft standards were widely circulated for comment in September 2009 including its placement on the **SAFE AND SUSTAINABLE** website. Steering Group members were also asked to circulate the document to members of their professional associations and networks, and the Children’s Heart Federation placed the document on their website and circulated it directly to their member groups. A list of organisations to which the standards were sent directly is listed in Appendix Q. The draft standards were discussed at a national stakeholder event in October

2009. Additional comments received from stakeholders were provided to the Standards Working Group at its meetings in November 2009 and February 2010, and by the Steering Group in January 2010. In order to help members of the Standards Working Group contextualise the comments, and to ensure that this document did not misrepresent comments received, members of the Standards Working Group were provided with respondents’ emails or letters in full to accompany this document.

The final version of the proposed standards was published in March 2010 (Appendix F).

Engagement Events 2010 executive summary

10 public engagement events were held by the **SAFE AND SUSTAINABLE** team in 2010. The key discussions and issues of concern raised at each engagement event have been captured and summarised in the Engagement Events Report to produce an overview of the engagement process. Please see Appendix R for the report. A summary of the process and the feedback is provided below.

The most prominent themes and issues throughout the whole engagement process included concerns about accommodation, travel, the future clinical pathway and continuity of care. Many delegates raised further points about the impact of government spending cuts, the impact on transition to adult services and the retention of skilled surgeons and support staff. Communication was also a recurring theme with delegates requesting clarification

on how different centres and outreach clinics would communicate with each other under the new programme.

Whilst these core themes reside, it is also evident that there are points of difference from region to region. In certain regions, for example, there was a slightly greater concern on the impact that the programme would have on transport to new centres. This issue was particularly prominent in Plymouth and Southampton where a number of participants, who live in locations throughout Cornwall, raised concerns about the long distances that they may be required to travel to their nearest specialist centre. In regions, such as Leeds, Leicester and Oxford there was a very clear focus on ensuring skilled staff would be retained and remain within the region.

At every event participants requested clarification on the future service model and how the centres would work in practice particularly when communicating with local outreach centres. This was particularly prevalent in London where participants sought greater understanding of how the networked model would work within the region.

Engagement Events What happened at the events?

A panel member, generally a clinician, provided an introductory presentation to provide delegates with a clear picture for the case for change and details on the proposed model of care. The presentation outlined that the key aims of the proposed reconfiguration was to ensure safety and sustainability.

Delegates' questions and comments were recorded in every location. A full written transcript⁴⁹ was then taken to document the discussions. Each transcript was then reviewed and summarised to produce the Engagement Events Report, which provides an overview of the key themes and issues raised at each event.

How issues that have arisen through stakeholder engagement are being addressed

These include:

- The standards and model of care – the proposed standards and model of care were informed by the outcome of a comprehensive public engagement held between September and December 2009; comments received during the exercise have been published so that stakeholders can see how their comments have informed the final proposals⁵⁰.
- Family accommodation - parents have raised as a concern the provision of appropriate family accommodation at surgical centres in the future; the standards seek to address this issue and Sir Ian Kennedy's panel was

asked to specifically assess the applicant centres against this standard; on the day of the assessment visits to each centre the panel met with a delegation of parents to hear their views.

- Journey times – parents and professionals have also raised as a concern the possibility of increased journey times, for both elective appointments and emergency retrievals; the criteria for the evaluation of potential options applied by the JCPCT has included a detailed analysis of travel times for elective appointments and an analysis of potential retrieval times against the current standards set out in the Paediatric Intensive Care Society standards.
- Financial costs – where the **SAFE AND SUSTAINABLE** review has not been able to respond to the concerns of parents because those concerns fall outside of the scope of the review – for example around the reimbursement of travel costs for families not entitled to financial assistance under the Healthcare Travel Cost Scheme - the **SAFE AND SUSTAINABLE** team has brought those concerns to the attention of the relevant government department (in this case the Department of Health).

- Engagement Events – a detailed report on the issues raised by stakeholders during the 2010 public engagement events was provided to the JCPCT early in its deliberations (Appendix R).
- Criteria for the evaluation of potential configuration options – the **SAFE AND SUSTAINABLE** team sought views from the potential criteria from two stakeholder groups in addition to the steering group and NHS commissioners (parents who registered for one of the engagement events and NHS staff working in the current surgical centres); the weighted criteria applied by the JCPCT was informed by the outcome of this exercise (see section 8).

Plans for ongoing stakeholder consultation

Plans for ongoing stakeholder consultation are set out in section 14.

⁴⁹ Engagement Event Transcripts, National Specialised Commissioning Team, **SAFE AND SUSTAINABLE** website Available at: http://www.specialisedservices.nhs.uk/safe_sustainable/heart-safe-sus-events

⁵⁰ National Specialised Commissioning Team, *Children's Heart Surgery Centres In England: Comments on Draft Service Specification Standards (Comments received up to 17 February 2010)*. Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>

PROJECT OBJECTIVES AND ASSESSMENT PROCESS

A robust and comprehensive process has been followed to identify the best options for providing new services for children with congenital heart disease in England. The assessment has taken into account:

- Ability of the centres to meet the quality standards in the future
- Comprehensive coverage of population of England and Wales
- Sustainability of services in the future
- Impact of proposed changes on other services commissioned by the NHS

Objectives of the programme

An options appraisal (assessment) process has been followed in order to present the best, viable, sustainable options for public consultation. The options appraisal process is explained in this section.

The assessment process

This section of the PCBC describes in detail the process for delivering recommendations for reconfiguration.

The reconfiguration of paediatric cardiac surgery services was approached as a quasi-procurement exercise, to ensure that all incumbent providers of those services being

reconfigured were treated fairly and equally and that the accreditation process was proportionate to the service reconfiguration and conducted in an appropriately transparent and non-discriminatory way in accordance with EU procurement law principles. It is intended that any new providers, if any, will be evaluated against the same accreditation evaluation criteria going forward.

Baseline information (January 2010)

Baseline information was provided by each centre to the *SAFE AND SUSTAINABLE* team in January 2010. These information returns did not formally constitute an element of the assessment process. Rather the returns provided baseline information on activity, staff establishment and infrastructures.

A standard questionnaire (Appendix U) was developed in consultation with commissioners nominated by the SCG Directors' Group and was shared with members of the *SAFE AND SUSTAINABLE* Standards Working Group for comment before circulation.

The questionnaire was sent to the Chief Executives of the 11 NHS Trusts that provide paediatric cardiac surgery in December 2009 for return by 31 January 2010. The *SAFE AND SUSTAINABLE* team established a process that ensured that 'questions and answers' about the questionnaire were copied in to all of the centres so as to achieve consistency in interpretation and definitions. This questionnaire was followed by a separate template (Appendix V) in January 2010 that address activity data sourced from the Central Cardiac Audit Database.

The assessment panel

An independent panel of experts was convened by the *SAFE AND SUSTAINABLE* review team in consultation with the relevant professional associations. The panel was chaired by Professor Sir Ian Kennedy in view of his considerable experience in the field and included Mr James Monro, a retired consultant congenital cardiac surgeon who chaired the previous Paediatric and Congenital Cardiac Services Review Group that reported in 2003. The panel also comprised experts in paediatric cardiology, anaesthesia / paediatric intensive care, children's nursing, NHS commissioning and lay representation.

Terms of reference and panel membership are set out in Appendix J.

Phase 1 - Self-assessment

Between March and May 2010 each centre was asked to demonstrate their current and future compliance against core designation standards through a self assessment template. The centres received the self-assessment template by email on 22 March 2010. The deadline for submission of their self-assessment was originally set for 4pm on 30 April 2010, giving the centres six weeks to complete this stage.

It was important that the centres had a full and detailed knowledge of the entire assessment process (as was known at the time).

The centres were provided with the following information in March 2010:

- Covering letter, explaining the process of assessment, including the next steps, deadlines, panel membership (Appendix W)
- Self assessment template for assessment visits, including full guidance on the self-assessment process and details of later stages of the assessment process (Appendix X)
- *SAFE AND SUSTAINABLE* clinical standards document

As indicated in the covering letter, additional information was requested from the centres and on 13 April 2010, two further documents were emailed to the centres:

- A template to collect information on the centres' potential ability to deliver one or more of three nationally commissioned services (NCS) if required (these are Cardiothoracic Transplants and Bridge to Transplantation, Extracorporeal Membrane Oxygenation (ECMO) for respiratory conditions, and Complex Tracheal Surgery.)
- Financial template requesting current and predicted future costs. (Appendix Z)

The centres were originally asked to respond by 30 April 2010 but the deadline for completion of all three templates (including the self assessment) was extended until the 7 May 2010 to give the centres more time for completion to reflect the later submission of the two templates.

To ensure consistency in responses, and to further strengthen the robustness of the information available for the option appraisal process, the *SAFE AND SUSTAINABLE* team asked the relevant host SCG commissioners to provide a commentary in response to the self-assessments by the centres. The SCGs were also asked to provide details of any exceptional reviews or investigations carried out at the Trust by regulatory bodies or the Strategic Health Authority since 1 April 2007 including:

- The reasons for the review or investigation
- The findings of the review or investigation (including interim findings)
- Subsequent action taken by the Trust (where applicable).

The commentary was not scored as part of the assessment process but it was used by the panel to identify areas for discussion on the day of the review. During the self-assessment stage, transparency was ensured throughout and the key stakeholders fully engaged. The self-assessment template, the scoring template for the assessment visits, along with the financial template and the Nationally Commissioned Services template, were shared with the members of the Steering Group in April 2010. At the same meeting, the Steering Group was invited to comment on the scoring system proposed for the assessment panel visits.

Identification of the criteria for the Phase 1 of the assessment process

The criteria for designation were taken from the proposed *SAFE AND SUSTAINABLE* clinical standards, which had been endorsed by the relevant professional associations and developed in partnership with stakeholders across the country (see Appendix F). Additionally other criteria were applied to this phase of the assessment process around 'leadership and strategic vision' and 'deliverability and achievability' based on the principles that underpin the standards (the need to review the strength of the organisation in terms of future sustainability and ability to ensure continuous improvement).

It was explained to the centres that the designation standards would be used in the future as an ongoing commissioning service specification.

The criteria were as follows:

- Leadership and Strategic Vision
- Strength of Network
- Staffing and Activity
- Interdependent Services
- Facilities and Capacity
- Age Appropriate Care
- Information and Choices
- Ensuring Excellent Career Deliverability and Achievability

The weightings presented to the steering group and shared with the centres at the outset of the assessment process were as follows:

RANK	CRITERION	MAX SCORE
1	Staffing and Activity The ability to build the right team of staff with the right skills to deliver the required activity was seen as the most important criterion. The need to generate a minimum of 400 procedures was seen as particularly important and weighted accordingly.	130
2	Leadership and Strategic Vision There is a supposed correlation between effective leadership and strategic vision with the organisation's ability to deliver a good service and good outcomes.	120
3	Deliverability and achievability It is important that the agreed configuration can be delivered, and so this was ranked third but not significantly above the next batch of criteria.	75
4	Strength of Network	70
4	Interdependent services	70
4	Facilities and capacity These are closely linked with delivery and hence were ranked just behind it.	70
7	Excellent care	60
8	Age Appropriate Care	45
8	Information and choice The purpose of the weightings is to highlight points of differentiation. It was considered that if the other criteria above are met then these will follow.	45
TOTAL		685

During the panel briefing (see below) the panel agreed that it would not score any of the centres on section 3 of the self assessment "Deliverability and Achievability". The reason was that the panel did not consider that it had the necessary expertise to score this section and that these issues would be appropriately considered by the Joint Committee of PCTs in developing recommendations for configuration

Phase 2 – Panel Assessment

The on-site assessment of each prospective surgical centre was undertaken by the panel of experts over a three-week period commencing in May 2010. The terms of reference (Appendix J) for the panel was to consider the safety and sustainability of each centre with reference to the proposed quality standards.

The panel was asked to assess compliance with the standards now and in the future and to consider how the centres could expand their facilities and workforce if necessary. The panel approached this task by assessing each centre separately. The panel did not seek to compare the centres as it made its deliberations.

The process was in part objective in so far as it drew together relevant data, and subjective in that it called for the judgment of experts as to the extent to which the facts put before them demonstrated compliance with the standards.

Information received by the panel

The panel received the following written information in advance:

- **SAFE AND SUSTAINABLE** standards
- Self-assessment submissions from all centres
- SCG commentaries on the self-assessment submissions
- A list of the supporting evidence supplied by the centres, which was available on request
- A website link to centre-specific Care Quality Commission reports for 2008/09
- Baseline information supplied by the centres to the national review team in January 2010

Assessments of each centre by the panel

The panel members separately assessed each centre in April 2010 based on a consideration of each centre's written submission in the form of self assessment. The centres were advised that the written submission alone would constitute the basis on which the panel would make its initial evaluation.

The panel members initially scored each submission against the assessment criteria on the basis of the information submitted.

Panel Briefing

The panel convened as a group for a briefing on the assessment's scoring process from the *SAFE AND SUSTAINABLE* team on 20 May 2010. The briefing outlined:

- Purpose of the assessment visits and the role of assessment panel
- *SAFE AND SUSTAINABLE* service standards
- Assessment framework
- Importance of ensuring that the process is transparent, proportionate and fair

The briefing also included a separate meeting between the panel members and parents and carers who were invited by the Children's Heart Federation and representatives of the CHF. The aim of this meeting was for parents and carers to highlight common issues of importance (that were not centre-specific) from their perspective.

Visits to the centres

The panel visited each centre between May and June 2010, meeting staff, parents, carers and patients.

The itinerary for the visits was developed in consultation with clinical and lay stakeholders. For example, on the advice of the Children's Heart Federation, a dedicated session with parents and patients was included and the professional societies advised on the clinical facilities that should be seen by the panel on the day.

The itinerary is attached as Appendix AB. While the format remained broadly identical for all visits to ensure consistency, it was up to each centre to choose who would represent them on the day.

The panel members took account of what they heard and saw on the day by re-assessing and discussing their initial scores to reach a consensus score for each of the relevant factors. The panel discussed their observations for each question in the assessment in the round and arrived at a set of conclusions under various headings.

The conclusions related directly to each of the 11 questions under section 1 (Leadership and Strategic Vision) and questions A, B and C for each of the 7 Core requirements. The panel undertook to assess the centres against:

- The current compliance with core standards: the panel assessed compliance of the centres against the core designation standards based on the self assessment and the visits.
- Development plans to meet core standards: the panel assessed the robustness and deliverability of the sites development plans, for meeting all core requirements from the standards.
- Impact of increased activity: the panel assessed the potential impact of national reconfiguration on a centre, for example, its activity levels.

SCORE	DEFINITION
1	Inadequate (no evidence to assure panel members).
2	Poor (limited evidence supplied)
3	Acceptable (evidence supplied is adequate, but some questions remain unanswered or incomplete)
4	Good (evidence supplied is good, and the panel are assured that the centre has a good grasp of the issues)
5	Excellent (evidence is exemplary)

Each question was scored from 1-5 (inadequate to excellent), based on robust evidence.

Scores were qualitative and based on the level of comfort panel members had on whether the site can achieve the standard. Each question was scored from 1-5 (inadequate to excellent), based on robust evidence.

Scoring and Sensitivity Analysis

Once the final scores for each centre were agreed by the panel, the weightings were applied to the consensus scores (see page x).

The panel convened in June 2010 to understand the various sensitivities that had been applied by NHS Specialised Services to the final scores to confirm the robustness of the scoring process.

These sensitivities included:

- Use of scores from section 2 only (Core Requirements)
- Use of Question "C" of the core requirements only
- Un-weighted (absolute) scores

DEFINITION	SCORE
Guys and St Thomas' NHS Foundation Trust (Evelina Children's Hospital)	535
Southampton University Hospitals NHS Trust	513
Birmingham Children's Hospital NHS Foundation Trust	495
Great Ormond Street Hospital NHS Trust	464
Royal Brompton and Harefield NHS Foundation Trust	464
University Hospitals Bristol NHS Foundation Trust	449
Newcastle Upon Tyne Hospitals Foundation Trust	425
Alder Hey Children's Foundation Trust	420
University Hospitals of Leicester NHS Trust	402
Leeds Teaching Hospital NHS Trust	401
Oxford Radcliffe Hospitals NHS Trust	237

When this sensitivity analysis was applied there was only some very minor movement of Trusts within the scoring, which gave the panel confidence in its process for scoring and in the weightings.

The panel agreed that they had applied a consistent approach to scoring. The panel members considered that their deliberations over the scoring of the initial centre were used consistently as a template to inform subsequent scoring. On this basis the panel agreed to confirm the scores they had assigned to each centre.

Each centre received preliminary feedback on the outcome of the assessment on 20 August 2010.

The full report on the outcome of the assessment of each centre is presented to the Joint Committee of PCTs as Appendix K1.

Phase 3 – Establishing a Shortlist of Viable Options

The next stage of the process was to test which of the potential 2,047 configuration options were theoretically possible⁵¹. The following high level thresholds were applied by the review team to identify un-viable rule options.

- Each site should carry out a minimum of 400 paediatric surgical procedures per year moving towards 500 per year in line with the proposed designation standards
- Sites will be included in the reconfiguration options in order of their assessment panel ranking; and
- Options should provide 'best fit' in terms of access to services across England and Wales.

This resulted in an initial set of 15 potential options being identified for detailed access mapping and activity re-distribution analysis. These 15 potential options included all sites in at least 3 of the potential options. The 15 potential options represented a 'first cut' of options used to test a set of hypotheses and to gather evidence to support or rule out the application of various principles to the wider pool of 2,047 potential options.

The 'configuration options development stage' of the process was an iterative one to ensure that no potential options or sites were ruled out until sufficient analysis and testing had been undertaken to support a series of further principles which could be added to the three thresholds set out above.

The analysis undertaken on the 15 potential options was:

- Detailed access mapping (for train and road journeys); and
- Activity re-distribution mapping.

Access mapping was undertaken initially using the assumption that patients would travel to their closest centre. Road journeys were calculated using data from a specialist mapping consultancy compiled over 20 years, measuring 24 hour average speeds per road type in the United Kingdom. Journeys were calculated from the centre of each postcode district (2,292 in England and Wales) to each surgical centre.

Train journey times were also mapped from the county town and largest town in each county to the closest centre. A later set of potential options were tested in collaboration with the SCG Directors by applying potential clinical networks; this superseded the assumption that patients travel to their closest site and tested whether potential future networks were viable.

Activity re-distribution mapping used the 2009/10 activity data validated by the Central Cardiac Audit Database (CCAD) and re-allocated activity according to the population in each postcode district. This analysis was undertaken in two ways:

- 1 Assuming that activity per centre was equally distributed across the postcode areas closest to each centre according to population density

⁵¹ All combinations of 10, 9, 8, 7, 6, 5, 4, 3, 2 and 1 sites.

2 Assuming that activity per centre was equally distributed across the postcode areas in each centre's current network according to population density

The variance in activity figures by centre using each set of underlying assumptions was not found to be significant. Final figures presented to the JCPCT are therefore based on the second set of assumptions, as they reflect current patient flows more accurately. It was assumed that the incidence of paediatric cardiac surgery is constant across the populations in each postcode district within each network.

This assumption was tested in the following ways:

- CCAD analysis shows that the incidence of paediatric cardiac surgery does not vary greatly across the population in England and Wales⁵². Where there are variations the consequential numbers of children with congenital heart defects remain small, and hence the impact of any variation is small.
- The birth rate per region, as a percentage of the total in England and Wales, was compared to the population per region, as a percentage of the total in England and Wales, and there were no significant variations except for London where the birth rate was significantly higher. Therefore, if anything, the activity estimates for London will be very slightly underestimated. Given no options were excluded on the basis of

a lack of activity or too onerous levels of activity at London centres this has not had an impact on the selection of options.

- The size of the catchment areas for each centre and the population within them are so large that the impact from any variation across counties, in terms of the incidence of cardiac surgery in groups of the population, will be statistically insignificant (in other words, each centre's network is likely to include areas of slightly higher incidence and areas of slightly lower incidence though this will be investigated further during the separate 'Health Impact Assessment').
- Population data used has been updated from the 2001 census data to take into account population growth and movements between 2001 and 2010. Therefore analysis is based on the most accurate picture of population sizes available.

A further iteration was then run, selecting a further 8 potential options on top of the 15 initially tested to allow for further conclusions to be drawn (and to test the robustness of the earlier hypotheses and principles).

The results of developing the reconfiguration options

The evidence generated from the detailed access mapping and activity-redistribution exercises was considered by SCG Directors.

On the basis of that evidence the following principles were agreed:

- Each site should carry out a minimum of 400 paediatric surgical procedures per year, ideally 500 per year⁵³. Options should contain 6 or 7 centres each on the basis that fewer than 6 centres requires all centres to perform over 700 procedures each, on a crude average, and more than 7 centres provide each centre with only 450 procedures, again on a crude average. Given the uneven geographical spread of referrals and the preferred number of procedures per centre of 500 per annum, it was agreed that options with more than 7 centres present a significant risk of some centres being referred below 400 procedures per annum.
- London requires at least 2 centres due to the size of the population in its catchment area (including East of England and South East England).
- The Oxford centre should be discounted from all options on the basis of sub-optimal quality, and given that it does not improve access times.
- The Birmingham centre should remain in all options due to the high level of referrals from the large population in its immediate catchment area.

- Based on a strict application of patients travelling to the nearest centre the Bristol and Southampton centres are mutually exclusive because there are not enough patients in South Central England, South West England and South Wales to ensure that both centres achieve the 400 minimum 'critical mass' without recommending potentially unreasonable changes to catchment areas for the London and Birmingham centres (subject to the caveat below). However, one of the two centres is required in all options to provide a centre for these populations.
- 'The North' (defined as Newcastle, Liverpool and Leeds centres) requires 2 centres because there are not enough patients to ensure all 3 achieve the 400 minimum while realistic networks are maintained. The 2 should be Liverpool and Newcastle or Liverpool and Leeds because Newcastle and Leeds cannot achieve the 400 minimum each while maintaining realistic networks and not significantly impacting access times.

The evidence to support these decisions is set out in Appendix AC.

⁵³ This principle was agreed early in the process. In reality it cannot be applied as a top down rule early in the process as it requires detailed activity redistribution analysis to be carried out on each option. Therefore it was used to inform the rule that over 7 or under 6 centre options are not viable. This along with the other evidence based rules applied here reduced the options from 2,047 to 12 which allowed detailed activity redistribution analysis to be carried out. This detailed analysis showed that some of the 12 were unviable on the basis of not achieving 400 procedures per year, these were therefore ruled out at that stage and the number of viable options for scoring was reduced.

Applying this set of 'rules' to the 2,047 different possible reconfiguration options results in a shortlist of 12 potentially viable options. An additional 2 potential options were added to these at the request of the JCPCT during an informal working meeting to reflect the highest scoring centres from Sir Ian Kennedy's panel assessments and to take account of emerging local intelligence about the impact of patients flows in South Central England as a result of the suspension of the paediatric cardiac surgical service at the John Radcliffe Hospital in Oxford.

The first of the additional two options takes the top 7 scoring sites, the second substitutes one

of the three London sites for the eighth best site (Liverpool) on the basis that taking the top 7 would only leave one site in 'the North'. These 2 additional options were added in the context of 'quality' being the highest ranking criterion and to ensure that an option with the highest scoring sites was scored by the JCPCT for comparison with other options.

These 14 potential options were analysed in detail. As a result, it is recommended to the JCPCT that the following assumptions should be applied to these shortlisted 14 potential options to reduce them to a shorter list of viable options:

- All centres in an option must be able to achieve the 400 minimum threshold for activity.
- Centres must not receive too onerous a caseload per annum (measured against their stated maximum capacity)
- Options must include a minimum of 3 centres capable of providing ECMO services, 2 centres providing transplant services and 1 centre providing complex tracheal surgery or they do not meet the minimum requirements for Nationally Commissioned Services (in line with the recommendations of the expert panel) See Appendix (A)

- Options must be able to meet the minimum requirements for retrieval outlined in the Paediatric Intensive Care Society 'Standards for the Care of Critically Ill Children, 2010'⁵⁴, which state that 'The retrieval team should arrive at the referring unit within three hours (extended to four hours in remote areas) of the decision to retrieve the child.

As a result of applying these assumptions, the 14 potential options were reduced to 6 viable potential options. This is shown below with reasons for finding 8 of the options 'unviable'.

6 of the 14 are potentially viable:

	7 SITES: 2 LONDON	7 SITES: 2 LONDON	7 SITES: 2 LONDON	7 SITES: 2 LONDON	6 SITES	6 SITES	6 SITES		6 SITES	7 SITES: 3 LONDON	7 SITES: 3 LONDON	7 SITES: 3 LONDON	7 SITES: 3 LONDON	TOP 7 SCORING	TOP 7 SCORING
OPTION	1	2	3	4	5	6	7		8	9	10	11	12	13	14
Liverpool	627	721	627	722	647	741	647		741	431	494	431	494	387	580
Southampton	478		478		478		478			478		478		382	382
Birmingham	602	472	602	472	976	725	790		660	976	725	790	660	842	725
Bristol	Retrival	420		420		420	NCS		420		420	NCS	420	360	360
Newcastle	406	406			406	526	NCS			406	526	NCS		854	526
Liverpool	445	445	400	400	445	445	400		400	445	445	400	400		445
Leicester	414	414	293	293			NCS					NCS			
Leeds			571	571			636		636			636	636		
Oxford															
TOTAL CENTRES	7	7	7	7	6	6	6		6	7	7	7	7	7	7

⁵⁴ Paediatric Intensive Care Society, *Standards for the care of critically ill children (4th Edition)*, June 2010

	DESCRIPTION	STEERING GROUP	%	SCGs	RANK	OVERALL RANK	OVERALL WEIGHT
1	Access and travel	15	18	9	=3	4	14
2	Quality	35	41	28	1	1	39
3	Deliverability	15	18	21	=3	3	22
4	Sustainability	20	24	22	2	2	25
5	Affordability	85 15	100	80 20	100		

- Option 1 was ruled as ‘unviable’ because it did not meet the standards for retrieval as retrieval times for patients in parts of Cornwall would exceed four hours (4hrs 15 minutes), and in parts of South West Wales would exceed 3 hours
- Options 3 and 4 were considered ‘unviable’ due to the redistributed activity levels at the Leicester centre being significantly below the 400 minimum threshold. The activity levels at the Leicester centre are low in these options because the Leeds centre is present and therefore the potential network for the Leicester centre is not extended on the northern boundary
- Options 5 and 9 were ruled ‘unviable’ due to the redistributed activity levels at the Birmingham centre being significantly above their stated maximum capacity of 800 cases per annum. The activity levels at the Birmingham centre are high in these options because neither Bristol nor Leicester nor Leeds are present in these options and therefore the Birmingham catchment area is extended through the Midlands and into south Wales

- Options 7 and 11 were ruled ‘unviable’ due to not meeting the minimum requirements of the Nationally Commissioned Services criteria. Neither of these options contain 3 centres which either currently provide ECMO or who were considered able to provide ECMO services in the future (Appendix A)
- Option 13 was ruled ‘unviable’ due to resulting in redistributed activity at all 7 centres that is either below the 400 minimum threshold or above the centre’s stated maximum threshold. This is due to an uneven distribution of centres across England and Wales with only one in the North and five in ‘the South’ (defined as London, Southampton and Bristol)

The application of these final assumptions leaves 6 potentially viable options.

Phase 4 - scoring the 6 viable reconfiguration options against the evaluation criteria

In order to decide which, if any, of the 6 potential configuration options were appropriate for public consultation they were evaluated

against the weighted evaluation criteria. The purpose of the scores is to guide the JCPCT in its deliberations as it considers all evidence in the round. The first exercise was to agree the weightings.

How the Weightings were Agreed

Weightings were informed by the views of stakeholders. The *SAFE AND SUSTAINABLE* team sought views from four stakeholder groups in July 2011:

- *SAFE AND SUSTAINABLE* steering group members
- Specialised Commissioning Group Directors
- Parents who had registered for one of the 2010 engagement events
- 5 clinicians from each the current surgical centres (nominated by their NHS Trust)

At the outset ‘Affordability’ had been included as a criterion and this was included in seeking stakeholders’ views. The Steering Group and SCG commissioners commissioning later advised to address only the non-financial

criteria to score the configuration options and treat ‘Affordability’ as a stand alone test.

The Steering Group and SCGs were asked to complete an excel spreadsheet in order to score the criteria out of ‘100’ in order to assess the relative importance of each criterion.

The scores given for ‘Affordability’ were apportioned across the other criteria in order to maintain the score out of 100. The rankings for these stakeholder groups were similar.

Parents and clinicians were surveyed using ‘Survey Monkey’ in order to test the importance of each criterion to these stakeholders. It was decided to use ‘Survey Monkey’ in order to make it as convenient as possible for people to respond. Respondents were asked to score each criterion out of 10 on how important the criterion is to them. It was decided not to use excel spreadsheets, which, by their nature, are technical for fear it would deter some people from responding and because it was not necessary for ranking purposes.

The average scores were as follows:

CRITERION	DESCRIPTION	CLINICIANS	RANK	PARENTS	RANK
1	Access and travel times	7.3	4	8.2	4
2	Quality	9.2	1	9.1	1
3	Deliverability	9.0	2	8.8	2
4	Sustainability	8.0	3	8.4	3
5	Affordability	33.5 7.6		34.5 6.4	

As the 'Affordability' criterion was being assessed separately, its score could be ignored here. The rankings for these stakeholder groups were the same. The rankings of the parents and clinicians very closely match the assessment of the Steering Group and SCGs. All stakeholders scored 'Quality' the highest and 'Access and travel times' the lowest. There is a slight difference in the rankings of 'deliverability' and 'sustainability' but the weightings for these criteria are fairly close.

For these reasons it is recommended that the following weightings are used to score the non-financial criteria and to carry out sensitivity analysis on the results in order to double check whether changing the reversing the weightings for 'deliverability' and 'sustainability' made a difference to the scoring.

The subsequent weightings in summary are therefore:

CRITERION	DESCRIPTION	OVERALL WEIGHTING
1	Access and travel times	14
2	Quality	39
3	Deliverability	22
4	Sustainability	25
5	Affordability Total	100

As part of this engagement exercise respondents were also asked to suggest any other criterion that should be applied when evaluating potential configuration options. No additional appropriate criterion were identified. Responses included criterion already proposed, issues that were already taken account of elsewhere in the review process such as parent facilities (which are addressed by the standards) or issues of

process such as a proposal to include services for adults with congenital heart disease in the review process.

The full list of responses can be found at Appendix AA. The *SAFE AND SUSTAINABLE* steering group advised that a system of weighting should be applied to the scoring process to ensure that core designation requirements were given sufficient emphasis.

The weightings presented to the steering group and shared with the centres at the outset of the assessment process were as follows:

EVALUATION

Access and travel

14

- The negative impact on travel times for elective admissions is kept to a minimum
- The retrieval team should arrive at the referring unit within three hours (extended to four hours in remote areas) of the decision to retrieve the child in accordance with the PIC Society 'Standards for the Care of Critically Ill Children, 2010'

Quality

39

- Designated surgical centres will deliver a high quality service
- Innovation and research is present across the networks and the national service
- Clinical networks are manageable, taking account of population and geography and the need for clear leadership and communication

Deliverability

22

- The NHS in England will continue to provide high quality:
 - paediatric cardiothoracic transplantation services in two centres
 - ECMO services for children with severe respiratory failure in at least three centres
 - complex tracheal surgery in one centre
- The negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum
- The negative impact on the NHS workforce is kept to minimum
- Transitional plans for implementation are in place by April 2013

Sustainability

25

- All designed centres are likely to perform at least 400 paediatric procedures per year, ideally 500
- No one designated surgical centre will receive too onerous a caseload that would exceed that centre's capacity to manage it
- All designated centres will be able to recruit and retain newly qualified surgeons and other specialist staff, will provide mentoring and training of junior surgeons and will be able to develop robust plans

The results of the scoring process

Proposed scoring was carried out on a five point scale, as shown below:

Absolute scores – version 1

SCORING SCALE	
0	Does not meet any elements of the criteria
1	Meets SOME elements of the criteria (areas where there are gaps in compliance exceed areas where there is compliance)
2	Meets MOST elements of the criteria (areas where there are gaps in compliance exceed areas where there is compliance)
3	Meets all elements of the criteria
4	Exceeds the criteria

The final output of the proposed scoring is shown in the table below. The rationale for the proposed scoring is described in detail in Appendix AC.

Weighted scores – version 1

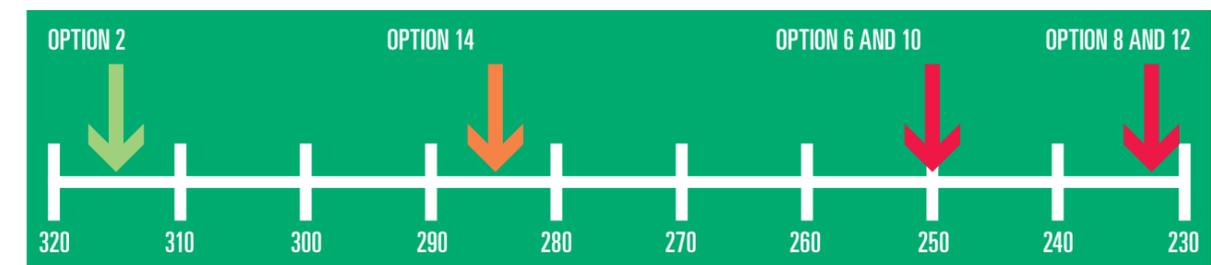
	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Access and travel	4	1	3	1	3	1
Quality	3	3	3	3	3	4
Deliverability	3	2	1	2	1	3
Sustainability	3	3	2	3	2	2

The weightings were then applied to arrive at total proposed scores per option. These proposed scores are shown on the scale below.

Weighted scores – version 1

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Access and travel	56	14	42	14	42	14
Quality	117	117	117	117	117	156
Deliverability	66	44	22	44	22	66
Sustainability	3	3	2	3	2	2
TOTAL	314	250	213	250	213	286

This would result in a proposed ranking of options:



Sensitivities were applied to the scores for travel and access and the scores for quality. The exercise resulted in 4 potential versions of the proposed scoring.

In all 4 versions Option 2 was the highest scoring option and Options 8 and 12 were the lowest scoring options. A full breakdown of the sensitivity scoring can be seen in Appendix AC.

Options recommended for public consultation

The reasons for the proposed discounting of the remaining 2 options are summarised below:

- It is recommended that options 10 and 12 are discounted for consultation on the grounds that two designated centres is the optimal configuration for the population of London, East of England and South East England. Whether or not there should be 2 or 3 centres in London will be a question that will be covered directly in the consultation.
- Given the proximity to each other of the three current centres London is uniquely placed to ensure that those centres that are designated as surgical centres can meet the optimal proposed critical mass of 500 paediatric procedures each year. The forecast activity levels for London and its catchment area (around 1,250 paediatric procedures each year at current levels) support two centres being able to meet this critical mass.

This could not be achieved with the retention of three centres in London unless patient flows were re-diverted from neighbouring catchment areas into London; the outcome of analysis suggests that this would impact significantly on access for patients outside of London, South East and East of England to an extent that could not be justified.

- Further, the advice of the **SAFE AND SUSTAINABLE** steering group is that two centres, rather than three, are better placed to develop and lead a Congenital Heart Network for London, South East England and England envisaged by the **SAFE AND SUSTAINABLE** model of care given geography, population and patient flows and the need for consistent clinical protocols and robust governance arrangements across the network.

The recommended options for consultation are

- Option 2: it is recommended that option 2 is viable as it is consistently the highest scoring potential option

- Option 14- is retained because it scored well and could have scored higher pending the outcome of debate about future patient flows, and because it is recommended that this potential option minimises the adverse risk of reconfiguration to national paediatric intensive care provision (Appendix B).
- Option 6- It is recommended that options 6 is viable
- Option 8- It is recommended that option 8 is viable

NB

Paediatric cardiothoracic transplantation (including mechanical device as 'bridge to transplant'), ECMO for children with severe respiratory problems and complex tracheal surgery are nationally commissioned services and all decisions about where they are provided can only be made by the Secretary of State for Health.

Were the JCPCT's final decision to be dependent on a change to the provision of any of these national services that would need to

be ratified by the Secretary of State for Health. Were he not to support the proposed change to national services, then the JCPCT would have to make a fresh decision about the location of Specialist Surgical Centres that did not require such a change.

Which 2 centres in London?

It is recommended to the JCPCT that two centres is optimal in London (see above)

For reasons given below the preferred two centres are the Evelina Children's Hospital and Great Ormond Street Hospital for Children. The question of which 2 centres will be explicitly addressed in the consultation.

The recommendation is based on the outcome of an analysis of the application of the same criteria that has been used to evaluate potential configuration options to the three centres. This application results in the following scores:

SCORING THE LONDON SITE: SUGGESTED SCORES							
CRITERIA	WEIGHTING						
	GOSH	EVELINA	RBH	GOSH Weighted Score	EVELINA Weighted Score	RBH Weighted Score	
<p>ACCESS AND TRAVEL TIMES</p> <p>The negative impact on travel times for elective admissions is kept to a minimum.</p> <p>The negative impact on retrieval travel times for emergency admissions is kept to a minimum, taking account of expert views on emergency transportation.</p>	3	3	3	42	42	42	14
<p>QUALITY</p> <p>Designated surgical centres will deliver high quality service.</p> <p>Innovation and research is present across networks and the national service.</p> <p>Clinical networks are manageable, taking account of population and geography and the need for clear leadership and communication.</p>	3	4	2	117	156	78	39
<p>DELIVERABILITY</p> <p>the NHS in England will continue to provide the relevant high quality Nationally Commissioned Services.</p> <p>The negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum.</p> <p>the negative impact on the NHS workforce is kept to a minimum.</p> <p>Transitional plans for implementation are in place by April 2013.</p>	4	3	2	88	66	44	22
<p>SUSTAINABILITY</p> <p>All designated centres sites are likely to perform at least 400 procedures each year, ideally 500 paediatric procedures each year.</p> <p>No one designated surgical centre will receive too onerous a caseload that would exceed the centre's capacity to manage it.</p> <p>All designated centres will be able to recruit and retain newly qualified surgeons and other specialist staff, will provide mentoring and training of junior surgeons and will be able to develop robust succession plans.</p>	4	4	4	100	100	100	25
	TOTAL SCORE			347	364	264	

Access and travel times – due to the close proximity of the centres to each other the potential impact on travel times for parents and children is not a material issue when considering which of the three centres should be designated; likewise for reasons of geography and proximity all centres are equally capable of meeting the Paediatric Intensive Care Society standards⁵⁵ around retrieval times.

Quality – The proposed score for the Evelina reflects the outcome of the expert panel assessment and the findings of the panel around research and innovation. GOSH and Royal Brompton were ranked equally by the panel and the proposed difference in scores across Great Ormond Street and Royal Brompton is attributable to the higher score applied to GOSH under the separate consideration by the panel of each centre's capacity for 'research and innovation'. Due to geography and proximity the sub-criterion about 'manageable networks' is not a material consideration.

Deliverability – It is proposed that GOSH scores higher as the retention of GOSH in potential configuration options would retain three nationally commissioned services in their current location (cardiothoracic transplantation, ECMO and complex tracheal surgery). It is proposed that the Royal Brompton Hospital is scored lower than the Evelina Children's Hospital due to the application of the sub-criterion 'the negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum'. As the PICU at the Royal Brompton Hospital exists predominately to support cardiac surgery the exclusion of this unit from potential configuration options presents limited risk to local and national PICU provision. The sub-criterion around workforce was not applied during this exercise for the reasons set out in Appendix AD

Sustainability – it is proposed that all units are scored equally under these criteria as all of the three centres could meet the proposed critical mass of activity in a 2-London centre option and none of the centres would receive 'too onerous' a caseload. The sub-criterion around recruitment and retention of staff was not applied during this exercise for the reasons set out in Appendix AD.

⁵⁵ Paediatric Intensive Care Society, *Standards for the care of critically ill children (4th Edition)*, June 2010

THE PAEDIATRIC CONGENITAL HEART SERVICE AT THE JOHN RADCLIFFE HOSPITAL, OXFORD

On 14 October 2010 the Chair of the Joint Committee of Primary Care Trusts wrote to the Chief Executive of the Oxford Radcliffe Hospitals NHS Trust with the following:

'I am writing to let you know that on the basis of information currently available the SAFE AND SUSTAINABLE review team is minded to recommend to the Joint Committee of Primary Care Trusts (JCPCT) that the eventual options for reconfiguration that are put out for public consultation in 2011 do not include the children's heart surgery service at the John Radcliffe Hospital'.

In order that emerging findings and recommendations were shared with relevant stakeholders this information was also shared at the time with Health Overview Scrutiny Committees in Oxford, the parent group 'Young Hearts' and the relevant local authorities.

This section explains the rationale for the recommendation to not include the John Radcliffe Hospital in any viable options for consultation.

Assessment Panel Score

The John Radcliffe Hospital was a statistical outlier in terms of the outcome of the assessment of the hospital's ability to meet the proposed SAFE AND SUSTAINABLE standards.

The average score (excluding the John Radcliffe Hospital) was 457 (or 75% of the total possible score). The John Radcliffe Hospital scored 237 (or 39% of the total possible score).

The panel applied a scoring scale between '1' (inadequate – no evidence) and '5' (excellent – evidence is exemplary). The John Radcliffe Hospital scored a '1' or a '2' (poor – limited evidence) against 24 of the 32 standards. No other centre scored a "1" in any question or any more than four "2s".

The Trust's poor outcome cannot be explained by the weightings attached to the various criteria for assessment. When a sensitivity analysis was applied to the weighted scores there was only some very minor movement of Trusts within the scoring, which gave the panel members confidence in the process for scoring and in the weightings.

The concerns of the panel can be summarised as:

- Concerns around governance
- Significant challenges (workforce and infrastructure) around increasing activity to meet the proposed critical mass of surgical procedures

The analysis was applied to the following potential options:

OPTION X	OPTION Y	OPTION Z
Oxford	Oxford	Oxford
London 1	London 1	London 1
London 2	London 2	London 2
Liverpool	Liverpool	Liverpool
Newcastle	Newcastle	Birmingham
Birmingham	Birmingham	Newcastle
Bristol	Southampton	Leicester

- Limited evidence of how the critical mass could be achieved
- Panel was not persuaded that paediatric cardiac surgery was a strategic priority for the Trust
- Significant challenges in leading a Congenital Heart Network over a larger geography outside of its traditional catchment
- Non-compliance with professional standards around Paediatric Intensive Care
- Limited evidence of innovative practice

The detailed report on the panel's assessment of the John Radcliffe Hospital and other hospitals is attached as Appendix K1.

Access

Notwithstanding the concerns about the ability of the John Radcliffe Hospital to meet the proposed standards in the future, the SAFE AND SUSTAINABLE team undertook further analysis to test whether the inclusion of the Trust in potential configuration options provided a better outcome for access.

These potential options were identified by applying the following emerging findings at the time:

- London requires at least 2 surgical centres to sustain the forecast levels of activity based on the population of London, South East and East England; this activity is unlikely to decrease given there will be no new surgical centres; there will continue to be no surgical centre in South East England or East of England
- Birmingham should remain as a surgical centre due to the density of the population in and around Birmingham and the forecast level of activity based on population
- The North of England requires 2 surgical centres, one of which must be in Liverpool taking account of forecast activity, population and travel times, and either Leeds or Newcastle should be the other surgical centre

The outcome of this analysis suggested that the retention of the John Radcliffe in potential options would not improve access.

Based on an analysis of patients travelling to their closest surgical centre:

- The John Radcliffe would fail to generate enough patients to meet the proposed critical mass of surgical procedures (a minimum of 400 procedures) even if the two other centres in the South of England were to cease providing surgery (Bristol and Southampton)
- The John Radcliffe Hospital could only meet the proposed critical mass by the cessation of surgery at Bristol and Southampton and if children from Cornwall, Somerset, Bath and Bristol were to flow to Oxford rather than Birmingham which is some of closer to these areas
- Access times are not improved under these potential scenarios compared to other potential options

- The very large Congenital Heart Network that would have to be led by the John Radcliffe Hospital under these scenarios incorporating South West England, Bristol and South Central England (Option Z) plus the geographical areas referred to above) does not provide assurance given the panel's concerns about the Trust's ability to lead a larger clinical network

Consideration of all these factors in the round led the *SAFE AND SUSTAINABLE* team to recommend to the JCPCT that no potential configuration option could be considered 'viable' if it included the John Radcliffe Hospital. Given the duty on the NHS to consult only on 'viable' options, the Chief Executive of the Trust was duly informed that the JCPCT would be advised that the eventual options for reconfiguration that are put out for public consultation in 2011 do not include the children's heart surgery service at the John Radcliffe Hospital.

Although the report of the investigation into the paediatric cardiac surgical service at the John Radcliffe Hospital by South Central SHA has not been formally considered during the *SAFE AND SUSTAINABLE* review, the report's findings provide assurance about the recommendation to the JCPCT that the John Radcliffe Hospital is not a viable provider of children's heart surgery in the future. The report's findings also highlight the concerns that underpin the *SAFE AND SUSTAINABLE* 'case for change'.

For example, the 'case for change' recognises the need for junior surgeons to be appropriately mentored and supervised by senior colleagues. This is best achieved in larger teams. The Oxford report found that supervision and mentoring was inadequate at the John Radcliffe Hospital and makes the point that 'in a larger unit than Oxford's it would generally be straightforward to arrange for mentorship to be provided by an experienced surgeon⁵⁶'.

The 'case for change' is also built on a need to concentrate medical expertise in larger teams so that all clinicians within the team benefit from seeing a 'critical mass' of patients each year. Only by seeing a sufficient number of complex cases can the clinicians in a team maintain and develop their specialist skills. The Oxford report found that the low volume of cardiac work at the John Radcliffe Hospital was 'not conducive to less experienced staff

gaining experience in the full range of post-operative cardiac situations⁵⁷'. Specialist children's services are best delivered by professionals expert in the care of children, whereas the Oxford report found that the perfusion service that served the paediatric cardiac surgical service at the John Radcliffe Hospital was 'in essence, an adult department that performed some paediatric work⁵⁸'.

Smaller units can become isolated and not as up to date with techniques and other innovations – aspects of team working at the John Radcliffe were described as 'idiosyncratic⁵⁹' and described how 'some aspects of practice not yet adopted at Oxford have been shown to reduce morbidity⁶⁰'. The report also describes how a junior surgeon, having arrived at Oxford from 'one of the world's leading centres and used to the latest techniques and equipment, found that all of the unit's staff, facilities and equipment were geared to working around one individual⁶¹' (the senior surgeon).

Larger surgical units also have supporting infrastructures that provide more flexibility in responding to emergencies and unforeseen events. This is highlighted by the availability of paediatric intensive care services. The small Paediatric Intensive Care Unit at the John Radcliffe meant that there was a higher risk of cancelled operations and made it difficult to plan when it would next be possible to operate on postponed children⁶².

⁵⁶ Para 8.10, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁵⁷ Para 6.2.5, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁵⁸ Para 6.4.1, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁵⁹ Para 6.7.1, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁶⁰ Para 6.4.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁶¹ Para 6.7.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁶² Para 6.3.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

FINANCIAL ASSESSMENT - AFFORDABILITY AND VALUE FOR MONEY

This section reports on the conclusions of work undertaken by the **SAFE AND SUSTAINABLE** Finance Group, comprising senior finance staff from each of the 10 SCGs in England and chaired by the Interim Chief Operating Officer of East of England Specialised Commissioning Group (Appendix I)

The core objective of **SAFE AND SUSTAINABLE** is to improve services for children with congenital heart conditions and not for the purposes of achieving financial savings. Nevertheless it is important to consider affordability and value for money for the tax payer.

Summary of conclusions

There is consensus within the Finance Group that the 11 potential configuration options including the potential shortlist of 4 options for consultation are affordable to NHS commissioners, and there is a reasonable expectation that the set up and legacy costs can be managed by the providers.

The key focus of the Finance Group's work has been to provide relevant information to enable the JCPCT to assess options along with the non-financial elements of the evaluation so as to reach recommendations on viable options for consultation. As in any option appraisal the costs and implications are considered for comparison purposes but it is recognised that there will need to be a detailed and

costed implementation plan for whichever configuration option is agreed following consultation. At this stage transitional and implementation costs are discussed and broadly outlined, but not estimated in detail as they depend on individual decisions and local circumstances.

The conclusion of the financial analysis is that the proposed shortlisted options which are highlighted in green in the tables below are affordable, and the proposed non-shortlisted options shown in pink do not offer significant financial benefits over the shortlisted options. JCPCT requested that key differences between options are highlighted to them. Table 4 summarises the financial analysis undertaken.

The advice to JCPCT is that option 2 is affordable and suggests best value for money as it requires the least capital investment and leaves the least legacy cost of the proposed shortlisted options.

It is concluded that the increased costs of implementing the Congenital Heart Networks should be met from economies of scale.

Analysis

Whilst the spend on paediatric cardiac services (including surgery, interventional cardiology and critical care) in England in 2009/10 was £98m, a large sum in absolute terms, it was relatively small compared to the overall spend on the NHS representing less than 0.2% of the total commissioning spend.

A financial data capture template was issued to the centres to obtain the income, non recurrent set up costs and potential impact of losing cardiac surgery status. (Appendix Z) These returns were validated by finance leads of the SCGs and form the basis of the analysis used below.

The key issues that the Finance Group considered were:

- Need to test or accept that tariff at least covers the costs of providing the service;
- Impact on future reference costs;
- Commissioners meet local prices;
- Set-up costs to be identified and confirmed to be met by the centre;
- Impact of losing designation and knock on implication for inter-dependent services;
- Costs of network and other services;
- Network approach and pathway may lead to potentially more spells; and
- Workforce implications – costs of staff changes, (re) training, impact on capacity and timing.

All the factors above have a potential impact on affordability to commissioners. The discussion below considers these factors and comments on the impact on the options as applicable.

Findings

Tariff

As these procedures are covered by the national PbR tariff⁶³, commissioners will continue to purchase the activity at tariff and hence there should be no increase in overall cost given the same level of activity. What may impact differentially is the Market Forces Factor (MFF) cost as commissioners switch commissioning from one centre to another. This will be identified and analysed as the new commissioning arrangements are put in place. Identified below are suggested changes to the pricing mechanism under paragraphs 3 and 7.

Future Reference Costs

Over time only modest increases in national activity are forecast based on the number of future births (Appendix O). It is expected that even though there are additional capital and revenue investments required by the designated surgery centres to meet the proposed standards and delivering additional activity the capital programmes, additional tariff income and economies of scale should offset these additional costs (see paragraph 10 below). Over time the costs and savings will be reflected in the provider reference cost and will influence the level of tariff, although the final tariff charge is also determined by other factors. In terms of activity and tariff the conclusion is that the costs are affordable to commissioners. The Finance Group wishes to make clear that it expects the providers to deliver the required efficiencies implied in the national tariff.

⁶³ Department of Health, *Confirmation of Payment by Results (PbR) arrangements for 2010-11*, February 2010

Local Prices

There are local prices for Paediatric Intensive Care Units (PICU) and on a few occasions' additional charges for high cost drugs and devices. It is recommended that the local prices for PICU would need to be renegotiated as the PICUs expanded or reduced capacity as required. There could be a differential impact on commissioners as local prices are finalised, although this should not be significant as economies of scale in the majority of PICUs should offset the losses of scale in others. It is the view of the Finance Group that consideration should be given to a national tariff for PICU. The PbR National Team at the Department of Health has agreed a national currency for adult and neo natal intensive care

and this will be collected from 1 April 2011 in advance of work on national tariffs for these services. No such work is planned for paediatric intensive care at this stage. Re-negotiation of local prices should assist in controlling these costs but there could still be a differential impact on commissioners as discussed above.

The National PbR Team state that some of the costs of critical care are already included in admitted patient care Health Resource Groups (HRGs) and hence tariff, and implementing a national tariff before the activity and total cost baseline is understood (and therefore taking them out of the admitted patient care tariffs) would lead to commissioners paying for this activity twice.

Furthermore at a time of strategic change in a service with both potentially fluctuating costs and activity is not the time to introduce a national tariff. For these reasons there will need to be renegotiation of local prices around the country.

Set up Costs

It is recognised that there will be set-up costs and stepped costs involved in increasing capacity to deliver additional procedures in the designated paediatric surgery centres. At the same time there is additional income, potential savings from optimising the delivery of these services and through economies of scale. Some centres have not provided estimates at this stage, preferring to wait for more certain scenarios

and no specific set up costs are included for transferring nationally commissioned services. The Finance Group expects designated surgery centres to meet such costs from their capital programmes, tariff income and savings, and centres are planning and have indicated their intentions to do this in their returns. The table below represents the non-recurrent set up costs, the majority of which is capital.

The set up costs in table 1 are estimates based on the information supplied by the centres. *(Figures in italics have not been supplied by the centres and therefore represent estimates to support the option appraisal)*

Table 1 - Set up costs (£ GBP)

	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B		OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
Liverpool	424	424	424	424		424	424	424	424	424
Birmingham	9,915	2,985	18,005	9,967		9,915	18,005	9,967	9,915	9,976
Bristol	0	919	919	919		919	0	0	919	919
Newcastle	477	477	477	477		0	477	477	0	477
Leicester	1,480	1,480	0	0		0	0	0	0	0
Leeds	0	0	0	0		<i>2,000</i>	0	0	<i>2,000</i>	0
Oxford	0	0	0	0		0	0	0	0	0
Southampton	5,671	0	0	0		0	0	0	0	5,671
Evelina	5,000	5,000	5,000	5,000		5,000	2,000	2,000	2,000	5,000
GOSH	500	500	500	500		500	500	500	500	500
Brompton							1,000	1,000	1,000	
TOTAL	23,467	11,785	25,325	17,287		18,758	22,406	14,368	16,758	22,967

The key differentiating factor across the options is the different levels of expansion required by Birmingham. Option 2 requires Birmingham to do at most no more surgery than it currently does, but recognises the need to invest in critical care to maintain services. Options 1, 8 and 12 requires a stepped cost to deliver up to 100 new cases, with a marginal increase in options 6b, 10b and 14 to deliver up to an extra 200 cases. There is then another stepped cost to deliver the additional 300 cases required in 6a and 10a.

It is considered that the transfer of interventional cardiology procedures to the Specialist Surgery

Centres may incur additional revenue costs, but any such costs will be covered by the tariff income. No centre has suggested that any additional capital will be required.

Conclusion is that Option 2 suggests the least capital investment of £12m. The other options range from £17m to £26m.

Impact of De-Designation

This is the most significant known financial factor to be considered. Those centres losing paediatric cardiac surgery status will lose income and have surplus capacity and there

are potential knock on implications for other services. In relative terms the income for cardiac surgery and inter dependent services is small for the large acute hospitals involved at less than 2% of total income. On average the costs of providing the service are 70% direct costs, 10% indirect and 20% fixed costs. On this basis the hospital could be left with legacy costs of between 20% to 30% of the cost which represents less than 0.4% to 0.6% of the total income. Some of this lost income will be regained from children transferring for post operative recovery to the cardiology centre to be nearer home. Nevertheless there would be a marginal increase to each hospital's

savings programme in order to recover the legacy costs. There may be some one off costs associated with reducing surgical capacity, the key one being staffing, and that is discussed below. There should be no additional costs to commissioners, but see paragraph 11 below regarding risk sharing.

The table below compares the impact across the configuration options of losing paediatric cardiac surgery and the potential impact on inter dependent services including nationally commissioned services.

Table 2 - Legacy costs (£ GBP)

	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B		OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
Liverpool										
Birmingham										
Bristol	3,646									
Newcastle						12,361			12,361	
Leicester			15,134	15,134		15,134	15,134	15,134	15,134	15,134
Leeds	5,300	5,300	5,300	5,300			5,300	5,300		5,300
Oxford	2,870	2,870	2,870	2,870		2,870	2,870	2,870	2,870	2,870
Southampton		6,053	6,053	6,053		6,053	6,053	6,053	6,053	
Evelina										
GOSH										
Brompton	16,860	16,860	16,860	16,860		16,860				16,860
TOTAL	28,676	31,083	46,217	46,217		53,278	29,357	29,357	36,418	40,164
ESTIMATED FIXED COSTS	8,603	9,325	13,865	13,865		15,983	8807	8807	10,925	12,049

The information in table 2 shows that three centres, Leicester, Newcastle and The Royal Brompton Hospital may have significant impacts on other services if paediatric heart surgery is ceased. In the case of Leicester and Newcastle this is largely related to the nationally commissioned services undertaken there (Appendix A). At the Royal Brompton Hospital the impact on PICU and inter related services are cited as the reason. (Appendix B).

Conclusion is that the shortlisted Option 2 has the least legacy costs.

Cost of Congenital Heart Network Model of Care

The model of care as described in Section 6 above discusses the need for formal networks of Specialist Surgery Centres, Children's Cardiology Centres and District Children's Cardiology Services. In order to ensure the network operates effectively it is recommended that paediatricians with expertise in cardiology are deployed at some DGHs. The number and disposition of these paediatricians has to be considered during the implementation phase by local commissioners in conjunction with the network. Furthermore medical teams may have to travel further to hold out-patient clinics and will have to maintain more formal multi disciplinary team (MDT) working. This is likely to mean additional cost but such costs can be controlled and timed to suit local circumstances, and paid for from tariff income. The network approach may also reduce costs as telemedicine is extended through the networks and the paediatricians with an expertise will be

able to assess and care for children who do not need the care of a cardiologist.

At present there are some, largely informal networks across various geographical patches with paediatricians in place who have gained expertise through experience or more recently studied the joint curriculum⁶⁴. The Royal College of Paediatrics and Child Health has found it difficult to substantiate the number and level of skill of these paediatricians, and hence to estimate whether there is sufficient to meet future needs.

It can take 12-18 months for a Consultant Paediatrician to train to acquire the necessary skills and recognition as a paediatrician with expertise in cardiology. There are clearly opportunity costs and potential actual costs as paediatricians undertake the training and their normal workload needs to be covered. The exact impact depends on the number and the need to backfill or not.

Currently individual DGHs employ these paediatricians and charge local commissioners for the activity for outreach outpatient clinics. The specialist centre recharges the DGH for the time of the cardiologist attending the clinics. This arrangement relies on the local commissioners supporting these network arrangements now and going forward through the service change. Given the model of care needs more formalised networks working effectively across the country this approach would be facilitated by identifying the paediatric cardiac service, including the network, as specialist, and for the National Commissioning Board to contract with

the specialist surgical centres for the network. The specialist centres would then contract with the district cardiac services for the time of the paediatrician/equipment/facilities engaged on paediatric cardiac services. This should enable all networks to be consistently resourced, and for the specialist centre to lead on the development of the network.

Network Leading to More Spells

The main thrust of the network model is to ensure that as much of the care as possible can be delivered local to the child, with only the specialist surgery and interventional cardiology interventions potentially requiring a longer journey. An implication of this is that once the child has recovered post surgery, s/he would be transferred to the most appropriate local setting for her/his continued recovery. This would mean the one spell is split into two, or even three, and if nothing changed the commissioner could be charged for those spells. The recommendation of the Finance Group is that the tariff is split to recognise this changing world. The view of the national PbR team is that local PbR flexibilities should allow this change to be recognised and adjusted for by commissioners. This will need to form part of the implementation plan.

Workforce implications and risks

The workforce implications and risks are discussed in Appendix AD. The potential financial implications are recruitment, relocation costs, retraining and redundancy costs. The latter will be avoided as far as possible. It is

difficult to determine accurately these costs as they depend on decisions made by individual members of staff once the JCPCT has reached a decision after consultation in the autumn of 2011. As described in the workforce Appendix (AD) some options are more disruptive for staff than others, requiring more relocation or retraining of staff. A more detailed piece of work is required to determine the optimal staffing structures for the agreed configuration option, but for the purposes of considering options a draft 'to be' structure was identified and used to assess the risk of the staffing changes required.

Further risks are associated with the relocation of staff from non designated centres and these are discussed under the workforce section.

In cost terms, two of the larger centres estimated potential redundancy costs to be c£2m per centre and, given this, the total redundancy cost could be between £8- £10m.

⁶⁴ Curriculum for Paediatrician with Special expertise in Cardiology. Available at: www.rcpch.ac.uk/doc.aspx?id_Resource=1901

Costs of Implementation and Transition

The table below summarises the likely level of costs associated with the implementation and transition arrangements. The costs incurred by the providers are as discussed above. The set up costs are planned to be met by capital programmes, contract income and savings. Redundancy, legacy costs and other staffing costs would also need to be met from savings. From the commissioners point of view in order to implement the decision from consultation

it is recommended to establish a resourced project approach. Much of this will be provided by existing post holders and hence represents opportunity costs. There will, however, need to be some additional dedicated investment at national and network levels to assure successful implementation and achievement of the benefits and savings as early as possible. The table below and its costs are for the two year implementation period.

Recurring Costs and Savings

The costs to commissioners in principle remain unchanged for a given level of activity as costs are determined by tariff. The key recurring increased costs are associated with maintaining formal clinically managed networks and implementing the model of care through them. These costs will be incurred by the centres and, other things being equal, will be translated into reference costs and tariff. It is expected, however, that with fewer centres concentrating on these procedures, there will be economies of scale and the cost per procedure should fall. The impact on tariff and cost to commissioners depends on the balance between the costs of the network and the savings from economies of

scale. Commissioners should seek to influence this balance.

The main increased cost of maintaining the managed networks and implementing the model of care is the need to invest in paediatricians with expertise in cardiology (PECs). The advice of the Network Group is to base the PECs in large maternity units. After further discussion this is based on maternity units with births in excess of 3,000 births per annum (Appendix N). The gross cost of the PECs would be c£2.88m. This cost would be offset by those PECs who already exist, and so represents the worst case scenario.

Table 3 - Outline costs of implementation and transitional costs (NB for 2 year period, £ GBP)

PROVIDERS	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B		OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
Set up costs	23,467	11,785	25,325	17,287		18,758	22,406	14,368	16,758	22,967
Redundancy	8,000	8,000	8,000	8,000		10,000	10,000	10,000	8,000	8,000
Legacy costs	8,603	9,325	13,865	13,865		15,983	8,807	8,807	10,925	12,049
Other staffing	1,000	1,000	1,000	1,000		1,000	1,000	1,000	1,000	1,000
TOTAL	41,069	30,110	48,190	40,152		45,741	42,213	34,175	36,683	44,016

COMMISSIONERS	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B		OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
Project managers	600	600	600	600		600	600	600	600	600
Network directors	1,400	1,400	1,200	1,200		1,200	1,400	1,400	1,400	1,400
TOTAL	2,000	2,000	1,800	1,800		1,800	2,000	2,000	2,000	2,000

Table 4 - Estimated recurring costs p.a (£ GBP)

PROVIDERS	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B		OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
Network directors	700	700	600	600		600	700	700	700	700
Clinical leads	20	20	20	20		20	20	20	20	20
PECs	2,880	2,880	2,880	2,880		2,880	2,880	2,880	2,880	2,880
TOTAL	3,600	3,600	3,500	3,500		3,500	3,600	3,600	3,600	3,600

The worst case increase in recurrent costs is £3.6m which is less than 4% of the current costs of providing these services. Economies of scale giving rise to a 4% saving would more than offset these costs and are not an unreasonable target to be achieved.

Risk Sharing

As is indicated above some of the transition costs, including workforce costs, are difficult to estimate. The Finance Group propose that there is a managed process through implementation to ensure that the financial issues are monitored and any consequential disproportionate impacts on local health economies are risk shared.

The factors that will be included are differential impacts of:

- Market Forces Factor
- Costs of networks
- Staffing implications
- Service transition including interdependent services
- Other

Quality, Innovation, Productivity and Prevention

There is international evidence to suggest that in centres with more surgeons carrying out more procedures the outcomes are better than smaller centres with fewer surgeons carrying out fewer procedures⁶⁵.

The proposed standards require each designated surgical centre to have 4 wte surgeons carrying out at least 400 paediatric procedures and ideally 500 paediatric procedures. This should lead to improved outcomes and a more resilient service.

The intention is that the surgeons will each undertake a minimum of 100 to 125 surgical procedures each year. This will avoid occasional practice, develop surgical skills and hence improve productivity and outcomes.

The improved productivity will lead to reductions in unit price which will feed into future reference costs and tariff.

Conclusions

The conclusion of the financial analysis is that the proposed shortlisted configuration options as identified:

- Are affordable to NHS commissioners and manageable by centres
- There are no overriding financial benefits from the non shortlisted options
- Option 2 suggests the best value for money based on capital investment required and legacy costs to be managed and furthermore
- The Finance Group recommends: that a fully costed implementation plan and risk sharing agreement is drawn up as soon as possible after a final agreement on configuration is made which should include the following financial aspects:
 - Impact on commissioners of MFF
 - Renegotiation of local prices for PICU
 - Implement the contractual arrangements for managing the Congenital Cardiac Networks

- Split the tariff to ensure the Specialist Surgery Centres and Children's Cardiology Centres are appropriately reimbursed for the services supplied
- Ensure providers meet their responsibilities – set up costs, legacy costs and staffing implications
- Agree the extent of the risk sharing policy.

⁶⁵ Ewart, H. *The Relation Between Volume and Outcome in Paediatric Cardiac Surgery; Public Health Research Unit - A Literature Review for the National Specialised Commissioning Group* (2009). Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>

OPTIONS FOR CONSULTATION

At its meeting on 16 February, the Joint Committee of PCT is recommended to put forward to the public consultation the following options:

Summary

Option A (option 2 in analysis)

- Seven surgical centres at:
 - Freeman Hospital, Newcastle
 - Alder Hey Children’s Hospital, Liverpool
 - Glenfield Hospital, Leicester
 - Birmingham Children’s Hospital
 - Bristol Royal Hospital for Children
 - 2 centres in London

Option B (option 14 in analysis)

- Seven surgical centres at:
 - Freeman Hospital, Newcastle
 - Alder Hey Children’s Hospital, Liverpool
 - Birmingham Children’s Hospital
 - Bristol Royal Hospital for Children
 - Southampton General Hospital
 - 2 centres in London

Option C (option 6 in analysis)

- Six surgical centres at:
 - Freeman Hospital, Newcastle
 - Alder Hey Children’s Hospital, Liverpool

- Birmingham Children’s Hospital
- Bristol Royal Hospital for Children
- 2 centres in London

Option D (option 8 in analysis)

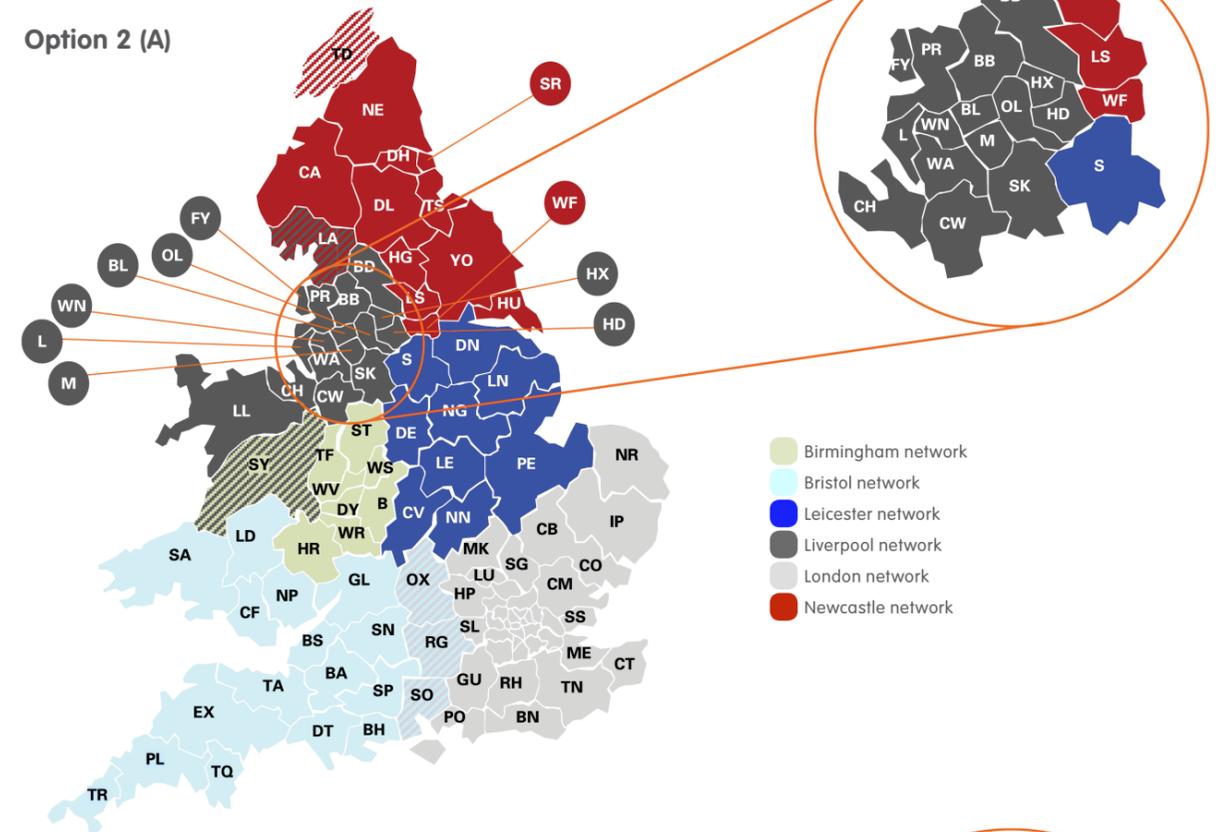
- Six surgical centres at:
 - Leeds General Infirmary
 - Alder Hey Children’s Hospital, Liverpool
 - Birmingham Children’s Hospital
 - Bristol Royal Hospital for Children
 - 2 centres in London

The preferred two London centres in the four options are:

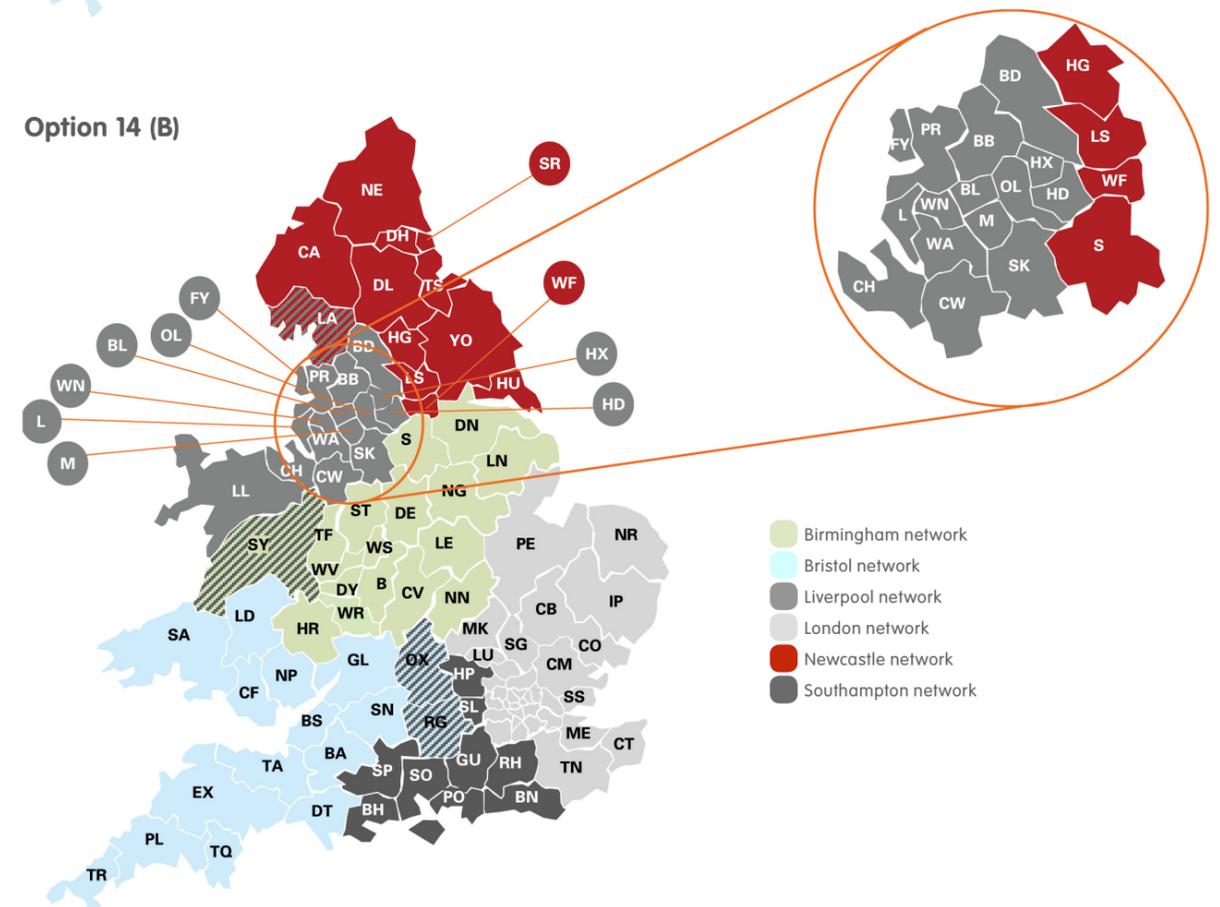
- Evelina Children’s Hospital
- Great Ormond Street Hospital for Children

On the next page are maps depicting at a high level the future potential networks. The networks are shown at postcode area level; some postcode areas will have many District General Hospitals in them and occasionally those DGHs will currently refer to different centres. We have shown this by ‘striping’ the postcode area affected. This does not replace detailed network mapping which will be required during consultation.

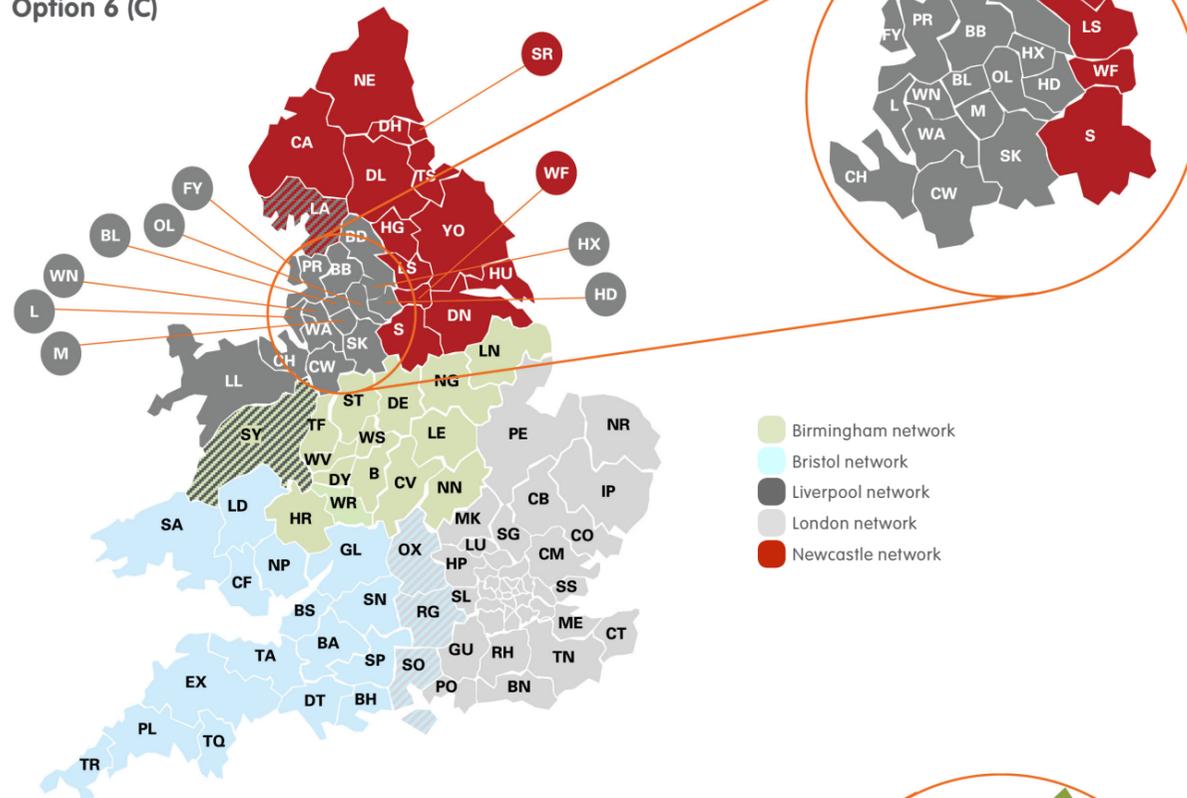
Option 2 (A)



Option 14 (B)

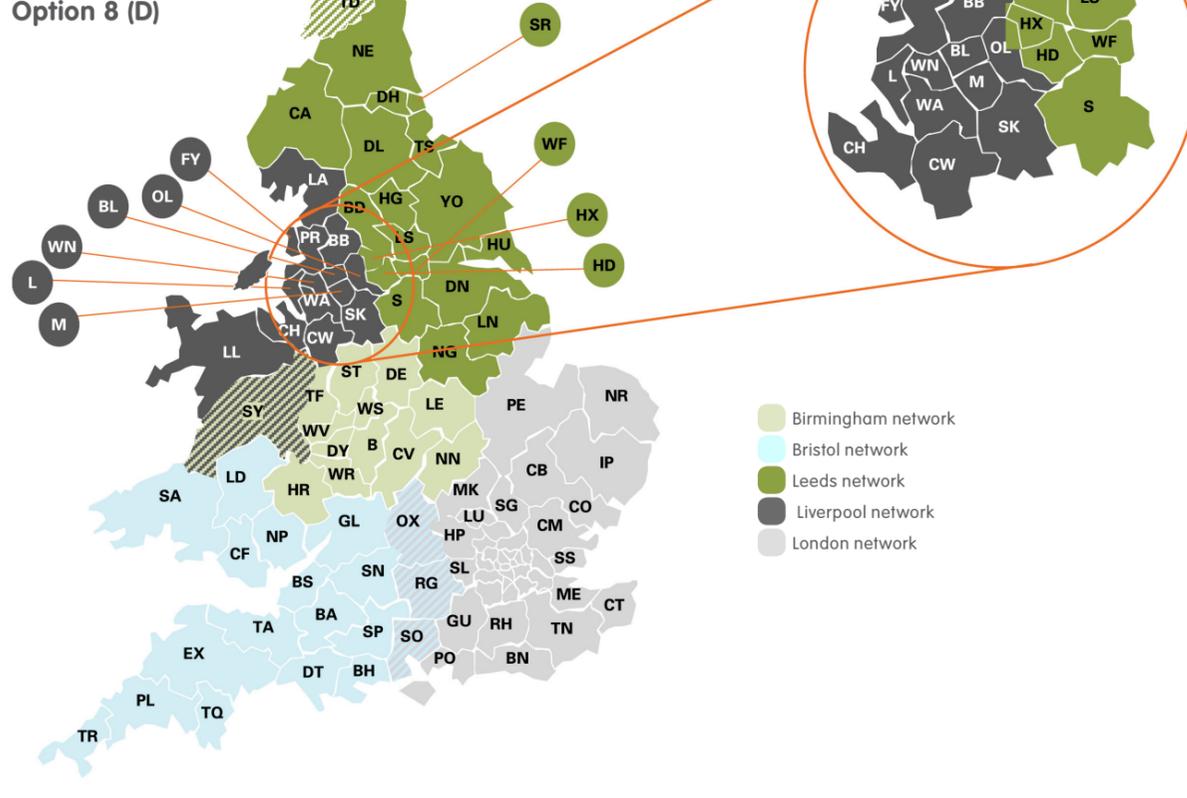


Option 6 (C)



- Birmingham network
- Bristol network
- Liverpool network
- London network
- Newcastle network

Option 8 (D)



- Birmingham network
- Bristol network
- Leeds network
- Liverpool network
- London network

MONITORING OUTCOMES IN THE FUTURE

The process for monitoring clinical outcomes at children's congenital heart services in the United Kingdom is amongst the best in the world but it could be made even stronger

The NHS should be proud of the achievements of the Central Cardiac Audit Database (CCAD), widely considered to be pioneering in the collection, validation and analysis of clinical data about surgical and interventional procedures undertaken by congenital heart services in the United Kingdom. The CCAD information portal has been developed by 'The Information Centre' for health and social care in collaboration with the Society for Cardiothoracic Surgery in Great Britain and The British Congenital Cardiac Association.

CCAD oversees a continuous process that involves an annual submission of data by all congenital heart services in the UK, validation of the data by experts in the field and the reporting of the data on a public portal website⁶⁶. The information on the public portal provides the overall numbers and the overall percentage chance of survival of the more common procedures carried out for congenital heart disease. The information does not provide the precise risk of an individual patient dying during or after a procedure as this is dependent on the individual patient's circumstances such as age, general health and the specific detail of the heart abnormality.

It is not CCAD's role to review clinical outcomes in individual centres. If the analysis of data were to suggest that a unit's outcomes for a particular procedure were statistically poorer than average, the Information Centre would notify the CCAD Project Board which includes the Presidents of the Society of Cardiothoracic Surgeons of Great Britain and the British Congenital Cardiac Association. The CCAD Board would in turn, notify the Medical Director and the doctors at the unit in question and a detailed examination of the unit's results would take place. There are established procedures involving the Royal College of Surgeons, NHS commissioners and / or the Care Quality Commission which can be put into action if the detailed assessment confirms concerns about the results⁶⁷.

Although the process for monitoring clinical outcomes of congenital heart services in the UK is considered to be amongst the best in the world, a number of stakeholders have suggested during the *SAFE AND SUSTAINABLE* review that the NHS should explore how to make the monitoring process even more robust in the future. Such concerns have also been voiced outside of *SAFE AND SUSTAINABLE*, for example within the separate investigation of

the paediatric congenital heart service at the John Radcliffe Hospital commissioned by South Central Strategic Health Authority in 2010⁶⁸.

The concerns are:

- The absence of a 'real-time' monitoring system – the current monitoring process is retrospective in that the validation of clinical data can take up to two years
- The current system for collecting, validating and reporting data could be improved further - the CCAD database does not always capture or reflect the complexity of individual cases which may as a result be inappropriately coded
- The absence of morbidity data – a focus solely on mortality data does not provide a meaningful understanding of the overall quality of a particular congenital heart service; other factors such as the incidence of brain damage following surgery are also important indicators of quality

The recommendations are set out below for endorsement by the JCPCT:

1. Congenital cardiac units that are designated for cardiac surgery on children must have robust audit processes and cycles that provide early warning of system deficiencies. These units should implement a CUSUM-type 'real time' alert system

for monitoring clinical outcomes in this specialty as has been implemented by the NHS for other relevant specialities such as cardiothoracic transplantation. This should be achieved by 2013 and monitored by the relevant NHS commissioner

2. CCAD should make available information on expected mortality by procedure groups in such a way that facilitates units to construct the appropriate statistical process control charts⁶⁹
3. CCAD should consider how the outcome of the 'real time' alert systems used in the surgical units relates to its own reporting of data and analyses in the future
4. CCAD should review its systems for the collection, validation and coding of data so that there is assurance that the reporting of data is timely, accurate and meaningful
5. Designated surgical centres should undertake greater scrutiny of their results, to ensure that CCAD presents on its public portal a fair, accurate and transparent portrayal of their results such that parents and the public can readily understand them.
6. The professional associations, CCAD and NHS commissioners should develop a system for the routine collection, analysis and reporting of morbidity data. The aim should be for routine reporting by 2013. The complexity of this task is acknowledged, but this should not prohibit attempts to improve the current situation

⁶⁶ Congenital Heart Disease website (or CCAD website). Available at: <http://www.ccad.org.uk/congenital>

⁶⁷ Congenital Heart Disease website (or CCAD website). Available at: <http://www.ccad.org.uk/002/congenital.nsf/vwContentInformation%20for%20Patients?Opendocument>

⁶⁸ NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

⁶⁹ Recommendation 10 - *Review of Paediatric Cardiac Services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010, South Central Strategic Health Authority

IMPLEMENTATION

- The new centres and networks are expected to be operational from 2013, subject to the outcome of the public consultation
- The implementation of proposed changes will be coordinated nationally but it will be driven and implemented locally
- The NHS recognises that there are challenges to implementation but continues to plan how to overcome them

Implementation Plan

Implementation of the eventual decision on the future configuration of children's congenital heart services will present complex challenges. The NHS will need to respond to these challenges, maintaining safe services throughout, whilst many organisations themselves are subject to change during a tighter financial environment.

Subject to the Health and Social Care Bill⁷⁰ being approved by Parliament, it is anticipated that the NHS Commissioning Board (NHS CB) will take responsibility for commissioning children's congenital heart services from April 2012. There will need to be a smooth transition of responsibility as this passes from the current specialised commissioning arrangements to the NHS CB.

We are confident that this can be achieved in view of the effective input to this review through the Specialised Commissioning

Directors (SCG) Group, and the SCG Financial Leads Group, facilitated by the National Specialised Commissioning Team. These groups have supported the work of the JCPCT, testing and confirming the data and analysis against their local commissioning knowledge and information. This collective working will continue.

During the period of implementation, the SCG Directors Group and if appropriate its successor body will work with NHS Trusts to:

- Ensure stability at all parts of the patient pathway, including compliance with central access and waiting time requirements
- Ensure high quality services at all parts of the patient pathway
- Minimise workforce risks
- Minimise financial risk to NHS trusts and NHS commissioners
- Regularly communicate progress to stakeholders and the public

The proposed transfer of specialised commissioning to the NHS CB from April 2012 presents new opportunities that will facilitate implementation. For example, there will be:

- A single commissioner (the NHSCB) of the new configuration of congenital heart networks rather than ten SCGs as now.
- A single specification for services to drive up standards of care and equity across the country.
- A consistent approach to tariff and funding to facilitate the delivery of specialist care equitably across the networks.
- A single point of responsibility (the NHS CB) facilitating a swift and flexible response to any emerging challenges or issues.

National Coordination and Sub National Commissioning

Sound implementation will continue to rely on national project coordination, but in addition, stronger arrangements through identified commissioning leads will need to be put in place sub nationally to oversee the commissioning of change. These will be aligned with the agreed future configuration of surgical centres and their emerging congenital heart networks.

During the period of implementation, the appointed commissioning leads for the new congenital heart services will meet with the national project team. An immediate priority for them, following the decision on the configuration, will be to determine in detail the appropriate future area to be served by

each of the networks, taking into account views received during the consultation and the need to meet agreed activity standards. These commissioners will need to work, with the new networks and other representative groups to define the service delivery points in the network in addition to surgery. In other words, the viable future locations for children's cardiology centres and local paediatric cardiology services. The aim will be to facilitate equitable access to services across the network and reduce unnecessary travel for children and their families. The national project team will facilitate a collective oversight of this process to ensure coherent decision-making and coverage across England and Wales. The National Project Team will meet regularly with the commissioning leads for congenital heart networks as well as identified leads from finance, information and public health.

The congenital heart network commissioning leads will be responsible for the following, working with their providers:

- Ensuring providers develop detailed project plans, undertake full risk assessments and set up credible project management arrangements to take forward change effectively
- Oversee implementation of the **SAFE AND SUSTAINABLE** standards (Appendix F) for designated surgical centres
- Identify implementation resource issues in designated centres and clinical networks (staff, equipment and HR change)
- Plan and oversee the de-commissioning of surgical services in centres that are

⁷⁰ Department of Health, *Health and Social Care Bill*, January 2011

not designated for surgery, including the implementation of service standards for children's cardiology centres

- Plan and oversee changes that may be required to interdependent services, including paediatric intensive care, retrieval services and nationally commissioned services
- Designate adult congenital heart centres in accordance with the proposed standards for GUCH services (Appendix AE)
- Establish a managed congenital heart network, including implementation of service standards for local paediatric cardiology services.

Contract Arrangements

The new congenital heart networks will embrace many organisations and professionals needed to deliver care to patients and their families, but the NHS CB contract for delivering specialised congenital heart services must be with a legal entity and this will be with the Trust that provides the surgical centre. The Trust will host the network, be responsible for overseeing its development and creating the working partnerships with clinical teams and organisations that will take forward the changes required. This host trust will receive the resources to deliver these complex integrated services across the organisations providing the pathway of care, including for example, outreach specialist clinics in DGHs. The host trust will need to develop formal agreements with each organisation in the network that reflect mutual responsibilities.

An alternative approach which may be considered is to commission with formal consortia of provider trusts as a legal entity.

Developing the Congenital Heart Network

It is well recognised that clinical networks thrive best when there is mutual professional respect and trust, encouragement of a learning environment; supported by organisations, through data collection, communication systems, time for audit and Continuing Professional Development, CPD etc. Developing this climate, when there are complex changes to take forward that affect NHS staff and patients, as well as organisations will require significant leadership and sensitivity.

Trusts hosting the networks will need to respond to this challenge by appointing an overall senior clinical lead supported by a very senior manager and team, experienced in leading change and working across organisational boundaries.

The host trust will need to establish project arrangements to implement change, engaging the key organisations affected by the decision on configuration. They will also need to set up a Congenital Heart Network Group to develop the clinical services, bring clinicians together from across the network.

The Congenital Heart Network Group will be expected to deliver:

- The network approach across a patient pathway that involves prenatal diagnosis, maternity and obstetrics services, and which addresses the transition to services for adults with congenital heart disease

- A network that is aligned with networks for fetal services and networks for adults with congenital heart disease. How the network relates to retrieval systems is also important
- Common clinical protocols and guidelines across the network for the management of patient pathways and treatment thresholds, including the care of children with cardiac pathways and treatment thresholds, including the care of children with cardiac conditions requiring associated non-cardiac interventions
- Protocols for the transfer of children requiring interventional treatment
- A strong network of specialist nursing support
- Guidelines for communication between services in the network
- Common record keeping throughout the network, ensuring each professional has access to records at the point of treatment. Hand held records should also be introduced for children and their families
- Regular multi-disciplinary team meetings, the composition of which is pathway driven
- Agreed outcome measures and plans to achieve them
- Consistent processes for data collection, analysis, benchmarking, reporting and acting on conclusions, including notification recording and dissemination of serious incidents that occur across the network
- Audit referral data and waiting times
- Development of tele-medicine across the network
- Research activities across the network to instil best practice
- Training strategy (and annual plan) for professionals in the network

- Best practice quality assurance
- An annual report on the effectiveness of the network
- Consistent high quality information for parents and children, including directories of support services
- Ongoing active engagement with local parent/patient groups.

Membership of each Congenital Heart Network Group will reflect local circumstances but common features will be:

- The Network Group will be chaired by a senior clinician reflecting the leadership role envisaged by the *SAFE AND SUSTAINABLE* standards (Appendix F). It will have senior managerial and administrative support.
- Lead clinicians from the member organisations in the network, as well as clinical representation from key specialties.
- Parent and patient representation
- The attendance of NHS commissioners

National Overview

Progress on implementation will be monitored by the national project team and lead commissioners who, for each group, will report into the SCG Directors Group (acting as a national overview group) in order to ensure a consistent approach to implementation and to address supra-regional issues.

This group will also contribute to the process for the development of the Central Cardiac Audit Database, including the routine collection, reporting and analysis of morbidity data and oversee implementation of the standards for GUCH services (see below). It will establish 'task and finish' groups to respond to specific issues such as retrieval as required.

Congenital Heart Network Implementation Advisory Group

The *SAFE AND SUSTAINABLE* Steering Group (Appendix D) has been an invaluable source of advice during the development of the review. Similar guidance will be needed to support implementation.

The national overview of progress will be supported by an Implementation Advisory Group. This group will be established in 2011 to assist the SCG Directors during the implementation phase and to ensure the appropriate development of networks. It may bring together the clinical leads of networks at intervals to ensure that learning is shared.

Proposed membership includes:

- The President of the British Congenital Cardiac Association
- A general practitioner nominated by the Royal College of General Practitioners
- Chief Executive of the Children's Heart Federation
- A representative of the GUCH Patients' Association
- A consultant paediatrician with expertise in cardiology nominated by the Royal College of Paediatrics and Child health
- A children's nurse nominated by the Royal College of Nursing
- An intensivist nominated by the Paediatric Intensive Care Society (replacing the lead clinician from the intensivist's 'home' centre)
- NHS commissioners nominated by the SCG Directors' Group or its successor
- A representative of the HR and Finance Group
- A representative of each of the devolved administrations

The Implementation Advisory Group will oversee also set up arrangements to develop quality standards for children's cardiology centres and peripheral paediatric cardiology services.

Adult Congenital Heart Services

Each relevant SCG will also establish in 2011 a separate group to oversee implementation of the designation of GUCH services in accordance with the proposed standards for GUCH services (Appendix AE). These groups will report into the SCG Directors Group given the necessary synergy with the development of services and networks for children with congenital heart disease.

A GUCH working group will support the SCG Directors Group (directly and not as a working group to the IAG):

- Terms of reference will be to advise the SCG Directors Group (and successor) on the process for the designation of GUCH services in accordance with the proposed standards for GUCH services.

Membership:

- President of the BCCA or nominated clinical representative from the Implementation Advisory Steering Group
- A clinical lead from each of the centres currently providing GUCH services
- A representative of the GUCH Patients Association (from the steering group)
- NHS commissioners nominated by the SCG Directors' Group

CONSULTATION

- The consultation will launch on 28 February 2011 and end on 1 July 2011
- A consultation plan has been developed to support the public consultation
- Consultation with the public will be organised and delivered in local settings across England and Wales

The consultation process

The process will be co-ordinated nationally by the *SAFE AND SUSTAINABLE* review team but delivered in partnership with the 10 Specialised Commissioning Groups and the NHS in Wales.

When to consult

In developing the consultation plan the review team have considered the Cabinet Office Code of Practice on consultation⁷¹ and taken its recommendations into account.

Duration

The length of the consultation is longer than the norm because of the complexity of the consultation process and interruptions to the consultation timeline due to local government elections and a national referendum.

Clarity of scope and impact

Our intention is to ensure the consultation document contains clear information about the process and the nature of what is being proposed.

It is very important that materials ensure participants understand the rationale for change, the recommendations and the preferred option – as well as the impact of proposed changes for the service as whole, for their area, for them/ their family and for future children. Equally, consultation materials will not just highlight the impact of proposed changes on surgery, but rather on the whole model of care.

Accessibility

The consultation will be carefully targeted. Audiences include young people with a heart condition, their parents, parent and young people's groups, clinicians working in cardiac care, appropriate royal colleges and professionals' groups and relevant NHS managers.

The document will be written in plain English and technical terms will be explained. A glossary will also be provided. The review team will consider the need for translations in addition to Welsh. A variety of materials will be provided online and in print.

A series of consultation events will provide people with a face to face opportunity to make their comments. Events designed for both adults and young people will be hosted across the country.

The review team will ensure that everyone's view is heard, including those whose views are harder to reach. All parents with children with heart conditions will be encouraged to engage in the process.

Burden

The review team will seek to avoid burdening people as much as possible by making the consultation process as straight forward as possible.

Capacity to consult

The review team have sought guidance on the running of the consultation from a range of independent third parties including parent and patient groups (Appendix AF).

In addition, the consultation process follows a period of extensive stakeholder engagement.

The following are key objectives:

- Ensure people with an interest in children's heart services, including surgery - but not exclusively - are aware of the consultation,

- the recommendations and the preferred option
- Ensure people know and understand how they can participate
- Provide a choice of different channels for people to engage with the consultation process
- Ensure materials are accessible and in plain English
- Ensure as many people as possible from all parts of the country and from all the different interest groups with an interest in the subject matter respond to the consultation with their view

Key Messages

- Have your say; get involved in the consultation
- We want your views on the recommendations and preferred option
- We would like as many people as possible to respond to the consultation

Implementation

The following four pillars of communications will be used to implement the consultation process:

- Printed communications – such as the consultation document and newsletters
- Face to face events and focus groups – for young people, parents, parent groups, clinicians and other interested parties
- Media relations – national, trade and regional
- Stakeholders – such as the professional bodies and parent groups

⁷¹ HM Government, *Code of Practice on Consultation*, July 2008

Scope

Consultation activities will be aimed at the populations of England and Wales, though the populations of Scotland and Northern Ireland will be made aware of the review and invited to submit their views via advertisements in local newspapers.

Online communications

The *SAFE AND SUSTAINABLE* website will host a range of information including:

- Materials that set out the need for change
- The issues that matter to parents
- Quotes and case studies (in both written and video format) – from young people, parents and clinicians
- Images, facts and figures
- An electronic form to submit comments about the consultation
- The background to the review

The consultation document and other literature will also be available in Welsh.

It is planned that other websites carry information about the consultation and it is hoped that some parent groups will host forums and have plans in place to keep content fresh and balanced.

Printed communications

Consultation document

The consultation document will be the main tool that people will want to read and comment on. This will be published electronically and in print on 28 February. The document will be available in Welsh and we will also consider whether other formats or translations may be necessary.

Promotional material

Flyers and posters to support the events will be designed and printed for SCGs and stakeholders to distribute. Posters have been provided to the BBC, ITV and Channel 4 for placement in hospital-related television programmes that are planned for transmission during the consultation period. Promotional materials for the events in Wales will be available in Welsh.

Distribution

All printed materials will be sent to those who have confirmed they would like to receive materials from the *SAFE AND SUSTAINABLE* team. We will also be providing materials to local and national parent groups, LINKs, overview and scrutiny bodies, providers, royal colleges and associations, clinicians and a range of other parties. We will encourage interested parties to cascade information. We are seeking attendance from a wide range of people including parents whose children have had extensive surgery and those who have had little or none.

Face to face events

We intend to co-ordinate consultation events in the cities where the 2010 engagement events were held. We will be holding three events that are aimed at young people. We are appointing an independent expert facilitator to chair these events. Senior clinicians will be invited to speak at the events to share their thoughts and experiences, and to answer people's questions. Using senior clinicians will also help signify the importance of the events and to encourage attendance.

Specific events are also planned with members of the Society for Cardiothoracic Surgery of Great Britain, the British Congenital Cardiac Association and other professional associations.

Structure

The structure for the events will be designed to maximise informed discussion of the recommendations and preferred option. The exact structure for each event will be determined once the numbers of delegates are known. The structure will also be amended slightly to allow for regional variation as necessary.

The structure is likely to include the following elements:

- The rationale for change and the available evidence
- The issues that parents have raised with us and how we have taken these into account
- An overview of all the recommendations and the impact on key factors, such as access and journey times, regionally
- The preferred option and the impact on key factors, such as access and journey times, regionally
- Discussion and debate – this is likely to be in the form of a theme based Q&A, rather than break out sessions, because of the numbers expected

Young people's events

We will hold three events aimed at teenage patients (London, York and Birmingham). These events give us the opportunity to consult directly with those who use the service. The structure will reflect the needs of the younger audience.

Widening participation

The events will have crèche facilities for young children to encourage parents to attend. Using the Internet for streaming the events has been considered but is cost prohibitive.

Media relations

It is intended to work with the media to ensure as many interested parties as possible have the opportunity to participate in the consultation. Opportunities to work with local, national and trade journalists – online, broadcast and print, will be explored. There are three major opportunities to exploit and manage during this phase.

They are as follows:

Warming up the media

In February 2011 we will offer briefings with key national journalists to keep them informed of the progress of the review. Relationship building with local journalists is also key. We will consider using well known people to add their support to ensure as many people as possible have their say.

The start of the consultation period

The start of the consultation process is our main opportunity to ensure as many of our target audiences know about and understand the review as possible. Media will be encouraged to direct people to the website and to attend events in their area. This piece of activity needs strong support from national and local clinicians.

March to June 2011 – consultation events

Each consultation event provides a further opportunity for local media. It is important to work with local media in the run up to the events

to ensure people are aware and that the media provide informed and balanced coverage.

Leaks can cause damage as they create distrust and often spread misinformation. We are mindful that as the final recommendations are agreed, the risk of leaks increases significantly. A separate media plan has been prepared.

Engaging third parties

There is often cynicism about consultation processes. Engagement with as many stakeholders as possible is vital to ensure the review is informed about the feedback and all are encouraged to use their networks to encourage people to participate in the consultation. A stakeholder engagement plan is being developed – a key target list of influencers we want to reach before the consultation goes live. We will recommend a number of 1-1 briefings, written materials and other opportunities to inform these people about the consultation.

A briefing has been prepared for HOSCs which asks them to confirm how they wish to be consulted. Briefings are being prepared for MPs and local authorities and GPs.

How the feedback from consultation will be analysed

An independent expert party (Ipsos Mori) has been commissioned to develop an objective question set that will form part of the consultation documentation, to analyse the responses received and to report to the JCPCT.

NEXT STEPS

The responses received during public consultation will be analysed and reported by an independent third party (Ipsos Mori). Interim findings will be shared with the *SAFE AND SUSTAINABLE* steering group in September 2011 before the final report to the Joint Committee of Primary Care Trusts at a meeting in October 2011.

The JCPCT will consider the outcome of consultation and, if it is able based on the contributions received, will reach a final decision on the future configuration of children's congenital cardiac services.

GLOSSARY

Acute: Used to describe a disorder or symptom that comes on suddenly and needs urgent treatment. It is not necessarily severe and often lasts only a short time. Acute is also used to describe hospitals where treatment for such conditions is available. In this document, the term 'acute' is used interchangeably with the term 'emergency'

Acute services: Medical and surgical interventions provided in hospitals

Acute trusts: Hospitals or a group of hospitals that provide acute (unplanned or emergency) care and elective (planned) medical treatment and surgical procedures

Antenatal Care: Monitoring the health of mother and baby throughout pregnancy until birth

Antenatal scan: An ultrasound scan uses high-frequency sound waves, which bounce off solid objects. This creates a screen image of the uterus and nearby organs, as well as the baby, the baby's organs and the placenta

Aorta: The aorta carries oxygenated blood from the left side of the heart to the rest of the body

Artery/Arteries: The heart needs a constant supply of blood. This is supplied by two large blood vessels called the left and right coronary arteries

Assessment: The child will undergo a series of tests that lead to a diagnosis

Birth Defect: When the body does not form correctly in the womb. Congenital heart disease is a common birth defect

Cardiologist: A doctor who specialises in investigating and treating diseases of the heart. Cardiologists diagnose and treat congenital heart problems and carry out invasive interventional cardiology procedures, such as inserting a catheter or other device through the skin into the heart

Caseload: Number of children who will receive surgery

Central Cardiac Audit Database (CCAD): Collects information for the National Heart Disease Audits creating profiles of every congenital heart disease centre in the UK. This includes the number and range of procedures they carry out and survival rates for the most common types of treatment. This information is provided to inform the general public

Clinician: Any health professional who is directly involved in the care and treatment of patients, for example, nurses, doctors, therapists, and midwives

Commissioning: The full set of activities that local authorities and primary care trusts (PCTs) undertake to make sure that services

funded by them, on behalf of the public, are used to meet the needs of the individual fairly, efficiently and effectively

Congenital Heart Disease: Congenital heart disease refers to conditions children are born with that affect the heart

Congenital Patient: A patient with a condition present at birth

Consultant: A senior doctor who is a specialist in a particular area of medicine

Diagnostics: Medical tests used to identify a medical condition or disease (e.g., measuring blood pressure, checking the pulse rate).

Disability: A substantial and long-term physical or mental impairment that reduces functions such as mobility, dexterity, speech, hearing, sight and memory, and adversely affects individual independence. The Disability Discrimination Act (2005) aims to increase opportunities for people with disabilities to take part in the everyday life of the community on an equal basis with others.

Extracorporeal Membrane Oxygenation (ECMO): Removing blood from a patient, taking steps to avoid clots forming in the blood, adding oxygen to the blood and pumping it artificially to support the lungs

Foetus: An unborn baby

Follow-up care: Care provided after surgery or interventional procedures

Gateway Review: The Office of Government Commerce's (OGC) Gateway Review process is an independent assurance of the programme management of the reconfiguration proposals.

Health inequalities: Narrowing the health gap between disadvantaged groups, communities and the rest of the country, and on improving health overall

Heart anomaly: An irregular or unusual sounding heartbeat or a problem with the way the heart has developed physically

Heart Chamber: The heart has four chambers. There are two small chambers at the top of the heart called atria, and two larger chambers at the bottom which are called ventricles.

Health visitors: Qualified and registered nurses or midwives who have undertaken further (post registration) training. The role of a health visitor is to promote health and the prevention of illness in all age groups.

Hospital trust: The organisation which runs one or more acute hospitals.

Joint Committee of Primary Care Trusts: A committee that has been set up locally to consider the outcome of the consultation, comprising local commissioners representing each region of England. The committee has authority from the PCTs to take decisions on the PCTs' collective behalf.

Mortality rates: Formulated by analysing the number of deaths of a certain group, for instance children undergoing a heart transplant, during a set time period

Multidisciplinary Team: A team involving many different professions e.g. doctors, nurses, therapists

Multidisciplinary Team Meetings (MDTs): MDT meetings bring together experts in different specialties to discuss the management of patients with a given condition or disease

Murmur: An irregular or unusual sounding heartbeat. Not all children with a murmur have congenital heart disease

National Clinical Advisory Team (NCAT): NCAT provides an independent assurance of the clinical aspect of the proposed changes to services.

Need for Change: A document published by the *SAFE AND SUSTAINABLE* team in 2010 setting out the need for change in the provision of children's cardiology services

NHS London: The Strategic Health Authority (SHA) for London with responsibility for all the NHS healthcare services provided in London

Non-interventional Care: Preventing and managing potential and existing heart problems without surgery or having to insert devices through the skin-

Outcomes: A change in the health status of an individual, group or population, for example, improved survival and recovery rates, reducing inequalities or increasing longevity

Outpatient Clinics: Clinics at which patients receive treatment or care without needing to stay overnight

Overview and Scrutiny Committee (OSC): A committee made up of local government councillors. It may also have representatives from voluntary organisations and patients' forums. It is concerned with issues of health service changes, health inequalities and strategic direction rather than how hospitals have performed against targets.

Oxygenated Blood: Blood enriched with oxygen

Paediatric: A branch of medicine providing care for children

Patient Groups: A group of patients with similar conditions or interests. The group may work to inform or promote public awareness and engagement with their interests

Parent Groups: A group for parents of patients with similar conditions or interests. The group may work to inform or promote public awareness and engagement with their interests

PCBC: Pre-Consultation Business Case

Postnatal: The time period immediately after childbirth

Primary Care Trusts (PCTs): Organisations providing local health and social care services to meet the needs of the local community

Professional Associations: An organisation which represents a specific profession

Pulmonary Artery: A vein that carries oxygenated blood from the lungs to the heart

Referral: Sending a patient to a specialist for expert care

Specialists: A clinician whose work is concentrated on a particular area of medicine

Specialised Commissioning Group (SCG): In England, there are 10 Specialised Commissioning Groups (SCGs) that commission specialised services for their regional populations, which range in size from 2.8 million people to 7.5 million people. Examples of such services include haemophilia and blood and marrow transplantation. The National Specialised Commissioning Group (NSCG) facilitates working across the 10 SCGs at a regional and pan-regional level

Standards: A framework for delivering a high quality service

Strategic Health Authority (SHA): The local headquarters of the NHS, responsible for ensuring that national priorities are integrated into local plans. It is responsible for performance of local NHS organisations.

Surgeons: A clinician who is qualified to practice surgery

Surgical Unit: A centre at which surgery is provided

Survival Rates: An estimate of the risk attached to a particular condition or treatment

Ultrasound: A scan of the body where ultrasound waves are used to produce an image

Valves (of the heart): Valves allow blood to move forwards through the heart and prevent it flowing backwards into the previous chamber

APPENDIX LIST

The following list of appendices includes only what can be found in this document. A full list of appendices are available at the following address: www.nhsspecialisedservices.nhs.uk

APPENDIX	TITLE	
A	Nationally Commissioned Services (NCS)	●
B	Paediatric Intensive Care Unit (PICU) and Interdependent Services	●
C	Membership of Joint Committee of Primary Care Trusts (JCPCT) and Terms of Reference	●
D	Steering Group Membership	●
E	Standards Group Membership	●
F	Children's Congenital Cardiac Services in England - Service Standards	●
G	Scientific Evidence	●
H	Network Group Membership	●
I	Finance Working Group Membership	●
J	Assessment Panel Terms of Reference and biographies	●
K1	Reports of the Independent Expert Panel Chaired by Professor Sir Ian Kennedy	●
K2	Response to the Analysis of Mortality data of NHS Trusts in England providing paediatric cardiac surgery 2000-2009 (Including Terms of Reference and Membership)	●
L	Health Impact Assessment Terms of Reference and membership	●
M	National Clinical Advisory Team (NCAT) report	●
N	District General Hospitals (DGHs) that currently have more than 3,000 births per year	●
O	Future Activity projections	●
P	October 2009 Stakeholder Event - Delegates and Minutes	●

APPENDIX	TITLE	
Q	Recipients of the working document 'Draft Service Specification Standards' in 2009	●
R	Engagement Events report	●
S	Travel time analysis	●
T	Retrieval time analysis	●
U	Baseline Information template	●
V	Activity data template	●
W	Self Assessment Covering Letter	●
X	Self Assessment template	●
Y	Nationally Commissioned Services (NCS) Self Assessment template	●
Z	Finance Self Assessment template	●
AA	Responses received to Evaluation Criteria	●
AB	Assessment Visit itinerary	●
AC	Evidence supporting the options assessment	●
AD	Workforce Implications	●
AE	Grown-Up Congenital Heart (GUCH) Standards	●
AF	Stakeholders that have been consulted in regard to the consultation process	●
AG	Estimate of redistributed Activity	●

STATUS: ● Within PCBC document
● Attached

APPENDIX A - NATIONALLY COMMISSIONED SERVICES

As part of the Safe and Sustainable review it was important to explore whether, if designated as a paediatric cardiac provider in the future, centres may be in the position to also provide one or more of the Nationally Commissioned Services in case a current provider of one or more of these services were to be de-designated as a provider of children’s heart surgery services

There are three services nationally commissioned by NHS Specialised Services that require either paediatric cardiac surgery or surgical back up to be safe. In England they are provided by the designated paediatric cardiac surgery providers as set out below.

An assurance is required that whatever the future configuration of paediatric cardiac surgery provision, the nationally commissioned

services can continue to be provided to a high quality standard of care with good geographical access across England.

All 8 of the current providers of paediatric cardiac surgery in England (who do not currently provide one or more of the nationally commissioned services) were invited to express an interest in providing one or more of the nationally commissioned services if

Nationally Commissioned Services

SERVICE	PROVIDER
Paediatric Cardiothoracic Transplantation and Mechanical Device as a Bridge to Heart Transplantation	Freeman Hospital, Newcastle
	Great Ormond Street Hospital for Children, London
Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory failure	Freeman Hospital, Newcastle
	Glenfield Hospital, Leicester
	Great Ormond Street Hospital for Children, London
Complex Tracheal Surgery	Great Ormond Street Hospital for Children, London

designated as a paediatric cardiac surgery centre in the future. A template was sent to the Chief Executive of each of the providers and included guidelines which indicated the level, type and complexity of the three services in

question. The providers were asked to consider the guidelines and to judge the implications to their organisation in providing these services. The guidelines provided are set out below.

Service Guidelines

SERVICE	SOURCE
Paediatric Cardiothoracic Transplantation and Mechanical Device as a Bridge to Heart Transplantation	National Heart and Lung Transplant Standards, 2006, National Specialist Commissioning Advisory Group
	National Standards for Organ Retrieval from Deceased Donors, 2010, NHS Blood and Transplant
Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory failure	Extracorporeal Life Support Organization (ELSO)
	Guidelines for Paediatric Extracorporeal Membrane Oxygenation, most recently updated in 2002.
Complex Tracheal Surgery	Criteria derived from case definition applied by Great Ormond Street Hospital and agreed with clinical and commissioning experts in 2010

Nationally Commissioned Services Expert Panel

An expert panel was convened to examine the submissions from the centres that expressed an interest in delivering one or more of the nationally commissioned services and to provide the Joint Committee of PCTs with recommendations on which centres may be able to provide these services in the future. Members of the NCS Assessment Panel were clinicians with an expertise in one or more of the services considered. They were independent of the centres considered under the review

The objectives of the panel are set out below as within the Terms of Reference:

- advise JCPCT on ability and capacity of each applicant to develop the service/s as set out in the applications
- specifically advise JCPCT on workforce risks and clinical risks of re-location of a service(s)
- advise on the potential impact to other relevant areas of service delivery, including donor organ retrieval and PICU
- advise on potential risks to clinical outcomes in the future as a result of re-location
- advise on transition issues (relocation of a service from one centre to another)

Expert Panel Membership

NAME	CONSTITUENCY	ROLE
Dr Patricia Hamilton CBE	Chair of the Panel	Immediate Past President of Royal College of Paediatrics and Child Health and Chair of <i>SAFE AND SUSTAINABLE</i> steering group
Dr Martin Ashton-Key (observer / secretariat)	Secretariat / Adviser	Medical Adviser, NHS Specialised Services
Professor James Neuberger*	NHS Blood and Transplant	Associate Medical Director, Directorate of Organ Donation and Transplantation
Dr Kenneth Palmer	ECMO Specialist	Karolinska Institute, Sweden
Professor John Wallwork	Cardiothoracic Advisory Group	Consultant Cardiothoracic Transplant Surgeon, Papworth Hospital NHS Foundation Trust

* Professor James Neuberger sent apologies when the Panel met

- advise on overall viability and risks associated with re-location
- identify other relevant issues that JCPCT should address

Scoring

In order to quantitatively evaluate the potential of each provider that submitted an application to provide one or more of the NSC, each application was scored by the NSC Expert Panel on 23 June 2010.

The areas scored against were:

- Workforce requirements and risks
- Ability to meet the required capacity
- Team working and infrastructure
- Network arrangements
- Continuous professional development, training and education
- Governance structure and risk management

Each area was equally weighted and scored as follows:

1	Inadequate (the centre is unable to meet this requirement)
2	Poor (it is unlikely that the centre will be able to meet the requirement)
3	Unsatisfactory (there are significant risks or issues involved in the centre meeting this requirement)
4	Good (evidence supplied is good, and we are assured that the centre is in a good position to be able to meet the requirement)
5	Excellent (evidence is exemplary and absolutely certain that the centre can meet the requirement)

Applications received

Applications were received from the following providers:

PROVIDER	SERVICE
Freeman Hospital, Newcastle	i) Complex Tracheal
Bristol Royal Hospital for Children	i) ECMO
Leeds Teaching Hospital	i) Transplantation ii) ECMO iii) Complex Tracheal
Alder Hey, Liverpool	i) Transplantation ii) ECMO iii) Complex Tracheal
Birmingham Children's Hospital	i) Transplantation ii) ECMO iii) Complex Tracheal

Findings of the NCS Expert Panel

Overall

The panel concluded that:

- All three Nationally Commissioned Services require paediatric cardiac surgical back-up
- All three of the current providers are delivering good outcomes
- The optimum is to maintain Nationally Commissioned Services in their current locations if possible
- However, there are obvious sustainability issues at some of the Nationally Commissioned Services providers
- Single-handed Nationally Commissioned Services are not sustainable in any event

Transplantation

The panel agreed that given the demands in national caseload, flexibility, resilience and geography two centres in England is the optimum, and that high ICU stays (Bridge to Transplant patients) are a risk to potential providers.

In conclusion the panel had confidence in the ability of Birmingham Children's Hospital to develop a transplant service if required but did not have confidence in the ability of any of the other centres to develop a transplant service.

Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory failure

There are currently three centres in England and one in Scotland which provide ECMO and the panel concluded that a minimum of three centres in England is required although four centres in England, in view of population and case distribution may be the optimum. The panel agreed that high ICU stays are a risk to potential providers, long treatment periods exacerbate travel and accommodation issues for parents and the Adult ECMO service at Glenfield Hospital may be vulnerable if paediatric ECMO is relocated from this centre.

In conclusion the panel, had confidence in the ability of Birmingham Children's Hospital to develop an ECMO service if required and considered that Bristol's application had some merit, but that Bristol would require considerable support in developing an ECMO service. The panel did not have confidence in the ability of any other centre to develop an ECMO service.

Complex Tracheal Surgery

The panel concluded that given the national caseload one centre in England is optimum, and did not have any confidence in the ability of any of the applicant centres to develop a complex tracheal service from the submissions received.

The findings of the NCS Expert Panel were reported to the JCPCT on 7 July 2010 and 1 September 2010 and were applied as part of the process for the evaluation of potential configuration options under the criterion for the evaluation of potential configuration options.

Expert panel scoring

Paediatric Cardiothoracic Transplantation and Mechanical Device as a Bridge to Heart Transplantation

PROVIDER	SCORE (MAXIMUM – 30)
Great Ormond Street Hospital	30
Freeman Hospital, Newcastle	30
Birmingham Children's Hospital	24
Alder Hey, Liverpool	18
Leeds Teaching Hospital	15

Expert panel scoring

Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory failure

PROVIDER	SCORE (MAXIMUM – 30)
Great Ormond Street Hospital	30
Glenfield Hospital, Leicester	30
Freeman Hospital, Newcastle	30
Birmingham Children's Hospital	27
Bristol Royal Hospital for Children	24
Alder Hey, Liverpool	22
Leeds Teaching Hospital	19

Expert panel scoring

Complex Tracheal Surgery

PROVIDER	SCORE (MAXIMUM – 30)
Great Ormond Street Hospital	30
Birmingham Children's Hospital	21
Freeman Hospital, Newcastle	19
Leeds Teaching Hospital	19
Alder Hey, Liverpool	16

APPENDIX B - PAEDIATRIC INTENSIVE CARE UNIT (PICU) AND INTERDEPENDENT SERVICES

Percentage of cardiac activity (2009) into PICUs in current centres

CENTRE	%
Royal Brompton	88%
Freeman Hospital, Newcastle	78%
Glenfield Hospital, Leicester	71%
Birmingham Children's Hospital	45%
Evelina Children's Hospital	43%
Alder Hey Children's Hospital	41%
Great Ormond Street Hospital for Children	40%
Bristol Royal Hospital for Children	40%
Leeds Teaching Hospital	39%
John Radcliffe Hospital, Oxford	33%
Southampton General Hospital	29%

Impact on Paediatric Intensive Care Services

The Critical Interdependencies Framework⁷² posed the question: 'as cardiac services account for 30% of paediatric intensive care unit (PICU) admissions, if the services are reconfigured how could the PICU remain able to manage its remaining work?'

The **SAFE AND SUSTAINABLE** review has sought to assess the viability and resilience of PICUs in surgical centres that are not designated as providers of paediatric cardiac surgery in the future. The approach was to use PICANET⁷³ data from the following sources:

- the 2007, 2008 and 2009 PICANET annual reports
- an initial data review using high level data provided by PICUs
- a more detailed review using Paediatric Critical Care Minimum Data Set data⁷⁴ which identified the breakdown of specialist PIC activity in specific NHS Trusts (or cities) with more than one PICU
- qualitative information provided by relevant Specialised Commissioning Groups

The methodology was informed by discussions with the current President of the Paediatric Intensive Care Society.

The table below shows the number of PICU admissions to each hospital⁷⁵ in 2009 less the number attributable to paediatric cardiac cases.

CENTRE	TOTAL 2009 ADMISSIONS	2009 CARDIAC ADMISSIONS	2009 NON-CARDIAC ADMISSIONS
Royal Brompton Hospital	451	398	53
Freeman Hospital	317	248	70
Glenfield Hospital	390	277	113
John Radcliffe	335	112	223
Bristol Royal Hospital for Children	738	293	445
Leeds TH	802	311	491
Southampton	740	214	526
Alder Hey	1103	453	650
Evelina Children's	1151	498	653
Birmingham Children's	1314	593	721
GOSH	1620	653	967

⁷² Based on analysis of PICANET reports (2007, 2008 and 2009) and analysis of PICU minimum data set

⁷³ Paediatric Intensive Care Audit Network website. Available at: <http://www.picanet.org.uk/>

⁷⁴ Paediatric Critical Care Minimum Data Set Overview. Available at: http://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/overviews/paediatric_critical_care_minimum_data_set_overview.asp?shownav=0

⁷⁵ Based on analysis of PICANET reports (2007, 2008 and 2009) and analysis of PICU minimum data set

Recommendations to JCPCT

Based on this analysis:

- Some PICUs would become unviable as a consequence of losing paediatric cardiac surgery (Leicester, Freeman and Brompton). However, as these PICUs exist predominately to support cardiac surgery (and because all three cities have existing alternative PICU provision for non-cardiac admissions) this presents limited risk to local and national PICU provision.
- All other PICUs in the other hospitals would remain 'viable'. The John Radcliffe Hospital would continue to meet the critical mass necessary for a Level 2 PICU (200 to 350 admissions); Bristol and Leeds would sustain the critical mass necessary for a Level 3 PICU (350 to 500 admissions); the remaining centres would meet the critical mass for Lead PICU Centre (500+ admissions).
- In assessing the 'resilience' of depleted PICUs the JCPCT should take account of the following:
 - The degree of risk to local and national PICU provision were the resilience of the integrated PICUs to be diminished through loss of paediatric cardiac surgery. A reduction in overall PICU capacity may result in less flexibility in responding to historical winter pressures, for example.

- The ability of smaller PICUs to maintain retrieval services, staffed by Consultant Intensivists, would also need to be considered, as would the implications of units designated to provide paediatric cardiac surgery having to retrieve children from larger geographical areas (manpower and retrieval time issues).
- The impact of a PICU's ability to continue to recruit and retain high-calibre staff over time; there may be a move of skilled staff to the larger PICU units over time and there may be a de-skilling of staff in smaller units that provide a reduced range of specialised children's services.
- Smaller PICUs may be less equipped to act as training units, with a particular impact on anaesthetic training. PICUs whose ventilated admissions fall below 350 admissions a year can only be recognised for a 1-year training programme as opposed to the 2-year programme.
- The need for assurance that hospitals that are designated to provide paediatric cardiac surgery are able to sufficiently increase PICU provision.

It is recommended that the following action is taken by local services and local commissioners during, and beyond, the phase of implementation of the eventual agreed recommendation made by **SAFE AND SUSTAINABLE**. This will require some national coordination, particularly retrieval provision.

- Develop a plan for Congenital Heart Networks and PICU with clear protocols and relationships
- Develop capacity plans for PICU to include all specialist children's services
- Develop plans to managing peaks and troughs in demand and activity
- Review plans for PICU in the context of other service reviews or configurations in local trusts including the clinical inter-dependency framework
- Develop plans for retrieval services that take account of any new arrangements and explore new arrangements that will maximise efficiencies
- Develop recruitment and retention policies for networks
- Develop plans for step down and HDU
- Develop a commissioning plan for PICU which is reviewed and monitored regularly

Impact on services that have a relationship with paediatric cardiac surgery

SAFE AND SUSTAINABLE has explored the impact to relevant interdependent services within local health economies in the event of de-designation of a current provider of paediatric cardiac surgery.

The Critical Interdependencies Framework⁷⁶ identifies four clinical services (other than paediatric cardiology) that have a relationship with paediatric cardiac surgery:

- Oncology (Amber 1 relationship)
- Major trauma (Amber 2 relationship)
- ENT Airway (Amber 2 relationship)
- Specialised Paediatric Surgery (Amber 1 relationship)

An Amber relationship is defined as a 'relationship under some circumstances, requiring varying levels of access and contact between specialists, but not necessarily co-location'

- Amber 1 is defined as 'a planned intervention in a timescale as required'
- Amber 2 is defined as 'visit by consultant or transfer of care by the next working day'

As the Critical Interdependencies Framework does not consider paediatric cardiac surgery to be a core service upon which any of the four services is reliant. **SAFE AND SUSTAINABLE** has concluded that the removal of paediatric cardiac surgery does not threaten the viability of any of the four services that may also be provided by the hospital in question.

In assessing the potential impact to local health economies **Safe and Sustainable** has obtained a detailed description from each of the current 11 centres on existing protocols with other NHS Trusts in their catchment areas that provide one or more of the four services.

As co-location of these services with paediatric cardiac surgery is not considered

⁷⁶ Department of Health, 'Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies', September 2008

mandatory the conclusion is that there are no significant issues to report. All current centres recognise their roles in supporting the inter-dependent services but whilst there are some formal protocols the majority rely on informal relationships that provide for the transfer of care to the cardiac surgical centre.

It is recommended to the JCPCT that in the future, formal protocols are developed through the proposed Congenital Heart Networks.

Services for adults with Congenital Heart Disease (GUCH services)

When a young person with Congenital Heart Disease reaches 16 years they become known as a Grown Up Congenital Heart (GUCH) patient. GUCH is one of the terms used to describe an adult with congenital heart disease (Grown-Up with Congenital Heart Disease). Other patients may prefer to be called ACHD patients (Adult with Congenital Heart Disease).

SAFE AND SUSTAINABLE is just one part of a wider NHS review of congenital heart services. The NHS is reviewing how best to deliver adult congenital services for GUCH patients in the future and is using the same principles of safety, sustainability and good quality outcomes that **SAFE AND SUSTAINABLE** has adopted.

A seamless transition from paediatric to adult services is optimal for the patient but this does not necessitate the co-location of paediatric and adult services. More important is the quality of the different services and how they relate to each other

Report of Professor Sir Ian Kennedy, 2010

Due to advances in cardiac surgery and cardiology there are now more adults than children with congenital heart disease, though children still account for around 80% of all congenital heart operations in the United Kingdom⁷⁷. Most adults with CHD will need life-long monitoring but most will not need surgery.

Twenty one English NHS Trusts performed heart surgery on adult congenital patients in 2008/09⁷⁸ though the number of procedures varies significantly between the hospitals.

The NHS has developed a separate set of proposed standards that designated GUCH services must meet in the future⁷⁹. Some of the key requirements are:

- All GUCH patients aged 16 years and over should be seen at least once by a GUCH specialist. This will either take place at the specialist GUCH centre or at a local GUCH centre depending on how complex a patient's condition is and how far they have to travel to the service.
- Specialist GUCH centres should be linked to centres that in 2011 are designated as

children's cardiac surgical centres and children's cardiology centres.

- Local GUCH centres and local clinical networks are created to ensure all patients are seen once by the expert GUCH cardiologist with clear care plans agreed for on-going management at the specialist centre, local GUCH centre or DGH.
- Local GUCH centres should receive greater clinical support and leadership from the specialist GUCH centre with clearly defined roles and responsibilities established for each service on a local basis.

SAFE AND SUSTAINABLE - addressing the needs of GUCH patients

Although neither the proposed standards for children's or adult congenital heart services require congenital cardiac services for adults and children to be co-located on the same hospital site some of the existing children's surgical centres also provide care to GUCH patients. However, **SAFE AND SUSTAINABLE** has taken account of the needs of GUCH patients and their services:

- A number of senior congenital heart clinicians were members of both separate groups responsible for developing the respective clinical standards
- There is concordance between the **SAFE AND SUSTAINABLE** standards and the GUCH standards for example around the important issue of transition

- The expert panel, led by Sir Ian Kennedy, considered the quality of the children's surgical centres' transition arrangements and the panel met with GUCH patients

After the **SAFE AND SUSTAINABLE** consultation, should the NHS decide to make changes to children's heart services, the NHS will subsequently consider the provision of GUCH services. This will involve a formal process to establish which hospitals can meet the agreed GUCH quality standards and are able to meet future demand. It is proposed that an expert group of clinicians and patient representatives will be convened to advise NHS commissioners on the process. Commissioners will ensure there is a consistent approach across the country not just for adult services, but also to ensure synergy with the development of services and networks for children with Congenital Heart Disease. The NHS will consult on any proposed changes to GUCH services.

This table overleaf gives the current CCAD data on GUCH activity by centre, and the potential flow of patients following reconfiguration of surgical centres under each potential option for consultation. The assumption here is that the GUCH patients will flow the same way as the paediatric surgical cases from the centres that cease surgery to the new Congenital Heart Networks.

⁷⁷ Source: Central Cardiac Audit Database

⁷⁸ Source: Central Cardiac Audit Database

⁷⁹ Designation of Specialist Service Providers for Grown-Ups with Congenital Heart Disease (GUCH) / Adults with Congenital Heart Disease (ACHD), (Including National GUCH service specification Standards) - 28th September 2009

GUCH Implications

current surgery procedures 2008/09

CENTRES	CURRENT	OPTION 1	OPTION 2	OPTION 6A	OPTION 6B
London	200	200	241	241	241
Birmingham	19	44	19	80	60
Bristol	65		106	106	106
Liverpool	7	7	7	7	7
Leicester	41	61	61		
Leeds	56				
Newcastle	88	124	124	124	144
Southampton	66	122			
Oxford	16				
SUB TOTAL	558	558	558	558	558
Other centres	300	300	300	300	300
TOTAL	858	858	858	858	858

GUCH Implications

current surgery procedures 2008/09

CENTRES	OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
London	246	247	247	247	205
Birmingham	40	90	74	39	75
Bristol	106	106	106	106	73
Liverpool	7	7	7	7	7
Leicester					
Leeds	159			159	
Newcastle		108	124		124
Southampton					74
Oxford					
SUB TOTAL	558	558	558	558	558
Other centres	300	300	300	300	300
TOTAL	858	858	858	858	858

Cardiological Interventions

The table below gives indicative numbers for the number of cardiological interventions performed in 2009/10. These procedures will be carried out at the specialist surgery centres in the future as surgical back-up would be available in the rare event that it is required. As part of the designation process centres were asked to address potential capacity issues that may arise as a result of increased interventional procedures. These procedures are carried out in catheter laboratories or similar facilities.

Cardiological Interventions performed in NHS Hospitals

TYPE	HOSPITAL	2009/10
Catheter	Alder Hey Hospital	207
	Birmingham Children's Hospital	358
	Bristol Children's Hospital	113
	Freeman Hospital	107
	Great Ormond Street Hospital for Children	262
	Glenfield Hospital	139
	Evelina Children's Hospital	181
	Leeds General Infirmary	179
	Royal Brompton Hospital	178
	John Radcliffe Hospital	90
	Southampton General Hospital	105
		1919

N.B. Some centres did not return all 'electrophysiological' procedures to CCAD in this year and so the figures may be understated.

APPENDIX C - THE CREATION OF A JOINT COMMITTEE OF PRIMARY CARE TRUSTS FOR THE PURPOSES OF FORMAL PUBLIC CONSULTATION AND DECISION MAKING ABOUT THE PROVISION OF PAEDIATRIC CARDIAC SURGERY SERVICES IN ENGLAND

ACTION

The board is asked to receive this paper and resolve to accept its recommendations, in accordance with its Standing Orders.

Purpose Of Paper

To record the policy context for the establishment of the Joint Committee for Primary Care Trusts (JCPCT) for the purpose of formal consultation on the models of care for and location of surgical centres for the provision of paediatric cardiac surgery in England; the consequent action to be taken by Primary Care Trusts; and to confirm the role and remit of the JCPCT.

1.1 Introduction

The 'SAFE AND SUSTAINABLE' review of paediatric cardiac surgical services in England was instigated in 2008 in response to long-standing concerns held by NHS clinicians, their professional associations and national parent groups around the sustainability of the current service configuration. Surgeons are spread too thinly across surgical centres (31 congenital cardiac surgeons spread over 11

surgical centres), leading to concerns around lack of surgical cover in smaller centres and the potential for sudden closure or suspension of smaller centres.

A steering group comprising the relevant clinical and lay associations and NHS commissioners was established, chaired by the Immediate Past President of the Royal College of Paediatrics and Child Health. The steering group has developed clinical quality standards, informed by contributions from NHS clinicians, the public, NHS commissioners and other stakeholders, against which centres seeking designation as paediatric cardiac surgical centres were assessed in May and June 2010.

The outcome of the review is likely to be a recommendation for fewer, larger centres of specialist expertise but within a national model of care that develops the delivery on non-interventional diagnostic and follow-up care in local hospitals; this will be achieved by strengthening a commitment to shared clinics and by developing the roles of cardiac liaison teams and of Consultant Paediatricians with Expertise in Cardiology. The NHS will

hold formal public consultation on options for change between October 2010 and January 2011.

The review is led by the National Specialised Commissioning Group on behalf of the ten Specialised Commissioning Groups in England and their constituent Primary Care Trusts. In December 2009 the National Specialised Commissioning Group recommended the establishment of the JCPCT with delegated powers of consultation and decision making. This recommendation was endorsed by the Secretary of State for Health in July 2010.

1.2 Geographical Coverage

It is proposed that the JCPCT will comprise delegates representing every PCT in England, and, should the Welsh Assembly determine to join the JCPCT, a delegate from Wales because Welsh patients receive these services in England.

1.3 Statutory Framework

The relevant statute is the National Health Service Act 2006 and specifically sections 1 to 3 which impose a duty on the Secretary of State for Health to provide a comprehensive Health Service. The NHS (Functions of Strategic Health Authorities and Primary Care Trusts and Administrative Arrangements) (England Regulations 2002 SI 2002/2375) allocates certain of those functions to Primary Care Trusts and amongst other provisions authorises those Trusts to make arrangements for their functions to be exercisable jointly with other NHS bodies and permits the delegation of the exercise of those functions to committees or

sub-committees including joint committees. If a body delegates its relevant functions to a joint committee and that committee reaches a decision the body will be bound by that decision.

1.4 Application

Guidance issued by the Department of Health in July 2003 ("Overview and Scrutiny of Health – Guidance") recommends as follows:

Paragraph 10.3.2

"In circumstances where a proposed service change spans more than one PCT, they will need to agree a process of joint consultation. The Board of each PCT will need to formally delegate the responsibility to a Joint Committee, which should act as a single entity. Following the consultation the Joint PCT Committee will be responsible for making the final decision on behalf of the PCTs for which it is acting. See Regulation 10 of SI 2002/2375 for relevant PCT provisions".

Although this is only guidance, the circumstances of the paediatric cardiac surgery consultation warrant a Joint Committee arrangement.

1.5 Establishment

The Chief Executive of every Primary Care Trust in England is being asked to obtain approval of the Trust Board to the following decisions:

- a) That the Trust resolves to use its authority under the 2002 Regulations to share decision making powers on this consultation with every other PCT.

- b) That the Primary Care Trusts appoint a Joint Committee in accordance with the terms of reference below.
- c) That the Joint Committee comprise of the following members:
 Chair: The Chief Executive of East of England Strategic Health Authority
 The Chairs or PCT Chief Executive nominees of the ten regional Specialised Commissioning Groups
 The Director of National Specialised Commissioning
 A representative appointed by the Welsh Assembly should the Welsh Assembly determine to join the Joint Committee
- d) That the members of the Joint Committee shall elect a Vice Chair from among their number.
- e) That the Joint Committee shall adopt the Standing Orders relating to the handling of meetings, agendas and declaration of interest, and also Standing Financial Instructions of the East of England Strategic Health Authority. Such Standing Orders will regulate compliance with the Public Bodies (Admission to Meetings) Act 1960 and associated arrangements for the publication of dates of meetings, issue of papers etc. Thus the Joint Committee will meet in public when appropriate.

1.6 Terms Of Reference Of The Committee

Primary Care Trust Boards are also asked to agree that the role of the Committee shall be to carry out the following functions as the formal consulting body in respect to the provision of paediatric cardiac services in England:

- a) Approve the method and scope of the consultation.
- b) Approve the text of and issue the consultation document.
- c) Act as the formal body in relation to the Joint Overview and Scrutiny Committees established for this Consultation by the relevant Local Authorities.
- d) Take decisions on issues which are the subject of the Consultation.

1.7 Procedure

Primary Care Trusts are also asked to agree:

- a) The Joint Committee adopts the Standing Orders of the East of England Strategic Health Authority.
- b) Each member of the Joint Committee shall have one vote and the Joint Committee shall reach decisions by a simple majority

of the members present, but with the Chair having a second and deciding vote if necessary.

- c) That the Joint Committee will make decisions on the issues being consulted on, taking proper account of all the consultation responses and all other relevant matters, including an Equalities Impact Assessment.
- d) The decisions of the Joint Committee shall be binding on all member Trusts.

Recommendations

The PCT Board is asked to pass the following resolutions:

1. The Primary Care Trust resolves to use its authority under Regulation 10 of the NHS (Functions of SHAs and PCTs and Administration Arrangements) (England) Regulations 2002 to share decision making powers on its consultation with every other PCT in England.
2. The Primary Care Trust is content with the establishment, terms of reference and the procedure of the JCPCT, as set out in paragraphs 1.5, 1.6 and 1.7 above.

JOINT COMMITTEE OF PRIMARY CARE TRUSTS MEMBERSHIP

NAME	CONSTITUENCY		ROLE	DATES
Sir Neil McKay CBE	Chair, Joint Committee of Primary Care Trusts;		Chief Executive, East of England SHA	From July 2010
Sophia Christie	West Midlands SCG		Chief Executive, Birmingham East & North PCT	From July 2010
Ailsa Claire	Yorkshire and the Humber SCG		Chief Executive, Barnsley PCT	From July 2010
Jon Develing	North West SCG		Chief Officer North West SCG	From July 2010
Deborah Evans	South West SCG		Chief Executive, Bristol PCT	From July 2010
Catherine Griffiths	East Midlands SCG		Chief Executive, Leicestershire County & Rutland PCT	From July 2010
Dr Lise Llewellyn	South Central SCG		Chief Executive, Berkshire East PCT	From July 2010
Teresa Moss	National Specialised Commissioning		Director of NHS Specialised Services	From July 2010
Steve Phoenix	South East Coast SCG		Chief Executive, West Kent PCT	From July 2010
Chris Reed	North East SCG		Chief Executive North of Tyne PCT	From July 2010
Caroline Taylor	London SCG		Chief Executive, Croydon PCT	From July 2010
Paul Watson	East of England SCG		Chief Executive, Suffolk PCT	From July 2010
Stuart Davies (Observer)	Welsh Health Specialised Services Committee		Former Acting Chief Executive of former Health Commission Wales	July 2010 - January 2011
Simon Dean (Observer)	National Assembly for Wales		Director of Strategy and Planning, Department for Health and Social Services,	From July 2010
Sue Dodd (Observer)	Department of Health		Vascular programme	From July 2010
Dr Patricia Hamilton CBE (Clinical Adviser to JCPCT)	Safe and Sustainable Steering Group		Chair of the Steering Group and Immediate Past President of Royal College of Paediatrics and Child Health	From July 2010
Mr Leslie Hamilton (Clinical Adviser to JCPCT)	Safe and Sustainable Steering Group		Vice Chair of Safe and Sustainable Steering Group and Immediate Past President of the Society for Cardiothoracic Surgery in Great Britain and Ireland	From July 2010
Cerilan Rogers (Observer)	Welsh Health Specialised Services Committee		Director of Specialised and Tertiary Services and Committee Secretary	From January 2011

APPENDIX D - MEMBERSHIP OF THE STEERING GROUP

NAME	CONSTITUENCY		ROLE	DATES
Dr Patricia Hamilton CBE (Chair)	Chair of the Steering Group		Immediate Past President of Royal College of Paediatrics and Child Health	Continuous
Nicola Anderson	National Specialised Commissioning Team		Paediatric Cardiac Programme Manager	January 2010 - June 2010
Dr Martin Ashton-Key	National Specialised Commissioning Team		Medical Adviser	April 2009 - present
Mr William Brawn	British Congenital Cardiac Association (Immediate Past President)		Consultant Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust	Continuous
Dr Geoffrey Carroll	NHS in Wales		Medical Director, Welsh Health Specialised Services Team	December 2008 - October 2010
Katherine Collins	NHS in Scotland		Programme Director, National Services Division	Continuous
Steve Collins	National Specialised Commissioning Team		Deputy Director of National Specialised Commissioning	December 2008 - June 2010
Michaela Dixon	Royal College of Nursing		Nurse, University Hospitals Bristol NHS Foundation Trust / University of West England	December 2008 - December 2009
Dr Sarah Pinto- Duschinsky	NHS Commissioning		Executive Chairman, Commissioning Support for London / Board member of London SCG	Continuous
Sue Dodd	Department of Health (observer)		Emergency & Acute Care Manager, Vascular Programme, Department of Health	Continuous
Professor Martin Elliott	British Congenital Cardiac Association		Consultant Paediatric Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust	April 2009 - present
Deborah Evans	NHS Commissioning		Chief Executive, Bristol PCT / Chair of South West SCG	Continuous
Janice Fawell	National Specialised Commissioning Team		Interim Director of National Specialised Commissioning	January 2009 - September 2009
Jeremy Glyde	National Specialised Commissioning Team		Safe and Sustainable Programme Director	April 2009 - present
Dr Kate Grebenik	Association of Cardiothoracic Anaesthetists		Consultant Anaesthetist, Oxford Radcliffe Hospitals NHS Trust	Continuous
Catherine Griffiths	NHS Commissioning		Chief Executive, Leicestershire County and Rutland PCT / Chair of East Midlands SCG	Continuous

NAME	CONSTITUENCY		ROLE	DATES
Mr Leslie Hamilton (Deputy Chair)	Society for Cardiothoracic Surgery in Great Britain and Ireland (Immediate Past President)		Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust	Continuous
Maria von Hildebrand	Patients and public		Independent Patient Advocate	Continuous
Dr Sue Hobbins	Royal College of Paediatrics and Child Health		Consultant Paediatrician with Expertise in Cardiology, South London Healthcare NHS Trust	Continuous
Dr Ian Jenkins	Paediatric Intensive Care Society (Immediate Past President)		Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust	Continuous
Anne Keatley-Clarke	Patients and public		Chief Executive, Children's Heart Federation	Continuous
Candy Morris CBE	Strategic Health Authorities		Chief Executive, South East Coast SHA	Continuous
Teresa Moss	National Specialised Commissioning Team		Director of National Specialised Commissioning	September 2009 - present
Dr Sally Nelson	Public Health		Medical Adviser, South Central SCG	Continuous
Professor Shakeel Qureshi	British Congenital Cardiac Association (President)		Consultant Paediatric Cardiologist, Guy's and St Thomas' NHS Foundation Trust	Continuous
Chris Reed	NHS Commissioning		Chief Executive, NHS North of Tyne PCT / Chair of North East SCG	Continuous
Dr Anthony Salmon	British Congenital Cardiac Association (President Elect)		Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust	December 2009 - present
Fiona Smith	Royal College of Nursing		Adviser in Children and Young People's Nursing, RCN	December 2009 - present
Dr Graham Stuart	British Congenital Cardiac Association		Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust	Continuous
Dr Dirk Wilson	NHS Wales		Consultant Paediatric Cardiologist, Cardiff and Vale UHB	January 2011 - present
Vacant	NHS Northern Ireland			

APPENDIX E - STANDARDS GROUP MEMBERSHIP

NAME	CONSTITUENCY		ROLE	DATES
Mr William Brawn	Chair of the Standards Working Group and President of British Congenital Cardiac Association		Consultant Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust	April 2009 - February 2010
Dr Martin Ashton-Key	National Specialised Commissioning Team		Health Medical Adviser, NSC Team	April 2009 - February 2010
Dr Geoffrey Carroll	NHS in Wales		Medical Director, Welsh Health Specialised Services Team	April 2009 - February 2010
Steve Collins	National Specialised Commissioning Team		Deputy Director of National Specialised Commissioning	April 2009 - February 2010
Michaela Dixon	Royal College of Nursing		Nurse, University Hospitals Bristol NHS Foundation Trust / University of West England	April 2009 - December 2009
Professor vMartin Elliott	British Congenital Cardiac Association		Consultant Paediatric Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust	April 2009 - February 2010
Jeremy Glyde	National Specialised Commissioning Team		Safe and Sustainable Programme Director	April 2009 - February 2010
Dr Kate Grebenik	Association of Cardiothoracic Anaesthetists		Consultant Anaesthetist, Oxford Radcliffe Hospitals NHS Trust	April 2009 - February 2010
Mr Leslie Hamilton	Society for Cardiothoracic Surgery in Great Britain and Ireland (Immediate Past President)		Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust	April 2009 - February 2010

NAME	CONSTITUENCY		ROLE	DATES
Dr Sue Hobbins	Royal College of Paediatrics & Child Health		Consultant Paediatrician, South London Healthcare NHS Trust	April 2009 - February 2010
Dr Ian Jenkins	Paediatric Intensive Care Society (Immediate Past President)		Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust	April 2009 - February 2010
Anne Keatley-Clarke	Patients and public		Chief Executive, Children's Heart Federation	April 2009 - February 2010
Teresa Moss	National Specialised Commissioning Team		Director of National Specialised Commissioning	September 2009-Present
Dr Sally Nelson	Public Health		Medical Adviser, South Central SCG	December 2009 - February 2010
Professor Shakeel Qureshi	British Congenital Cardiac Association (President Elect)		Consultant Paediatric Cardiologist, Guy's and St Thomas' NHS Foundation Trust	April 2009 - February 2010
Peter Ripley	Ambulance Trust		Assistant Director of Operations, East Midlands Ambulance Service NHS Trust	July 2009 - November 2009
Fiona Smith	Royal College of Nursing		Adviser in Children and Young People's Nursing, RCN	December 2009 – February 2010
Dr Graham Stuart	British Congenital Cardiac Association		Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust	December 2009 - February 2010
Louise Tranmer	SCG Directors Group		Director, South West SCG	December 2009 - February 2010



**CHILDREN'S CONGENITAL CARDIAC
SERVICES IN ENGLAND**

**SERVICE STANDARDS
APPENDIX F**

‘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 - EVIDENCE SUPPORTING THE OPTIONS ASSESSMENT

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 CONGENITAL HEART NETWORK**
- B PRENATAL SCREENING AND SERVICES**
- C THE SPECIALIST SURGICAL 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 hospital in England that provides heart surgery for children.

We have concluded that a minimum of 4 consultant congenital cardiac surgeons is necessary in each designated surgical unit 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 cardiac surgical unit in England. We have therefore set out a minimum volume of 400 paediatric surgical procedures for each

Specialist Surgical Centre – with an ideal of 500 paediatric surgical procedures for each designated hospital - sensibly distributed across the 4 consultant congenital cardiac surgeons.

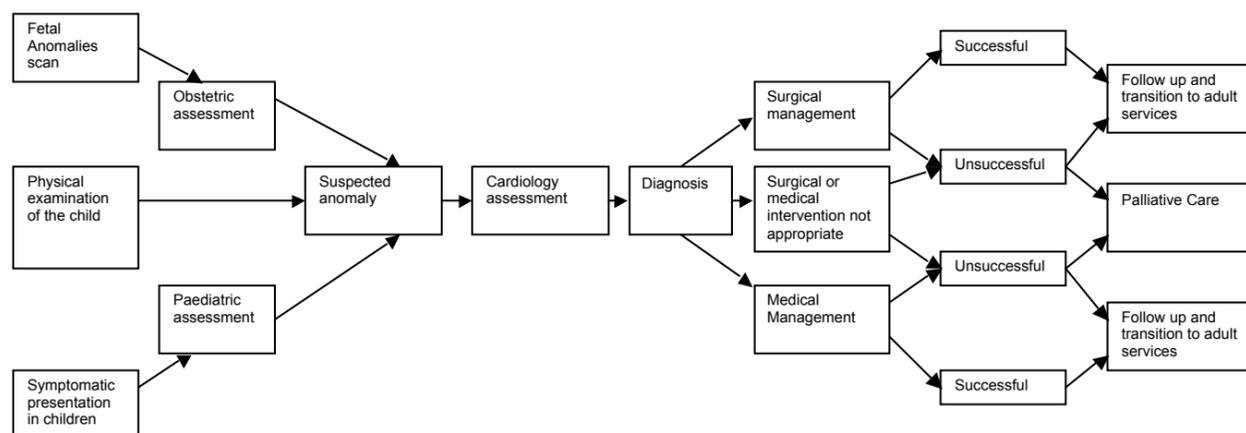
Incidence and activity projections for Congenital Heart Disease (CHD)

Currently around 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 Congenital Heart 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 surgical units 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 Congenital Heart Networks within which the designated surgical units 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 regional Congenital Heart Networks, and that regional Congenital Heart Networks by definition are best developed by local services with regard to local circumstances.

In this document we describe ‘the Congenital Heart Network’ through the relationship

between three key services for children with congenital heart disease:

Specialist Surgical Centre

The Specialist Surgical Centre 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 Specialist Surgical Centre for this purpose. In addition to foetal diagnostic services, the Specialist Surgical Centres will also provide the full range of diagnostic and follow-up care, reflecting the fact that for children who live close to the Specialist Surgical Centre, this will also be their ‘local’ assessment and follow-up service.

Children’s Cardiology Centre

Children’s Cardiology Centres 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 Children’s Cardiology Centre to the Specialist Surgical Centre. Regular combined clinics will be delivered by the Specialist Surgical Centre and Children’s Cardiology Centres. The role of Children’s Cardiology Centres 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

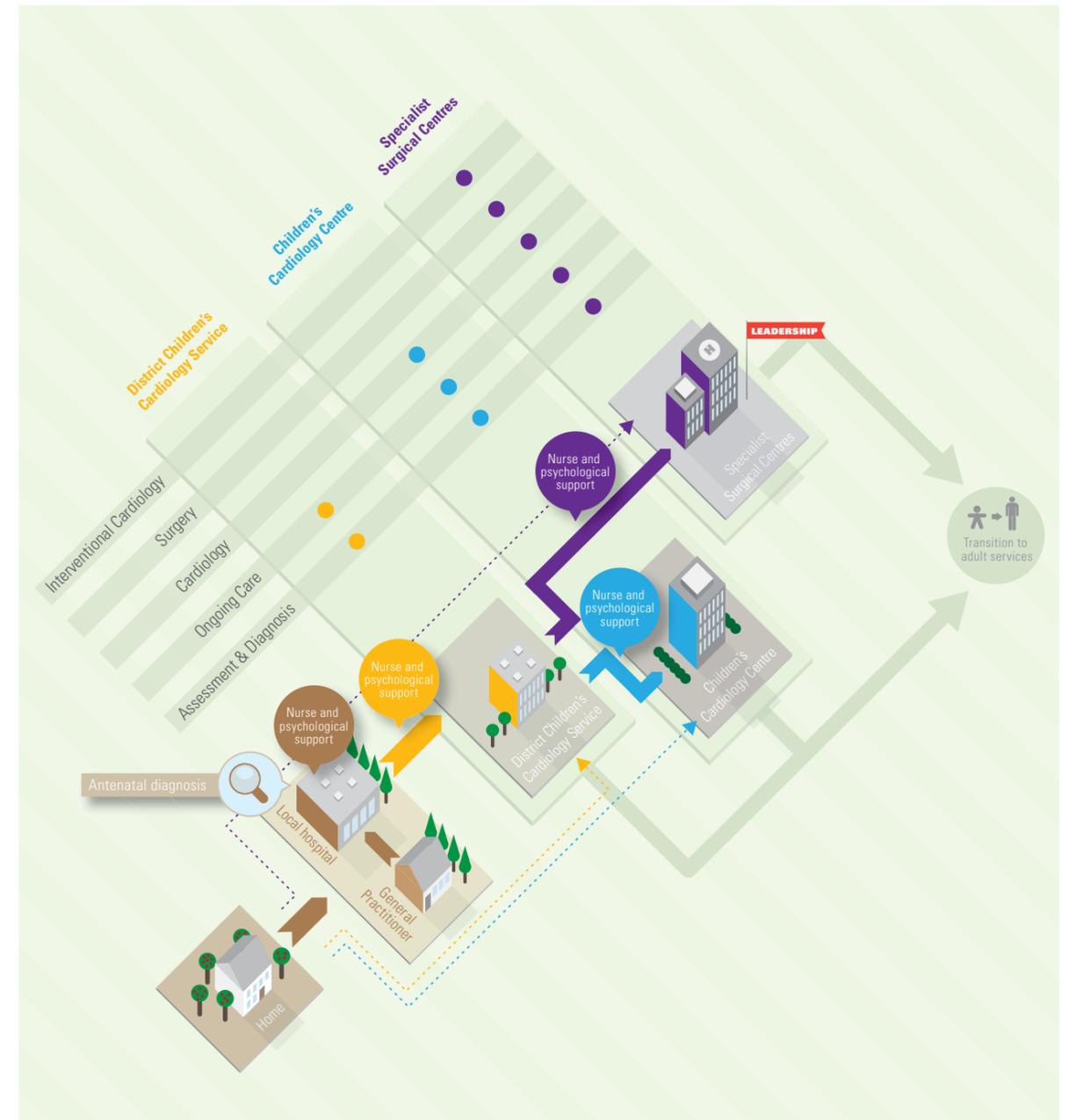
surgery and interventional procedures on children who will stop this in the future because they are not designated as a Specialist Surgical Centre, and that will become a Children's Cardiology Centre.

District Children's Cardiology Services

District Children's Cardiology Services will be delivered in some, but not all, local hospitals and they will have close working relationships with Specialist Surgical Centres and Children's Cardiology Centres 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 Specialist Surgical Centre or Children's Cardiology Centre so that combined paediatric cardiology clinics are held regularly at the District Children's Cardiology Service.

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 Specialist Surgical Centre or Children's Cardiology Centre so that the most appropriate care and treatment and an agreed plan of care after delivery can be determined.

The precise shape of each Congenital Heart 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 Congenital Heart 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 children's 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 Children's Congenital Cardiac 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 Specialised Surgical 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 Specialist Surgical Centres have been designated in 2011 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.

It is proposed to develop separate designation standards for Children's Cardiology Centres and District Children's Cardiology Centres in 2011.

MANDATORY FOLLOWING DESIGNATION

- MANDATORY**
 - Must be in place immediately once designated
 - Any failure or change in status would prompt immediate review of designation status
- MANDATORY AMBER**
 - Following designation, robust plans/intentions must be in place to achieve all outstanding mandatory standards within a timescale agreed with NHS commissioners
 - Any failure or change in ability to meet the standard within the agreed timescale would prompt immediate review of designation status

NON-MANDATORY

- HIGHLY DESIRABLE**
 - Highly desirable following designation
- DESIRABLE**
 - Desirable following designation
- VALUE ADDED**
 - Value added following designation.

A

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY				
A1	Specialist Surgical Centres (in partnership with NHS commissioners) will provide active leadership in the Congenital Heart Networks This will include: <ul style="list-style-type: none"> Managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures Performance monitoring and audit, professional training and development Facilitating the development of as much care and treatment as possible close to the child's home and the transition to adult services 	<p>Written protocols and policies</p> <p>Documented pathways</p> <p>Outcome of audits</p> <p>Evidence of formal contracts accompanied by Service</p> <p>Agreements between commissioners and all providers in the Congenital Heart Network</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>	MANDATORY AMBER
A2	Specialist Surgical Centres in partnership with the Congenital Heart Network 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 care and treatment should be provided as close as possible to the child's home and that the child and family travel to the Specialist Surgical Centre only when essential, while ensuring timely access for interventional procedures and the best possible outcome for the child	Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital Heart Network	<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 Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	MANDATORY AMBER
A3	The Specialist Surgical Centres and services within the Congenital Heart Network will hold regular multi-disciplinary meetings 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	<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 Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	MANDATORY
A4	Each Specialist Surgical 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	<p>Name of Lead</p> <p>Job and role description</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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY				
A5	Each Specialist Surgical Centre will have a formally nominated Lead Nurse The role of the Lead Nurse is set out in Appendix B	<p>Name of Lead</p> <p>Job and role description</p>	<p>Advice from Royal College of Nursing (2010)</p> <p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p>	MANDATORY AMBER
A6	Pathways must involve prenatal diagnosis, maternity and obstetric services, transition to adult congenital cardiac services and palliative care Congenital Heart Networks should be aligned with networks for foetal services and adult congenital services; the transition from foetus → child and child → adolescent and adolescent → adult requires a joined up approach with treatment continuity	<p>Written protocols</p> <p>Documented pathways</p>	<p>Standards for Providers of Services for Adults with Congenital Heart Disease (2010)</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>	MANDATORY AMBER
A7	Specialist Surgical 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>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>	MANDATORY AMBER
A8	Specialist Surgical Centres will agree clinical protocols with their Congenital Heart Networks, based upon these and other national standards The Specialist Surgical Centres will be responsible for advising colleagues within the Congenital Heart 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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY			
A9	There will be specific protocols within each Congenital Heart Network for the transfer of children requiring interventional treatment	Written protocols 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 Service'	MANDATORY
A10	Interventional procedures must only be undertaken at a Specialist Surgical 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'	MANDATORY
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 Specialist Surgical Centres, representatives of the Congenital Heart 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 People and Maternity Services (2003 and as modified)	MANDATORY
A12	Specialist Surgical 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	HIGHLY DESIRABLE

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY			
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 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 Reference Group for Psychologists Working in Paediatric Cardiology (2010) National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	MANDATORY AMBER
A14	The Specialist Surgical 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)	MANDATORY AMBER
CHILDREN'S CARDIOLOGY CENTRES AND DISTRICT CHILDREN'S CARDIOLOGY SERVICES			
A15	To ensure that children receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by specialised Children's Cardiology Centres and District Children's Cardiology Services established	Documented pathway Children's Cardiology Centres and District Children's Cardiology Services established British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY AMBER
A16	Each Children's Cardiology Centre and District Children's Cardiology Services will have telemedicine facilities to link with the Specialist Surgical 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'	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY				
A17	Each Children's Cardiology Centre and District Children's Cardiology Service 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 Congenital Heart Network members	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY AMBER
A18	Each District Children's Cardiology Services will have a named Consultant Paediatric Cardiologist from the Specialist Surgical Centre or Children's Cardiology Centre, and regular combined paediatric cardiology clinics should be held within the District Children's Cardiology Service	Name of Consultant Job description and staff contracts	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY AMBER
A19	Each District Children's Cardiology Service will have a named Consultant Paediatrician with expertise in paediatric cardiology who is closely involved in the organisation, running of and attendance in the District Children's Cardiology Service 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 Specialist Surgical 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 Specialist Surgical 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'	MANDATORY AMBER
A20	Each Children's Cardiology Centre and District Children's Cardiology Service 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'	MANDATORY AMBER
A21	Each Children's Cardiology Centre and District Children's Cardiology Service 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 respond to parents in a timely fashion	Staff names Job descriptions and staff contracts	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY				
A22	Each Children's Cardiology Centre and District Children's Cardiology Service 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'	MANDATORY AMBER
A23	Each Children's Cardiology Centre and District Children's Cardiology Service 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'	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY			
<p>A24 Each Children's Cardiology Centre and District Children's Cardiology Service will provide pathways of care and management of congenital heart defects agreed with the Specialist Surgical Centres</p> <p>a) Prenatally Diagnosed Congenital Heart Defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be transferred to the Specialist Surgical Centre or the Children's Cardiology Centre, as appropriate Discussions will take place about the location of the delivery of the baby</p> <p>b) Newborns with a murmur and otherwise clinically well</p> <p>c) Neonates and infants diagnosed with congenital heart defects</p> <p>Each Children's Cardiology Centre and District Children's Cardiology Service 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) New referrals of older infants and children from GPs and paediatricians</p> <p>Local hospitals will refer children to a Children's Cardiology Centre or District Children's Cardiology Service, as appropriate, for the following categories of referrals:</p> <ul style="list-style-type: none"> Murmurs Cyanosis Chest pain Palpitations Syncope or dizziness Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes Kawasaki disease <p>e) Ongoing care of children and young people diagnosed with congenital heart defects</p> <p>Local hospitals will refer children to the Children's Cardiology Centre or District Children's Cardiology Service 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 adjustment of various cardiac drugs</p>	<p>Written protocols</p> <p>Audit of service activity</p>	<p>British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'</p>	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
A A CONGENITAL HEART NETWORK FOR THE CHILD AND FAMILY				
A25	The management of patients should be discussed and planned at combined cardiac surgery and cardiology Multi-Disciplinary Team (MDT) meetings at the Specialist Surgical Centre to ensure the best possible care and outcomes	MDT register of attendance and activities	<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>	MANDATORY
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	<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>	MANDATORY
A27	Staff from across the Congenital Heart Network should be encouraged by the Specialist Surgical Centre to attend Multi-Disciplinary Team (MDT) meetings when, for example, an individual's care is complex or involves more than one specialty team If physical attendance is not possible, it is essential that all staff from across the Congenital Heart Network are fully involved in the MDT process including by video / teleconferencing and in the decision making about their patient, where necessary	MDT register of attendance and activities	<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>	MANDATORY
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'	MANDATORY

B

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
B PRENATAL DIAGNOSIS				
B1	Specialist Surgical Centres and Children's Cardiology Centres must meet the 'Foetal Cardiology Standards' developed by the British Congenital Cardiac Association	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards'	MANDATORY
B2	Children's Cardiology Centres and District Children's Cardiology Services that do not provide a foetal diagnostic cardiology service must work within the protocols defined by the Specialist Surgical Centre in their Congenital Heart Network in accordance with the 'Foetal Cardiology Standards' developed by the British Congenital Cardiac Association	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards'	MANDATORY AMBER
B3	Each Specialist Surgical Centre will agree and establish protocols with fetomaternal medicine units and tertiary neonatal units in their Congenital Heart Networks for the care and treatment of pregnant women whose foetus has been diagnosed with a major heart condition. The protocols must meet the 'Foetal 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) 'Foetal Cardiology Standards' National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	MANDATORY
B4	The timing of foetal cardiac scans for high risk mothers should be in line with the foetal cardiology standards of the British Congenital Cardiac Association	Written protocols and audit of compliance	Foetal Anomaly Screening Programme, National Standards and Guidance for England (2010) British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards'	MANDATORY
B5	If the obstetric screening anomaly scan indicates that the foetus may have a heart problem, the mother should be offered a specialist foetal cardiology assessment within 1 week, and preferably within 48 hours	Written protocols and audit of compliance	Foetal Anomaly Screening Programme, National Standards and Guidance for England (2010) British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards'	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
B PRENATAL DIAGNOSIS				
B6	Counselling for major congenital cardiac anomalies should be performed by foetal 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) 'Foetal Cardiology Standards' National Reference Group for Psychologists working in Paediatric Cardiology (2010)	MANDATORY
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 and support within 48 hours of diagnosis. Parents should also be given contact details for relevant local and national support groups at this point	Written protocols and audit of compliance Job descriptions	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards'	MANDATORY AMBER
B8	At diagnosis a plan should be agreed between the Specialist Surgical Centre, the specialist fetomaternal 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) 'Foetal Cardiology Standards' British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY
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 Specialist Surgical Centre if necessary (for example, at a linked obstetric unit)	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards' British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY
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 Specialist Surgical 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	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards' British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service' Report of the Paediatric Congenital Cardiac Services Review Group (2003)	MANDATORY

C

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C THE SPECIALIST SURGICAL CENTRE <i>PROFESSIONAL COMPETENCE</i>				
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 Services (2003 and as modified)</p>	MANDATORY
C2	All paediatric cardiac surgical cases should be carried out by a dedicated paediatric cardiac surgical team	<p>Posts in place</p> <p>Audit of operating logs</p>	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p>	MANDATORY
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	<p>Posts in place</p> <p>Named individuals</p> <p>Record of nurse staffing</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>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	MANDATORY
C4	Each Specialist Surgical 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 Specialist Surgical Centre	<p>Named individuals</p> <p>Job descriptions</p> <p>Evidence of qualifications, experience and training</p>	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Consensus reached at Safe and Sustainable national stakeholder event, October 2009</p>	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C THE SPECIALIST SURGICAL CENTRE <i>PROFESSIONAL COMPETENCE</i>				
C5	Arrangements must be in place in each Specialist Surgical Centre for consultant congenital cardiac surgeons to operate together on complex or rare cases, within legally compliant rotas	<p>Written protocols and audit of compliance</p>	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p>	MANDATORY
C6	Each Specialist Surgical Centre must 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.	<p>Posts in place</p> <p>Audit of operating logs</p> <p>Submission of data to CCAD</p> <p>A 'paediatric surgical procedure' is defined as any open or closed cardiac surgical procedure i) performed on a child on or before the 16th 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 Appendix C).</p>	<p>This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons</p> <p>Appendix D for relevant papers</p>	MANDATORY AMBER
C7	Each Specialist Surgical Centre should 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.	<p>Submission of data to CCAD</p> <p>A 'paediatric surgical procedure' is defined as any open or closed cardiac surgical procedure i) performed on a child on or before the 16th 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 Appendix C).</p>	<p>This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons</p> <p>Appendix D for relevant papers</p>	HIGHLY DESIRABLE
C8	Each Specialist Surgical Centre must be staffed by a minimum of 1 consultant paediatric cardiologist per half million population served	<p>Named individuals</p>	<p>Report of the Paediatric Congenital Cardiac Services Review Group (2003)</p>	HIGHLY DESIRABLE

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C THE SPECIALIST SURGICAL CENTRE <i>PROFESSIONAL COMPETENCE</i>				
C9	Each Specialist Surgical 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'	MANDATORY
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 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	Submission of data to CCAD Submission of transplant data to National Specialised Commissioning Team	NSCAG / CTAG Cardiothoracic Transplant Standards	MANDATORY
C11	Paediatric Intensive Care Unit (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'	MANDATORY
CRITICAL INTERDEPENDENT SERVICES: CO-LOCATION AS DEFINED BY THE FRAMEWORK OF CRITICAL INTER-DEPENDENCIES				
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)	MANDATORY
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)	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C CRITICAL INTERDEPENDENT SERVICES: CO-LOCATION AS DEFINED BY THE FRAMEWORK OF CRITICAL INTER-DEPENDENCIES				
C14	Specialised Paediatric Surgery	Description of services available and physical evidence of co-location	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	MANDATORY
C15	Paediatric Intensive Care Unit (PICU): Level 3 / Level 4 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards)	Description of services available and physical evidence of co-location Audit of compliance with national standards	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 Care Service Standards in Caring for Neonates, Children and Young People' Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	MANDATORY
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) Each Specialist Surgical 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	Description of services available and physical evidence of co-location Audit of compliance with national standards	Guidelines under development by the Royal College of Anaesthetists, Association of 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)	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
C OTHER CRITICAL INTERDEPENDENCIES			
C17	Paediatric Neurology: access as stipulated in the Framework of Critical Inter-Dependencies (CID) Description of services available Audit of compliance with CID Framework	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	MANDATORY
C18	Paediatric Respiratory Medicine: 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:	MANDATORY
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)	MANDATORY
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)	MANDATORY
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)	MANDATORY
C CO-LOCATION (AS DEFINED BY THE FRAMEWORK FOR CRITICAL INTERDEPENDENT SERVICES) WITH CORE CLINICAL SERVICES			
C22	Adolescent Congenital Cardiac Surgery Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C23	Adolescent Congenital Cardiology Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
C CO-LOCATION (AS DEFINED BY THE FRAMEWORK FOR CRITICAL INTERDEPENDENT SERVICES) WITH CORE CLINICAL SERVICES			
C24	General Paediatrics Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C25	General Paediatric Surgery Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
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'	MANDATORY
C27	Physiotherapy Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C28	Dietician Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
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'	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C	CO-LOCATION (AS DEFINED BY THE FRAMEWORK FOR CRITICAL INTERDEPENDENT SERVICES) WITH CORE CLINICAL SERVICES			
C30	Local facilities for transferring patients between airfields and helipads and the Specialist Surgical Centre	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
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'	MANDATORY
C32	Hospital School with teachers	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C33	Bereavement Support	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C34	Breast Feeding Support	Description of services available Evidence of qualifications, training and experience	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)	MANDATORY
C35	Social Work Services	Description of services available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C	CO-LOCATION (AS DEFINED BY THE FRAMEWORK FOR CRITICAL INTERDEPENDENT SERVICES) WITH CORE CLINICAL SERVICES			
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 Services'	MANDATORY
C37	Foetal Diagnostic Cardiology	Description of services available	British Congenital Cardiac Association (2010) 'Foetal Cardiology Standards' Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C38	Obstetrics and Maternity	Description of services available	National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	HIGHLY DESIRABLE
C39	Landing facilities for helicopter	Description of services available	Paediatric Intensive Care Society (2010) 'Standards for the Care of Critically Ill Children'	DESIRABLE
C40	Paediatric Neurosurgery	Description of services available Evidence of qualifications, training and experience	Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	DESIRABLE
C41	Genetics	Description of services available Evidence of qualifications, training and experience	National Service Framework for Children, Young People and Maternity Services Diagnostic and Statistical Manual of Mental Disorders IV (1994)	DESIRABLE

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C CO-LOCATION (AS DEFINED BY THE FRAMEWORK FOR CRITICAL INTERDEPENDENT SERVICES) WITH CORE CLINICAL SERVICES				
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)	DESIRABLE
C43	Dental	Description of services available	National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	DESIRABLE
CO-LOCATION WITH NON-PATIENT CONTACT SERVICES				
C44	Biochemistry	Description of services available		MANDATORY
C45	Pathology: dedicated cardiac morphology	Description of services available		DESIRABLE
C46	Pharmacy	Description of services available Evidence of qualifications, training and experience		MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C EQUIPMENT				
C47	Electrophysiology	Description of services available		MANDATORY
C48	Echocardiography (ECHO)	Description of services available		MANDATORY
C49	Cardiac catheterisation laboratory	Description of services available Evidence of qualifications, training and experience		MANDATORY
C50	Intra-operative ECHO	Description of services available Evidence of qualifications, training and experience		MANDATORY
C51	Transoesophageal ECHO	Description of services available Evidence of qualifications, training and experience		MANDATORY
C52	Magnetic Resonance Imaging (MRI)	Description of services available Evidence of qualifications, training and experience		MANDATORY
C53	Computerised Tomography (CT)	Description of services available Evidence of qualifications, training and experience		MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C EQUIPMENT				
C54	Post operative extra corporeal life support (Non nationally designated ECMO)	Description of services available	MANDATORY AMBER	
C55	Access to Isotope Imaging	Description of services available	HIGHLY DESIRABLE	
C PAIN MANAGEMENT				
C56	Specialist Surgical Centres must provide a co-located multi-disciplinary 24-hour pain management service	available	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	MANDATORY
C57	Specialist Surgical 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

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C MEETING DEMAND				
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 08%	Records of delayed or cancelled admissions or operations Refused entry audit	HIGHLY DESIRABLE	
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	MANDATORY
C63	Unplanned readmission to Paediatric Intensive Care Unit (PICU) will only occur in less than 10%	Emergency re-admission statistics (clinical indicator) for inpatient and re-admissions to High Dependency Unit (HDU) / PICU	MANDATORY AMBER	
C64	Sufficient staff will be available at the Specialist Surgical Centre to meet the demand for in-patient beds, critical care beds, theatre capacity and service provision as generated by the Congenital Heart Network When a Specialist Surgical Centre cannot admit a patient for whatever reason it is the responsibility of that Specialist Surgical Centre to find another bed at another Specialist Surgical Centre	Staff rotas Audit of refusals and onward referrals (including reports from other Specialist Surgical Centres)	MANDATORY	
C65	Sufficient capacity will be available at the Specialist Surgical Centre to ensure that the demands of emergency and elective surgery can be flexibly managed in daytime lists	Theatre utilisation records	MANDATORY	

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C MEETING DEMAND				
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 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)	MANDATORY
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'	MANDATORY
C RETRIEVAL AND REPATRIATION				
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"> 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 services Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care 	Refusal audit (including reports from other Specialist Surgical Centres) Record of delayed admissions Record of precipitate discharges Record of lengths of stay Audit data for paediatric cardiac surgery patients within acute cardiac surgical beds	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 Service'	MANDATORY

D

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
D AGE APPROPRIATE CARE				
D1	The transition to adult services will be tailored to reflect individual circumstances, taking into account any 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' Report of the Paediatric Congenital Cardiac Services Review Group (2003) National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	MANDATORY AMBER
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)	MANDATORY AMBER
D3	Each Congenital Heart Network shall have designated transition nurses to facilitate effective and timely transition from children's to adult services (Appendix E for role)	Named staff Job descriptions	Advice from Royal College of Nursing (2010)	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
D AGE APPROPRIATE CARE				
D4	The patient's management plan should be reviewed at each consultation – in all services that comprise the local Congenital Heart Network - to make sure that it continues to be relevant to their particular stage of development	Written protocols Audit of patient records	Standards for Providers of Services for Adults with Congenital Heart Disease (2010) 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)	MANDATORY AMBER
D5	Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present	Written protocols Patient / parent literature	General Medical Council '0-18 Years Guidance' National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	MANDATORY AMBER
D3	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	Written protocols Patient / parent literature	Standards for Providers of Services for Adults with Congenital Heart Disease (2010) National Reference Group for Psychologists Working in Paediatric Cardiology (2010) 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) British Psychological Society (2003) 'Working with Children with Medical Conditions'	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
D AGE APPROPRIATE CARE				
D7	All services that comprise the local Congenital Heart 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>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 (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>	MANDATORY AMBER
D8	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>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> <p>National Service Framework for Children, Young People and Maternity Services (2003 and as modified)</p>	

E

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
E INFORMATION AND MAKING CHOICES				
E1	Specialist Surgical 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	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Parent / User questionnaires</p>	<p>NHS Constitution 2009</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>	MANDATORY
E2	Specialist Surgical 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	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Parent / User questionnaires</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>	
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	<p>Role description</p> <p>Patient / parent literature</p> <p>Audit of attendance</p> <p>Parent / User questionnaires</p>	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'</p> <p>Advice from Royal College of Nursing (2010)</p>	MANDATORY AMBER
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	<p>Named staff</p> <p>Role description</p> <p>Patient / parent literature</p> <p>Access audit</p> <p>Parent / User questionnaires</p>	<p>National Reference Group for Psychologists Working in Paediatric Cardiology (2010)</p> <p>British Psychological Society (2003) 'Working with Children with Medical Conditions'</p>	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
E INFORMATION AND MAKING CHOICES				
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	<p>Patient / parent literature</p> <p>Access audit</p> <p>Parent / User questionnaires</p>	<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>	MANDATORY AMBER
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	<p>Patient / parent literature</p> <p>Parent / User questionnaires</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>	MANDATORY
E7	Where surgery or intervention is planned, the child and their parents or carers should have the opportunity to visit the Specialist Surgical 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 procedure	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Parent / User questionnaires</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>	MANDATORY AMBER
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	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Audit of compliance</p> <p>Parent / User questionnaires</p>	<p>Department of Health (2009) 'Reference Guide to Consent for Examination or Treatment'</p> <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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
E INFORMATION AND MAKING CHOICES				
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 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>Role description</p> <p>Written protocols</p> <p>Patient / parent literature</p> <p>Access audit</p> <p>Parent / User questionnaires</p>	<p>Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class 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>	MANDATORY AMBER
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) '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>	MANDATORY
E11	Specialist Surgical Centres must demonstrate that parents and carers are offered support or cooperation in obtaining further opinions or referral to another Specialist Surgical Centre	<p>Written protocols</p> <p>Patient / parent literature</p> <p>Audit of onward referrals</p> <p>Parent / User questionnaires</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>	MANDATORY
E12	Parents and carers must be given details of available support groups at the earliest opportunity	<p>Patient / parent literature</p> <p>Parent / User questionnaires</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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
E INFORMATION AND MAKING CHOICES				
E13	Specialist Surgical Centres must demonstrate that arrangements are in place for parents and carers to be given an agreed, written care plan that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents	Written protocols 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)	MANDATORY AMBER

F

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
F THE FAMILY EXPERIENCE				
F1	There should be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support)	Facilities available	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 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)	MANDATORY
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	Role descriptions Written protocols	Advice from Royal College of Nursing (2010)	MANDATORY
F3	Specialist Surgical 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 (Appendix F)	Role descriptions	Advice from Royal College of Nursing (2010)	MANDATORY AMBER
F4	Each Congenital Heart Network must have a minimum of 7 whole time equivalent Children's Cardiac Specialist Nurses working within a functioning Cardiac Liaison Team. The number of required nurses will depend on geography, population and the Congenital Heart Network	Staff records Role descriptions	Advice from Royal College of Nursing (2010) Report of the Paediatric Congenital Cardiac Services Review Group (2003)	MANDATORY AMBER
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'	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
F THE FAMILY EXPERIENCE				
F6	<p>There must be facilities in place to ensure easy and convenient access for parents and carers. Facilities and support include:</p> <ul style="list-style-type: none"> • accommodation for at least two family members to stay at the Specialist Surgical Centre • parents / carers to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate) • access to refreshments • ability of parents / carers to play and interact with their child (and their other children) • an on-site quiet room completely separate from general family facilities 	<p>Services available</p> <p>Parent / User literature</p> <p>Access audit</p> <p>Parent / User questionnaires</p>	<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>	MANDATORY
F7	Specialist Surgical Centres must establish a patient hotel service	<p>Services available</p>	<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>	MANDATORY AMBER
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 Children, Young People and Maternity Services (2003 and as modified)</p>	MANDATORY
F9	Children should have access to general resources including toys, books, magazines, computers and other age appropriate activity coordinated by play therapy teams	<p>Facilities available</p> <p>Parent / User questionnaires</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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
F THE FAMILY EXPERIENCE				
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	<p>Patient / Carer literature</p> <p>Parent / Carer questionnaires</p>	<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>	MANDATORY
F11	Specialist Surgical Centres must refund travel expenses to qualifying parents / carers at the time of each appointment in accordance with the 'Healthcare Travel Costs Scheme'	<p>Patient / Carer literature</p> <p>Parent / Carer questionnaires</p> <p>Audit of compliance</p>	Department of Health's 'Healthcare Travel Costs Scheme'	MANDATORY
F12	Children, their parents and carers should be encouraged to provide feedback on the quality of care and their experience of the service, and Specialist Surgical Centres must demonstrate ongoing structured liaison with parent and groups. They should be encouraged to participate in surveys of outcomes and/or experience. Specialist Surgical 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	<p>Written protocols</p> <p>Written records of complaints or feedback</p> <p>Written records of how feedback was considered and acted upon</p> <p>Patient / Carer literature</p> <p>Parent / Carer questionnaires</p>	<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>	MANDATORY
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	<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>	MANDATORY
F14	There must be access (for patients and family members) to support services including faith support and interpreters	Facilities 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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
F THE FAMILY EXPERIENCE			
F15	The outcome of relevant local and national audits will be made easily available to patients, parents / carers and the general public	<p>Publication of audits</p> <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>	MANDATORY

G

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
G EXCELLENT CARE			
G1	Each Specialist Surgical 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	<p>Named professionals</p> <p>Record of attendance and activities</p> <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>	MANDATORY
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. Specialist Surgical Centres must provide resources to sufficiently support these educational needs	<p>Training register and training records</p> <p>Staff appraisal documentation</p> <p>Written outcome of reviews of training programmes</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>	MANDATORY
G3	Specialist Surgical Centres must provide a number of cardiac clinical nurse educators that is sufficient to deliver standardised training and education competency-based programmes across the Congenital Heart Network. These programmes must focus on the acquisition of knowledge and skills such as diagnosis and assessment and treatment, facilitating and evaluating care, evidence based practice and communication	<p>Staff records</p> <p>Training available</p> <p>Advice from Royal College of Nursing (2010)</p>	MANDATORY AMBER
G4	All clinical teams will operate within a robust and documented clinical governance framework that includes clinical audit, including in Children's Cardiology Centres and District Children's Cardiology Services	<p>Written protocols and guidelines.</p> <p>Evidence of audits</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>	MANDATORY

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
G EXCELLENT CARE			
G5	Each Specialist Surgical Centre will report on adverse incidents. In addition to contractual and national reporting requirements Specialist Surgical Centres must demonstrate how details of adverse incidents are disseminated across the local and national Congenital Heart Networks	Reported adverse health care events, including reports from other Specialist Surgical Centres Report of the Paediatric Congenital Cardiac Services Review Group (2003)	MANDATORY
G6	Each Specialist Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). Audit of clinical practice should be considered where recognised standards exist or improvements can be made. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance should be undertaken annually	Database entry 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)	MANDATORY
G7	Specialist Surgical 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'	MANDATORY
G8	Each Specialist Surgical 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 Commission 'Annual Health Check'	MANDATORY AMBER
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'	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS
G EXCELLENT CARE			
G10	Specialist Surgical Centres must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. The Specialist Surgical 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)	MANDATORY
G11	Specialist Surgical 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)	HIGHLY DESIRABLE
G12	Each Specialist Surgical Centre must have, and regularly update, a research strategy and programme that documents current and planned research activity, the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other Specialist Surgical 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	Staff records Training available Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service' Report of the Paediatric Congenital Cardiac Services Review Group (2003)	MANDATORY
G13	Each Specialist Surgical 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'	MANDATORY
G14	Specialist Surgical 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)	MANDATORY AMBER

APPENDIX A: MEMBERSHIP OF STANDARDS WORKING GROUP

NAME	MEASURES	COMPATIBLE EVIDENCE BASE
Mr William Brawn (Chair)	British Congenital Cardiac Association (Immediate Past President – President until November 2009)	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust
Dr Martin Ashton-Key	National 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 Specialist Surgical Centre and across the Congenital Heart Network. As a senior member of the clinical team at the Specialist Surgical Centre they will also contribute to the strategic development of the whole service across the Congenital Heart 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 roler 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 Congenital Heart 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: EXCLUDED PROCEDURES

- 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
- 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
- 154306.** Unplanned reoperation during current admission
- 155000.** Cardiac catheterisation complication
- 158052.** Postprocedural left pleural effusion
- 158055.** Postprocedural chylothorax
- 158061.** Pleural effusion requiring drainage
- 158090.** Intraoperative phrenic nerve injury (paralysed diaphragm)
- 159001.** Postprocedural complication
- 171002.** Medical therapy for endocarditis

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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 Specialist Surgical Centre and Congenital Heart Network
- 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 Specialist Surgical Centre 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

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APPENDIX H - NETWORK GROUP MEMBERSHIP

NAME	CONSTITUENCY		ROLE
Dr Sue Hobbins	Chair of the Network Group Royal College of Paediatrics & Child Health		Consultant Paediatrician, South London Healthcare NHS Trust
Cathy Edwards	SCG Commissioning		Director, Yorkshire and Humber SCG
James Ford	Grayling (Media Support)		Managing Director, Public Sector, Grayling
Jeremy Glyde	National Specialised Commissioning Team		Programme Director, Specialised Services Team
Dr Ian Jenkins	Paediatric Intensive Care Society (Immediate past President)		Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust
Anne Keatley-Clarke	Patients, parents and public		Chief Executive, Children's Heart Federation
Teresa Moss	National Specialised Commissioning Team		Director, National Specialised Commissioning
Dr Victor Ofoe	NHS Wales		Paediatric Congenital Cardiologist, Cardiff and Vale UHB (for NHS Wales)
Dr Tony Salmon	British Congenital Cardiac Association (President Elect)		Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust
Fiona Smith	Royal College of Nursing		Adviser in Paediatric Nursing, RCN
Simon Williams	SCG Commissioning		Divisional Director, London SCG
Maria von Hildebrand	Patients, parents and public		Patient and Public Stakeholder Engagement Manager, DH
Dr Jonathan Howell	Public Health Consultant, SCG Public Health Group		West Midlands Specialised Commissioning Team
Professor Shakeel Qureshi	British Congenital Cardiac Association (President)		Consultant Paediatric Cardiologist, Guy's and St Thomas' Hospital
Dr Dirk Wilson	NHS Wales		Paediatric Congenital Cardiologist, Cardiff and Vale UHB (for NHS Wales)

APPENDIX I - FINANCE WORKING GROUP MEMBERSHIP

NAME	CONSTITUENCY		ROLE
Neil Wilson - Chair	East of England SCG		Interim Chief Operating Officer, East of England SCG
John Anderson	North East SCG		Head of Contracting and Performance, North East SCG
Neil Brent	South West SCG		Associate Director of Planning & Analysis, South West SCG
Frances Carey	Yorkshire and Humber SCG		Deputy Director of Finance, Yorkshire and Humber SCG
Pete Davies	East Midlands SCG		Head of Finance, East Midlands SCG
Garth Gilham	Support to National Specialised Commissioning Team		Manager, KPMG
John Hasson	South East Coast SCG		Associate Director - Finance & Information, South East Coast SCG
Phil Heywood	North West SCG		Head of Finance, North West SCG
Deborah Lane	West Midlands SCG		Finance Manager, West Midlands SCG
Paul Larsen	National Specialised Commissioning Team		Finance Lead, National Specialised Commissioning Team
Stewart Lewis	South Central SCG		Senior Finance Manager, South Central SCG
Ges Molina	London SCG		Senior Finance Manager, London SCG
Veronica Watson	East of England SCG		Director of Finance & Performance, East of England SCG

APPENDIX J - ASSESSMENT PANEL TERMS OF REFERENCE AND BIOGRAPHIES

Membership

A consistent single panel will be convened, whose members will be available to participate in all review visits. The panel will be identified by the Chair of the *SAFE AND SUSTAINABLE* Steering Group and Director of National Specialised Commissioning in consultation with relevant professional associations having regard to the need for the panel to have:

- Appropriate qualifications, experience and understanding
- No existing, direct relationship with any of the current providers of paediatric cardiac surgery in England that could reasonably constitute a conflict of interest
- No other circumstances that could reasonably constitute a conflict of interest
- Ideally, experience of similar reviews

The panel members will individually be expert in the following:

- Paediatric cardiac surgery
- Paediatric cardiology
- Paediatric anaesthesia / paediatric intensive care
- Paediatric nursing
- Paediatrics and child health
- Lay representation
- NHS commissioning

In addition, the Chair of the *SAFE AND SUSTAINABLE* Steering Group and Director of National Specialised Commissioning will identify a Chair of the panel having regard to the need for the Chair to have appropriate experience and standing.

The role of the Chair will be to:

- Ensure that the review visit process is delivered with sufficient probity, impartiality and rigour
- Oversee the review visits such that they are delivered in a consistent manner and that no centre is unreasonably disadvantaged by any aspect of process
- Manage each post-visit panel meeting to deliver the required outputs
- Bring to the attention of the Director of National Specialised Commissioning any relevant issues about process that become apparent during the period of the review visits
- Bring to the attention of the Director of National Specialised Commissioning any concerns about safety that become apparent during the period of the review visits
- Represent the panel at meetings of the joint PCT committee and NSCG, as required

Specialised Commissioners

A Specialised Commissioning Group Director (SCGD) will attend each review visit as an observer on behalf of the SCG Directors' Group.

Assessment process

In advance of the review visits, the panel will receive from the NSC Team a written brief (in a consistent format) on each centre comprising:

- A self assessment by the centre against the designation criteria
- A commentary from the centre's NHS commissioning body
- Background information on the centre prepared by the NSC Team and approved by the centre's NHS commissioning body

In advance of the review visits the panel will each, individually, score each self assessment submission having regard to evaluation criteria developed by the NSC Team.

The panel will then visit each centre between May and June 2010. The structure of the visit will be consistent across all centres.

The purpose of the review visit is for the panel to reconsider their previous scoring based on interviews with clinical and executive staff and patient representatives, and on inspection of premises and facilities. At the conclusion of each visit the panel will collectively discuss the outcome of the visit and will agree a consensus score against each of the designation criteria. At the conclusion of the review visit process the panel will meet with the Chair of the *SAFE AND SUSTAINABLE* Steering Group and Director of

National Specialised Commissioning to sign-off the final scores and ranking of centres against the designation criteria. The outcome of this work will be used by the National Specialised Commissioning Team and joint PCT committee in the evaluation of configuration options.

Secretariat support

The panel will receive secretariat support from the NSC Team.

Confidentiality

All information received by the panel will be regarded as confidential and will not be disclosed to other parties unless with the express agreement of the Director of National Specialised Commissioning.

At the conclusion of this work the panel will return all paperwork to the NSC Team.

Public announcements

The panel will not make any public announcement unless with the express agreement of the Director of National Specialised Commissioning.

Impartiality and probity

The panel will not discuss any aspect of the review process or the outcomes of the review process with officers or representatives of any centre or other parties except as part of the process as set out in these terms of reference. Members of the panel will immediately inform the Chair if a conflict of interest or potential conflict of interest becomes apparent.

Transparency

Details of the panel will be made publically available.

Assessment Panel Biographies

Professor Sir Ian Kennedy

Professor Sir Ian chaired the public inquiry into the care of children receiving heart surgery at the Bristol Royal Infirmary between 1984 and 1995. His landmark 'Kennedy Report' in 2001 highlighted fundamental flaws in the planning, delivery and management of paediatric cardiac surgical services and it made a number of recommendations around safety, medical competency and public involvement relevant to the NHS as a whole. He was Chair of the Healthcare Commission from 2003 to 2009, after which he became Chair of the Kings Fund inquiry into the quality of general practice in England. In 2009 he also became Chairman of the Independent Parliamentary Standards Authority.

Dr Michael Godman

Dr Godman is a retired Consultant Paediatric Cardiologist. He worked in the Royal Hospital for Sick Children in Edinburgh until 1999, during which time he was also a Senior Lecturer in the Department of Child Life and Health, and the Medical Director for the hospital. From 1999 to 2008 he worked in Riyadh, Saudi Arabia as Co-Chairman of the Department of Cardiac Sciences. He is Chairman of the Association of European Paediatric Cardiologists, and also President of the British Paediatric Cardiac Association.

Maria von Hildebrand

Maria von Hildebrand has been working in patient and public involvement since 1995. She is the founder of Constructive Dialogue for Clinical Accountability, a national charity set up in partnership with patients, the public and clinicians. The objective of her work has been to improve the information exchange between health care professionals and patients, to ensure there is knowledge transfer and shared responsibility for the process of informed consent resulting in improved quality and safety outcomes for public benefit.

She has worked as a policy adviser to the Department of Health, including input to the National Service Framework for Children, the Every Child Matters Framework, the Paediatric Review for Paediatric and Congenital Cardiac Services, as an independent patient advocate for both adult and paediatric Cardiac Audit Data Committees and the National Bowel Cancer Audit Prospectus Committee. In June 2009 she took up her current post as Patient and Public Stakeholder Engagement Manager for the Research Capability Programme.

Dr David Mabin

Dr Mabin is a Consultant Paediatrician with expertise in cardiology working for the Royal Devon & Exeter NHS Foundation Trust. He is the Convenor for Paediatric Cardiology at the Royal College of Paediatrics and Child Health. He also sits on the British Congenital Cardiac Association Council and is Clinical Sub-Dean at the Peninsular Medical School in Exeter.

Mr James Monro

Mr Monro was a Consultant Congenital Cardiac Surgeon in the NHS until 2004. He was President of the Society of Cardiothoracic Surgeons of Great Britain and Ireland from 2000-2002, President of the European Association for Cardiothoracic Surgery from 2030-2004 and was founding Chairman of the EACTS Congenital Cardiac Surgical Committee. Mr Monro was co-chairman of the committee which produced the 'Report of the Paediatric and Congenital Cardiac Services Review Group' in 2003.

Dr Neil Morton

Dr Morton is a Consultant in Paediatric Anaesthesia and Pain Management at the Royal Hospital for Sick Children in Glasgow and a Senior Lecturer at the University of Glasgow. He has specialised in paediatric cardiac anaesthesia since 1989. He is currently President of the Association of Paediatric Anaesthetists of Great Britain and Ireland and Editor-in-Chief of the international Journal of Paediatric Anaesthesia.

Sally Ramsay

Sally Ramsay is registered as a children's nurse. Her NHS career culminated in 8 years as Director of Nursing in a children's hospital. For the past 7 years she has worked independently. Her work has included service and education reviews, preparing expert reports and writing standards and clinical guidance documents for the Royal College of Nursing.

Julia Stallibrass MBE

For the last 20 years Julia Stallibrass has worked in the NHS in various public health and commissioning roles, most recently as Head of Specialised Services Commissioning in the National Specialised Commissioning Team. She has also worked for the Department of Health where she was the policy lead for commissioning specialised services. Whilst at the Department of Health she produced the Carter Report on the 'Review of Commissioning Arrangements for Specialised Services' (May 2006). She retired in 2009 and in that year she received an MBE for services to the NHS.

APPENDIX L - HEALTH IMPACT ASSESSMENT STEERING GROUP TERMS OF REFERENCE

1. CONSTITUTION OF THE GROUP

1.1 Background

The National Health Service Management Board (NHSMB) has asked the National Specialised Commissioning Group (NSCG) to:

Develop proposals for a **SAFE AND SUSTAINABLE surgical service for children with congenital heart disease in England and to make recommendations to NHSMB and Ministers.**

The final decision on the future configuration of services will be made by the Joint Committee of Primary Care Trusts (JCPCT). The NHS Specialised Services has established a Health Impact Assessment (HIA) Steering Group, which will be accountable to the JCPCT and will manage the development of a Health Impact Assessment on children and their families and carers on the proposals to improve services for children with congenital heart disease in England and Wales.

1.2 Principles

The purpose of the HIA is to produce a set of evidence-based practical recommendations that will inform decision-makers on how best they can promote and protect the health and well-being of local populations.

1.3 Terminology

Health Impact Assessment is used in this document as a term comprising Health Impact Assessment and Equality Impact Assessment, as defined by legislation.

1.4 Purpose and scope

HIA will be part of a suite of evidence necessary for JCPCT to consider as part of its decision-making process.

In accordance with the Department of Health guidance, in particular, *Health Impact Assessment of Government Policy: A guide to carrying out a Health Impact Assessment of new policy as part of the impact assessment process* (published in 2010), HIA on children and their families and carers on the proposals to improve surgery for children with congenital heart disease in England and Wales will consist in the following stages:

A) Screening. At the end of this stage, the screening question will be used to decide whether to proceed to further stages.

B) Identify health impacts. At the end of this stage, a long list of all the potential impacts on the health of the population – major or less serious, direct or indirect and occurring at any stage of the implementation of the proposals will be identified.

C) Identify impacts with important health outcomes. At the end of this stage, the most important health impacts will be identified, especially those that may:

- Impact on the whole population or on specific age groups, ethnic groups, religious groups or socioeconomic groups
- Be difficult to remedy or have an irreversible impact
- Be medium to long term
- Cause a great deal of public concern
- Have cumulative or synergic impacts

D) Quantify or describe important health impacts. At the end of this stage, qualitative and quantitative judgement about the important health impact will be made, including their potential costs and benefits, how health varies in different circumstances and why.

E) Recommendations to achieve most health gains. This is the most important stage in HIA and the end of this, the recommendations will be made about how the proposals can be amended to deliver the greatest possible health gain for the population in relation to the overall costs of the proposals. The recommendations will:

- Identify the health impact
- State whether the impact is positive or negative
- Set out changes to the proposals that would improve the health outcomes of the population affected by the proposals

The HIA will answer two key questions:

- What are the positive and negative impacts of the proposed changes on communities within England and Wales, particularly in respect of (a) health; (b) health inequalities; (c); access (d) carbon footprint and (e), equalities taking specific regard, but not exclusively, to the groups defined in legislation?
- How can any adverse impacts be mitigated and positive impacts enhanced?

The HIA will be based on the following principles:

- A robust and objective methodology will be used for the assessment of the impacts of changes to services
- The legal requirements for health impact assessment are met
- There is consideration of key 'traditionally under represented' groups across England and Wales

1.5 Membership and governance

Membership of the HIA Steering Group is drawn from JCPCT, clinicians, patient and public representatives and other key stakeholders. A Quorum would consist of the Chair, Joint Committee of PCTs Sponsor plus three other members, of whom at least one would be a clinician and a patient, carer and public representative. The membership list is attached as **Annex A**.

The JCPCT has appointed a Sponsor who reports to JCPCT and seeks JCPCT's sign off at different stages of the work programme. The HIA Steering Group will be supported by a HIA Work Group and the Secretariat.

Frequency

The HIA Steering Group will meet on at least three occasions. The frequency of meetings will depend on progress made in between meetings and some work may be carried out via e-mail.

2. FUNCTIONS AND RESPONSIBILITIES

2.1 HIA Steering Group

Within the timeframe set by JCPCT, the purpose of the HIA Steering Group is to define potential impacts of these changes on communities in England and Wales, particularly in respect of (a) health; (b) health inequalities; (c); access (d) carbon footprint and (e), equalities taking specific regard, but not exclusively to the groups defined in legislation. This will be achieved by the Group through:

- Providing part of the governance and challenge for a HIA to be undertaken on the proposals for improving surgical services for children with congenital heart disease in England and Wales
- Guiding the development of HIA by quality assuring HIA and advising of whether the legal requirements for health impact assessment are met
- Defining potential impacts of these changes on communities in England and Wales, particularly in respect of (a) health; (b) health inequalities; (c); access (d) carbon footprint and (e), equalities taking specific regard, but not exclusively to the groups defined in legislation

- Overseeing the development and implementation of a HIA that incorporates disability, race and ethnicity, religion or belief, age, gender and sexual orientation
- Identifying underlying themes and actions required to address any adverse impact on any equality group
- Signing off key stages of HIA for consideration of the JCPCT
- Reviewing methodology for the HIA
- Acting as a source of independent advice and guidance for providers and the Secretariat
- Receiving and reviewing reports on HIA with a view to recommend improvements to current processes and procedures relating to HIA
- Monitoring progress of the HIA against the key milestones

2.2 Chair

The key tasks and objectives of the Chair are to:

- Ensure that the process is delivered with probity, impartiality and rigour
- Manage the process to deliver the required outputs
- Chair the Group meetings. In the absence of the Chair, a senior member of the HIA Steering Group, appointed by the Chair, will chair the meeting
- Ensure that issues identified by the Steering Group are reported to the JCPCT via the JCPCT Sponsor

- Ensure that the Group is quorate and operates within the governance framework
- Bring to the attention of the Director of NHS Specialised Services any relevant issues
- Represent the panel at meetings of the JCPCT and Paediatric Cardiac Steering Group as required

2.3 All Members of the HIA Steering Group

- Provide independent expertise and advice to guide the development of the HIA
- Act independently and without bias towards their organisations and/or associations
- Attend all meetings of the HIA Steering Group
- Understand the role of the Group and the responsibilities of a HIA Steering Group member
- Apply due diligence in discharging the duties of a member by considering and evaluating all information provided, and being satisfied that all appropriate assurances can be taken from this
- Prepare appropriately for all HIA Steering Group meetings

2.4 Provider

Following the tendering process, Mott MacDonald has been appointed by NHS Specialised Services to carry out the HIA on the proposals to improve paediatric congenital cardiac services in England and Wales. The key tasks and objectives of Mott MacDonald are to:

- Ensure the development of a robust and

objective methodology to be used for the health impact assessment of the impacts of changes to services

- Review and assess relevant secondary evidence based information that informs the HIA provided by *SAFE AND SUSTAINABLE* Team and HIA Steering Group, as appropriate, or sourced externally
- Review outcomes from public events, Overview and Scrutiny Committee meetings and existing recent reports of activity and access that informs the HIA
- Undertake primary consultation with health and equality organisations and traditionally under-represented groups across England and Wales. Nine health and equality forums will be undertaken in parallel with the formal public consultation and will facilitate the qualitative assessment of the views of local representatives about the potential impact of the configuration options on health inequalities and equality groups. Primary consultation will also include one focus group with representatives who may be disproportionately impacted by the configuration options. Direct consultation with this group will assist with the development of actions to limit adverse measures
- Undertake operational site and travel access and carbon footprint assessments of the proposals based on modelling changes to travel times for ambulance, public transport and private car use and changes in activity volumes across the sites
- Identify the positive impacts of the proposed changes and how these may be enhanced as well as any negative impacts and how these may be mitigated

- Provide progress reports and feedback on emerging issues to the HIA Steering Group and Work Group
- Review and work with the option appraisal process to ensure that the criteria selected address inequalities
- Prepare the Scoping and Initial Assessment interim report (**Phase 1 Scoping Report**) of the emerging findings for the HIA Steering Group by 18 January 2011
- Prepare the **Phase 2 Draft Main HIA report** for the HIA Steering Group in time for the JCPCT meeting in the Summer to discuss the outcome of the consultation (currently planned for mid-July)
- Prepare the **Phase 3 Final Output Reports and Monitoring Recommendations** which will include an addendum in light of the Final Business Case (FBC) including any variant option(s) for the HIA Steering Group by mid-August 2011. This is subject to FBC/variant options having been identified and agreed

2.5 Secretariat

The *SAFE AND SUSTAINABLE* Team will act as secretariat for the HIA Steering Group. The key tasks and objectives of the Secretariat are to:

- Monitor progress of the HIA through regular contact with providers
- Check whether HIA action plan is completed.
- Review the HIA process as and when necessary
- Report to HIA Steering Group and to JCPCT on a regular basis on progress and key outcomes from HIA

A **Project Coordinator** will be appointed from within the Secretariat. The key tasks and objectives of the Project Coordinator are to:

- Guide the development of the governance and workplan throughout the project
- Direct the preparation of papers for the HIA Steering Group as appropriate in accordance with the project's workplan
- Prepare the agenda for each meeting, in consultation with the Chair, the JCPCT Sponsor, and the provider, with reference to the project's workplan and the programme's key milestones
- Liaise with appropriate individuals to obtain relevant HIA Steering Group papers. Ensure all appropriate actions are carried out as directed by the HIA Steering Group, in accordance with the agreed timescales
- Ensure the provision of a secretariat function that supports the HIA Steering Group in:
 - distributing the papers for each meeting, at least five working days in advance
 - preparing the minutes and distributing them within 10 working days of the meeting and disseminating them on the project website. All relevant papers, including minutes, once ratified, may be circulated by members and will be published on the NHS Specialised Services website unless they are clearly marked confidential
 - submitting the minutes and reports to the JCPCT as appropriate and when relevant

3. REVIEW

The HIA Steering Group will formally review its Terms of Reference after the decision on future options is made by the JCPCT. At its formation the presumption is that the HIA Steering Group will complete its work by autumn of 2011 and will then disband subject to JCPCT's agreement.

4. CONFIDENTIALITY

The members of the HIA Steering Group undertake not to divulge any confidential information relating to the business or affairs of the HIA Steering Group.

5. IMPARTIALITY AND PROBITY

The HIA Steering Group will not discuss any aspect of the review process or the outcomes of the process with officers or representatives of any centre or other parties except as part of the process as set out in these terms of reference.

Members of the HIA Steering Group will immediately inform the Chair if a conflict of interest or potential conflict of interest becomes apparent.

6. TRANSPARENCY

Details of the HIA Steering Group will be made available to the public.

NAME	CONSTITUENCY		ROLE
Professor Michael Simmonds	Independent Lay Chair		Chairman, <i>SAFE AND SUSTAINABLE</i> HIA Steering Group
Deborah Evans	Joint Committee of Primary Care Trusts		Chair, South West Specialised Commissioning Group / Chief Executive, Bristol PCT
Stephanie Newman	NHS Commissioning		Director Specialised Commissioning, South East Coast Specialised Commissioning Group
Mr Andrew Parry	Paediatric Cardiac Surgery		Consultant Congenital Cardiac Surgeon, Bristol Royal Hospital for Children
Dr John Thomson	Paediatric Cardiology		Consultant in Adult Congenital Heart Disease, Leeds Teaching Hospitals NHS Trust
Dr Hilary Robinson	Paediatrics		Consultant Paediatrician with Expertise in Cardiology Royal United Hospital Bath NHS Trust
Kerry Gaskin	Nursing		Chair of Congenital Cardiac Nurses Association
Dr Peter-Marc Fotune	Paediatric Intensive Care		Clinical Director of Critical Care, Theatres & Anaesthetics, Children's Division, Central Manchester University Hospitals NHS Foundation Trust
Dr Jane Moore	Public Health		Associate Regional Director of Public Health, NHS London
Rob Willoughby	Local Authorities'– Children's Services		Senior Officer - Children & Young Peoples' Services Wolverhampton City Council
Dr Sunjai Gupta	Department of Health		Deputy Director, Head of Public Health Strategy and Social Marketing Branch Health Improvement and Protection Department of Health
Kulvinder Kang	Hard-to-reach communities		Honorary Diversity Manager, Children's Heart Federation
Dr David Simpson	NHS in Scotland		Associate Clinical Director of Anaesthesia, Theatres & Critical Care Royal Hospital for Sick Children, Edinburgh
Mr Hugo van Woerden	NHS in Wales		Consultant in Public Health Medicine, Welsh Specialised Services Committee
Zuzana Bates	National Specialised Commissioning Team		Senior Project Liaison Manager
Bashir Arif	Health Impact Assessment Advisor		Advisor
Vacant	Patient Transport Organisation Representative		
Vacant	Northern Ireland		

APPENDIX N - NHS TRUSTS WITH DISTRICT GENERAL HOSPITALS THAT CURRENTLY HAVE MORE THAN 3,000 BIRTHS PER YEAR

NHS Trusts with District General Hospitals (DGHs) that currently have more than 3,000 births per year (excluding trusts with current paediatric cardiac surgery centres)

NAME OF TRUST	BIRTHS 2009/10
South London Healthcare NHS Trust	11,328
Heart Of England NHS Foundation Trust	11,284
Pennine Acute Hospitals NHS Trust	10,343
Imperial College Healthcare NHS Trust	10,224
Nottingham University Hospitals NHS Trust	10,200
Barking, Havering And Redbridge University Hospitals NHS Trust	9,677
Liverpool Women's NHS Foundation Trust	8,758
North Bristol NHS Trust	7,340
Birmingham Women's NHS Foundation Trust	6,961
Barnet And Chase Farm Hospitals NHS Trust	6,801
Sheffield Teaching Hospitals NHS Foundation Trust	6,775
Mid Yorkshire Hospitals NHS Trust	6,591
East Lancashire Hospitals NHS Trust	6,573
Guy's And St Thomas' NHS Foundation Trust	6,524
County Durham And Darlington NHS Foundation Trust	6,223
Sandwell And West Birmingham Hospitals NHS Trust	6,138
Bradford Teaching Hospitals NHS Foundation Trust	6,065
Derby Hospitals NHS Foundation Trust	6,012
Portsmouth Hospitals NHS Trust	6,005
University Hospital Of North Staffordshire NHS Trust	5,999
United Lincolnshire Hospitals NHS Trust	5,974
Cambridge University Hospitals NHS Foundation Trust	5,909
Gloucestershire Hospitals NHS Foundation Trust	5,866

NAME OF TRUST	BIRTHS 2009/10
Kingston Hospital NHS Trust	5,727
Norfolk And Norwich University Hospitals NHS Foundation Trust	5,721
Western Sussex Hospitals NHS Trust	5,644
East And North Hertfordshire NHS Trust	5,633
Hull And East Yorkshire Hospitals NHS Trust	5,627
Brighton And Sussex University Hospitals NHS Trust	5,623
University Hospitals Coventry And Warwickshire NHS Trust	5,605
Royal Berkshire NHS Foundation Trust	5,586
Worcestershire Acute Hospitals NHS Trust	5,571
West Hertfordshire Hospitals NHS Trust	5,559
Calderdale And Huddersfield NHS Foundation Trust	5,545
Chelsea And Westminster Hospital NHS Foundation Trust	5,493
Central Manchester University Hospitals NHS Foundation Trust	5,427
East Kent Hospitals University NHS Trust	5,378
Heatherwood And Wexham Park Hospitals NHS Foundation Trust	5,363
Whipps Cross University Hospital NHS Trust	5,339
Buckinghamshire Hospitals NHS Trust	5,326
South Tees Hospitals NHS Trust	5,311
University College London Hospitals NHS Foundation Trust	5,251
Doncaster And Bassetlaw Hospitals NHS Foundation Trust	5,248
Newham University Hospital NHS Trust	5,167
Luton And Dunstable Hospital NHS Foundation Trust	5,076
Shrewsbury And Telford Hospital NHS Trust	5,040
St George's Healthcare NHS Trust	5,014
Epsom And St Helier University Hospitals NHS Trust	5,004
North West London Hospitals NHS Trust	4,978
Maidstone And Tunbridge Wells NHS Trust	4,940
Frimley Park Hospital NHS Foundation Trust	4,796
Wiltshire PCT	4,729
Royal Bolton Hospital NHS Foundation Trust	4,707
Northern Lincolnshire And Goole Hospitals NHS Foundation Trust	4,697

NAME OF TRUST	BIRTHS 2009/10
The Dudley Group Of Hospitals NHS Foundation Trust	4,674
Medway NHS Foundation Trust	4,546
Barts And The London NHS Trust	4,428
Homerton University Hospital NHS Foundation Trust	4,416
Basildon And Thurrock University Hospitals NHS Foundation Trust	4,393
Mayday Healthcare NHS Trust	4,363
Northampton General Hospital NHS Trust	4,353
Surrey And Sussex Healthcare NHS Trust	4,351
King's College Hospital NHS Foundation Trust	4,320
West Middlesex University Hospital NHS Trust	4,319
Royal Cornwall Hospitals NHS Trust	4,237
Colchester Hospital University NHS Foundation Trust	4,126
Great Western Hospitals NHS Foundation Trust	4,100
The Hillingdon Hospital NHS Trust	4,096
The Whittington Hospital NHS Trust	4,065
Peterborough And Stamford Hospitals NHS Foundation Trust	4,035
East Sussex Hospitals NHS Trust	4,009
Stockport NHS Foundation Trust	3,898
Ashford And St Peter's Hospitals NHS Trust	3,852
Mid Essex Hospital Services NHS Trust	3,849
The Princess Alexandra Hospital NHS Trust	3,830
Plymouth Hospitals NHS Trust	3,805
The Royal Wolverhampton Hospitals NHS Trust	3,796
Kettering General Hospital NHS Foundation Trust	3,753
Milton Keynes Hospital NHS Foundation Trust	3,736
Walsall Hospitals NHS Trust	3,649
Southend University Hospital NHS Foundation Trust	3,626
North Tees And Hartlepool NHS Foundation Trust	3,621
Dartford And Gravesham NHS Trust	3,571
Royal Devon And Exeter NHS Foundation Trust	3,517
Wirral University Teaching Hospital NHS Foundation Trust	3,515

NAME OF TRUST	BIRTHS 2009/10
University Hospital Of South Manchester NHS Foundation Trust	3,484
Burton Hospitals NHS Foundation Trust	3,438
University Hospitals Of Morecambe Bay NHS Trust	3,391
City Hospitals Sunderland NHS Foundation Trust	3,377
York Hospitals NHS Foundation Trust	3,276
The Lewisham Hospital NHS Trust	3,259
Taunton And Somerset NHS Foundation Trust	3,258
North Middlesex University Hospital NHS Trust	3,254
Warrington And Halton Hospitals NHS Foundation Trust	3,250
Tameside Hospital NHS Foundation Trust	3,230

APPENDIX O - FUTURE ACTIVITY PROJECTIONS

The *SAFE AND SUSTAINABLE* review needs to ensure that the future configuration of congenital cardiac services has sufficient capacity for current and projected activity levels

The *SAFE AND SUSTAINABLE* review has assumed a current national caseload for the English surgical centres as 3,600 operations on children per year. This figure is the result of a validation exercise undertaken by CCAD⁸⁰ with the surgical centres in July 2010. This includes children seen in English surgical units who live in Wales, Scotland, Northern Ireland, Channel Islands and Isle of Man.

The 2009/10 data has been independently validated and is shown below. The 2009/10 data (representing 1 April 2009 to 31 March 2010) has been used to underpin most of the analysis given it is the most up to date validated data available and in view of concerns (recognised by CCAD) about the reliability of more historical data on the CCAD database. The projected activity levels for each centre in the various potential options are shown in Appendix AG.

The figure excludes foreign private patients on the grounds that future flows of foreign private patients are largely dependent on global economics and would never in any event be commissioned by the NHS. The figure includes UK private patients as it is feasible that these patients may in the future choose to have their treatment funded by the NHS.

CENTRE	2009/10
Liverpool	400
Birmingham	555
Bristol	277
Newcastle	255
GOSH	541
Leicester	225
Evelina	337
Leeds	316
Royal Brompton	353
Oxford	108
Southampton	231
TOTAL	3,598

CCAD and the professional associations advise that the incidence of CHD in children over recent years has been steady, though there has been a gradual increase in the number of adults with CHD due to better diagnosis and treatment of children. Other countries also report these findings⁸¹.

In proposing, for planning purposes, an assumption of limited growth consistent with the projected birth rate for England and Wales, the review has considered a number of factors that may individually contribute towards an increase or decrease in future need.

Factors that may suggest an increase in future need:

Projected growth in the birth rate

population projections by UK National Statistics⁸² suggest an increase in the paediatric population of England and Wales by 13.7% by 2025 which could reasonably translate into a corresponding increase in the need for paediatric cardiac surgery.

More timely and accurate antenatal diagnosis

improved screening practices that increase the incidence of diagnosis of CHD before birth may result in a higher need for paediatric cardiac surgery (and because there is an association between antenatal diagnosis and better outcomes). However, we cannot make any firm projection based on this factor as many babies who are currently not diagnosed in the womb are subsequently diagnosed with CHD after birth and receive surgery.

Improved neonatal care

improved neonatal rescue including advanced techniques in neonatal intensive care may suggest an increased need for paediatric cardiac surgery, but difficult to quantify at this time.

Population growth for specific populations

the review has considered the future need of areas with high Black and Ethnic Minority groups in response to evidence that the projected birth rate may be higher for some ethnic community groups⁸³. It has also been suggested that there may be a higher incidence of congenital heart defects in the offspring of consanguineous couples. The population data that has been applied by the review has been sourced from a specialist geographic information solutions third-party. It is taken from Census data which is updated typically twice per year in line with 'Postcode Release' updates. The original Census counts are from the 2001 Census but counts are projected based on shifts in delivery counts from the most up to date postcode release at the time.

Therefore, account has been taken of the growth up to 2010 at locality level. Future growth has not been projected at postcode level, but nationally. It has been proposed that for planning purposes, at this stage in the process this level of detail is not required given that the relatively low incidence of total activity nationally suggests that it is reasonable to assume that any higher rates of incidence in specific areas can be managed within planned capacity assumptions.

⁸⁰ 2009/10 CCAD validated data, surgical procedures only

⁸¹ Commission for Paediatric Heart Interventions, *Concentration of congenital heart surgery and catheter interventions*, June 2009 Document translated from Dutch by Ubiquis, London

⁸² UK National Statistics website - Available at: <http://www.statistics.gov.uk/hub/index.html>

⁸³ Sadiq M, Stümper O, Wright JG, De Giovanni JV, et al. (1995). *Influence of ethnic origin on the pattern of congenital heart defects in the first year of life. British Heart Journal*; 73(2): 173-176

Factors that may suggest a decrease in future need:

More timely and accurate antenatal diagnosis
this may increase the number of terminated births in the future, but is difficult to quantify.

More sophisticated cardiology interventions
as interventional cardiology procedures become more sophisticated they are replacing surgery as the preferred intervention for some congenital heart conditions.

Better quality surgical services

the professional associations advise that one of the potential benefits of a higher quality service in the future (achieved through the establishment of fewer, larger surgical centres and the development of managed paediatric cardiology networks) is a reduced incidence of 're-operations' following the primary surgical procedure.

New Technology and drugs

medical advances in such areas as gene therapy and the introduction of new drugs may also reduce the need and frequency of some operations.

The review has taken into account population distribution and means that no area or population should be unduly disadvantaged by reducing the number of surgical centres. However, the Health Impact Assessment will provide a thorough means of assessing the impact of options for consultation on specific minority groups.

On the opposite page is a summary of the paper prepared by Dr Martin Ashton-Key, Medical Advisor to *SAFE AND SUSTAINABLE* on: "Congenital Cardiac Disease Review – An Overview of Surgical Activity (2006/07) and projections to 2025 based on National Statistics Population Projections".

Source of data

The analysis was conducted on the 2006/07 validated CCAD⁸⁴ data which was the latest available validated data at the time of the analysis (August 2009).

Aggregated Surgical Activity Trends 2002 – 2007

Aggregated activity for paediatric and adult surgical cases was extracted from CCAD for each year from 2002/03 to the last available data (2006/07) and shows the relatively stable paediatric workload but highlights the slow and continuous rise in adult surgical cases.

Estimated future trends (2006 – 2025) in paediatric cardiac surgery based on National Statistics Population Projections

Population projections are produced by UK National Statistics⁸⁵. The 2006-based National Population Projections present modelled annual

populations in 5-year age bands from 2006 to 2031 for England, England and Wales, Scotland, Northern Ireland, Great Britain and the United Kingdom, with longer range predictions to 2081.

For the purpose of estimating possible future trends in paediatric cardiac surgical activity the following age ranges were used: (0 – 4 years, 5 – 9 years and 10 – 14 years) to establish the projected changes in the paediatric population. The next age range (15 – 19 years) was not included because three of the five years included cover an adult population. Population projections beyond 2025 were not assessed.

These data revealed very small percentage changes in the paediatric population over the coming two to three years for each of the UK nations. However, the longer term projections from 2006 to 2025 suggest significant and variable percentage changes in the paediatric populations of the UK nations and are summarised in Table 1.

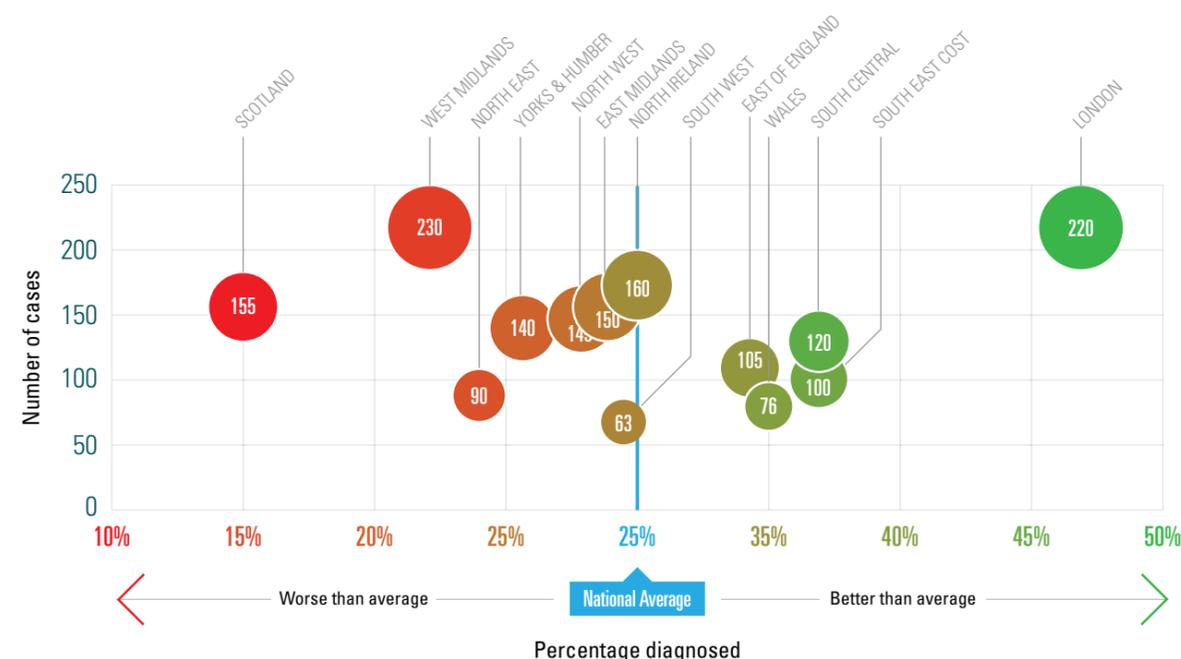
Table 1

Percentage change in the paediatric population (by 5-year age band) between 2006 and 2025 for UK country / countries based on the National Statistics 2006-based National Population Projections

AGE (YEARS)	ENGLAND	ENGLAND & WALES	SCOTLAND	NORTHERN IRELAND	GREAT BRITAIN	UNITED KINGDOM
0 – 4	16.0 %	15.6 %	-0.2 %	6.2 %	14.4 %	14.1 %
5 – 9	18.0 %	17.3 %	0.0 %	6.0 %	15.9 %	15.5 %
10 – 14	9.0 %	8.4 %	-7.0 %	-0.3 %	7.1 %	6.9 %
0 – 14	14.2 %	13.7 %	-2.6 %	3.9 %	12.3 %	12.0 %

⁸⁴ Congenital Heart Disease website (or CCAD website) - Available at: <http://www.ccad.org.uk/congenital>

⁸⁵ UK National Statistics website - Available at: <http://www.statistics.gov.uk/hub/index.html>



Assuming the epidemiology of congenital cardiac disease at an individual level does not change over the coming years and assuming the current activity reflects the true need, then a pragmatic approach to modelling the future need for paediatric cardiac surgery would be to apply the percentage change in population size to the 2006 paediatric cardiac surgery activity related to the country(ies) of interest. Table 2 gives the estimated annual paediatric cardiac surgery activity for English paediatric cardiac surgical units (covering English and Welsh

patients) and the paediatric cardiac surgical units in Scotland and Northern Ireland (thus reflecting the UK workload).

As can be seen the national caseload in Scotland and Northern Ireland is not projected to change significantly by 2025. However, the national caseload for England and Wales combined (reflecting the patterns of activity in the current English paediatric cardiac surgery units) is estimated to increase by approximately 480 cases per annum by 2025.

Table 2

Estimated paediatric cardiac surgery activity in 2025 based on National Statistics 2006-based National Population Projections applied to 2006/07 activity

	PAEDIATRIC CARDIAC SURGERY ACTIVITY (2006/07) – NUMBER OF CASES	PROJECTED PERCENTAGE CHANGE IN PAEDIATRIC POPULATION (USING 0 – 14 YEARS AS THE PROXY FOR THE WHOLE PAEDIATRIC POPULATION) FROM 2006 TO 2025	ESTIMATED PAEDIATRIC CARDIAC SURGERY ACTIVITY (2025) – NUMBER OF CASES
English paediatric cardiac surgery units (covering populations of England & Wales)	3,509	13.7%	3,990
Scottish paediatric cardiac surgery unit	273	(2.6)%	266
Northern Irish paediatric cardiac surgery unit	73	3.9%	76

Conclusions

Conclusions

The latest CCAD data confirms that current paediatric cardiac surgery activity has been constant for the past few years in the UK with approximately 3,600 paediatric cardiac surgery procedures performed each year, but that there is a slow but continuing increase in the number of surgical procedures performed on adults with congenital cardiac disease.

However, population projections produced by UK National Statistics would suggest increases in the paediatric population in England and Wales in the order of 13.7 % by 2025 which is likely to translate into a corresponding increase in the need for paediatric cardiac surgery activity by 2025 compared with 2006/07 activity levels. Smaller and less significant changes are projected for activity in Scotland and Northern Ireland.

This estimated increase has been modelled in Appendix AG. However the increase may be tempered by technological advances and increased rates of screening.

APPENDIX Q

Recipients of the working document 'Draft Service Specification Standards' in 2009 (not an exhaustive list)

Chief Executives, and clinical and management leads in the 11 surgical centres in England

Belfast Royal Hospitals

Yorkhill Children's Hospital, Glasgow

The 10 Strategic Health Authorities in England

Chairs and Directors of the 10 Specialised Commissioning Groups in England

Health Commission Wales

National Services Division, Scotland

Department of Health

British Congenital Cardiac Association

Association of Cardiothoracic Anaesthetists

Society for Cardiothoracic Surgery in Great Britain and Ireland

Paediatric Intensive Care Society

Children's Heart Federation and member organisations

British Cardiovascular Society

British Heart Foundation

Children's Heart Association

Children's Heart Surgery Fund

Heartline

Take Heart

British Association for Cardiac Rehabilitation

British Association for Nursing in Cardiovascular Care

Congenital Cardiac Nurses Association

British Association of Perinatal Medicine

Heart Research UK

Heart UK

National Heart Forum

Children's Cancer and Leukaemia Group

Royal College of Paediatrics and Child Health

Royal College of Surgeons

Royal College of Nursing

Royal College of Midwives

Royal College of Anaesthetists

Royal College of Physicians

Royal College of General Practitioners

British Medical Association

BMA Patient Liaison Group

Care Quality Commission

Council of Paediatric Anaesthetists

Essex Cardiac and Stroke Network

Cardiothoracic Transplant Advisory Group

Specialised Healthcare Alliance

NHS Confederation

Welsh NHS Confederation

London Paediatric Intensive Care Consortium

Centre for Public Scrutiny

Welsh Local Health Boards

LINKs in England

RCPCH Patients and Carers Group

National Children's Bureau

British Association of Perinatal Medicine

British Paediatric Cardiac Association

National Reference Group for Psychologists Working in Paediatric Cardiology

Society of British Paediatric Neurosurgeons

APPENDIX S - TRAVEL TIME ANALYSIS

Table 1 shows the number of people who have to travel under 1 hour, 1 to 2 hours, 2 to 3 hours, 3 to 4 hours and over 4 hours to the surgical centre in their network under each option. The networks assumed under each option can be seen in Section 11. The London networks have not been defined and it is assumed that travel

times to all London centres in equal (based on centre with the shortest travel time).

Table 2 below show the number of people who's travel time to the surgical centre in their network has increased by 0 to 30 mins, 30-90 mins, and over 90 mins under each option.

Table 1

Travel times by patient numbers

	CURRENT CONFIGURATION	OPTION 2	OPTION 6/ OPTION 10	OPTION 8/ OPTION 12	OPTION 14
Up to 1 hour	2,352	1,958	1,875	1,934	1,946
1 – 2 hours	1,000	1,194	1,140	1,215	1,091
2 – 3 hours	168	376	486	380	465
3 – 4 hours	65	57	82	56	83
Over 4 hours	13	13	13	13	13
Total	3,598	3,598	3,598	3,598	3,598

Table 2

Number of patients who experience an increase in travel time under each option

	CURRENT CONFIGURATION	OPTION 2	OPTION 6/ OPTION 10	OPTION 8/ OPTION 12	OPTION 14A
Increase of up to 30 mins	2,975	3,005	3,090	3,080	2,975
Increase of 30 – 90 mins	475	468	377	294	475
Increase of over 90 mins	148	126	130	224	148
Total	3,598	3,598	3,598	3,598	3,598

Note:

All options include: A minimum of two sites in London, Birmingham, Liverpool and Bristol. Option 2 includes Leicester. Option 14 includes Southampton. Options 2, 6, 10 and 14 include Newcastle. Options 8 and 12 include Leeds.

Source:

Population figures per postcode district in England and Wales and travel times data is for road journeys using 24 hour average speeds per road type. Underlying data base from Geoplan, Access Mapping Consultancy

APPENDIX T – RETRIEVAL TIME ANALYSIS

The sub-criterion applied to the evaluation of potential options was:

‘The retrieval team should arrive at the referring unit within three hours (extended to four hours in remote areas) of the decision to retrieve the child in accordance with the Paediatric Intensive Care Society ‘Standards for the Care of Critically Ill Children, 2010⁸⁶’

In order to test this, normal road journey times from the potential surgical units to near coastal District General Hospitals were taken from the Directgov website for various times of the day. The table shown on page 234 for departure times starting at noon, which gave the marginally longest travel times. Although ‘blue light’ ambulance journeys may be quicker in urban areas, it is unlikely to be much different on A-roads and motorways and so for the purposes of this evaluation car journey times have been used to give a ‘worst case’ timing.

This approach was agreed with the Immediate Past President of the Paediatric Intensive Care Society in December 2010.

The evaluation demonstrates that there would be an increase in retrieval times for populations whose current nearest surgical centre were to no longer provide surgery.

The evaluation suggests that all potential options comply with the 3-hour threshold stipulated by the PICS standards except those that would remove Bristol as a surgical unit (potential options 1, 7 and 11). For example, the retrieval times for children from the Truro area, which is already over 3 hours from Bristol, increases to over 4 hours in travelling to Southampton or Birmingham. Some other locations which are currently within 3 hours of Bristol such as Barnstaple, Plymouth and South West Wales would also exceed 3 hours under this scenario.

The potential impact on retrieval times is illustrated in the tables on the next few pages where the grey highlighted times are the current times to Bristol, the red highlighted time exceeds 4 hours, the yellow highlighted times exceed 3 hours and the blue highlighted times indicate no change.

It is recognised that the need for emergency retrieval is rare for children with congenital heart problems but time is of the essence when it is required. For this reason it is recommended to the JCPCT that Options 1, 7 and 11 are not viable and should not be an option for public consultation.

It is also recognised that in reconfiguring paediatric cardiac surgery centres there will be a consequential need to review the configuration of retrieval services.

⁸⁶ Paediatric Intensive Care Society, *Standards for the care of critically ill children (4th Edition)*, June 2010

Option 1

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM
Truro	03:04	04:15			
Barnstaple	02:12	03:26			
Plymouth	02:16	03:25			
Aberystwyth					02:55
Haverfordwest	02:33				03:52
Carmarthen	01:43				03:01
Swansea	01:24				02:42
Bournemouth		00:41			
Dorchester		01:13			
Yeovil	01:20	01:42			
Portsmouth		00:29			
Brighton				01:48	
Margate				02:00	

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				02:17
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

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Option 2

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				02:17
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

Option 6a

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth	03:06				02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25			02:34	
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

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Option 6b

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25	02:50			
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

- Current time
- Over 3 hours
- Over 4 hours
- Change < = 3
- No Change

Option 7

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04	04:15				
Barnstaple	02:12	03:26				
Plymouth	02:16	03:25				
Aberystwyth					02:55	
Haverfordwest	02:33				03:52	
Carmarthen	01:43				03:01	
Swansea	01:24				02:42	
Bournemouth		00:41				
Dorchester		01:13				
Yeovil	01:20	01:42				
Portsmouth		00:29				
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				
Scarborough	01:38				
Whitehaven		02:33	03:00		
Carlisle	02:33	01:31			
Barrow/ Furness			02:23		
Ashington	02:14	00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

Option 8

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				
Scarborough	01:38				
Whitehaven		02:33	03:00		
Carlisle	02:33	01:31			
Barrow/ Furness			02:23		
Ashington	02:14	00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD	NEWCASTLE
Ipswich	02:45	02:08	04:02	02:57	02:40	-
Great Yarmouth	03:19	03:08	04:34	03:32	03:38	-

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Option 10a

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		



NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25			02:34	
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

Option 10b

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich	02:45	02:08	04:02	02:57	02:40
Great Yarmouth	03:19	03:08	04:34	03:32	03:38

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Option 11

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04	04:15				
Barnstaple	02:12	03:26				
Plymouth	02:16	03:25				
Aberystwyth					02:55	
Haverfordwest	02:33				03:52	
Carmarthen	01:43				03:01	
Swansea	01:24				02:42	
Bournemouth		00:41				
Dorchester		01:13				
Yeovil	01:20	01:42				
Portsmouth		00:29				
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				
Scarborough	01:38				
Whitehaven		02:33	03:00		
Carlisle	02:33	01:31			
Barrow/ Furness			02:23		
Ashington	02:14	00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

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Option 12

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth	02:17	00:41				
Dorchester	01:52	01:13				
Yeovil	01:20					
Portsmouth		00:29		02:02		
Brighton				01:48		
Margate				02:00		

- Current time
- Change < = 3
- Over 3 hours
- No Change
- Over 4 hours

NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25				
Scarborough	01:38				
Whitehaven		02:33	03:00		
Carlisle	02:33	01:31			
Barrow/ Furness			02:23		
Ashington	02:14	00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

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Option 14

WEST & SOUTH ENGLAND & SOUTH WALES - 12:00 travel time

	BRISTOL	SOUTHAMPTON	OXFORD	LONDON	BIRMINGHAM	LEICESTER
Truro	03:04					
Barnstaple	02:12					
Plymouth	02:16					
Aberystwyth					02:55	
Haverfordwest	02:33					
Carmarthen	01:43					
Swansea	01:24					
Bournemouth		00:41				
Dorchester		01:13				
Yeovil	01:20					
Portsmouth		00:29				
Brighton		01:42				
Margate				02:00		



NORTH ENGLAND & NORTH WALES - 12:00 travel time

	LEEDS	NEWCASTLE	LIVERPOOL	BIRMINGHAM	LEICESTER
Grimsby	01:25			02:34	
Scarborough	01:38	02:23			
Whitehaven		02:33			
Carlisle		01:31			
Barrow/ Furness			02:23		
Ashington		00:33			
Bangor			01:40		
Aberystwyth			02:55	02:55	

EAST ENGLAND - 12:00 travel time

	LEICESTER	LONDON	LEEDS	BIRMINGHAM	OXFORD
Ipswich		02:08			
Great Yarmouth		03:08			

APPENDIX AA - RESPONSES RECEIVED TO EVALUATION CRITERIA

COMMENTS ON CRITERIA	NUMBER OF COMMENTS
ACHD/ transition to adult services should be included in the review process	18
Access to Foetal medicine and maternity units on the same site	7
Emotional benefits of locally provided care	6
Parent facilities and other amenities e.g. parking	4
Communication between centres	4
Critical interdependencies including theatres, PICU and cardiology	4
Continuity of care (same surgeon)	4
Impact of missed schooling/ impact of parent staying away from home	3
Quality of non surgical care/ after care	3
Affordability for parents (increased travel and child care, etc)	3
Blue light distance (ambulance travel time and retrieval)	2
Co-location of ECMO	2
Multi-disciplinary care	2
Importance of complex surgery (including continuity of care)	2
Sustainability of dependent services at centres facing closure	2
Focus on simple procedures as opposed to complex procedures with long treatment times	1

COMMENTS ON CRITERIA	NUMBER OF COMMENTS
No more than 500 procedures a year to keep service personal	1
Seamless transition of configuration options	1
Transfer of information between health professionals	1
Local long term specialisation on complex care	1
Prompt access to surgery	1
Open and honest communication with patients	1
Willingness of staff to relocate	1
Location of transport links	1
Patient choice (surgeons)	1
PROMS and quality of service	1
Risk of failed implementation	1
External support for parents	1
Access to local follow up care	1
Networks	1
Emergency transfer	1
Quality of hospital as a whole	1

APPENDIX AC - EVIDENCE SUPPORTING THE OPTIONS ASSESSMENT

Phase 3 evidence

As set out in Section 8, a number of working assumptions were applied as a result of detailed analysis completed on a number of different options. All sites were included in at least 3 different options. The results of the analysis suggested a number of evidence based assumptions that could be applied to the 2,047 theoretical options to shortlist 14 potentially viable options.

The assumptions are set out in Section 8; the evidence to support those assumptions is set out below.

The reconfigured service should have 6 or 7 centres

By applying the high level threshold recommended by the JCPCT, that all centres should carry out 400 procedures per annum as a minimum and preferably 500 per annum, it

was agreed that the potential reconfiguration options should focus on 6 and 7 centre options.

It is recommended that potential options with less than 6 centres are not viable on the basis that each centre would be required to carry out 720 procedures per annum if activity were equally spread across the centres. In reality, activity would not be equally spread and some centres would be required to carry out far in excess of this amount per annum at a level that is not safe and sustainable. It is recommended that this did not provide options for reconfiguration that were sustainable.

It is recommended that options with more than 7 centres are not viable on the basis that although each centre would carry out 450 procedures per annum if activity were equally spread across the centres, in reality activity would be unevenly spread potentially leaving some centres with less than the minimum 400 procedures. This assumption is backed up

with evidence that even under some 6 and 7 centre options, given network configurations and population density; some centres would be unable to attract the minimum critical mass of 400 procedures per annum. This situation would worsen under an 8 or 9 centre option. Therefore it was recommended that analysis would focus on 6 and 7 centre options only.

London requires at least 2 centres

The three London centres performed 1,231 procedures in 2009/2010. They have not performed fewer than 930 combined procedures per year in the last 10 years according to CCAD validated data.

It is assumed that this level of activity in London will not significantly decrease post re-configuration due to the large population in London itself and in East of England and South East England. Therefore for one site in London to perform this level of activity alone it would

require the one remaining site to more than double its current capacity. Although there is no agreed maximum activity level for a centre, it is recommended by the national review team that when a centre is expected to perform over 700 procedures per year the option must be scrutinised very closely to ensure networks are manageable in such a large catchment area and that the centre would have the capacity to manage that level of activity.

Therefore it is recommended that maintaining only one centre in London is not viable.

Therefore it is recommended that there should be at least two centres in London.

John Radcliffe Hospital, Oxford

Oxford’s assessment panel score was a statistical outlier and significantly below any of the other centres scores. The panel scored each site on;

- its current ability to meet the standards;
- its development plans in place to meet the standards in the future; and
- its ability to meet the standards should it receive 400+ referrals per year.

Across all categories, Oxford scored the lowest two scores: 1 = inadequate (no evidence) and 2 = poor (limited evidence) in 24 of a total of 32 questions. No other centre scored a 1 in any question or more than four “2s” across all 32 questions.

In addition, the following table shows the percentage of the population of England and Wales who are able to access their closest site within hourly intervals. Options including

Oxford do not improve access times. The most significant (negative) impact on access times is due to whether Bristol is present in an option or not.

Note:

Options shown here form part of the ‘iterative process’ discussed in section 8 of this business case. Many options were selected for detailed analysis giving rise to sufficient evidence for the JCPCT to agree the set of rules described here. Therefore the Option numbers shown in this table do not correspond to the final shortlist of 14 options described in section 8.

Option J includes: GOSH, Evelina, Bristol, Oxford, Birmingham, Liverpool and Newcastle. Option K includes: GOSH, Evelina, Southampton, Oxford, Birmingham, Liverpool and Newcastle. Option N includes: GOSH, Evelina, Oxford, Leicester, Birmingham, Liverpool and Newcastle.

The table below shows that potential options excluding Bristol have the worst access times (options E to H and K have 1.3% of the population travelling for over 4 hours and option 14 has 3.4% of the population travelling for over 4 hours compared to just 0.4% under the other options. The options with Oxford included (J, K and N) do not improve access times compared to the other options. Option J shows only 0.4% of the population travelling for over 4 hours however this is the same as options A to D that exclude Oxford. This suggests that including Oxford instead of Southampton has little inverse effect on travel times but it does not improve the access times. Therefore it is recommended that as it does not improve access, the quality issues are not counteracted and it is recommended that the Oxford site should not appear in any of the potential reconfiguration options for consultation.

Further information on the John Radcliffe Hospital is provided in section 9.

The centre in Birmingham should remain in all options

Throughout the extensive analysis looking at all 2,047 theoretical options and in more detail at the 6 site and 7 site options it became clear that the negative impact of removing the Birmingham centre was so significant that it is recommended that is not viable to propose the removal of the Birmingham centre from potential options.

Birmingham is the second largest conurbation in England and Wales, after London and the Birmingham centre is one of the largest surgical units in England and Wales performing 555 paediatric cardiac procedures in 2009/10. The size of the population and the fact that it is so densely populated around the city centre meant that every potential option explored without Birmingham had a significant impact on the travel times for significant number of people.

Journey times by road (% of the population of England and Wales)

	CURRENT CONFIGURATION (11 OPTIONS)	AVERAGE OF OPTIONS A – D (ALL EXCLUDE OXFORD BUT INCLUDE BRISTOL & SOUTHAMPTON)	AVERAGE OF OPTIONS E – H (ALL EXCLUDE OXFORD & BRISTOL BUT INCLUDE SOUTHAMPTON)		OPTION J (INCLUDES BRISTOL & OXFORD BUT NO SOUTHAMPTON)	OPTION K (INCLUDES SOUTHAMPTON AND OXFORD BUT NO BRISTOL)	OPTION N (INCLUDES OXFORD BUT NO BRISTOL OR SOUTHAMPTON)
Up to 1 hour	65.4%	54.1%	53.4%		52.1%	51.4%	43.4%
1 – 2 hours	27.6%	34.9%	33.1%		35.8%	33.7%	33.8%
2 – 3 hours	5.5%	9.0%	9.0%		10.7%	10.6%	15.2%
3 – 4 hours	1.1%	1.6%	3.1%		1.0%	3.1%	4.2%
OVER 4 HOURS	0.4%	0.4%	1.3%		0.4%	1.3%	3.4%

Bristol and Southampton are mutually exclusive based on ‘nearest centre’ analysis (subject to emerging local intelligence)

Based on an analysis of patients moving to their nearest centre both Bristol and Southampton failed to reach the minimum of 400 procedures per year under any of the options explored where both centres were present along with 2 London sites and Birmingham. This resulted in Southampton attracting between 242 and 344 procedures per year and Bristol between 279 and 337 per year depending on the other centres in the potential configuration option.

This assumption was tested to see if both sites could achieve 400+ procedures per year by increasing their catchment areas at the expense of London and Birmingham sites which achieve far in excess of the 400 minimum per year under this assumption. It was not possible to ensure that both Southampton and Bristol achieved the 400 minimum whilst maintaining realistic catchment areas/networks. In the test to identify whether both could achieve 400:

- Southampton’s catchment area and network was extended to include Brighton (BN) and Redhill (RH) which currently flow to London and Oxford (OX) and Reading (RG) which currently flow to Oxford. In this way it is proposed that Southampton could achieve 400 procedures per year whilst leaving much of its western catchment area to Bristol.

- However, it is proposed that Bristol is unable to achieve the 400 minimum even when its catchment area and network is extended to include Hereford (HR) and Worcester (WR) which currently flow to Birmingham; Swindon (SN) which is currently shared with Oxford and Salisbury (SP), Bath (BA), Dorchester (DT) and Plymouth (PL) which are currently shared with Southampton.

Although it is proposed to apply this assumption based on the ‘nearest centre’ analysis to the further testing of potential configuration options, it is recommended that a potential configuration option that retains both the Southampton and Bristol centres is potentially viable in view of local intelligence about the impact of patient flows in South Central England due to the suspension of the paediatric cardiac service at the John Radcliffe Hospital in Oxford. It is recommended that the viability of such a potential option is explored in detail during public consultation.

The North must have 2 centres: Liverpool and Newcastle or Liverpool and Leeds

From the extensive analysis conducted around access and activity redistribution it is recommended that the population in the north

of England can only sustain two of the current three centres ensuring a minimum of 400 procedures per year.

Currently the three centres in the north achieve the following activity levels:

Historical activity levels at centres in the North of England

	2006/07	2007/08	2008/09	2009/10
Newcastle	241	233	264	255
Liverpool	380	356	336	400
Leeds	281	261	267	316

Source: CCAD Validated Data excluding foreign private patients

To see whether all three centres could achieve the 400 minimum by changing the networks currently in place a testing of potential catchment areas was applied by extending current catchments. It was not possible to ensure all three centres achieved 400 procedures per year based on the population in the north of England and Wales. When the Newcastle catchment area was extended south (resulting in Newcastle achieving the 400 minimum), the knock-on impact suggested that the Liverpool and Leeds catchment areas are also moved further south and both centres would then fail to achieve the 400 minimum.

There is a limit to how far south it is realistic to extend the Liverpool and Leeds catchment areas as patients living in Birmingham and Leicester postcode areas and postcode

areas that are direct ‘suburbs’ or part of that conurbation are very unlikely to ever be re-directed to a centre considerably further north. This testing was not intended to suggest that these ‘catchment areas’ represent current or future potential networks; rather it was an exercise to identify if there are enough people in the North of England and Wales to sustain three centres meeting the 400 minimum critical mass of procedures. It is recommended that there are not.

Therefore, there are three options for the reconfiguration of centres in the North of England:

- Liverpool and Newcastle;
- Leeds and Newcastle; and
- Leeds and Liverpool

Each of the above potential configurations were analysed in detail against the following sets of assumptions:

- Patients travel to their closest site;
- Catchment areas are extended along SCG border lines where possible to ensure both centres achieve the 400 minimum; and
- Catchment areas are extended according to distance and access times (ignoring SCG boundaries) to ensure both centres achieve the 400 minimum.

In each case, the impact on the movement of catchment areas on the other centres, particularly Birmingham and Leicester was monitored. The impact on Leicester was analysed in particular detail due to the fact that in the initial 15 options analysed based on the assumption that patients travel to their closest site, Leicester often failed to achieve the 400 minimum. The particular results around the Leicester centre are dealt with later in this business case, the results for the north are summarised below.

Liverpool and Newcastle

Options with Liverpool and Newcastle but without Leeds were explored as part of the initial 15 options under the assumption that patients travel to their closest site. The output was that Newcastle does not achieve the minimum of 400 procedures per year but Liverpool does. Therefore, the analysis then looked at the catchment areas to see whether they could be extended so that both centres achieved the 400 minimum. The JCPCT is advised that both centres are able to achieve the 400 procedure minimum when catchment areas are extended along SCG boundary lines. However, there is an impact on access as the population of Doncaster (DN), Hull (HU), Leeds (LS), Wakefield (WF), Bradford (BD), Harrogate (HG) and York (YO) are assumed to flow north to Newcastle rather than west to Liverpool or south to Leicester or Birmingham.

The JCPCT is advised that both centres are able to achieve the 400 procedure minimum when catchment areas are extended ignoring SCG borders but according to distance and travel times. However, again there is an impact on access as the populations of Hull (HU), York (YO), Leeds (LS), Wakefield (WF), Harrogate (HG), Bradford (BD) and Lancashire (LA) flow north to Newcastle rather than west to Liverpool. Patients from Doncaster (DN) and Sheffield (S) are expected to flow to Liverpool under this scenario.

Therefore it is recommended that the option of Liverpool and Newcastle is a viable one.

Leeds and Newcastle

Options with Leeds and Newcastle but without Liverpool were explored as part of the initial 15 options under the assumption that patients travel to their closest site. The output was that Newcastle does not achieve the minimum of 400 procedures per year but Leeds does. Therefore, the analysis then looked at the catchment areas to see whether they could be extended so that both centres achieved the 400 minimum.

The JCPCT is advised that it is only possible to extend the catchment areas to ensure both sites achieve the 400 procedure minimum by significantly impacting access and creating unusual catchment areas.

For example, to ensure that Newcastle attracts 400 procedures per year, by extending Newcastle's catchment area, patients would need to travel from postcode areas bordering Leeds (such as York, Harrogate and Bradford) away from their closest centre in Leeds to Newcastle. In addition, some patients in a postcode area just north of Liverpool (such as Blackpool, Preston, Wigan, Bolton, Oldham or Blackburn) would have to flow to Newcastle. The impact on access times is significant and furthermore the JCPCT and SCG Directors agreed that such a network would be unviable.

Therefore due to the population distribution in the North of England, the JCPCT is advised that a Leeds and Newcastle option for the north is not viable.

Leeds and Liverpool

Options with Leeds and Liverpool but without Newcastle were tested as part of the original 15 options under the assumption that patients travel to their closest site. Under this set of assumptions, both centres are able to achieve over the 400 minimum procedures per year. Further testing of potential future catchment areas was conducted and showed that both centres can easily achieve the 400 minimum without significantly impacting access times. Compared to the current configuration there is an increase in travel times, particularly for patients in Newcastle (NE), DH, SR, DL, TS as it is assumed they will travel down to Leeds. However, in the absence of the Newcastle centre, Leeds is their closest site so it does not create unrealistic catchment areas of networks.

Therefore the JCPCT is advised that Leeds and Liverpool is a viable option for the north of England.

Suggested scoring of options presented to JCPCT for discussion

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Total	4	1	3	1	3	1
Travel times for elective admissions	4	1	3	1	3	1
Retrieval times	4	4	4	4	4	4

Stage 4 rationale

Rationale behind the scoring

Scores for travel and access

The table above shows the breakdown of proposed scores against this criterion.

The rationale behind the scores for the travel times sub-criteria: *“The negative impact on travel times for elective admissions is kept to a minimum”* is based on the data set out in Appendix S:

- The JCPCT is advised that option 2 performs better than the other options both because it has the highest number of patients in the shortest journey category and the joint lowest number of patients in the longest journey category and because it has the highest number of patients whose journey time is increased by the smallest amount (0 – 30 minutes) and joint lowest number of patients whose journey time is increased by the largest amount (over 90 minutes). Therefore it is suggested that it scores higher than all other options. It is suggested that it is awarded a score of 4

- The JCPCT is advised that options 6, 10 and 14 have the highest number of patients whose journey increases by over 4 hours. Therefore it is suggested that these options score lower than the other options are and awarded a score of 1
- The JCPCT is advised that options 8 and 12 perform somewhere in the middle of the pack compared to the other options. Therefore it is suggested they are awarded a score of 3

The rationale behind the scores for the retrieval times sub-criteria:

The standard “The retrieval team should arrive at the referring unit within three hours (extended to four hours in remote areas) of the decision to retrieve the child in accordance with the PIC Society ‘Standards for the Care of Critically Ill Children, 2010” is based on the analysis set out in Appendix T:

- All options allow for retrieval times within the standard
- The proposed combined score for the travel and access criteria is an amalgamation of the scores for the two sub criteria. Given that the proposed scores for retrieval are the same for all options, the proposed scores for travel and access have been used

Suggested scoring of options presented to JCPCT for discussion

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Total Score for Quality	3	3	3	3	3	4
High quality service	3	3	3	3	3	4
Innovation and Research	3	3	3	3	3	4
Clinical Networks	4	4	4	4	4	3

Scores for Quality

The table above shows the breakdown of proposed scores against this criterion.

The rationale behind the scores for the high quality service sub-criterion:

“Designated surgical centres will deliver a high quality service” is based on the Assessment Panel scores shown in Appendix K1.

- Option 14 includes the 8 ‘top scoring’ centres minus a London centre. Therefore the rationale for including option 14 in the scoring process is based on the panel scores. It is suggested that this should be reflected in the scores and Option 14 be awarded a score of 4
- The other options’ combined average panel scores were presented to the JCPCT for discussion however it was agreed that the range between scores was small. All options got between 95% and 100% of the maximum score. In addition it was agreed that all centres, aside from Oxford which is not present in any of the shortlisted options, achieved a score from the panel assessments which indicated that the service was safe and sustainable

Therefore it was agreed that there should be no differentiation in score for the other options. It is suggested that all other options are awarded a score of 3.

The rationale behind the scores for the innovation and research sub-criterion: “Innovation and research is present across the networks and the national service” is based on Sir Ian Kennedy’s panel score of each centre against core standard G12.

“Each Tertiary Centre must have, and regularly update, a research strategy and programme that documents current and planned research activity, the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other 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.”

Those scores are shown in the table below:

5	Evelina GOSH
4	Birmingham, Bristol, Southampton
3	Newcastle
2	Leeds, Leicester, Liverpool, Royal Brompton
1	Oxford

When these scores are applied to the potential options, Option 14 performs better than the other options. The other potential options perform less well when comparing total scores and the number of centres with top scores of 4 or 5 in each option. However, with the 2 London centres undecided these options have a range of outcomes when compared to options with 3 London centres. On this basis the JCPCT is advised that option 14 should be awarded a higher score while the other options score equally and slightly lower than Option 14. It is suggested that Option 14 is awarded a score of 4 while all other options are awarded a score of 3.

The rationale for the scores on the clinical networks criterion:

“Clinical networks are manageable, taking account of population and geography and the need for clear leadership and communication”

The networks presented to the JCPCT are an outcome of this assessment process (by applying the minimum critical mass levels against populations and patient flows, including a ‘sense check’ from SCG

Directors). Although the potential networks are an outcome of a sound and thorough methodology the JCPCT is not being advised that these should be considered as actual networks for the future; rather that the viability of these potential networks should be tested during formal public consultation.

Based on the analysis to date, the JCPCT is advised that all of the potential networks are considered potentially viable but with a caveat that the viability of option 14 demands more detailed attention during consultation to test:

- The reasonableness of the potential patient flows as set out therein
- The impact to patient flows in South Central England of the suspension of the paediatric cardiac surgical service at the John Radcliffe Hospital in Oxford

On this basis, the JCPCT is advised that all potential options are awarded a score of 4 except Option 14 which is awarded a score of 3.

The combined score for quality is an amalgamation of the scores for the three sub criteria. Because scores for Innovation and Research and Clinical Networks cancel each other out, it is recommended that the overall scores are based on the assessment panel scores.

Scores for deliverability

The JCPCT is advised not to apply a score against the ‘workforce’ criterion at this stage of the process. This is because all centres (whether they are designated or de-designated) will face potential movement of

staff, either to scale up its workforce to meet projected increases in activity or as a result of non-designation. Furthermore, the review reaches consultation stage it is not possible to consult with individuals and therefore it would be unreasonable to take a view as to whether individuals at centres that are de-designated will choose to move centre, stay at their existing centre or take voluntary redundancy/early retirement.

The table below shows the breakdown of suggested scores presented to the JCPCT for discussion against this criterion.

Suggested scoring of options presented to JCPCT for discussion

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Total Score for Deliverability	3	2	1	2	1	3
NCS	4	3	1	3	1	3
PICU and Interdependent Services	1	1	3	1	3	2
Workforce	N/A	N/A	N/A	N/A	N/A	N/A
Transition plans	N/A	N/A	N/A	N/A	N/A	N/A

The rationale behind the scores for the Nationally Commissioned Services sub-criterion: “The NHS in England will continue to provide high quality:

- paediatric cardiothoracic transplantation services in two centres

- ECMO services for children with severe respiratory failure in at least three centres
- complex tracheal surgery in one centre” is based on the analysis undertaken as set out in Appendix A

It should be noted that paediatric cardio-thoracic transplantation (including mechanical device as 'bridge to transplant'), ECMO for children with severe respiratory problems and complex tracheal surgery are nationally commissioned services and all decisions about where they are provided can only be made by the Secretary of State for Health.

Were the JCPCT's final decision to be dependent on a change to the provision of any of these national services that would need to be ratified by the Secretary of State for Health. Were he not to support the proposed change to national services, then the JCPCT would have to make a fresh decision about the location of Specialist Surgical Centres that did not require such a change.

Transplant:

The JCPCT has been advised by an expert panel that there must be a minimum of 2 centres providing transplant services must be included in the option and these could be either, Great Ormond Street Hospital (GOSH) / Newcastle, GOSH/ Birmingham or Newcastle/ Birmingham. All potential options would include GOSH (see sections 8 and 11) and Birmingham but it is recommended that options that include Newcastle score highly as no new ECMO service needs to be established.

ECMO:

The JCPCT has been advised by an expert panel that there must be a minimum of 3 centres providing ECMO included in the configuration options. All potential options would include GOSH (see sections 8 and 11) and Birmingham which means that viable options must include at least one centre out of Newcastle, Leicester or Bristol for delivering ECMO services.

It is recommended that options that retain Newcastle and Leicester score highly as no new ECMO service needs to be established.

Complex tracheal surgery:

The JCPCT has been advised by an expert panel that there must be a maximum of 1 centre providing this service in every option. The one centre currently providing this is GOSH. The expert panel did not have confidence in the ability of any other centre to develop a complex tracheal service.

Complex tracheal surgery is very rare and has a national caseload of approximately 10 patients per year. Therefore the scores for nationally commissioned services are based primarily on provision of services for ECMO and transplant, and not complex tracheal surgery.

When this analysis is applied to the shortlisted options it results in the following ranking of the options:

OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14

- Options containing both Newcastle and Leicester
- Options containing Newcastle but not Leicester
- Options Containing neither Newcastle nor Leicester

Therefore it is recommended that Option 2 is awarded a score of 4, Options 8 and 12 score of 1 and the remaining options a score of 3.

The rationale behind the score for the PICU and Interdependent services sub-criterion:

"The negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum" is based on the analysis set out in Appendix B. In summary:

- The **SAFE AND SUSTAINABLE** team have assessed the risk (viability and resilience) to PICUs presented by reconfiguration of cardiac surgical services.
- All PICUs remain 'viable' save for the three PICUs that primarily support cardiac surgery: Leicester, Newcastle and Brompton

- The steering group advise that the loss of these three PICUs to the national network is 'low risk' in the event of these centres not being designated for cardiac surgery as they do not support non-cardiac patients
- Although the remaining PICUs remain 'viable' there are potential risks around 'destabilisation' on which the JCPCT must take a view
- Bristol is most at risk of destabilisation given its higher volume of cardiac related admissions, followed by Leeds and then Southampton

The exclusion of Newcastle from option 8 would necessitate increased PICU capacity at Birmingham for transplantation and ECMO services.

When this analysis is applied to the shortlisted options it results in the following ranking of options:

OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14

- Options containing both Bristol and Leeds but not Southampton
- Options containing both Bristol and Southampton but not Leeds
- Options Containing Bristol but not Southampton or Leeds

Therefore it is recommended that Option 8 and 12 are awarded a 3, option 14 a 2 and the other options a 1.

Therefore the combined score for deliverability is an amalgamation of the scores for the two sub criteria.

Scores for sustainability

The table below shows the breakdown of suggested scores presented to the JCPCT for discussion against this criterion.

The rationale behind the proposed scores for the first two sub-criteria:
“All designated centres are likely to perform at least 400 paediatric procedures per year, ideally 500; and

Suggested scoring of options presented to JCPCT for discussion

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Total Score for Sustainability	3	3	2	3	2	2
Perform a minimum of 400 procedures per year	3	3	3	3	3	1
Too onerous a caseload	3	4	2	4	2	4
Recruit and retain newly qualified surgeons	N/A	N/A	N/A	N/A	N/A	N/A
Transition plans	N/A	N/A	N/A	N/A	N/A	N/A

No one designated surgical centre will receive too onerous a caseload that would exceed that centre’s capacity to manage it”

Each potential option’s proposed scores are based on an ability to meet the 400 minimum threshold and against its stated maximum capacity separately.

The JCPCT is advised that all centres in all options except Option 14 are able to meet the 400 minimum threshold and so are awarded a score of 3. Both Bristol and Southampton fail to reach the 400 minimum in Option 14 based on ‘nearest centre’ analysis and on 2009/10 CCAD activity and the networks as set out in Appendix AG.

Therefore for the purpose of this exercise it is recommended that option 14 is awarded a score of 1 and that the viability of the networks and patient flows are tested in detail during consultation.

When assessing whether options may result in too onerous a caseload for any particular centre, reference was made to the centre’s stated maximum capacity. In Option 6, 10 and 14 none of the centres receive a caseload above their stated maximum; therefore it is recommended these options are awarded a score of 4.

In Options 8 and 12, Leeds receives an estimated 636 procedures per annum which is above that the centre’s stated maximum. This is due to the absence of both Newcastle and Leicester. This is only 36 patients above the stated maximum for this centre and there is a

margin of error associated with Leeds projected activity levels of plus or minus 5.5%; therefore this option has not been ruled unviable and has been included to allow for further debate. However, on this basis it is recommended that Leeds should be marked down against this sub-criterion. It is recommended that both Options 8 and 12 be awarded a score of 2.

On option 2, both London centres receive an estimated 721 procedures per annum. While this is not above the stated maximum, it is high. Therefore it is recommended that this be awarded a score of 3.

Recruitment and retention issues require more detailed work as part of the implementation stage. As such the JCPCT is advised not to apply scores at this stage for the same reasons as outlined above regarding workforce issues. Therefore it is recommended that the combined suggested score for sustainability is an amalgamation of the scores for the two sub criteria.

Sensitivity testing on the scoring

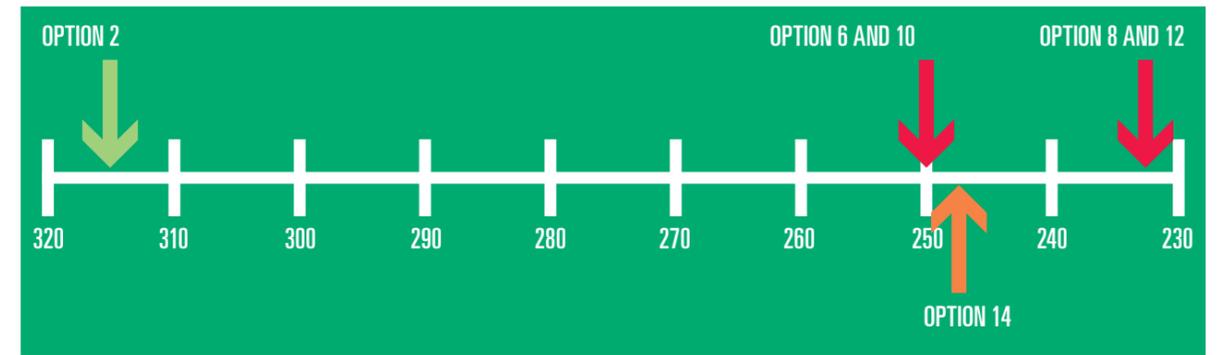
A sensitivity testing has been applied to show what the outcome of the scoring would be under various different scoring scenarios. These scenarios are outlined on the next page.

Absolute scores - version 2

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	4	1	3	1	3	1
Quality	3	3	3	3	3	3
Deliverability	3	2	1	2	1	3
Sustainability	3	3	2	3	2	2

Weighted scores - version 2

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	56	14	42	14	42	14
Quality	117	117	117	117	117	117
Deliverability	66	44	22	44	22	66
Sustainability	75	75	50	75	50	50
Total score	314	250	231	250	231	247



Version 2 of the suggested scores

The first scenario run looks at the impact on the overall result if all options were awarded an equal score against the quality criteria on the basis that the Assessment Panel scored individual centres against the Standards and did not produce comparative scores. The Assessment Panel’s findings supported the conclusion that all centres, with the exception of Oxford, are capable of meeting the minimum standards in the future (though JCPCT members should refer to the detail of the report of Professor Sir Ian Kennedy’s panel to take a view on the extent to which each centre could achieve an ‘optimal’ service).

The result of this change in scoring would be to replace Option 14’s score of 4 for quality with a score of 3 as shown above.

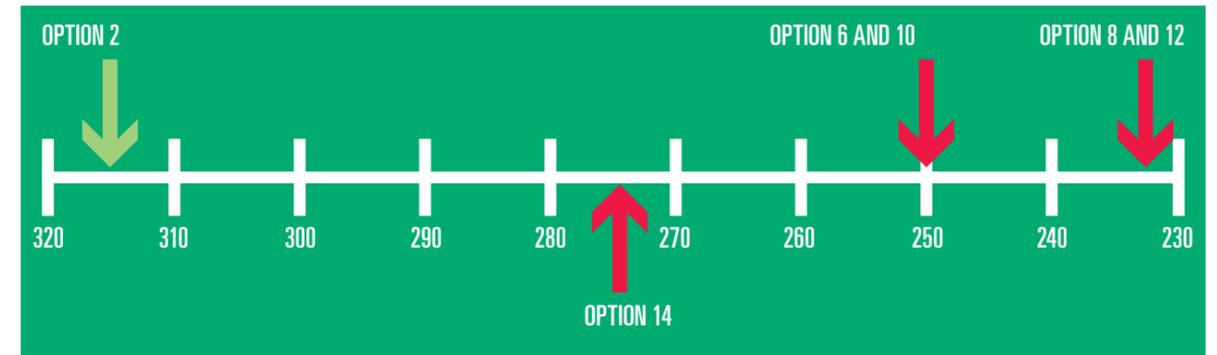
The outcome of running scenario 1 when compared to the suggested scoring as set out in section 7 would be that option 14 moves from second position down to second last position and options 6 and 10 move from second last position to second position as can be seen on the ranking indicator above. All other options would remain as they were.

Absolute scores - version 3

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	4	2	3	2	3	3
Quality	3	3	3	3	3	3
Deliverability	3	2	1	2	1	3
Sustainability	3	3	2	3	2	2

Weighted scores - version 3

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	56	28	42	28	42	42
Quality	117	117	117	117	117	117
Deliverability	66	44	22	44	22	66
Sustainability	75	75	50	75	50	50
Total score	314	264	231	264	231	275



Version 3 of the suggested scores

The second scenario run builds on version 2 and looks at the impact on the overall result if travel and access scores were awarded as a result of analysing the data in a different way. The travel and access data can be interpreted in different ways depending on whether more emphasis is placed on;

- Having the highest number of patients who can travel to their centre in less than 1 hour
 - Having the highest number of patients who can travel to their centre in less than 2 hours
 - Having the least patients who must travel for over 3 hours to their centre
 - Having the least patients who must travel for over 4 hours to their centre
 - Having the highest number of patients whose travel time only increases by up to 30 minutes
 - Having the least patients whose travel time increases by over 90 minutes
- Each factor gives a slightly different ranking of options in terms of best to worst

However there are some patterns that can be identified. For example, option 2 always scores the best (or equal best), options 8 and 12 appear towards the upper end of the rankings in most cases and options 6 and 10 appear towards the bottom end of the rankings in most cases.

A scenario has been run with the above scores to show the impact on the overall scoring.

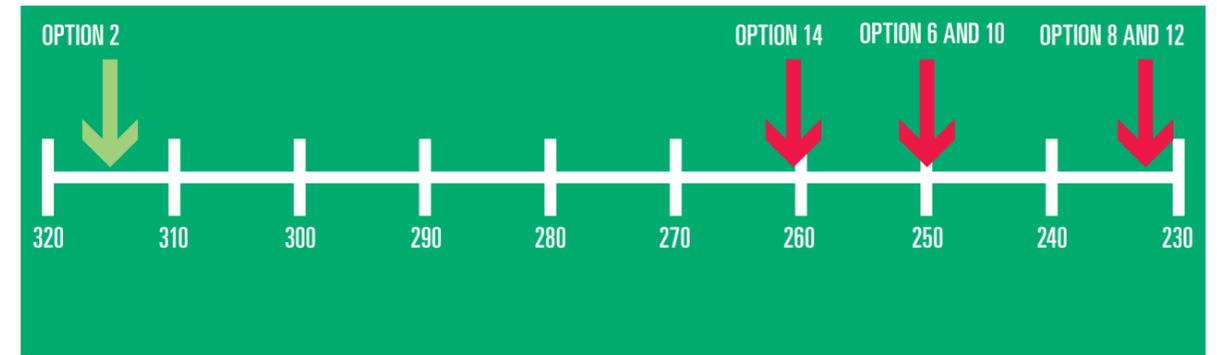
The outcome of running scenario 2 when compared to scenario 1 above is that option 14 comes back up the ratings. Option 2 would still be highest ranked and options 8 and 12 would remain lowest ranked.

Absolute scores - version 4

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	4	1	3	1	3	2
Quality	3	3	3	3	3	3
Deliverability	3	2	1	2	1	3
Sustainability	3	3	2	3	2	2

Weighted scores - version 4

	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14
Travel and Access	56	14	42	14	42	28
Quality	117	117	117	117	117	117
Deliverability	66	44	22	44	22	66
Sustainability	75	75	50	75	50	50
Total score	314	250	231	250	231	261



Version 4 of the suggested scores

The third scenario run ignores scores for retrieval times and focuses only on travel and access times. This could be justified on the basis that only a very small number of children with congenital heart disease require emergency transport, coupled with the outcome of the previous analysis that suggested that under most potential options most geographical areas would fall within the 3-hour threshold stipulated by the Paediatric Intensive Care Society⁸⁷.

The outcome of running scenario 3 is that scores for options 14, 6 and 10 would drop. However, Option 2 would remain highest ranked and options 8 and 12 would remain lowest ranked.

⁸⁷ Paediatric Intensive Care Society, Standards for the care of critically ill children (4th Edition), June 2010

Other Sensitivity Analysis

Other Sensitivity Analysis. The above analysis looks at variation in scores and the impact on rankings. The purpose of this section is to test to what extent adjusting the weightings may affect the rankings.

A. No weightings

CRITERION	DESCRIPTION	OVERALL WEIGHTING	OPTION 1	OPTION 2		OPTION 6A	OPTION 6B	OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
1	Access and travel times	14	2	4		3	1	3	3	1	3	1
2	Quality	39	3	3		3	3	3	3	3	3	4
3	Deliverability	12	2	3		2	2	1	2	2	1	3
4	Sustainability	25	3	3		2	3	2	2	3	2	2
		TOTAL	10	13		10	9	9	10	9	9	10
		RANKING	2	1		2	6	6	2	6	6	2

Option 2 remains the top ranked option, with option 14 and 6 following.

B. Reverse weightings for Sustainability and Deliverability

CRITERION	DESCRIPTION	OVERALL WEIGHTING	OPTION 1	OPTION 2		OPTION 6A	OPTION 6B	OPTION 8	OPTION 10A	OPTION 10B	OPTION 12	OPTION 14
1	Access and travel times	14	28	56		42	14	42	42	14	42	14
2	Quality	39	117	117		117	117	117	117	117	117	156
3	Deliverability	12	50	75		50	50	25	50	50	25	75
4	Sustainability	25	66	66		44	66	44	44	66	44	44
		TOTAL	261	314		253	247	228	253	247	228	289
		RANKING	3	1		4	6	7	4	6	7	2

Option 2 remains the top ranked and option 14 second ranked.

APPENDIX AD - WORKFORCE IMPLICATIONS

The JCPCT is advised not to apply a score against the 'workforce' criterion of the evaluation of potential options at this stage of the process. This is because all centres (whether they are designated or de-designated) will face potential movement of staff, either to scale up its workforce to meet projected increases in activity or as a result of non-designation. Furthermore, until the review reaches consultation stage it is not possible to consult with individuals and therefore it would be unreasonable to take a view as to whether individuals at centres that are de-designated will choose to move centre, stay at their existing centre or take voluntary redundancy or early retirement.

This appendix provides the JCPCT with a high-level overview of relevant workforce issues.

Overview of workforce

- Many surgeons providing paediatric cardiac surgery do not work wholly in paediatric cardiac surgery as they also undertake some adult congenital surgical work
- In general most anaesthetists and intensivists will provide some services for paediatric cardiac surgery; however they may also provide anaesthetics and intensivist services for other services and patient groups. Therefore the number of individuals who work as part of the multi disciplinary team providing paediatric

cardiac surgery services is greater than the 'whole time equivalent' providing this service.

- Cardiologists can either specialise in interventional or non interventional cardiology. Interventional cardiologists primarily focus on interventional work, which it is proposed must be provided in designated centres for paediatric cardiac surgery
- Within the nursing workforce that support the provision of paediatric cardiac surgery, only the PICU nurses, ward nurses and specialist nurses must be located in the designated surgical centre. The children's cardiac nurse specialists, clinical nurse educators and transition nurses are all located within the network

Risks to Reconfiguration

There are several risks associated with the reconfiguration of paediatric cardiac surgery that will impact on workforce planning for different staff groups. Some of these risks will apply to all configuration options whilst others become higher risk under different configurations.

Paediatric Cardiac Surgeons

One of the key risks that could arise as a result of the reconfiguration is the loss of surgeons either through early retirement or voluntary

redundancy. If many surgeons simultaneously chose early retirement or redundancy this could result in too few surgeons to meet the current demand for surgery on a national scale. The availability of relocation packages and the fact that there is now less of a stigma associated with relocating as a consultant makes it easier for consultants to relocate; however there is a cohort of surgeons that are nearing retirement age. Therefore there is an increased chance that these surgeons will choose early retirement as opposed to relocation if their centre is not designated.

If a significant proportion of surgeons leave the service, creating a gap in provision this will present recruitment and training challenges to fill these gaps.

Trainee Surgeons

In general SpRs tend to be more mobile than consultants as they are used to relocating for their rotations. SpRs rotas will be reconfigured through the consortia in line with the reconfiguration of centres therefore they are likely to relocate if their current centre is not designated. In addition, SpRs will often work in a different centre to where they did their training as only Birmingham and GOSH provide dedicated training for paediatric cardiac surgery.

Cardiothoracic training is, however, currently provided by 10 consortia and each consortium (with the exception of the East of England consortia) includes a centre that currently provides paediatric cardiac surgery in order to incorporate this element into the SpR training programme. Therefore these consortia will need to be reconfigured following the

reconfiguration of paediatric cardiac surgery in order to ensure that they can still provide some paediatric cardiac surgery training and some SpRs will be expected to relocate away from the centre where they did their cardiothoracic surgical training.

Paediatric Cardiologists

Paediatric cardiologists generally work independently of paediatric cardiac surgeons; however they need surgical back up for interventional cardiology hence the proposal for interventional cardiology to be undertaken only at a centre providing paediatric cardiac surgery. Therefore paediatric cardiologists who do not perform interventional cardiology will be able to continue working at their existing centre if their paediatric cardiac surgery centre is not designated; however interventional cardiologists would need to be located at designated paediatric cardiac surgery centres. A reconfiguration will therefore have a greater impact for centres that currently undertake a larger proportion of interventional cardiology work.

There will be risks that require mitigation in the planning and delivery of the proposed Children's Cardiology Centres. Although there are precedents for this model of care (existing Children's Cardiology Centres at Manchester, Edinburgh and Cardiff support nearby surgical centres) one of the key challenges for the NHS in the implementation phase of **SAFE AND SUSTAINABLE** is how to manage the transition from surgical unit to non-surgical unit and the potential movement of key staff away from these centres. A further challenge for the Congenital Heart Networks is to ensure that staff and patients of the Children's Cardiology

Centres do not consider these units to have been 'down graded' in any way. This will be an immediate challenge, but also over time as new cohorts of children receive their operations at the newly designated surgical centres, the cohort of children previously operated on at the Children's Cardiology Centres mature and transition to adult services and local hospitals gradually shift their referral patterns for acutely ill children. The risk is that this perception could cause reluctance amongst clinical staff to care for complex cardiac patients, with a resulting reduction in the skill level and experience of clinical staff. However, the establishment of robust Congenital Heart Networks with good collaborative working across the services would mitigate against these risks.

Anaesthetists and Intensivists

Whilst paediatric cardiac anaesthetists and intensivists would be affected by the cessation of the paediatric cardiac surgery service at their centre it may be possible for them to continue practising at their existing centre as some undertake a broader case mix and work pertaining directly to paediatric cardiac surgery might be a small proportion of their total workload. Paediatric intensivists work exclusively in paediatric intensive care whilst most paediatric cardiac anaesthetists may provide either a range of anaesthetics services for children or adult cardiac anaesthetics (in centres that provide services for adults as well as children) as well. In addition to providing paediatric cardiac anaesthetics support during surgery, the anaesthetists may also cover paediatric cath lab sessions and paediatric interventional cardiology.

The decision for anaesthetists and intensivists to remain in their existing centre if the paediatric cardiac surgery service closes will be a personal, individual decision based on whether the individual chooses to continue to focus on paediatric cardiac work and therefore any decision must be based on individual consultation.

The decision as to whether anaesthetists and intensivists choose to relocate may impact on the sustainability of the centres that remain under the configuration option; as these centres increase their activity this will have a knock on impact on the staffing requirements for anaesthetists and intensivists. Whilst the anaesthetists and intensivists who are based in centres that remain under the preferred configuration option may be able to take on additional paediatric cardiac sessions they may not choose to do this. If this is the case it will be necessary to recruit additional paediatric cardiac anaesthetists and they will need to undergo specialist training. It can be challenging to recruit paediatric cardiac anaesthetists as this is a highly specialised, and not always popular, area of anaesthesia so it may be necessary to recruit additional resources from abroad; if this is the case then a period of mentoring new anaesthetists is essential to ensure they are able to perform to the standard expected of paediatric cardiac anaesthetists trained in the UK.

Nurses

Ward nurses that work with paediatric cardiac surgery patients and Children's PICU nurses that work with paediatric cardiac surgery patients will be affected by the transfer of paediatric cardiac surgery to designated

centres. As ward nurses and PICU nurses tend to work on mixed wards that treat a variety of patients, the Trust will need to identify the number of beds that are dedicated to paediatric cardiac surgery patients, both on wards and in PICU. The number of nurses associated with these beds will be directly affected by the closure of these beds if the service is not designated at the centre. Children's cardiac nurses specialists, clinical nurse educators and transition nurses will not be as affected by the transfer of paediatric cardiac surgery to designated centres as these nurses tend to work within the network, and although they may be employed by the designated centre they can continue to be physically based in other hospitals within the network. For those nurses that choose not to relocate and consider redeployment into suitable alternative employment, non-designated centres that become cardiology centres will require cardiology nursing specialist skills which cardiac nurses may be suitable for. Alternatively, cardiac nurses have transferable nursing skills that could be applied in a variety of specialist areas including general surgery, theatres, ICU, renal and orthopaedics. It would be important that all the Trusts within the review assess and freeze relevant nursing vacancies at an appropriate point to the timing of local consultations, in order that redeployment opportunities are maximised.

Perfusionists

Perfusionists manage the heart-lung bypass equipment during heart surgery. ECMO represents an increasing element of the clinical perfusionist's role. Like anaesthetists, whilst perfusionists will be affected by the closure

of the paediatric cardiac surgery service at their centre, it would be possible for them to continue practising as they undertake a broader case mix and work across both adult and paediatric cardiac surgery. Perfusionists have a particularly prominent role in transplant surgery and ECMO services. Therefore any configuration option that will affect centres providing these services will have a greater impact on perfusionists.

Critically Interdependent Services

Some surgeons currently deliver highly specialised services including transplant, complex thoracic surgery and ECMO (Appendix A). If centres that are currently providing these services and their surgeons opt for redundancy or early retirement as opposed to relocation this may create challenges in delivering these services in the future as the process of training and mentoring a surgeon is lengthy and requires detailed succession planning. It is therefore essential to consult with these individuals should they be affected by the reconfiguration.

Support for all staff groups

Paediatric cardiac surgery teams form close knit multidisciplinary teams that develop established ways of working with specific clinical protocols, types of equipment and case-mix of patients. Changes to these teams through the reconfiguration will require organisational and team support from Trusts to enable them to either develop as newly designated surgical centres or as cardiology centres. Teams that re-form with new members may need development and support to gel as

a new team. This may include reviewing their ways of working, their clinical protocols, their team communication and their interaction with other teams within the Trust. Attention to these human factors will be essential to maintain a high quality service and ensure patient safety.

Impact of Reconfiguration on Training

Designation of Training Centres

Cardiothoracic Training

Cardiothoracic surgical training is currently provided across 10 consortia. These consortia are:

- Northern (NW & Mersey)
- East of England (Papworth and Norfolk & Norwich)
- North and South London
- Oxford and Southampton
- Plymouth and Bristol
- Birmingham and South Wales
- Scotland
- Northern Ireland
- East Midlands (Nottingham and Leicester)
- Yorkshire.

With the exception of the East of England consortium all consortia incorporate a centre that provides paediatric cardiac surgery and this training is provided in London for the East of England. These consortia will need to be reconfigured to ensure that all consortia

are able to provide an element of paediatric cardiac surgical training.

Paediatric Cardiac Surgery Training

Paediatric cardiac training is a sub-speciality of cardiothoracic surgery training. This training is provided for ST5s and above and there are dedicated training programmes at Birmingham and GOSH.

Paediatric Intensive Care Unit (PICU) Training

PICU training is a two year programme and there are 5 centres that currently provide paediatric cardiac surgery that are licensed to provide both years of the training programme. These centres are:

- Bristol
- Birmingham
- Liverpool
- GOSH
- Evelina

Other centres including Southampton are currently licensed to provide one year of training. Centres are granted a license based on their activity levels and case-mix. All PICU SpRs must complete some training at centres that provide paediatric cardiac surgery. Therefore the reconfiguration of paediatric cardiac surgery will impact on the licensing of PICUs as designated training centres.

Perfusionists Training

Trainee perfusionists follow a period of in-service training (incorporating practical experience under supervision), whilst studying for a postgraduate qualification at postgraduate diploma or MSc level in clinical perfusion science. Perfusionists must therefore undertake practical training at designated centres that undertake cardiac surgery and this must include an element of paediatric cardiac surgery. Therefore the location of the practical elements of clinical perfusionist training is dependent on the configuration of paediatric cardiac surgery.

Paediatric Cardiac Anaesthetics Training

Paediatric cardiac anaesthetists should undertake a minimum total of 18 months of full time training in paediatric anaesthesia. Of this at least 6 months should be spent in general paediatric anaesthesia and at least 6 months in paediatric cardiac anaesthesia. There is no specific designation of training centres; however this training must necessarily take place at centres that provide paediatric cardiac surgery. Following a period of training it is recommended that new consultants are mentored according to the level of training and competence achieved prior to consultant appointment. In some cases joint working of consultants may be part of the mentoring process, as will preoperative discussion of cases at a multidisciplinary meeting and regular morbidity and mortality meetings.

Nursing Training for Nurses that Support the Provision of Paediatric Cardiac Surgery

The risk of low numbers of nurses considering relocation may be improved if funding for post-registration training is offered as part of the relocation package. This training can be delivered through a number of methods, including E-learning and mentoring. The Royal College of Nurses is currently developing a framework for training for all nurses involved in the care pathway for paediatric cardiac surgery and congenital heart disease. This will outline the minimum training requirements for all nurses involved in delivering care to paediatric cardiac surgery patients. During the transition process there will be an increased need for clinical nurse educators, as centres that are designated will need to increase their staffing capacity as they absorb more activity from the centres that are not designated.

Numbers of Trainees

Paediatric Cardiac Surgeons

The aim of *SAFE AND SUSTAINABLE* is to encourage future cardiothoracic surgical trainees to choose paediatric cardiac surgery as a career by the development of larger world class surgical centres that are leaders in innovation, research and clinical outcomes.

The training programme for paediatric cardiac surgery takes 2 years. There are two dedicated centres providing paediatric cardiac surgical training at Birmingham Children's Hospital and Great Ormond Street Hospital and they each have one trainee at any one time. Therefore

one trainee completes their training a year from these centres. SpRs can choose to undertake training at other centres; however every paediatric cardiac surgery SpR must undertake two years of training before they receive their CCT. If a large number of surgeons choose voluntary redundancy or early retirement as opposed to relocation then this may impact on training numbers for the next few years, as the staff pool needs to be replenished.

It can be potentially challenging to recruit paediatric cardiac surgical trainees as these are recruited from a limited pool of cardiothoracic trainees. In recent years the number of cardiothoracic surgical trainees has varied significantly as follows:

• 2000-2003	Significant expansion in trainee numbers
• 2005-6	No trainee recruitment for two years
• 2007	5-7 posts
• 2008	16 posts
• 2009	23 posts
• 2010	23 posts

Paediatricians with Expertise in Cardiology (PECs)

The proposed Congenital Heart Networks envisage more Consultant Paediatricians with Expertise in Cardiology working at local hospitals that are linked to maternity units with more than 3,000 births each year (Appendix N lists the units which currently have more

3,000 births each year). The Royal College of Paediatrics and Child Health is unable to confirm the current number of PECs in England as there has historically been no common training curriculum. This means that there are currently a number of consultant paediatricians with an 'interest' in cardiology and who have different levels of cardiac-related skills and training.

The Royal College and Paediatrics and Child Health and the British Congenital Cardiac Association have now developed a joint training curriculum⁸⁸ and it is envisaged that both of the professional associations will work with the proposed Network Groups and NHS commissioners during the phases of consultation and implementation to advise the NHS on the required future number and location of PECs in the networks.

On average it is estimated that PECs will spend two sessions a week dedicated to cardiac duties.

PICU and Paediatric Cardiac Anaesthetics Training

The training programme for paediatric cardiac anaesthetists and intensivists is 2 years and PICU trainees tend to be ST4 and above. Whilst the location of licensed training PICUs may vary following reconfiguration of paediatric cardiac surgery this will not impact on the number of training posts required and WRT analysis indicates that the number of trained anaesthetists is projected to exceed demand until 2024⁸⁹.

Perfusionists

The supply of clinical perfusionists is forecast to grow steadily over the next few years as the perfusionist workforce is relatively young and retirement and attrition rates are low. In 2003/4 there was an increase in training numbers which resulted in an over-supply of perfusionists; however training numbers have stabilised and in 2007 there were 22 new perfusionist trainees and in 2008 there were 14.

Key Actions to support the consultation process:

The following key actions can be undertaken to ensure that the management structure and expertise to support the consultation process is established:

- Establish a national Human Resources subgroup to manage the workforce elements of implementation, working with the clinical units and emerging network leads
- Detailed modelling of staff numbers and costs associated with the potential options based on the outcome of consultation
- Develop protocol for redeployment and retraining packages
- Investigate and set up national redeployment mechanisms

Key Actions for consideration during implementation:

Once the recommended way forward has been agreed, the consultations can commence based on the preparatory work undertaken in the previous phase and the following actions can be undertaken:

- Consult with affected staff
- Implement redeployment mechanisms to support search for suitable alternative employment
- Estimate the number of new trainees required to replace any retirements
- Reconfigure training networks as appropriate
- Implement reconfiguration of services
- Initiate support for newly structured teams

⁸⁸ Curriculum for Paediatrician with Special expertise in Cardiology. Available at: www.rcpch.ac.uk/doc.aspx?id_Resource=1901

⁸⁹ Workforce Summary – Anaesthetics and Intensive Care Medicine, 2008 – England only

APPENDIX AF - STAKEHOLDERS THAT HAVE BEEN CONSULTED IN REGARD TO THE CONSULTATION PROCESS

STAKEHOLDER	ROLE/CONSTITUENCY
Jules Acton	Director of Engagement and Membership, National Voices
Tim Gilling	Deputy Executive Director, Centre for Public Scrutiny
Louise Hall	Parent
Suzie Hutchinson	Chief Executive, Little Hearts Matter
Anne Keatley-Clarke	Chief Executive, Children's Heart Federation
Suzanne McGregor	Community Development Coordinator, British Heart Foundation
Caroline Mutton	Parent
Jude Stephenson	Parent
Emma Strachan	Parent
Cecilia Yardley	External Affairs Manager, Children's Heart Federation

APPENDIX AG - ESTIMATE OF REDISTRIBUTED ACTIVITY

The table below shows the estimated annual surgical procedures referred to each centre under the 6 options.

The analysis is based on the following assumptions:

- 2009/10 CCAD validated data is used as the base data
- Activity is re-distributed from non-designated centres to designated centres based on the populations of the postcode districts within each networks.
- Networks are future estimated networks under each option as agreed with the SCG Directors

OPTION	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14A
Liverpool	445	445	400	445	400	445
Birmingham	472	725	660	725	660	725
Bristol	420	420	420	420	420	360
Newcastle	406	526		526		526
Leeds			636		636	
Oxford						
Southampton						382
Leicester	414					
London 1*	721	741	741	494	494	580
London 2*	721	741	741	494	494	580
London 3*				494	494	

Note:

It is assumed that activity referred to London is split equally between the two/ three sites included in the optional.

The table below shows the projected estimated annual surgical procedures referred to each centre under the 6 options in 2024/25.

The analysis is based on the following assumptions:

- 2006/07 CCAD validated data projected to 2024/25 based on a projected growth rate of 13.6%
- Activity is re-distributed from non-designated centres to designated centres based on the populations of the postcode districts within each networks.
- Networks are future estimated networks under each option as agreed with the SCG Directors

OPTION	OPTION 2	OPTION 6	OPTION 8	OPTION 10	OPTION 12	OPTION 14A
Liverpool	467	467	420	467	420	467
Birmingham	495	761	693	761	693	761
Bristol	441	441	441	441	441	377
Newcastle	426	552		552		552
Leeds			668		668	
Oxford						
Southampton						401
Leicester	434					
London 1*	757	778	778	518	518	609
London 2*	757	778	778	518	518	609
London 3*				518	518	

Note:

It is assumed that activity referred to London is split equally between the two/ three sites included in the optional.

Because the CCAD validated data on activity levels for each site fluctuates from year to year we have calculated a margin of error that can be applied to each centre’s estimated average activity under each option. We have chosen to calculate the margin of error on 10

years of data returns because the year on year variances are significantly smaller than when 5 years of 2 years of data is used. Therefore this gives the best indication of the long term level of fluctuation.

The range of activity for each centre is shown below.

The table below shows the projected estimated annual surgical procedures referred to each centre under the 6 options in 2024/25.

The analysis is based on the following assumptions:

- 2006/07 CCAD validated data projected to 2024/25 based on a projected growth rate of 13.6%
- Activity is re-distributed from non-designated centres to designated centres based on the populations of the postcode districts within each networks
- Networks are future estimated networks under each option as agreed with the SCG Directors

	MARGIN OF ERROR BASED ON 10 YEARS OF CCAD DATA	OPTION 2 – ACTIVITY RANGE	OPTION 6– ACTIVITY RANGE		OPTION 8– ACTIVITY RANGE	OPTION 10– ACTIVITY RANGE	OPTION 12– ACTIVITY RANGE	OPTION 14A– ACTIVITY RANGE
Liverpool	+/- 4.1%	427-463	426-463		384-416	427-463	384-416	427-463
Birmingham	+/- 10.6%	422-522	648-802		590-730	648-802	590-730	648-802
Bristol	+/- 2.7%	409-431	409-431		409-431	409-431	409-431	350-370
Newcastle	+/- 6.7%	379-433	491-561		-	491-561	-	491-561
Leicester	+/- 8.5%	379-449	-		-	-	-	-
Leeds	+/- 5.5%	-	-		601-671	-	601-671	-
Oxford	+/- 1.1%	-	-		-	-	-	-
Southampton	+/- 6.1%	-	-		-	-	-	359-405
London 1*	+/- 5.7%	680-762	669-783		669-783	466-522	466-522	547-613
London 2*	+/- 5.7%	680-762	669-783		669-783	466-522	466-522	547-613
London 3*	+/- 5.7%	-	-		-	466-522	466-522	-

