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SAFE AND SUSTAINABLE

A NEW VISION FOR CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND

CONSULTATION DOCUMENT - 1 MARCH 2011 TO 1 JULY 2011



Below is an extract from a letter that appeared in The Guardian on the 28 April 2010

Wednesday, 28 April 2010

NHS change must be driven by clinical evidence

Letter

There has been a wealth of clinical evidence for many years that specialist clinical services, such as stroke, trauma and heart surgery, should be concentrated in fewer centres. This would allow the latest equipment to be sited with a critical mass of expert clinicians who regularly manage these challenging clinical problems, and are backed by the most up-to-date research. The greater volumes of patients mean doctors are better at spotting problems and treating them quickly. Survival and recovery rates would improve markedly with many lives

saved. As techniques and technology have developed over recent years, speciality rather than proximity has become the key for patient safety. So increased patient safety and improved care must be the major drivers of any reconfiguration.

Patients may indeed have to travel further for some specialist care, but if it is significantly better care then we believe that centralisation is justified. However, at the same time there is also strong evidence to support a large amount of more routine care, currently taking place in hospitals, being carried out closer to where patients live in the community with GPs playing a crucial role in the delivery of services.

Delivering this requires strong leadership and brave decision-making

from doctors, managers and politicians. Simply condemning change as bad and defending the status quo as ideal is not serving the interests of patients.

Signed by all the Presidents of the following organisations at the time: *Academy of Medical Royal Colleges, Royal College of Physicians, Royal College General Practitioners, NHS Confederation, Royal College of Obstetricians and Gynaecologists, Royal College of Paediatrics & Child Health, Royal College of Psychiatrists, Royal College of Anaesthetists, Royal College of Radiologists, Royal College of Ophthalmologists, Faculty of Public Health Medicine, Faculty of Pharmaceutical Medicine, Faculty of Occupational Health*

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OVER THE LAST 50 YEARS SURGERY FOR CONGENITAL HEART PROBLEMS HAS GROWN INTO ONE OF THE MOST COMPLEX AREAS OF MODERN MEDICINE.

1. A CALL FOR CHANGE

Many of the 150 types of operation reach into the most complex, challenging and technically demanding areas of surgery. Success requires intricate surgery on hearts often no bigger than a walnut, coupled with finely balanced judgements drawn from a combination of advancing science, personal experience and compassion. This involves a range of highly trained individual team members who are involved before, during and after the operation. Their judgements have a direct and long-lasting impact, not only on the future of

each vulnerable child, but also on their families. The results of congenital heart surgery across the UK are good but we must not be complacent. Over the last few years we have seen several warning signs that the current arrangements are fragile. In addition, as medical science advances and public and professional expectations rise, this in turn raises the hopes of parents at a time of great personal anguish. We need to do everything possible to see their hopes fulfilled. Surgeons are tackling more complex problems

in smaller babies in more innovative and demanding ways. This means that to reduce the risk of surgery in sick children and improve their long term outlook we need to focus our surgical expertise in larger centres. This will ensure that individual surgeons and whole surgical teams gain greater experience from dealing with more cases so they become increasingly expert in these intricate and complex procedures.

These issues were first raised during the Bristol Royal Infirmary Inquiry which reported its findings a decade ago. Professional associations and national parent groups, who take a global view of these issues, have repeatedly called for a review of children's heart surgery services. They want to make sure our NHS is prepared for the complexity of future practice. We need to enable individual surgical teams to maximise their experience on particularly complex and rare conditions. The only way we can do this is by increasing the number of cases to which they are exposed. This cannot be achieved by simply tinkering at the edges of local services.

Surgery is usually a single short episode in what is often a lifetime relationship with specialist congenital cardiological services. Through this

review, we will seek to improve those services, particularly in those centres that will no longer offer surgery in the future so that children can be safely and expertly cared for nearer to home in the longer term.

We need to find a solution to a very real problem. For too long it has been filed away in the "too difficult" box. Time is now running out. We can either keep a service model that will inexorably fall behind other countries, or we can aspire to excellence and offer the most vulnerable members of the next generation the best possible start in life.

I want you to consider whether you think the proposed changes outlined in this document will deliver better care. Are there better solutions? We need an objective debate. In your deliberations refer to your own experience but please assess the options impartially, without regard to personal or emotional influences - it is more important we give children the very best chance in life.

Professor Sir Bruce Keogh
NHS Medical Director



2. SUMMARY

We believe change is needed in the way in which children's congenital heart services are planned and delivered. Change will improve outcomes for children and ensure services are *SAFE AND SUSTAINABLE*.

Expert clinicians and parents have highlighted the need for change. This is what we are trying to achieve:

- Better and more accessible diagnostic services and follow up treatment delivered through congenital heart networks
- Better results in surgical centres with fewer deaths and complications following surgery
- Improved communication between parents and all of the services in the network that see their child
- Reduced waiting times and fewer cancelled operations
- A highly trained workforce expert in the care and treatment of children and young people with congenital heart disease
- Better training for surgeons and their teams to ensure the sustainability of the service in the future
- An excellent service that delivers modern working practices using innovative techniques and continuing research and development to advance the quality of care children receive

WHAT ARE WE CONSULTING ON?

In order to make changes to the way services are organised the NHS wants to ask the public for its views. We would like to hear from anyone with a view on the future of congenital heart services including the people most affected: parents, young people and NHS staff. We would like your views on four main areas:



STANDARDS OF CARE

The proposed national quality standards that have been developed to ensure higher standards of care can be provided consistently across the country. Are they the right standards?



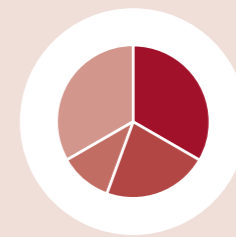
CONGENITAL HEART NETWORKS

We are proposing that surgical centres are not just responsible for the care they provide but that they would lead a congenital heart network. These networks would co-ordinate services and strengthen existing local assessment services where they exist and develop more outreach support in areas that have been neglected in the past. Are congenital heart networks the right model of care to improve services for children and young people?



LARGER SURGICAL CENTRES

We believe that the number of hospitals that provide heart surgery for children should be reduced from the 11 current centres to six or seven in response to evidence that suggests that only larger surgical centres can achieve true quality and excellence. Will fewer larger centres improve outcomes for children and young people?



MEASURING QUALITY

We are recommending that new systems are implemented for the analysis and reporting of mortality and morbidity data relating to treatments for children with congenital heart disease. Do you agree that new systems should be implemented to monitor outcomes?

The options for the number and location of hospitals that provide children's heart surgical services in the future are:

OPTION

A

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

C

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

LONDON

LONDON:

The preferred two London surgical centres in the four options are:

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

OPTION

B

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

D

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



Additionally, there are other recommendations for you to consider.

This document sets out the way in which the proposals for change have been developed and what they would mean for you.



On page 132 you will find details about how to give your view. The closing date for responses is 1 July 2011.

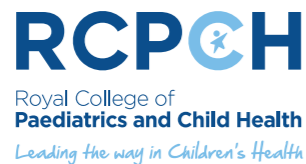


IN THIS SECTION YOU WILL FIND INFORMATION ABOUT

- Why are we doing this?
- The five principles behind the review
- The story so far
- The case for change

SUPPORT FOR CHANGE IS STRONG

Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS



Royal College of Nursing



3. INTRODUCTION

WHY ARE WE DOING THIS?

Proposing changes to children's congenital heart services is not inspired by any motivation to save money. The aspirations are safety, sustainability, better outcomes and excellent care for children. The NHS team responsible for this process, known as *SAFE AND SUSTAINABLE*, believes that change will result in better services. We also believe that without change the current service will not be sustainable in the future.

It is professional associations, surgeons, cardiologists, paediatricians, nurses and other clinicians who have urged the NHS for many years to centralise children's heart surgery in fewer, larger centres. Clinicians have been instrumental in leading the argument for change. Parent groups and the leading national heart charities also publicly support the fact that there needs to be change.

ACHIEVING EXCELLENCE



Congenital heart disease refers to defects in a child's heart that develop in the womb and are present at birth. Congenital heart disease is a life-long condition which can be life-threatening.

It is relatively rare affecting 1 in 133 children. Treatment is often extremely complex and requires expert clinical care from a team of heart specialists.

There are two main types of congenital heart disease:

CYANOTIC HEART DISEASE

where children do not have enough oxygen in their blood and;

ACYANOTIC HEART DISEASE

where the blood has enough oxygen but the heart pumps it abnormally often leading to high blood pressure and a weakened heart.

Consistent high standards. Excellent care for children that is provided locally wherever possible. And specialist surgical care performed by experts in fewer centres who are continually improving outcomes for children. These are the hallmarks that experts believe would deliver an excellent service for children with congenital heart disease.



TO ACHIEVE EXCELLENCE WE PROPOSE TO:

- Adopt new national quality standards that the service must meet in the future
- Develop congenital heart networks to ensure that care is better coordinated at all stages of children's lives and that assessment and ongoing care can be provided closer to where they live
- Pool expertise in children's heart surgery centres in England to provide better outcomes for children and ensure services are safe and sustainable
- Recommend that new systems are implemented for the analysis and reporting of mortality and morbidity data relating to treatments for children with congenital heart disease

THE FIVE KEY PRINCIPLES

SAFE AND SUSTAINABLE has been driven by five key principles.



CHILDREN

The need of the child comes first in all considerations. A principle enshrined in legislation by the Children Act 1989.



QUALITY

All children in England and Wales who need heart surgery must receive the very highest standards of NHS care.



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 Professor Sir Ian Kennedy in his 2001 report on children's heart surgery 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.

SAFE AND SUSTAINABLE has considered many different factors from quality to accommodation and journey times. Some existing heart surgery centres provide nationally commissioned services including highly complex heart transplantation and therefore we have considered the impact of moving such complex services. We have also looked carefully at the potential knock-on effect that the proposed

changes may have on other services such as paediatric intensive care units and on journey times both for planned surgery and transfers by ambulance. There are more details on all these considerations in section 6.

The *SAFE AND SUSTAINABLE* review is just one part of a wider review which is looking at both adult and children's congenital cardiac services.



PERSONAL SERVICE

The care that every congenital heart service plans and delivers must be based around the needs of each child and family.

"Children are not just little adults" is a phrase made repeatedly by the Royal College of Paediatrics and Child Health and by children's agencies around the world. Services and facilities for children must be designed and delivered around their specific needs.



CLOSE TO FAMILIES' HOMES WHERE POSSIBLE

Other than surgery and interventional procedures all relevant cardiac treatment should be provided by competent experts as close as possible to the child's home.

Whilst specialist clinical interventions, such as children's heart surgery, should be centralised, there have been many calls for the development of congenital heart networks that would result in better coordinated care and the delivery of assessment and ongoing care closer to the child's home.

Please see page 64 for more information on the importance of seamless care and the separate designation process for services for adults with congenital heart disease.



To what extent do you agree with each of the five key principles outlined here?

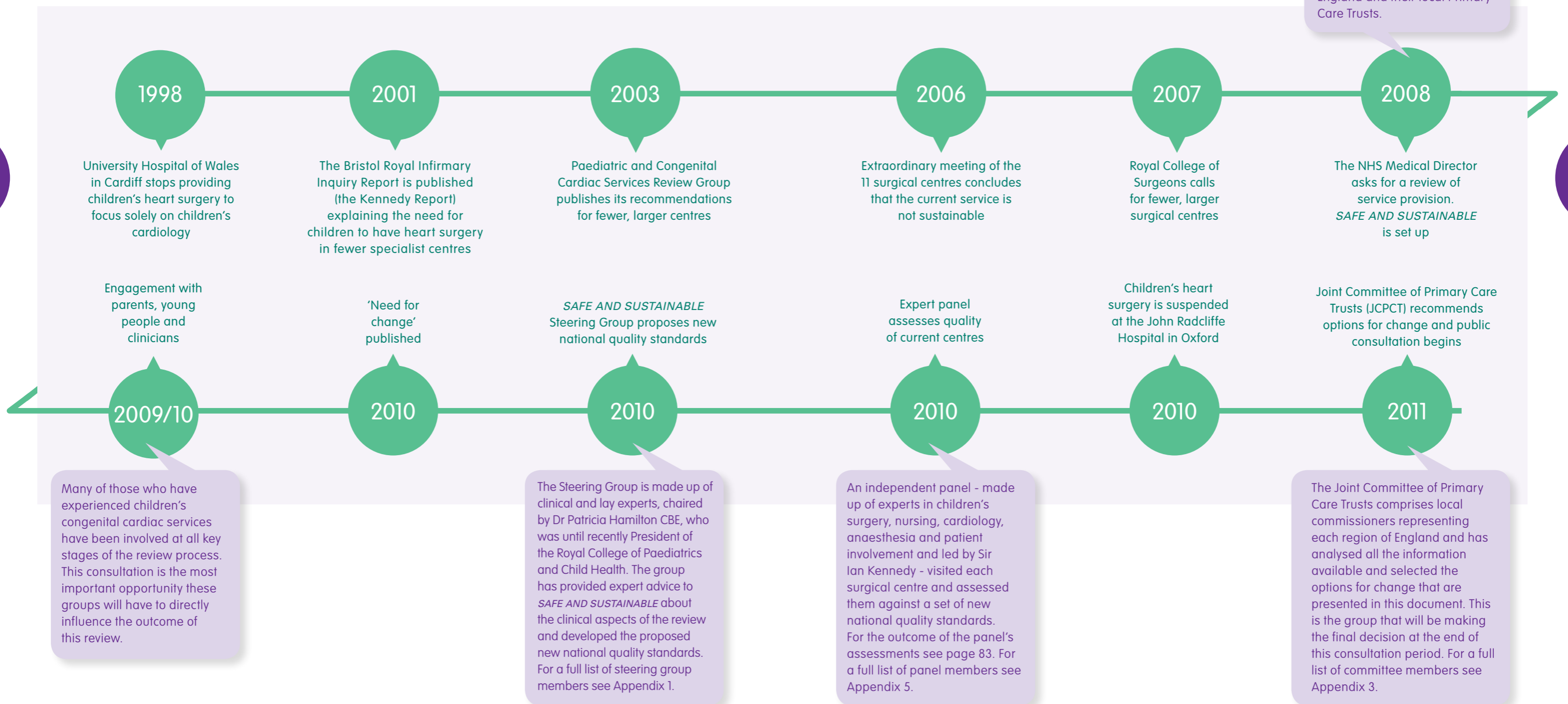
THE STORY SO FAR

The case for reducing the number of hospitals that provide children's heart surgery and the development of children's cardiology networks was made in two previous reviews in 2001 and 2003.

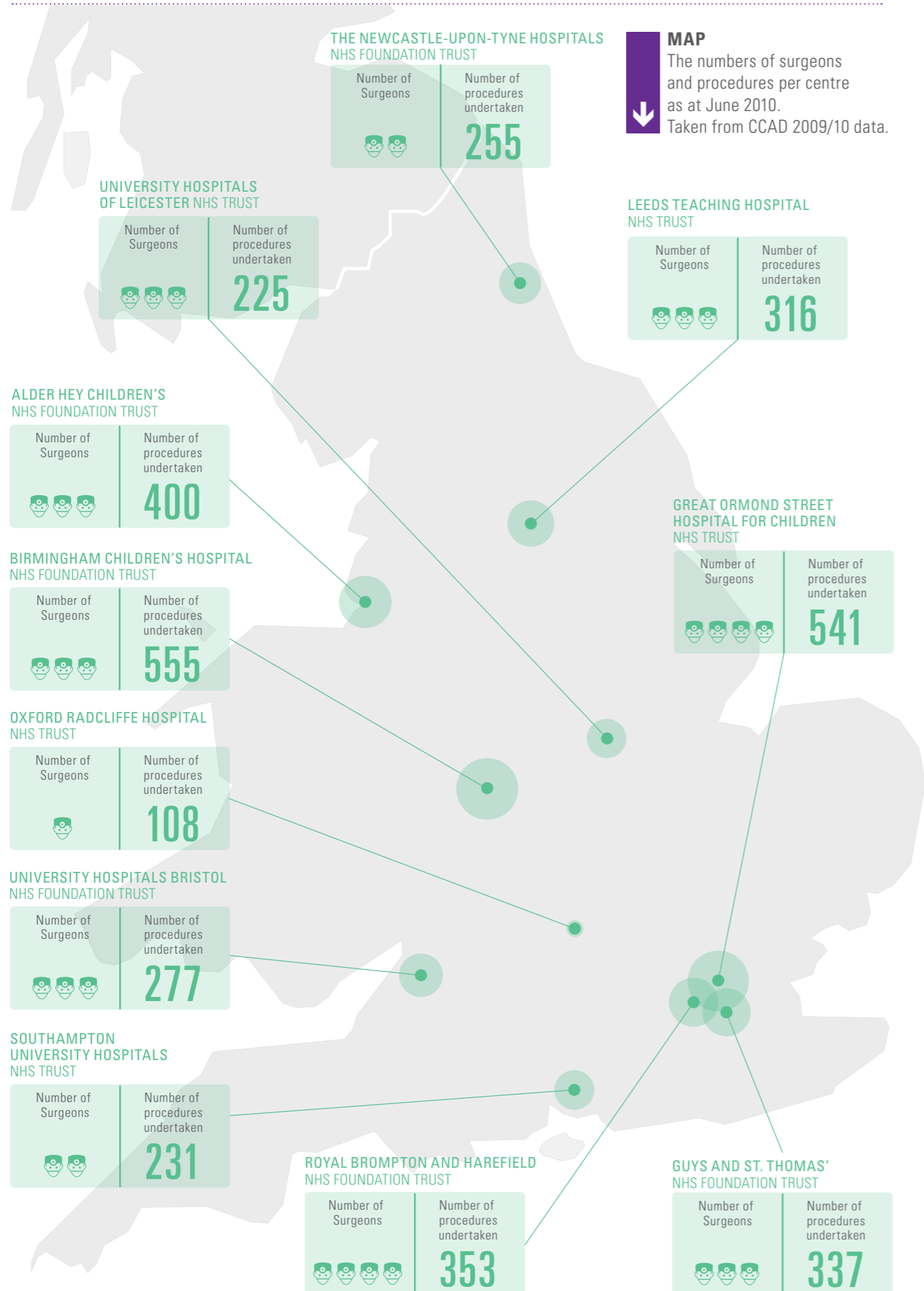
A meeting of all paediatric cardiac surgical centres in 2006 came to the same conclusion and in 2007 the Royal College of Surgeons added its voice to the call for change.

In 2008 the NHS medical director, a heart surgeon himself, asked the NHS to carry out a review and make recommendations for a *SAFE AND SUSTAINABLE* children's congenital heart service.

Many expert organisations – over many years – have highlighted the need to make changes to the service. The timeline below highlights the key milestones and groups of people that have played a role in the development of the review.



WHAT'S THE CURRENT SITUATION?



CASE FOR CHANGE

Without change there is a risk that in the future some children's congenital cardiac services may become neither safe nor sustainable.

WHY IS CHANGE NECESSARY?

- 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
- Available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes¹
- Fewer surgical centres are needed to ensure that surgical and medical teams are treating enough children to maintain and develop their specialist skills
- Having a larger and varied caseload means larger centres are best placed to recruit, mentor 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 Specialist 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

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

¹ Ewart, H. *The Relation Between Volume and Outcome in Paediatric Cardiac Surgery*; Public Health Resource Unit - A Literature Review for the National Specialised Commissioning Group (2009)
Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>



"Paediatric cardiac surgery in England is already carried out to high standards but some units remain small and heavily reliant on the goodwill of small dedicated teams. Consolidation into larger centres will address this but also needs to be matched to equitable and timely access for children and their families. This process aims to raise standards that need to be applied to the whole of the journey and seamless care into adulthood."

Dr Ian A Jenkins
Immediate Past President,
Paediatric Intensive Care Society

"I have no doubt that children will get better care if we accept the need for change. We must plan now so that the surgeons of tomorrow are properly trained and treat enough children so that they have enough experience. Unfortunately the answer is not recruiting more surgeons to the current centres. That would be a recipe for disaster as surgeons would not treat enough children to maintain their skills."

Professor Roger Boyle CBE
National Director for Heart Disease and Stroke

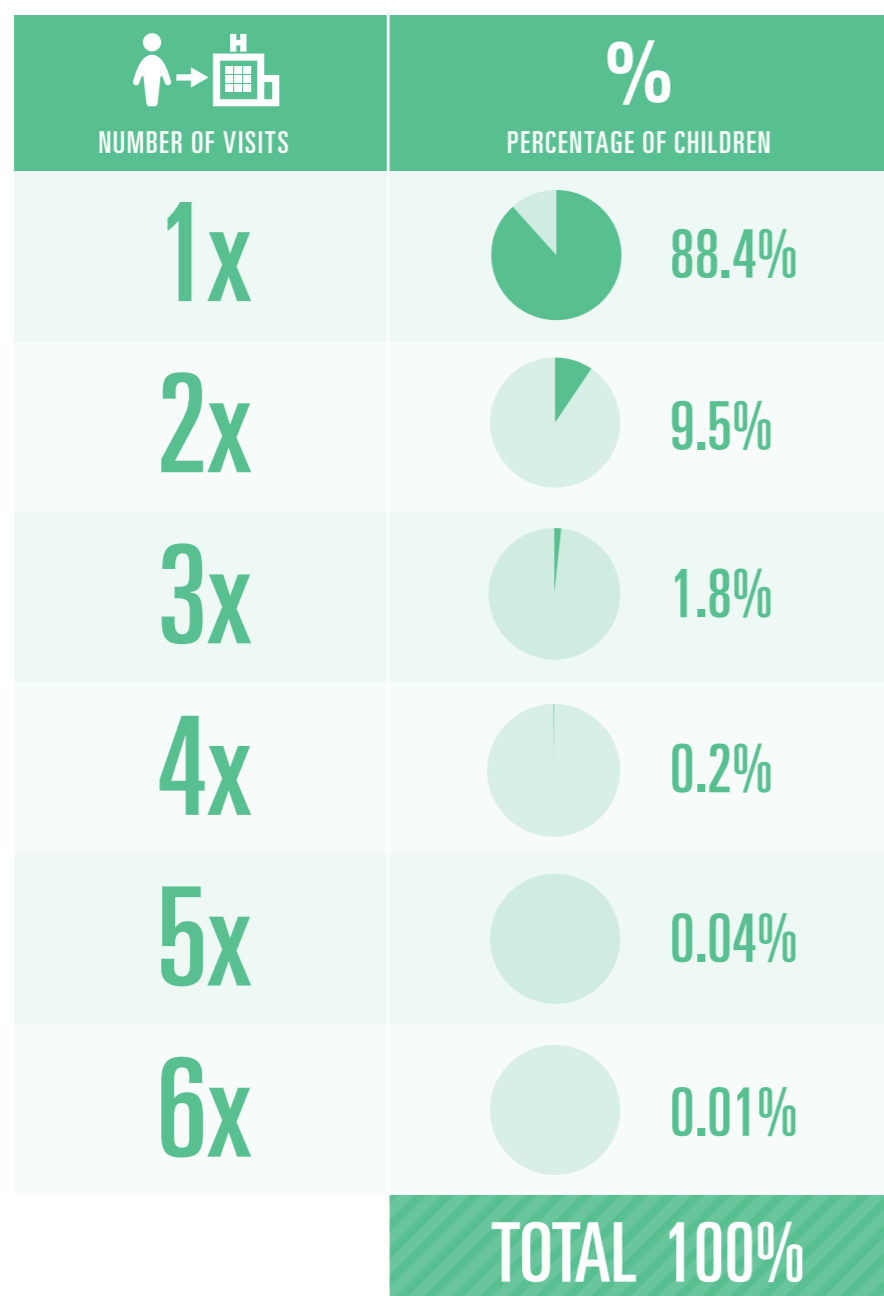
By its nature specialist surgery cannot be local to everyone. However, the distance from home to the surgical centre is a significant factor for families and *SAFE AND SUSTAINABLE* has taken travel times into account when developing the options for this consultation.

However surgery is not a regular occurrence for most children with congenital heart disease.

Children with congenital heart disease who need surgery generally only have it once. The table below shows that around one in ten children with congenital heart disease have two or more cardiac surgical or interventional procedures. Hospital admissions for surgery or interventional care are relatively rare whereas many children need regular ongoing support to help manage their condition.

HOW MANY CHILDREN HAVE ONLY ONE INTERVENTION?

↓ The number of times that children aged 15 and under are in hospital. The information refers to relevant cardiac surgical and interventional cardiology procedures between April 2000 and March 2010².



EVIDENCE SUPPORTING THE CASE FOR CHANGE

In this section we set out the evidence that supports the case for change.

RELATIONSHIP BETWEEN NUMBER OF PROCEDURES AND OUTCOMES FOR CHILDREN

A recommendation for the concentration of medical and nursing expertise in a smaller number of 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 Infirmary³. Subsequent working groups and reports have endorsed the recommendation, most recently by the Royal College of Surgeons in 2007⁴.

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 the outcomes in both morbidity and mortality⁵. Studies also suggest cumulative phenomena within institutions, in that higher-volume surgical units have increasingly better outcomes over time⁶.

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 outcomes⁷'.

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 surgery⁸.

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.

² Analysis undertaken of the Hospital Episodes Statistics data by National Cancer Services Analysis Team, September 2010

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

⁵ 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.

⁶ 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.

⁷ Ontario Ministry of Health and Long-Term Care (2002), 'Specialized Pediatric Services Review', *Report of the Minister's Advisory Committee*, 1-36.

⁸ Ewart, H. *The Relation Between Volume and Outcome in Paediatric Cardiac Surgery*; Public Health Resource Unit - A Literature Review for the National Specialised Commissioning Group (2009). Available at: <http://www.specialisedservices.nhs.uk/document/developing-model-care>

Two particular studies from the independent review by the Public Health Resource Unit 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 years⁹. This study concluded that large volume hospitals performed more complex operations and achieved superior results. A further¹⁰ study

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 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 report 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'

There is evidence that higher volume surgical units deliver better clinical outcomes and that the association between volume and outcome is evident in paediatric cardiac surgery.

⁹ 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.

¹⁰ 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.

¹¹ Department of Health, Paediatric and Congenital Cardiac Services Review Group, January 2001 – December 2003.

¹² The Royal College of Surgeons of England, *Surgery for children: Delivering a first class service*, London, July 2007

MINIMUM STAFFING LEVELS

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

In 2003 the report of the Paediatric and Congenital Cardiac Services Review Group¹¹ 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 centre¹² 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 national quality 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 rotas'*¹³

The case for a 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, such as 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 surgeons – rather than three - is the minimum number required in each surgical 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.

¹³ 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

EVERY SURGICAL CENTRE NEEDS FOUR SURGEONS

This diagram shows how surgeons in a four-surgeon centre would spend a typical working day. Looking at this it is clear to see how a centre with fewer than four surgeons would be stretched when any of the surgeons had to be away for any reason. It's difficult to see how a centre with two or three surgeons could be sustainable.

HEALTH WARNING

Things change. A surgeon's working day will vary from one day to the next. For instance, if there is an emergency or complications affecting a child having planned surgery, a surgeon's day will change. This diagram is for illustration only.

KEY

PLANNING CARE

Each morning the surgeons will meet to plan care for children having surgery that day, including coordinating care with the Paediatric Intensive Care Unit. Each week surgeons will need to attend multidisciplinary team meetings to discuss the treatment for individual children.

WARD ROUNDS AND CLINICS

Every morning surgeons will carry out ward rounds to check on the wellbeing of children either waiting for surgery or recovering. Often surgeons will perform a second ward round in the evening to check on children who had surgery that day. Surgeons will run an outpatient clinic during the week which gives children and parents the chance to discuss upcoming procedures and give consent for surgery.

SURGERY

Children's heart surgery is very complex. The amount of time a child spends in surgery can vary – some of the more complex procedures can last anything up to seven hours. This takes into account any complications that can arise during surgery, such as bleeding. A four surgeon centre will be able to run two operating theatres each day instead of one, meaning more surgery time and fewer cancellations.

ON CALL

At all times there is a surgeon who is working and is 'on call' for emergencies. Emergencies can arise when children are referred to the surgical centre during the day for urgent surgical or interventional cardiology procedures. Children needing emergency care can also be brought in overnight. If this happens the surgeon who is on call overnight may be called in to assist.

TRAINING

A core part of a surgeon's work is training. Surgeons need to train to maintain and improve their skills. This is known as Continual Professional Development. Without this training they are not allowed to continue practising surgery. Each surgical centre will also provide ward-based training and mentoring which may include a senior surgeon sitting in on a less experienced surgeon's surgery.

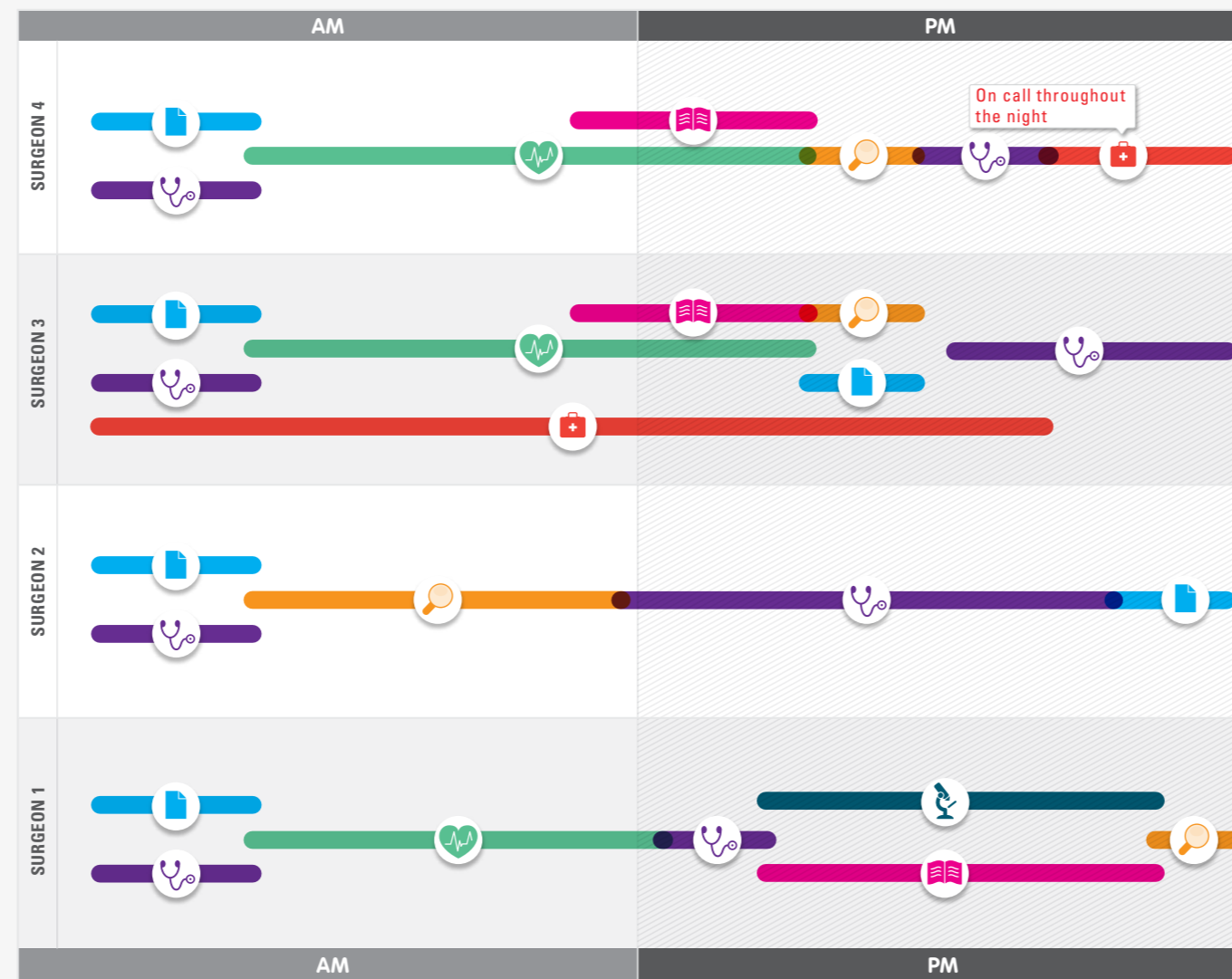
MDTs & AUDIT

Throughout the week each surgeon will need to attend multidisciplinary team meetings to discuss the treatment for individual children. As a profession surgeons have decided to submit data about the children's treatment so that outcomes can be monitored. This information is discussed during monthly audit meetings to check that the centre meets the highest standards and to identify any problem areas.

RESEARCH

Some surgeons should have an academic interest in children's heart surgery and their time may be split between working with a university on academic research and operating within a surgical centre. This work is vital as it helps to advance children's heart surgery, creating new techniques and improving existing ones.

A WORKING DAY IN A FOUR-SURGEON CENTRE



4 SURGEONS

Naturally, surgeons can't be expected to operate five days a week, 365 days a year without a break. There will often be times when one surgeon is away leaving just three surgeons at the centre. Absences can present serious problems for a small centre. However, if a centre has four surgeons, one surgeon's absence will not affect its ability to offer expert care 24/7.

Every surgeon has an agreed number of days a year for study leave and national duties. For example, some surgeons are also members of national professional bodies such as the Royal College of Surgeons and they are expected to represent these groups at conferences and meetings. Surgeons with an academic interest may also lecture at universities – this is important as it is helping to train the doctors of the future. However, study leave and national duties aren't the only times when a surgeon may be away from the centre. Each centre plans for surgeons' holidays and must take account of the fact that sometimes a surgeon will be on sick leave.

AT A GLANCE

In the morning two surgeons are in theatre together. Less experienced surgeons benefit from expert mentoring from senior colleagues. Another surgeon is attending a meeting with colleagues, known as a multidisciplinary meeting. Another surgeon is also carrying out planned surgery.

In the afternoon two surgeons are still in theatre operating on a child. One surgeon is carrying out vital research and another surgeon is running a clinic.

Throughout the night the senior surgeon is on call to deal with any emergencies that come in during the evening or overnight.

Whenever large changes to healthcare services are proposed, the National Clinical Advisory Team looks in detail at the clinical evidence to make sure that change is really necessary and that it will bring real improvements to the quality of care. The team is independent and its report into this review supports the case for changing the way that children's congenital heart services are delivered. Below are some comments from the report which was written by Dr Chris Clough, the Chairman of the National Clinical Advisory Team¹⁴.

"Using a figure of a minimum of four surgeons per unit as an absolute requirement does make sense and allows appropriate cover for colleagues and time for other activities that surgeons must pursue (e.g. clinical audit, teaching, management, research and professional development)."

Dr Chris Clough

Chairman of the National Clinical Advisory Team

¹⁴ National Clinical Advisory Team report on SAFE AND SUSTAINABLE 2010.

"The British Congenital Cardiac Association continues to offer its strong support for the reconfiguration of paediatric cardiac and surgical services with sufficient financial and local support. It supports the rationale that a smaller number of higher volume surgical centres are an essential pre-requisite to providing world class care for babies and children with congenital and acquired heart problems. The British Congenital Cardiac Association continues to highlight areas critical for the success of the project in delivering excellent quality and sustainable services in the future including seamless care across all age groups, modern integrated services and effective clinical networks."

"Our members have been instrumental in contributing to the SAFE AND SUSTAINABLE process and in developing the new national standards and the principles behind the proposed congenital heart networks. We must ensure that there is no impact on other children's services and that the children's cardiac services are properly funded to ensure that we achieve a modern workforce and facilities for world class care for these patients and families in the future. The British Congenital Cardiac Association will continue to highlight the importance of seamless care so that NHS services support a patient's journey through life from before birth into adulthood."

Professor Shakeel A Qureshi

President, British Congenital Cardiac Association

THE EVIDENCE FOR 500 PROCEDURES PER CENTRE

The proposed standards also require that each Specialist Surgical Centre should ideally perform at least 500 paediatric procedures per year. This is based on each of the four surgeons carrying out approximately 125 operations per year to ensure they perform enough surgery to maintain their skills and so that round the clock cover can be provided at every centre.

Many studies suggest that hospitals with bigger caseloads tend to perform more complex operations and achieve better results, while smaller centres tend to perform significantly worse when carrying out difficult procedures.

Sources: The Relationship between Hospital Surgical Case Volumes and Mortality Rates in paediatric Cardiac Surgery: a National Sample 1988-2005. Karl F Welke et al 2008. The complex relationship between paediatric cardiac surgical case volumes and mortality rates in a national clinical database. Karl F Welke et al 2009.

In recent years many countries have identified concerns around the safety and sustainability of their own congenital heart services for children.

Countries that have reviewed their planning and delivery of paediatric cardiac surgery include Sweden in 2000¹⁵, Canada in 2002, Australia in 2006¹⁶, The Netherlands in 2009¹⁷ and Germany in 2010¹⁸. Common themes throughout each of these reviews are clear:

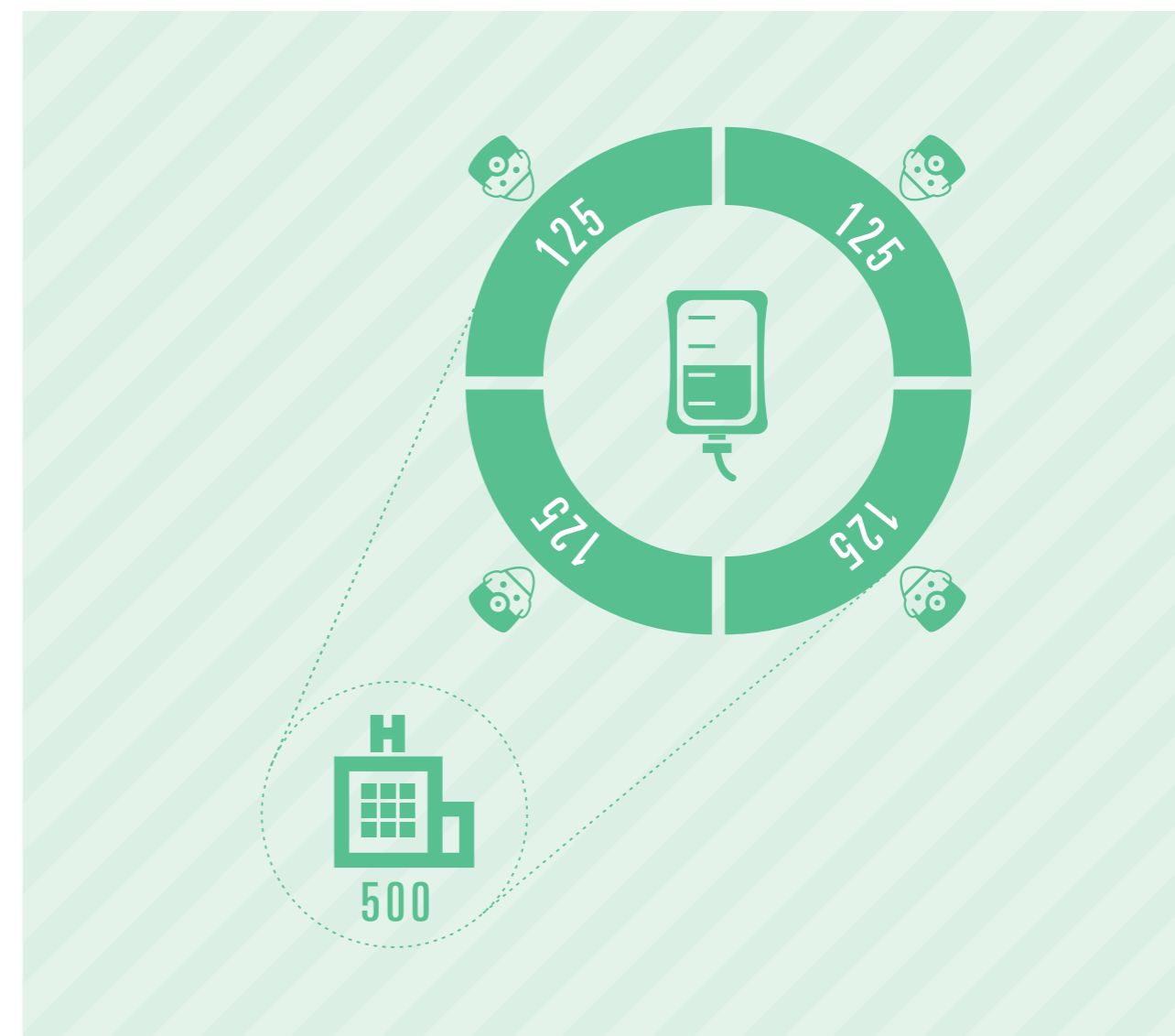
- Fragmented models of care for children with congenital heart disease are unsustainable (Australia, 2006)
- Congenital heart services need to comply with quality standards that set minimum staffing and activity requirements (Germany, 2010 and the Netherlands, 2009)
- The relationship between cardiac surgical volumes and outcomes (Canada, 2002 and Sweden, 2000).

¹⁵ Lundström, NR, Berggren, H, Björkhem, G, Jögi, P, Sunnegardh, J, *Centralization of Pediatric Heart Surgery in Sweden, Pediatric Cardiology*, 2000, 21:353-357

¹⁶ Queensland Government - Queensland Health, *Report of the Taskforce on Paediatric Cardiac Services*, August 2006

¹⁷ Commission for Paediatric Heart Interventions, *Concentration of congenital heart surgery and catheter interventions*, June 2009. Document translated from Dutch by Ubiquis, London

¹⁸ 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



Whilst confirming an association between volume and outcome in children's heart 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 number of paediatric surgical procedures that a Specialist Surgical Centre staffed with four surgeons must meet, the Steering Group considered the findings of the European Association for Cardio-Thoracic Surgery¹⁹. 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 125 surgical procedures each year for a full time surgeon.

¹⁹ '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.

"I have concluded that it is not acceptable to do nothing...One of the conclusions of the Kennedy review (the Bristol Royal Infirmary Inquiry 2001) was that there must be sufficient activity at centres for individual paediatric cardiac surgeons to maintain their skills. I have concluded it is no longer acceptable to have units with low activity."

Dr Chris Clough,
Chairman of the National Clinical Advisory Team



**WE WOULD
LIKE YOUR
VIEWS.**

Do you agree or disagree with the statement that 'Without change there is a risk that in the future some children's congenital cardiac services may become neither safe nor sustainable'?

IN THIS SECTION YOU WILL FIND INFORMATION ABOUT

- How the proposed standards would improve services for children
- The shape of the proposed new service
- How we propose to ensure the right treatment in the right place at the right time





4. NEW NATIONAL QUALITY STANDARDS TO IMPROVE CARE

Professor Sir Ian Kennedy's landmark report in 2001 recommended that national standards should be developed to cover all aspects of the care and treatment of children with congenital heart disease.

In our pursuit of excellence a set of new national quality standards has been developed as part of this review to help ensure that services produce better outcomes for children and are *SAFE AND SUSTAINABLE*. These are the quality criteria that experts believe must be met by any hospital that performs heart surgery on children. The proposed standards were developed in partnership with healthcare professionals, parents and patient groups and they are part of this consultation.

The standards are set out with reference to seven key themes as set out on the facing page.

 For a full list of the proposed national quality standards please see Appendix 4.

 For a list of members of the Standards Working Group, please see Appendix 4.1 of the standards.

SEVEN KEY THEMES

A CONGENITAL HEART NETWORKS

B PRENATAL DIAGNOSIS

C SPECIALIST SURGICAL CENTRE

D AGE APPROPRIATE CARE

E INFORMATION AND MAKING CHOICES

F FAMILY EXPERIENCE

G ENSURING EXCELLENT CARE

SEVEN KEY THEMES

A

CONGENITAL HEART NETWORKS

These standards cover the new structure of congenital heart networks that *SAFE AND SUSTAINABLE* is recommending. The standards set out the proposed roles for Specialist Surgical Centres, Children's Cardiology Centres and district level services, and how the different parts of the network will work together.

C

SPECIALIST SURGICAL CENTRE

These standards relate specifically to the Specialist Surgical Centres – the small number of centres that will be designated to perform surgical and interventional procedures on children. The standards cover issues including the required staffing levels, the minimum number of procedures that should be carried out each year and arrangements for meeting demand.

E

INFORMATION AND MAKING CHOICES

These standards cover the arrangements that would allow for parents and professionals to actively participate in decision-making at every stage of a child's care. Parents must be helped to understand their child's condition and the treatment they will receive, and know who to turn to to find out more.

G

ENSURING EXCELLENT CARE

The standards in this section relate to continuous professional training and development for staff involved in each stage of a child's care, establishing management groups to co-ordinate service delivery, the development of written protocols and guidance for clinical teams, and the collection and analysis of the relevant clinical data.

B

PRENATAL DIAGNOSIS

The fetal cardiology standards, developed by the British Congenital Cardiac Association, would have to be met. These standards also cover the protocols Specialist Surgical Centres will have to establish for Children's Cardiology Centres and district level services to improve prenatal diagnosis.

D

AGE APPROPRIATE CARE

These standards cover the measures that would ensure care is always age-appropriate. The standards set out the measures that would ensure a smooth transition from child to adult services.

F

FAMILY EXPERIENCE

Clinical and support facilities would be designed around the needs of children and their families, with the suitable facilities. These standards also set out how communication with patients and families would be improved, for example each child would have a named cardiac liaison nurse, staff would have communications training and families would be encouraged to provide feedback on the quality of their care.



WE WOULD LIKE YOUR VIEWS.

To what extent do you support or oppose the national standards within each of these seven key themes?



For a full list of the proposed national quality standards, please see Appendix 4 of the standards.

A CONGENITAL HEART NETWORKS

WHAT'S THE CURRENT SITUATION?

In 2010 Professor Sir Ian Kennedy and an expert independent panel assessed the existing surgical centres. They found that some working arrangements between services were often a result of informal relationships based on personal contacts. Some centres demonstrated only a limited understanding of the need for formal working arrangements with other parts of the health service. Hospitals were not always working together to share best practice and protocols.

Children with congenital heart disease rely on several different health services and unfortunately the way in which care is provided at the moment is inconsistent. Some services are too fragmented which means some children's care is not as well organised as it could be. There is also significant variation in

terms of what is available: some families have access to outreach services with assessment and diagnosis facilities led by a paediatrician with expertise in cardiology; others have to travel a considerable distance because the same service is not available where they live. Travel is an important consideration especially as some children with a heart condition never need specialist surgery but do need expert cardiology support near their family home and school. When a child with congenital heart disease gets a chest infection or other non-cardiac related illness some local hospitals are unable to treat the child because they do not have appropriately trained staff.

WHAT WOULD HAPPEN IN THE FUTURE?

Experts have advised the *SAFE AND SUSTAINABLE* review that in future children's congenital heart services should be more joined up. We are proposing that hospitals should be linked together to ensure that care for children and young people is better coordinated. This would ensure that expertise is pooled, information is shared effectively and that we can have more confidence that children will receive the right care

and surgery at the right time. We propose that new congenital heart networks are developed comprising all the NHS services that provide care to children with congenital heart disease and their families from prenatal screening and maternity services through to the to services for adults with congenital heart disease.



CONGENITAL HEART NETWORKS: THE SHAPE OF THE NEW SERVICE

Each network would include a **SPECIALIST SURGICAL CENTRE** and **DISTRICT CHILDREN'S CARDIOLOGY SERVICES** and may include a **CHILDREN'S CARDIOLOGY CENTRE**. The Specialist Surgical Centre would provide clear and effective leadership and a board of clinicians and lay people would oversee the running of each congenital heart network. Specific arrangements would also be developed

for each network to ensure the appropriate transition to adult services.

The diagram opposite illustrates the proposed new congenital heart network. It shows how mothers and children are referred by GPs and other health professionals, the different services they may use and the transition to adult services.

MORE PAEDIATRICIANS WITH EXPERTISE IN CARDIOLOGY

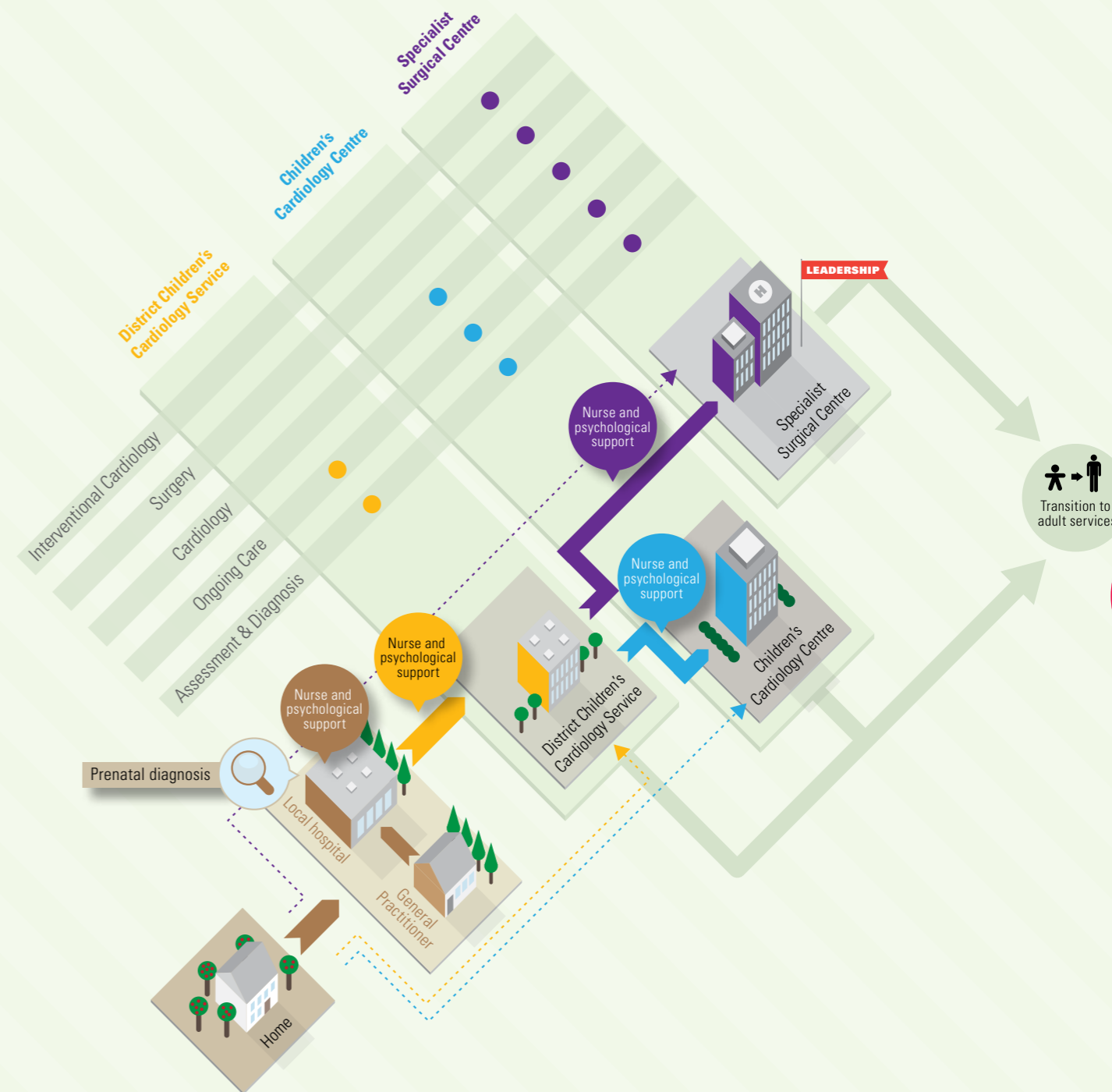
As the new networks develop a paediatrician with expertise in cardiology would be based at most large hospitals providing appropriate care closer to many families' homes. In some areas of the country families are already benefiting from local care and support. A parent describes how useful this role is below.

"My daughter receives all of her care from an outreach team based at our local hospital. She was born with lots of complex problems - her heart was the wrong way round, in the wrong place and only had one valve. She has needed ongoing care all her life and I can't falter the expert support we have received so far. The team at the local hospital are led by a paediatrician with expertise in cardiology and all the nurses are trained in how to care for her. I know I can ring them if she is unwell with a chest infection or for a second opinion if I spot something that doesn't seem right which puts my mind at ease. Having the team at our local hospital also means we don't have to travel to the surgical centre for things like check ups and swabs which makes it much easier for us."

Parent

WHAT ARE NETWORKS?

Networks are system of interconnected providers with contractual agreements in place that specify service requirements and outcomes.



THE ROLE OF THE DIFFERENT CENTRES AND SERVICES

DISTRICT CHILDREN'S CARDIOLOGY SERVICE

The District Children's Cardiology Service would be at the front line of the new congenital heart networks bringing expert care closer to home. We envisage that this service would be provided in hospitals which have large maternity units with at least 3,000 births per year. We envisage a strengthened role for paediatricians with expertise in cardiology.

These paediatricians look after babies and children with medical problems and have completed further training to develop their expertise and skills in caring for children with congenital heart disease. The Royal College of Paediatrics and Child Health and the British Congenital Cardiac Association have developed a joint training curriculum which sets the standard of training undertaken by these healthcare professionals to ensure consistently high standards of care.

A paediatrician with expertise in cardiology would be at the heart of this centre working directly with a named consultant paediatric cardiologist and other colleagues at Specialist Surgical Centres, Children's Cardiology Centres and other local hospitals.

Nursing staff would play a vital role working both within the different centres and providing vital outreach to families across the network.

THE SERVICES WOULD INCLUDE:

Expert cardiac care for newborn babies through to teenagers with heart conditions

Echocardiograms (taking detailed pictures of the heart)

Cardiac clinics for children and outreach cardiac clinics in tandem with a paediatric cardiologist

Care for pregnant women whose babies have been diagnosed in the womb so that they could give birth locally with the support of a paediatrician with expertise in cardiology if safe to do so

Babies and children suspected of having congenital heart disease whose condition is not identified before they are born would be referred to the District Children's Cardiology Service for diagnosis

The District Children's Cardiology Service would provide inpatient care for babies and children



WE WOULD
LIKE YOUR
VIEWS.

To what extent do you support or oppose the proposal to increase the role of paediatricians with expertise in cardiology in District Children's Cardiology Services across England?

CHILDREN'S CARDIOLOGY CENTRE

Centres that are currently providing children's heart surgery that cease to do so after this consultation process may become Children's Cardiology Centres. The centres will act as referral units for a designated Specialist Surgical Centre and would work to the same protocol to ensure a consistent service for children. Strong links between the two centres would be important.

Children's Cardiology Centres would be led by trained and experienced consultant paediatric cardiologists. Their teams would perform the full range of inpatient and outpatient diagnostic procedures that are not invasive (i.e. those that do not involve catheter treatment or surgery), as well as providing ongoing care for children with congenital heart disease. Children who need invasive surgical or other interventional procedures would be referred by the Children's Cardiology Centre to a Specialist Surgical Centre.

Existing children's cardiology units at Manchester, Edinburgh and Cardiff support nearby surgical centres. The Children's Cardiology Centres would function in a similar way providing a round the clock service seven days a week so that urgent care can be provided out of hours where necessary.

THE SERVICES WOULD INCLUDE:

Fetal diagnosis

Assessment and diagnosis for babies and children

Care for children between diagnosis and surgery and for those whose condition does not require surgery

Care for children in the paediatric intensive care unit

Care for those children who come to the Children's Cardiology Centre after surgery to recuperate and be monitored

On-going care to support children's conditions

Outreach diagnosis and other services provided by clinicians travelling to local hospitals



**WE WOULD
LIKE YOUR
VIEWS.**

To what extent do you support or oppose the proposal that current surgical units that are not designated for surgery in the future become Children's Cardiology Centres?

SPECIALIST SURGICAL CENTRE

A Specialist Surgical Centre would be responsible for leading each congenital heart network making sure services are better coordinated and working to common protocols. Specialist surgery and interventional procedures need to be delivered in a Specialist Surgical Centre by experts trained in performing the full range of procedures on children's hearts including the most complex problems.

Due to their specialist nature, the location of future children's heart surgery centres could not be 'local' to all people in England and Wales. However some children will have a Specialist Surgical Centre in their city – for these children it will be their local centre. Therefore Specialist Surgical Centres will provide the diagnostic and ongoing care services that we propose should be provided closer to all children's homes.

Parents need excellent communication between the different parts of the health service. Specialist Surgical Centres will take responsibility for effective communication with all the different healthcare professionals involved in a child's care. Regular multidisciplinary team meetings would be held where the care needs of children are discussed.

All key clinicians would attend these meetings and clinicians would spend time at outreach clinics with patients and colleagues. In all areas the use of online and audio-visual methods of expert-to-expert consultation (known as telemedicine) would help to share information across

different NHS services, speeding up children's assessments, review local investigations and appropriate referrals for children. This would avoid unnecessary duplication of some tests such as an echocardiogram.

On page 58 we set out more detail about the proposed changes to surgical care.

THE SERVICES WOULD INCLUDE:

Fetal diagnosis

Assessment and diagnosis

Care for children in the paediatric intensive care unit

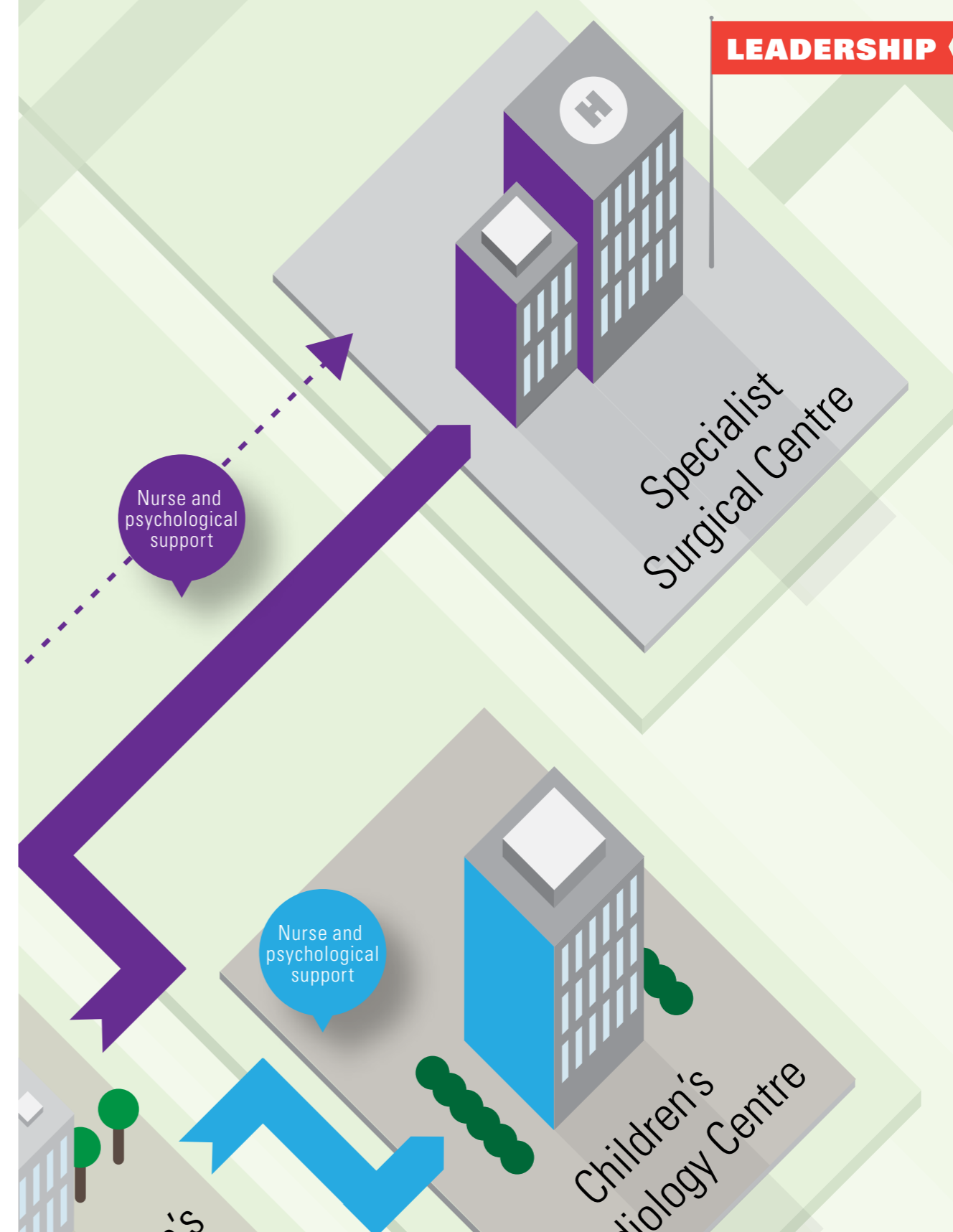
Surgical procedures

Interventional cardiology

On-going care to support children's conditions

Outreach diagnosis and other services provided by clinicians travelling to other hospitals

Collecting and supplying data on children's outcomes to the Central Cardiac Audit Database



ONGOING CARE

Ongoing care is vital. Experts have advised that up to half of children with congenital heart disease will not need surgery. They will require long term expert cardiology support and a few children will require medication to treat their condition. Many children with congenital heart disease have problems eating and gaining weight and will be placed on a special diet. They will also be more susceptible to illnesses such as chest infections. Ongoing care would be strengthened locally for more children under the proposed changes.

Dr Eva Stuwe is a paediatrician with expertise in cardiology who is based in a local district general hospital and runs cardiology clinics at the hospital, both screening clinics and joint clinics with tertiary centre cardiologist support.

“Through my work as a paediatrician with expertise in cardiology I see children who are suspected of having a heart condition and children who need ongoing care for their condition. Twice monthly echo clinics offer rapid local access, with around 130 children coming through these clinics every year from our catchment area. I may also be called in to provide expert advice on neonates with suspected heart disease, or the care

for children with CHD who are admitted to hospital for illnesses unrelated to their heart condition, for example chest infections or other medical problems. It is not always necessary for a child to visit the surgical centre, which in our case is 2 hours away. My training means that children in the area can access specialist assessment and treatment facilities locally. As well as routine tests such as blood tests, my clinic also carries out more specialist tests like echocardiograms, ECGs including ambulatory recordings and exercise tests, all of which allow to diagnose problems more quickly. At all times we work very closely with our expert colleagues at the tertiary centre to provide the best of service.”

IMPLICATIONS FOR CHILDREN IN WALES

Under the proposals children in Wales would continue to see experts at a Specialist Surgical Centre in England.

As you will see in section 6 it is proposed that children across Wales would continue to receive surgical care at their nearest surgical centre in England: any one of Bristol, Birmingham or Liverpool. The team of cardiologists in the children’s cardiology centre in Cardiff, along with local paediatricians with expertise in cardiology, would continue to provide non-surgical care to children in South and West Wales.

It is proposed that the Cardiff cardiologists would continue to work closely with the centre in Bristol.



WE WOULD LIKE YOUR VIEWS.

To what extent do you support or oppose the proposal to develop Congenital Heart Networks across England?

The following examples are fictional.

They illustrate some of the different services involved and how children’s care would be better coordinated.



HOW WILL THE NEW SERVICES WORK FOR CHILDREN WITH CONGENITAL HEART DISEASE?

MIRA



Mira's moderate heart condition is spotted by a fetal cardiologist working in the Children's Cardiology Centre before she is born. The cardiologist is able to see that Mira will require surgery, but not in the first few days of life.



Following a discussion between the paediatrician with expertise in cardiology based at Mira's local hospital and the family, it is agreed that Mira will be born at her local hospital.



Soon after birth she is assessed by the local paediatrician with expertise in cardiology who does the echocardiogram and discusses the findings with the cardiology team at the Specialist Surgical Centre.

Mira's condition is followed in her local clinic by the paediatrician with expertise in cardiology and with the cardiologist who attends a regular cardiac outreach clinic.



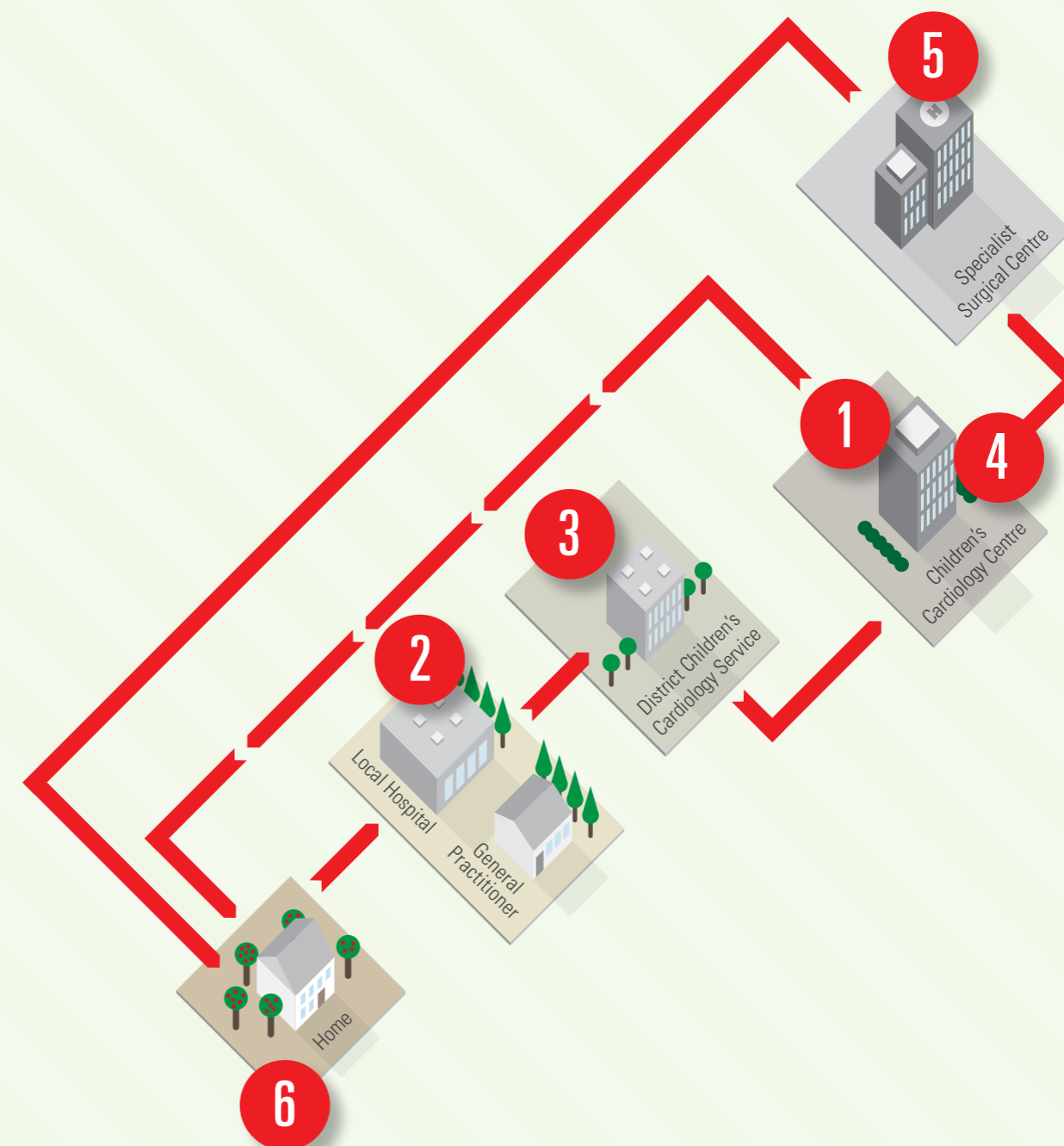
When Mira is two months old she is referred to the children's cardiology centre for further tests as the paediatrician with expertise in cardiology believes her condition has changed and needs the paediatric cardiologist to review her. The cardiologist presents Mira's case to the surgical/ medical conference meeting at the Specialist Surgical Centre. The decision to operate is made here.



Mira's family has regular telephone contact with the children's cardiac specialist nurse before the planned surgery and, because the family is very anxious, the nurse visits them at home. Before surgery the family is able to visit the Specialist Surgical Centre to meet the surgeon and to have a tour of the intensive care unit and ward.



After successful surgery Mira is assessed and her parents are reassured that she is making good progress. Her condition continues to be followed until the age of 16 at her local hospital by the paediatrician with expertise in cardiology and her cardiologist in regular outreach cardiac clinics.



JOANNE



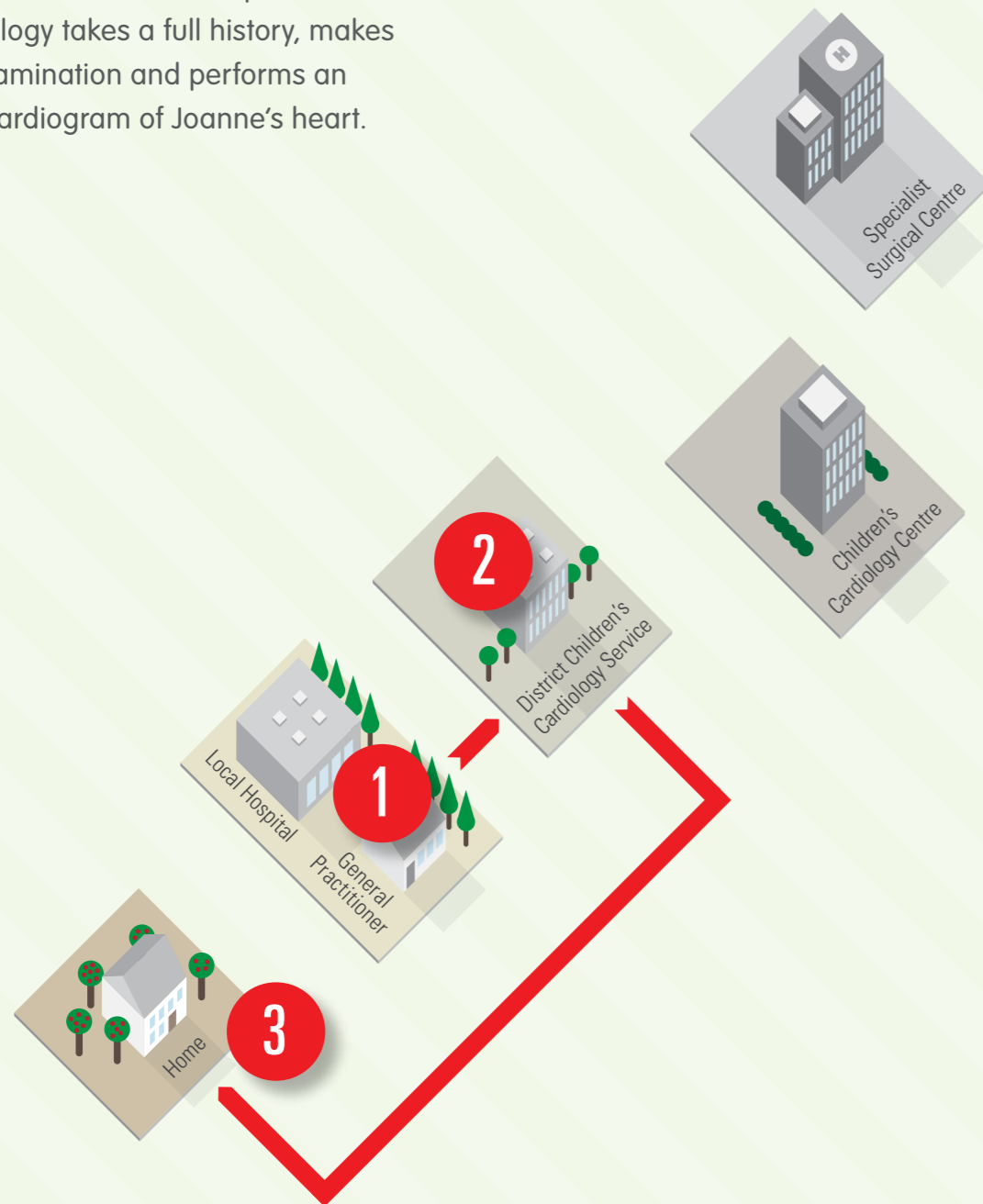
At six years of age Joanne is referred by her GP to a paediatrician with expertise in cardiology at her local hospital because of a heart murmur.



The paediatrician confirms that there is no underlying heart condition and is able to immediately reassure Joanne's parents and discharges Joanne from the clinic.



The paediatrician with expertise in cardiology takes a full history, makes an examination and performs an echocardiogram of Joanne's heart.



KOFI

Kofi's heart condition does not need surgery but does require ongoing care.

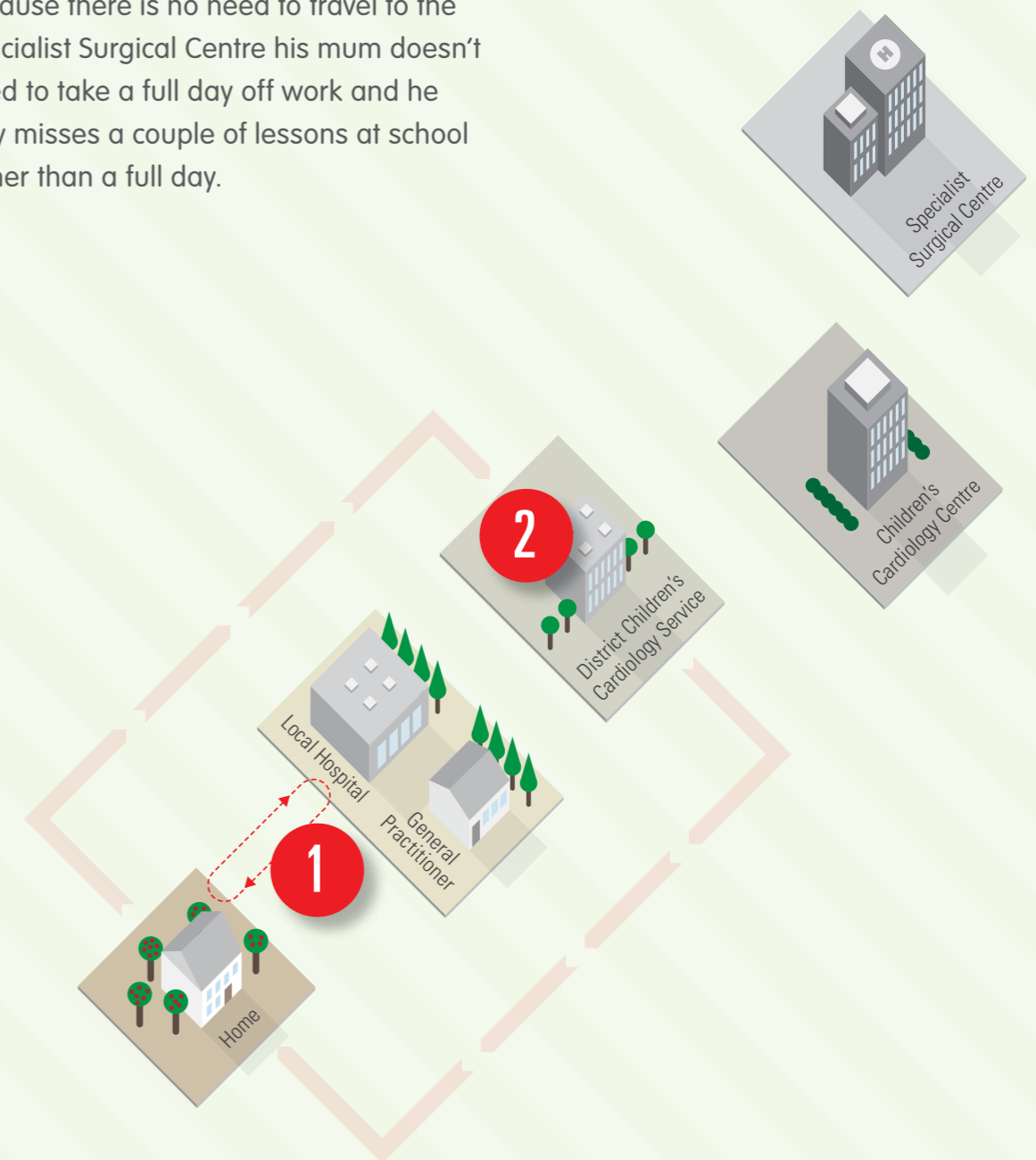


Kofi has never been to a Specialist Surgical Centre. Instead, every few months he sees his paediatrician with expertise in cardiology at his local hospital.



Once a year a cardiologist, working with the paediatrician with expertise in cardiology, assesses his condition at a cardiology outreach clinic.

Because there is no need to travel to the Specialist Surgical Centre his mum doesn't need to take a full day off work and he only misses a couple of lessons at school rather than a full day.



BILLY



Billy has complex cardiac surgery at the Specialist Surgical Centre. Whilst at the centre Billy and the family are visited by their children's cardiac specialist nurse who co-ordinates Billy's care.



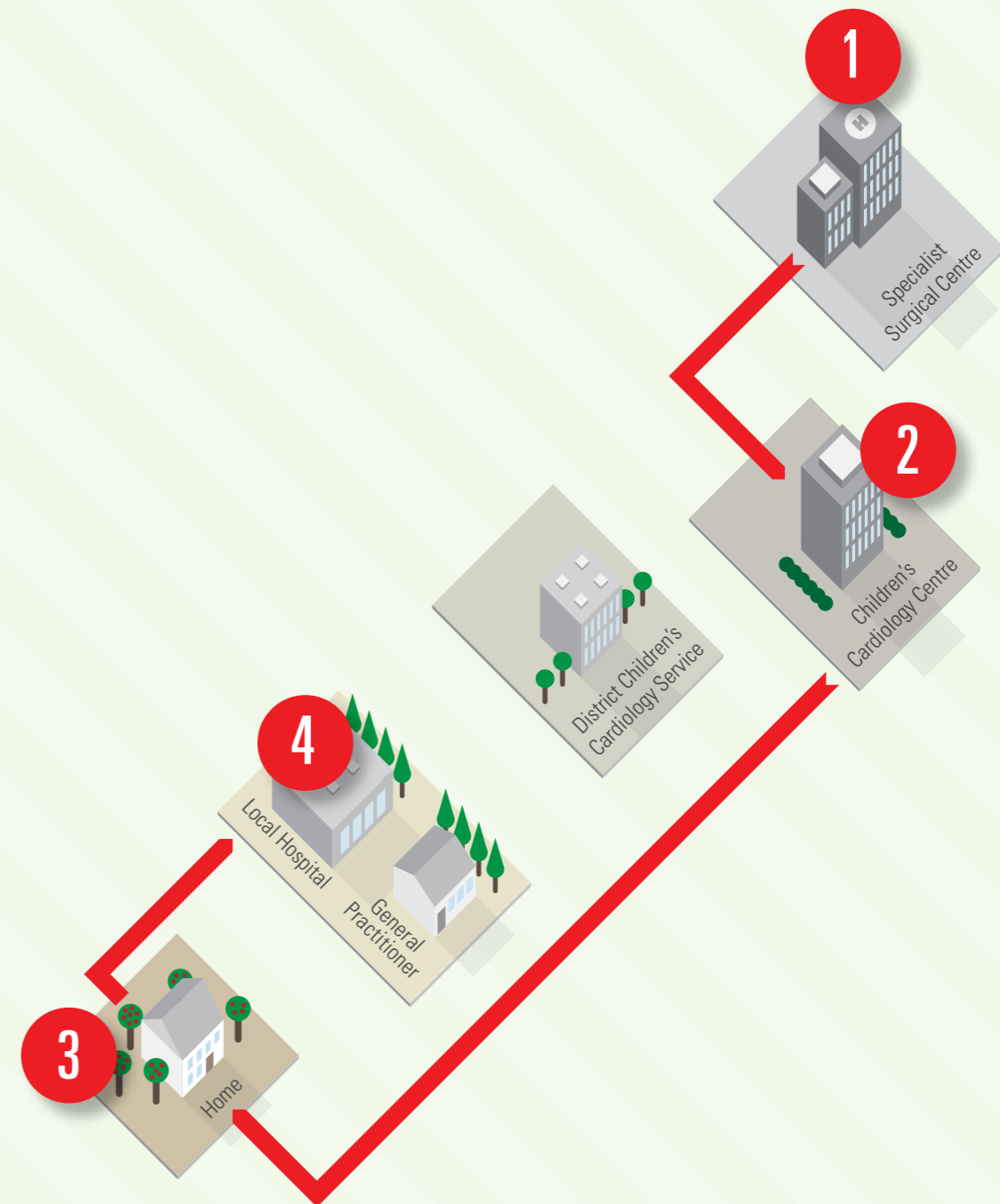
After the surgery Billy is transferred to the Children's Cardiology Centre where his condition is monitored until he is well enough to go home.



But, after two weeks at home, Billy's parents become worried that he is not eating enough. So they call their named cardiac nurse who contacts the local paediatrician with expertise in cardiology.



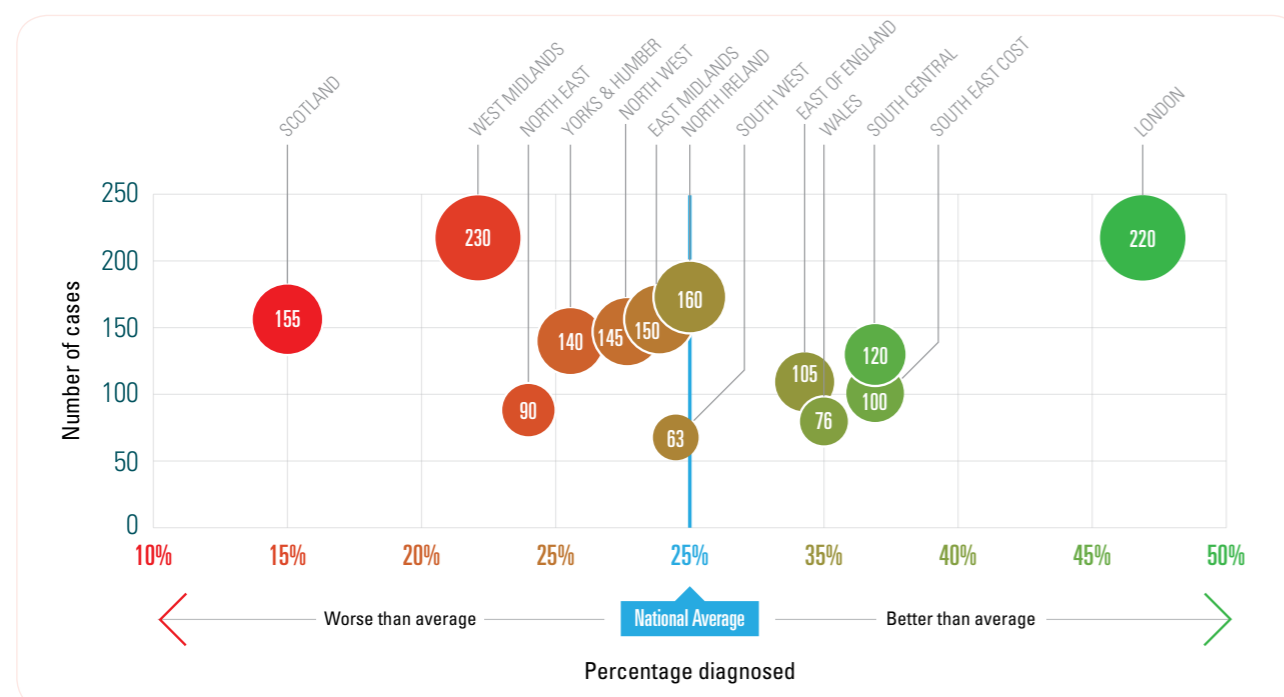
Billy is seen at the local hospital by the paediatrician with expertise in cardiology and a dietitian. Billy's progress is followed closely in Outpatients to ensure he gains weight and his cardiac nurse visits to help with feeding. A paediatric dietitian and clinical psychologist with expertise in children with congenital heart disease provide regular support.



B PRENATAL DIAGNOSIS

WHAT'S THE CURRENT PICTURE?

Far too many babies are diagnosed after they are born rather than in their mother's womb. The graph below shows that the numbers of children diagnosed before birth varies considerably across the country. Performance is inconsistent.



↑ Average percentage of cases where prenatal diagnosis has been made for children needing treatment in the first year of life, 2004-2008. Table taken from CCAD using 2009/10 data.

THE IMPORTANCE OF PRENATAL ASSESSMENT AND DIAGNOSIS

Prenatal diagnosis of major congenital heart disease improves results for children and can help to prevent serious complications such as brain damage. Timely diagnosis can mean the difference between life and death in the most severe cases. Knowing as soon as possible that a baby has a heart condition means the NHS can ensure mother and baby have the most appropriate care. An obstetric anomaly scan can identify heart anomalies such as an irregular or unusual sounding heartbeat or a problem with the way the heart has developed physically. If an irregularity is detected, the woman is referred to a fetal cardiologist for a fetal cardiology scan. If an unborn baby is

diagnosed with congenital heart disease, a fetal cardiologist works with the mother to develop a plan for how the baby will be born.

With complex conditions immediate surgery may be required and the cardiologist may recommend that the mother is transferred to a surgical centre shortly before birth. Sometimes the mother will give birth locally and the baby will be transferred to the nearest specialist centre immediately afterwards. When a heart condition is not detected in the womb the child may be diagnosed at birth or later in life depending on the severity of the condition.

WHAT WOULD HAPPEN IN THE FUTURE?



HIGH STANDARDS

All congenital heart networks would have to meet the Fetal Cardiology Standards developed by the British Congenital Cardiac Association. This would ensure that congenital heart disease is diagnosed prenatally far more often than it is today.



STRENGTHENED LOCAL ASSESSMENT AND DIAGNOSIS SERVICES

Expert assessment and diagnosis services would be provided as close to families' homes as possible. Children would be referred to experts closer to home qualified in carrying out the necessary assessments and diagnosis. This means that fewer parents and children would have to travel to a Specialist Surgical Centre for assessment and diagnosis.



FAST ASSESSMENT AND REFERRAL

If the obstetric anomaly scan performed by the obstetrician or sonographer indicates that the baby may have a heart problem, the mother would be referred for a specialist fetal cardiology assessment within one week and preferably within 48 hours. A faster referral would lead to earlier assessment which allows the mother and fetal cardiologist to plan for the birth of the baby.



SUPPORT AT THE RIGHT TIME

When a diagnosis is made the parents would have access to a clinical psychologist, nurse counsellor or specialist nurse. This is to ensure the necessary support and guidance is provided from the moment the child is diagnosed to enable parents to make informed decisions about care for their child.

C SPECIALIST SURGICAL CENTRES: THE NEED FOR SURGERY IN LARGER SPECIALIST CENTRES

WHAT'S THE CURRENT PICTURE?

Some surgical centres do not have enough surgeons. Some surgeons operate on relatively small numbers of children. Surgical expertise is currently spread too thinly across too many centres. This means that some children may be treated by surgeons and their teams who are not used to regularly performing a particular type of operation.

The table below shows the significant variation which currently exists between the centres. An obvious example is the difference between the

number of surgeons working at surgical centres. When the review started in 2009 there were 31 surgeons in 11 hospitals in England performing around 3,600 heart surgery procedures for children every year. The centres have different numbers of consultant cardiac surgeons – at the time the surgical centres were assessed the number of surgeons ranged from one to four. There is a similar level of variation in the number of procedures that were carried out in 2009, the latest year in which figures have been validated.

CENTRE	NUMBER OF SURGEONS ²⁰	NUMBER OF PROCEDURES ²¹
Alder Hey Children's NHS 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' 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 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

SOURCE: 2009/2010 data from CCAD

²⁰ Headcount based on centre's submissions to the National Specialised Commissioning Team, as at 30th June 2010.

²¹ 2009/10 CCAD validated data, surgical procedures only.



SMALLER CENTRES COME WITH RISKS

24/7

24 HOURS A DAY SEVEN DAYS A WEEK

Smaller centres with two or three surgeons are unable to operate safe rotas which guarantee care at all times of the day or night when a child needs it.



ISOLATION

Staff working in small centres that do not work in collaboration with other centres risk being isolated from their peers in larger busier centres. This can mean smaller centres might not use the latest techniques for children's care.



CANCELLATIONS

Some centres need to cancel planned surgery which can cause considerable distress and upheaval for families. Without enough surgeons at each centre planned operations are more likely to be cancelled especially if an emergency arises.



SUSPENSIONS IN SERVICE

Centres rely heavily on their staff. Sudden changes in staffing could destabilise a small centre meaning that surgery and cardiology services have to be suspended for a period of time.



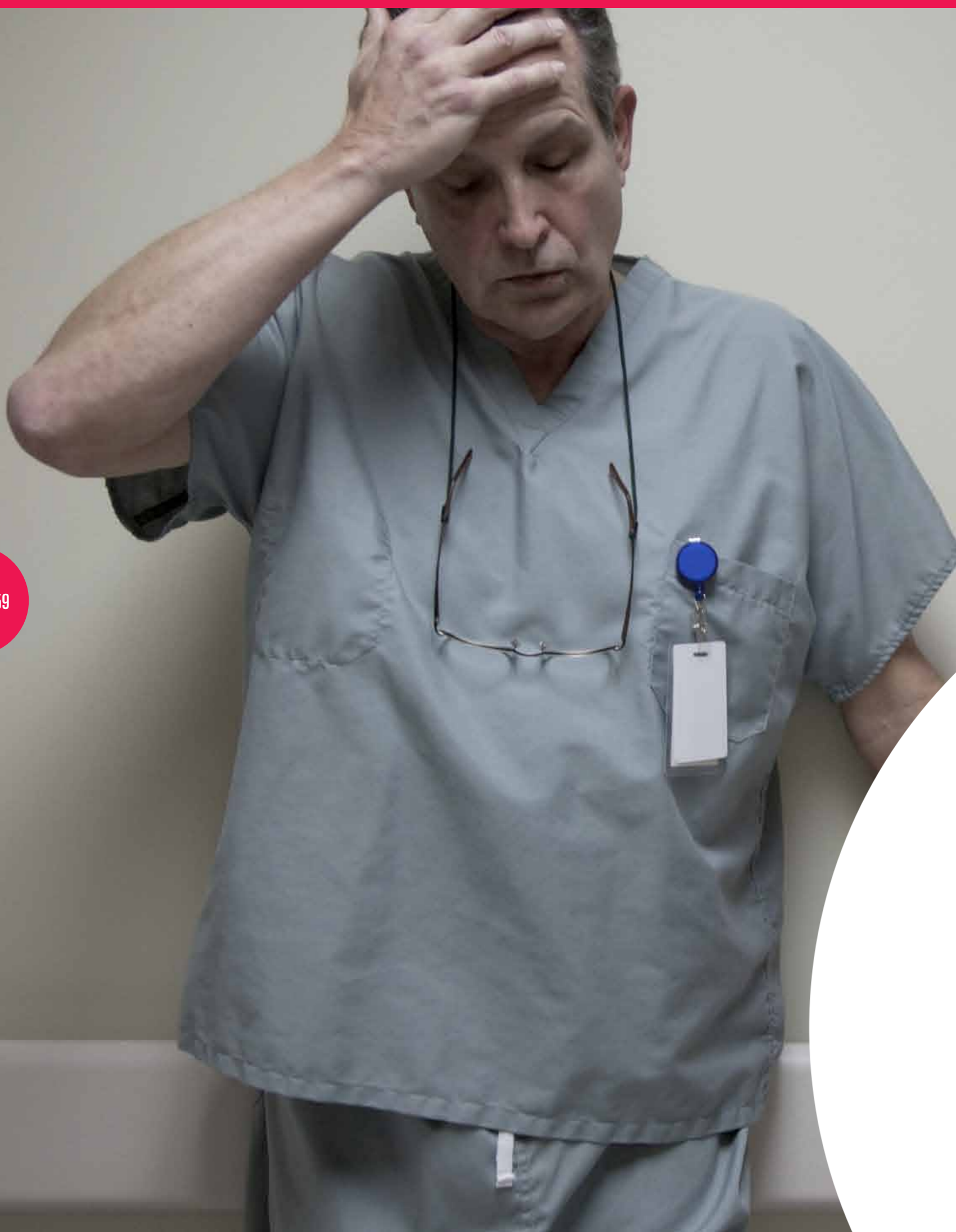
ATTRACTING AND RETAINING THE BEST STAFF

At smaller centres it is harder for surgical teams to see enough children with a variety of conditions to maintain their skills so that they can give children the very best care and attract other excellent staff.



STRAIN ON SURGEONS

Smaller teams place significant strain on surgeons particularly when urgent care is required. Imagine the strain on surgeons who may have performed operations all day and then get called out at night. It is not sensible for a surgeon who is over-tired to carry out complex surgery.



A surgeon's view

At an engagement event in 2010 a surgeon explained how vital it is for each centre to have enough surgeons.

"Let me tell you about the last three days of my working life. Three days ago I was up throughout the night operating on a congenital patient. The next night there was a referral during the night (with little sleep). I have operated throughout the day today and I am on call – if there is an urgent case I will be doing it as my colleague is away for a week. This is the reality of two surgeon practice. My colleagues in other centres have been in a similar position. If for some reason one colleague is unable to work with illness or holidays the pressure on the system is unbearable. This is not safe. This is not sustainable. There is nothing personal about this; it is for the children."

WHAT WOULD HAPPEN IN THE FUTURE?



LARGER CENTRES OF SURGICAL EXCELLENCE

It is important that each centre is big enough to cope, yet small enough to care. Larger centres would be safer and deliver better results for children. Urgent care could be provided when required 24 hours a day seven days a week and would reduce the risk of cancellations. In future surgical teams at all centres would see enough children to maintain and develop vital skills, and end the risk of children with particularly complex or rare conditions being seen by surgeons insufficiently experienced in the procedures needed. Expert care for children before and after heart surgery is vital. Paediatric Intensive Care Unit (PICU) consultants with skills in critical care for children with heart conditions would be available 24 hours a day.



CENTRES WOULD HAVE FOUR SURGEONS AND APPROPRIATE SURGICAL TEAMS

Working together in a team of four gives surgeons time to cover other responsibilities such as ward rounds, outpatient clinics, research, teaching or taking annual leave. As there is a growing trend for clinicians to specialise in particular procedures it is important to concentrate this expertise within larger teams.



Appendix 6 shows that the numbers of children with congenital heart disease requiring heart surgery is expected to remain roughly the same. *SAFE AND SUSTAINABLE* has considered population needs and is satisfied that it is unnecessary to increase the number of surgeons to plan for future demand.



MEETING THE STAFF

Parents of babies and children awaiting surgery or an interventional procedure would have the opportunity to visit the centre and meet the staff who will be responsible for their child's care. This should include meeting the surgeon or interventionist who would be undertaking the procedure.



INTERVENTIONAL CARDIOLOGY

For some congenital heart conditions interventional procedures are replacing surgical procedures as the primary form of treatment. Interventional cardiology is becoming more complex and presents a degree of risk to the child as devices are inserted into the child's heart. It is for this reason that should a complication arise the proposed new standards require interventional cardiology to only be carried out in Specialist Surgical Centres so that a congenital cardiac surgeon can assist if required.



WE WOULD LIKE YOUR VIEWS.

To what extent do you support or oppose:

- The need for 24/7 care in each of the Specialist Surgical Centres?
- The proposal that, in the future, interventional cardiology should be provided only by designated Specialist Surgical Centres?

KEY STANDARDS



 **500**

Ideally 500 children's heart operations would be carried out every year in each Specialist Surgical Centre with a minimum of 400 operations



24/7

Round the clock cover seven days a week would be provided – a consultant surgeon and specialist team available at all times



4

Each Specialist Surgical Centre would have a minimum of 4 full-time consultant congenital heart surgeons



D AGE APPROPRIATE CARE

This section refers to the transition arrangements for children.

SAFE AND SUSTAINABLE is just one part of a wider NHS review of congenital heart services. The NHS will review how best to deliver adult congenital services in 2011 and *SAFE AND SUSTAINABLE* recommends that the same principles of safety, sustainability and good quality outcomes which

it has used for children's services are considered. In this section we refer to both Adults with Congenital Heart Disease and Grown-Ups with Congenital Heart Disease (ACHD and GUCH).

WHAT'S THE CURRENT PICTURE ?

The expert assessment panel, led by Professor Sir Ian Kennedy, considered each centre's ability to meet the proposed national quality standards on transition arrangements and the panel met with GUCH patients. There is significant variation in the way hospitals plan and support young people's transition from children to adults' services.

- Transition planning is not always robust. Centres too often neglect the transition needs of children with congenital heart disease who have not required surgery.

- Some hospitals have transition clinics for young people in place. Some – although planned – had not been started.
- Several hospitals do not have dedicated transition nurses. This can mean that young people are not properly involved in decision making. Sometimes transition nurses are only available at a surgical centre rather than providing outreach support.

WHAT WOULD HAPPEN IN THE FUTURE?



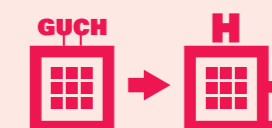
The *SAFE AND SUSTAINABLE* standards require that clear transition arrangements are in place between Specialist Surgical Centres and specialist adult units. Preparation should start from around the age of 12 with transfer to adult services usually at age 16 and normally completed by age 18.



All congenital heart networks must have a dedicated transition nurse to facilitate effective and timely transition from children's to adult services.



Young people must have the opportunity to be seen by a Clinical Psychologist on their own.



Specialist GUCH centres should be linked to children's Specialist Surgical Centres.



The *SAFE AND SUSTAINABLE* standards are in line with what the GUCH standards state on transition.



TAKING ACCOUNT OF ADULTS' NEEDS

- The NHS is addressing the needs of adult patients with congenital heart disease by ensuring that all hospitals wanting to provide services in the future will need to meet new quality standards. Some of the key requirements are:
- All patients aged 16 and over should be seen at least once by an adult congenital heart specialist. This will either take place at the specialist GUCH centre or at a local clinic for adults depending on how complex a patient's condition is and how far they have to travel to the service.
 - Local GUCH centres and local clinical networks would be created to ensure all patients are seen once by the expert GUCH cardiologist with clear care plans agreed for ongoing management at the specialist centre, local GUCH centre or local hospital.
 - 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.

HAVE YOUR SAY

No final decision on the future configuration of children's heart surgery services will be made until the outcome of the consultation has been considered. We would like GUCH patients and GUCH patient groups to be fully involved in the consultation, and to have the opportunity to ensure that the GUCH 'voice' is fully heard.

Please go to page 132 for information on how to get involved and respond to the consultation.

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. 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.

FACTS ABOUT ADULTS WITH CONGENITAL HEART DISEASE

20%

Fewer than 20% of children with congenital heart disease used to reach the age of 16

85%

Heart surgery and more recently interventional procedures have changed that. By the 1980's 85% of children reached adulthood



There are now more adults than children with congenital heart disease. This is largely the consequence of advances in cardiac surgery and has been described as one of the greatest triumphs of modern medicine



Most adults with congenital heart disease will need life-long monitoring. Some will need surgery



As people with congenital heart disease age acquired heart problems become more common. Therefore the clinicians must have expertise in congenital heart disease, adult cardiology and general medicine

H
21

Twenty one English NHS Trusts performed heart surgery on adult congenital patients in 2008/09. Source: Central Cardiac Audit Database



The number of procedures varies significantly between the hospitals

E INFORMATION AND MAKING CHOICES

WHAT'S THE CURRENT PICTURE?

Parents have told us of their frustration that the different NHS services that see children with congenital heart disease could be more 'joined up'. Parents complain that some services do not share information when they should and that too often they have to spend valuable time with clinicians telling their child's 'story' over and over again. Some parents have also expressed concerns about the quality of information that they receive about their child's condition. Too often parents complain that hospitals do not take the time to explain things in sufficient detail.



"Being a first time mum, hearing the news that my son had a heart condition was traumatic. We were told there and then that it was highly likely that he would need surgery to replace the valve. At this stage we felt a little in limbo. We left the hospital having been told he had a complex heart condition but with very little information about his condition and what to expect going forward. It was only after doing my own research that I was able to understand what was happening and what to expect. I really believe that the language used by the specialists seeing parents of children with congenital heart disease definitely needs to be more accessible – we would sometimes come away from appointments thinking 'Gosh, I didn't realise that was going to happen'."

Parent

WHAT WOULD HAPPEN IN THE FUTURE?



MEETING THE STAFF

Parents of babies and children awaiting surgery or an interventional procedure would have the opportunity to visit the centre and meet the staff who will be responsible for their child's care. This should include meeting the surgeon or interventionist who would be undertaking the procedure.



CHOICE

Clinical experts would continue to advise parents about where appropriate specialist care can be provided based on their child's needs, but parents would be able to make their own choices for their child.

For example some parents may decide that their child should be treated at a different hospital to the one recommended, even if sometimes this means travelling further for ongoing appointments or for surgery. It is the responsibility of the NHS in England to accommodate choice.



UP TO DATE RECORDS

Parents sometimes find themselves repeating information about their child's condition to different health professionals. Under the proposed changes all children would have their own care records containing information about their condition, the latest care given, contact details for the ward at the Specialist Surgical Centre, and the family's named specialist nurse, cardiologist and paediatrician with expertise in cardiology.

It would specify how the child's condition needs to be managed and/or what care is being delivered following surgery or intervention. Whenever a child receives additional care, the information would be updated.

F FAMILY EXPERIENCE

WHAT'S THE CURRENT PICTURE?

The support families receive is inconsistent. Accommodation for parents while their child is in surgery differs around the country. Regular access to specialist staff such as clinical psychologists and nurses that liaise closely with parents depends on where you live. This inconsistent picture needs to change. Families must be able to access excellent support during this highly stressful time.

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

WHAT WOULD HAPPEN IN THE FUTURE? A STRONGER ROLE FOR NURSES

7+

A minimum of seven full time Children's Cardiac Specialist Nurses would support families in each congenital heart network.



There would be greater consistency in the way in which staff are trained to communicate with children and parents. Training would include how to discuss with parents the outlook for children with particularly complex and rare conditions, and how to give difficult news about complications during surgery.



A named children's cardiac specialist nurse would be assigned to each child and liaise with the family and other specialists within the NHS to ensure the child gets the right care.

We know this is a vital role and that in areas where this model is already operating parents have indicated this type of nurse provides significant support. This nurse would also be responsible for providing further information relating to the condition and treatment options.

This service would be available on a consistent basis across the country.

"We left the hospital with a letter explaining her condition and a long list of medication needed to treat her. It was a worrying and bewildering time as we had no idea what to expect or how well our daughter would respond to the medication. Unfortunately our local GP was unsympathetic and refused to prescribe the medication. After a distressed call to the cardiologist he offered to speak to the GP who still refused to prescribe the medication. Leaving hospital with a child who you have discovered has a complex heart condition is not the same as leaving hospital with a completely healthy child. You worry about what could go wrong knowing that whatever did go wrong could be life threatening. Having the right support in place for parents and the child concerned is so important."

Parent



WHAT WOULD HAPPEN IN THE FUTURE?

In future cardiac liaison nurses would be known as children's cardiac specialist nurses and would be available more locally to provide vital support to families. Nurses and psychologists should be present during appointments with the consultant paediatric cardiologist, or should follow up with the parents within 48 hours after the appointment to provide further information and support.

"As a cardiac liaison nurse I play a vital role in providing the expert care and advice that children with congenital heart disease and their families receive. I help families understand what the disease is and what impact it may have on their child's life – and their own. I have more time to talk to families in detail about the possible implications of their child's condition than some of my colleagues. It's important that families know they have a person they know and trust who they can ring up at any time to ask questions."

Parents are often concerned about their baby struggling to put on enough weight to have surgery and raise queries from their child's schooling to travel insurance if they are planning a holiday. A large part of my role is educating those who come into contact with children with congenital heart disease about the condition from GPs, health visitors, psychologists and dietitians, to head-teachers and school nurses."

Nurse



BETTER ACCOMMODATION

Accommodation was raised by parents as a significant issue at engagement events in 2010. The proposed standards require all Specialist Surgical Centres to provide appropriate accommodation for families.

This would include facilities to allow a parent to stay at their child's bedside, where appropriate, and a patient hotel service for those parents needing to stay for a longer period of time.



"There was no accommodation available for my husband and me when my daughter went into hospital for her first surgery so we had to take it in turns to stay by her bedside. Three years later we were told to prepare for another surgery. Family and friends took time off work to look after our four other children as we prepared for a six week stay in hospital. My husband and I organised to rent a flat close to the hospital so that family could stay with us on weekends. The day before the surgery we received a call to say the surgery had been cancelled. We were disappointed to say the least and it was a hurdle we definitely didn't need."

Parent

G ENSURING EXCELLENT CARE

WHAT'S THE CURRENT SITUATION ?

- Centres that provide children's heart surgery could do better in learning from their own experiences and working together as a national network
- Some hospitals were unable to demonstrate a formal research strategy
- Some hospitals did not sufficiently describe an academic research portfolio
- Research and audit arrangements were not always deemed to be robust

WHAT WOULD HAPPEN IN THE FUTURE?



Each Specialist Surgical Centre would have a dedicated cardiology data collection manager responsible for timely audit and database submissions in accordance with necessary timescales.



All healthcare professionals must take part in a programme of continuing professional development that is recorded in a training register.



Centres would share learning from across the various services in their own congenital heart networks and across the national network.



Centres would be required to have a formal research strategy and to develop academic links with universities.





IN THIS SECTION YOU WILL FIND INFORMATION ABOUT

- How the standards and the model of care were developed
- How *SAFE AND SUSTAINABLE* has engaged with key stakeholders including parents, the public and clinicians
- The options assessment process – assessing the centres; mapping against populations to ensure each centre can see enough children; weighting the criteria

5. THE PROCESS BEHIND THE PROPOSED CHANGES

SAFE AND SUSTAINABLE has considered all the available evidence and advice before making recommendations for change. We have considered relevant existing professional guidance, recommendations of previous heart surgery reviews and looked at what happens overseas.

In this section we describe how we have taken advice from stakeholders and the way in which *SAFE AND SUSTAINABLE* has carried out all the necessary work to evaluate the existing surgical centres. We also explain the process of delivering four viable options for public consultation.



ENGAGING PARENTS AND 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 PARENT AND PATIENT GROUPS

LOCAL PARENT AND PATIENT GROUPS

NATIONAL PROFESSIONAL ASSOCIATIONS

NHS STAFF

NHS COMMISSIONERS

SCRUTINY BODIES

(Health Overview Scrutiny Committees and LINKs)

"I have concluded that the consultation process has been lengthy and detailed, involving the public, patients and parents of children with heart disease. It has consulted widely with the clinical workforce."

Dr Chris Clough, Director
National Clinical Advisory Team



DEVELOPING THE PROPOSED NATIONAL QUALITY STANDARDS AND MODEL OF CARE

Many different individuals and groups have had an opportunity to inform the content of the proposed national quality standards.

The *SAFE AND SUSTAINABLE* Steering Group has provided ongoing advice on the development of the proposed national quality standards and a Standards Working Group was set up to oversee their development. The draft standards were widely circulated for comment in September 2009 and were published 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 its website and circulated it directly to their member groups.

On 22 October 2009 *SAFE AND SUSTAINABLE* held a national event for professionals and parents. Two hundred delegates tested the draft service standards and provided feedback on potential models of care.

The Children's Heart Federation canvassed the views of parents by commissioning focus groups and survey work.

Questionnaires were sent to over 5,000 parents and over 1,000 responses were received and analysed. Parents told us that:

- Survival and quality of life was the most important priority
- The distance to hospital was the least important priority
- The four issues that concerned people most were:
 - Accommodation for families
 - Childcare
 - Cost of travel
 - Time off work and impact on family life

The Standards Working Group considered all the feedback and produced the proposed national quality standards in March 2010.



DEVELOPING THE CONGENITAL HEART NETWORK

The Steering Group has also led the design of the proposed congenital heart networks.

Details about this new model were published in the 'Need for Change' in April 2010 and we sought feedback from parents and stakeholders during the engagement events in 2010. Since then more detailed work has been carried out.

In summer 2010 over 1,000 people attended engagement events. The events were held in ten different accessible locations across the country. Parents were asked to share their

experiences of care and ask questions about the review.

Parents commented about issues from travel times to accommodation, from the vital role staff play to the impact on siblings and the wider family. The views are available on the website and have been part of the evidence available to the Joint Committee of Primary Care Trusts.

A Network sub group was formed to further refine the detail for the proposed congenital heart networks.



KEEPING PEOPLE INFORMED; INVITING FEEDBACK

- We have produced newsletters to keep parents informed of the progress of the review. The newsletters are issued direct to parents, parent groups and centres. The website has been continually updated and in 2010 it was redeveloped to be more accessible
- Materials have included a contact postal address, email address and a telephone number. The Programme Director has responded to emails and letters personally
- We have published details of the clinical and research evidence used in the review on the website together with agendas, minutes of meetings and updates on the review process
- In April 2010 we published the 'Need for Change' document which was widely reported in the media

- We have encouraged people to send in their views at any time. The following diagram illustrates how information has been captured and fed into the Joint Committee of Primary Care Trusts, the decision making body

Health and Overview Scrutiny Committees and Local Involvement Networks have been informed about the progress of the review. These groups were invited to the national stakeholder event in October 2009. In August and October 2010 all overview and scrutiny committees received briefings on the review and were asked how they would wish to be consulted as part of the formal consultation.



THE OPTIONS ASSESSMENT PROCESS

An options appraisal (assessment) process has been undertaken so that we can present the best, viable, sustainable options for public consultation. This section gives a detailed description of how we arrived at our recommendations for reconfiguration of the service.

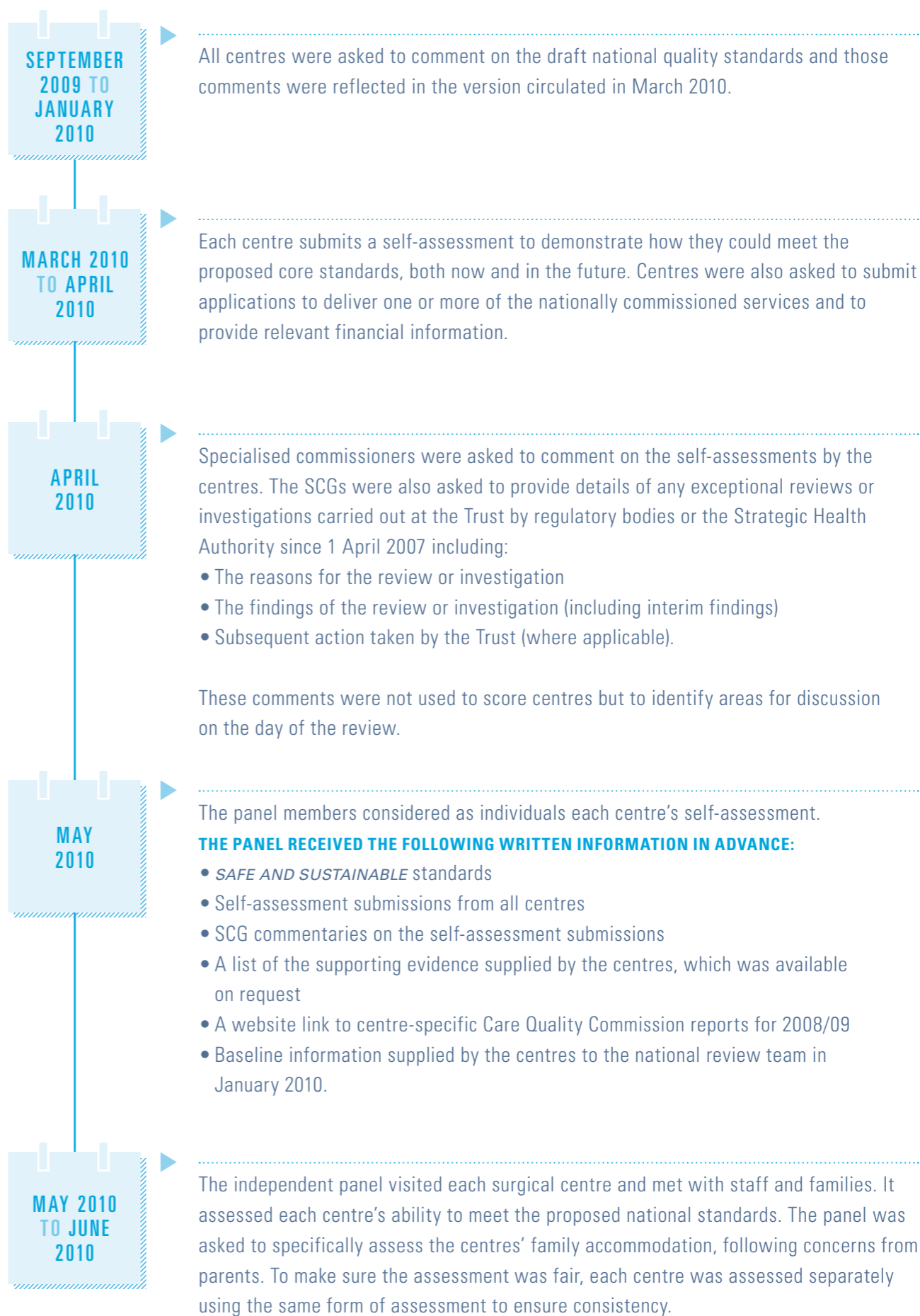
KEY PLAYERS AND TIMELINE FOR THE FIRST STAGES OF THE EVALUATION PROCESS

THE ASSESSMENT PANEL

The *SAFE AND SUSTAINABLE* review team brought together an independent panel of experts, chaired by Professor Sir Ian Kennedy and included Mr James Monro 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.

PHASES 1 – 2 OF THE ASSESSMENT PROCESS



THE CRITERIA AND THE WEIGHTINGS

The criteria for assessment of the centres and the weightings which were shared with the Steering Group and given to the centres at the start 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 link between effective leadership and strategic vision and the organisation's ability to deliver a good service and good outcomes.	120
3	DELIVERABILITY AND ACHIEVABILITY It is important that the agreed services 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 variation in the services. It was considered that if the other criteria above are met then these will follow.	45
TOTAL		685

The panel agreed that it would not score any of the centres on section 3 of the self-assessment "Deliverability and Achievability", as they did not consider they had the necessary expertise to do so. It was agreed that these issues would be decided by the Joint Committee of Primary Care Trusts as they developed their recommendations for configuration.

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, already endorsed by the relevant professional associations and developed in partnership with stakeholders across the country. Further criteria were used at this stage of the assessment process. These were 'leadership and strategic vision' and 'deliverability and achievability' based on the need to review the centre's future sustainability and ability to improve in the future.

EVALUATING VISITS TO THE CENTRES

The panel members used the information gained from the visits to re-assess their initial scores to reach a consensus score for each factor.

THE PANEL ASSESSED THE CENTRES AGAINST:

- How well they were currently meeting core standards based on the self-assessment and the visits.
- Robustness and deliverability of each centre's development plans to meet all of the standards' core requirements.
- Impact of increased activity: the panel assessed how centres could expand facilities and workforce.

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

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 of the highest standard)

FINAL PANEL SCORING

Once the panel had agreed each centre's final score it met again in June 2010 to check the robustness and accuracy of the scoring process.

These checks reassured the panel that their approach to scoring each centre had been consistent and gave them confidence in the weightings. The maximum possible score was 610 and the scores were:

535	GUYS AND ST THOMAS' NHS FOUNDATION TRUST (EVELINA CHILDREN'S HOSPITAL)
513	SOUTHAMPTON UNIVERSITY HOSPITALS NHS TRUST
495	BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST
464	GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS TRUST
464	ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST
449	UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST
425	NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST
420	ALDER HEY CHILDREN'S NHS FOUNDATION TRUST
402	UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST
401	LEEDS TEACHING HOSPITAL NHS TRUST
237	OXFORD RADCLIFFE HOSPITALS NHS TRUST

The report of the Independent Expert Panel chaired by Professor Sir Ian Kennedy can be found on our website www.specialisedservices.nhs.uk/safeandsustainable or at <http://bit.ly/eC2LDp>

PHASE 3: ESTABLISHING A SHORTLIST OF VIABLE OPTIONS

Based on the 11 centres there are 2,047 possible different ways to configure the service²².

The next stage of the process was to test which of these options were theoretically possible. To rule out options which were not viable, the following thresholds were applied:

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

This gave an initial set of 15 potential options and, in at least 3 of them, included all sites. The next part of the process was to apply a series of further principles in addition to the three thresholds.

The analysis undertaken on the 15 potential options included:

- Detailed access mapping (for train and road journeys) based initially on the assumption that patients would be travelling to their closest centre
- Activity re-distribution mapping based on the population in each postcode district
- A consideration of how existing clinical networks reconciled with access and redistribution mapping

Based on that evidence, the following principles were agreed:

6 or 7 sites is optimal - Each site should carry out a minimum of 400 children's heart surgical procedures per year and ideally 500 per year. Each option should include 6 or 7 centres because fewer than 6 would involve all centres, on average, having to carry out over 700 procedures each and more than 7 centres would mean each

England's smallest surgical centre, The John Radcliffe Hospital in Oxford, does not appear in any of the options. The Oxford centre has been carrying out about 120 procedures a year making it about half the size of the next smallest centre. Professor Sir Ian Kennedy's independent assessment of the service found that it was a statistical outlier; it received the lowest ranking assessment of the current 11 centres by a significant margin.

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".

Oxford is therefore the least likely of the 11 surgical centres to meet all the new quality standards for children's heart surgery. This is why the John Radcliffe hospital is not included in any of options for change. Instead, it is proposed the Oxford centre will continue to provide specialised cardiology services for children.

centre, on average, would carry out only 450 procedures. In some areas, options with more than 7 centres ran the risk that some centres would carry out less than the minimum recommended 400 procedures per year

London - London requires at least 2 centres due to the size of the population it covers (including East of England and South East England)

John Radcliffe Hospital, Oxford - The Oxford Centre should be discounted from all options on the basis that it is not viable to assume that this centre could meet the quality standards in the future and because retention of the centre would not improve access arrangements

Birmingham Children's Hospital - The Birmingham centre should remain in all options because of the high number of referrals it gets due to the large population in its immediate catchment area

Southampton and Bristol - Based on the assumption that patients will travel to their nearest centre and a consideration of existing clinical networks, the Bristol and Southampton centres are not both viable in the same configuration options as there are too few patients in South Central England, South West England and South Wales to ensure both centres carry out the minimum 400 procedures, without making potentially unreasonable changes to catchment areas for the London and Birmingham centres (but see below). One of these two centres will be required in all options to meet the needs of these populations

North of England - Northern England (defined as Newcastle, Liverpool and Leeds centres) needs 2 centres as there are not enough patients to ensure all 3 achieve the 400 procedure minimum. These 2 should either be Liverpool and Newcastle or Liverpool and Leeds as Newcastle and Leeds cannot achieve the 400 minimum each while maintaining strong networks and access times

SAFE AND SUSTAINABLE also considered the potential positive impact that retaining the centre could have on journey times.

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

- The John Radcliffe Hospital 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 provide surgery to 400 children if surgery at Bristol and Southampton ceased

- Access times are not improved under these potential scenarios compared to other potential options

- The Joint Committee of Primary Care Trusts was not persuaded that the hospital was able to lead the very large congenital heart network that would have been necessary incorporating South West England, Bristol and South Central England

²² All combinations of 10, 9, 8, 7, 6, 5, 4, 3, 2 and 1 sites



Case study: John Radcliffe Hospital, Oxford

Although the report of the investigation into children's heart surgery 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 further assurance 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 surgeon'²³.

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 situations'²⁴. 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 children's heart surgery service at the John Radcliffe Hospital was 'in essence, an adult department that performed some paediatric work'²⁵.

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 'idiosyncratic'²⁶ and described how 'some aspects of practice not yet adopted at Oxford have been shown to reduce morbidity.'²⁷ 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 individual'²⁸ (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 Hospital 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 children whose operations had been postponed²⁹.

For further information on how the recommendation was reached please see page 84.

²³ Para 8.10, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁴ Para 6.2.5, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁵ Para 6.4.1, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁶ Para 6.7.1, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁷ Para 6.4.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁸ Para 6.7.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

²⁹ Para 6.3.4, NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010

A further 2 configuration options were added based on centres that received the highest scores during the assessment visits to each centre. They were scored by the JCPCT to compare them with other options. These 14 potential options were analysed in detail and the following additional factors considered.

- Centres must not have too heavy an annual caseload as centres that are too large are not safe or sustainable

- To meet the minimum requirements for nationally commissioned services, all options must include a minimum of 3 centres capable of providing respiratory ECMO services, 2 centres providing transplant services and 1 centre providing complex tracheal surgery

- All options must be able to meet the minimum requirement to collect a child by ambulance (known as retrieval) within three hours of being contacted by the referring unit in accordance with the Paediatric Intensive Care Society standards

After applying these criteria six potential options were left as set out in the box below.

RULED OUT OPTIONS

OPTION 1 was ruled as 'unviable' because it did not meet the standards for retrieval times. Retrieval times in parts of Cornwall would exceed four hours (4hrs 15 minutes) and in parts of South West Wales 3 hours.

OPTIONS 3 and 4 were 'unviable' because the new activity levels at the Leicester centre would be significantly below the 400 minimum threshold. As the Leeds centre remains in this option, the potential network for the Leicester centre would not extend sufficiently far on the northern boundary.

OPTIONS 5 and 9 were 'unviable' because the new activity levels at the Birmingham centre would significantly exceed the 800 cases a year the centre said it could handle. The activity levels at the Birmingham centre are high in these options because neither Bristol, Leicester or Leeds would remain and

therefore the Birmingham catchment area would be extended through the Midlands and into south Wales.

OPTIONS 7 and 11 were 'unviable' because they would not meet the minimum requirements of the nationally commissioned services criteria. That is, neither of these options contains 3 centres which either currently provide ECMO services or were considered able to provide ECMO services in the future (Appendix 2).

OPTION 13 was 'unviable' because it would result in the new number of procedures at all 7 centres being either below the 400 minimum threshold or above the centre's stated maximum threshold. This is due to the 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).

APPLYING THESE FINAL ASSUMPTIONS LEAVES 6 POTENTIALLY VIABLE OPTIONS.

Forecast number of paediatric cardiac operations per year

KEY:
NCS - Nationally Commissioned Services

	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
London (per centre)	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	Retrieval	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

PHASE 4: SCORING THE 6 VIABLE RECONFIGURATION OPTIONS AGAINST THE EVALUATION CRITERIA

To decide which of these remaining 6 potential options were appropriate for public consultation the *SAFE AND SUSTAINABLE* steering group advised that a system of weighting should be used to make sure that core designation standards had sufficient priority.

The first exercise was to agree the weightings.

HOW THE WEIGHTINGS WERE AGREED

The views from four stakeholder groups obtained by the *SAFE AND SUSTAINABLE* team in July 2010 were used to agree the weightings.

While 'Affordability' had been included as a criterion when seeking stakeholders' views, the Steering Group and specialised commissioners were later advised to use only the non-financial criteria to score the

options. 'Affordability' was treated as a stand-alone test.

The Steering Group and Specialised Commissioning Groups were asked to score the criteria out of '100' to decide their relative importance.

THE AVERAGE SCORES WERE AS FOLLOWS:

	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		

Parents and clinicians were surveyed in order to test the importance of each criterion and asked to score them out of 10.

THE AVERAGE SCORES WERE:

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 was not included here. The rankings given by both parents and clinicians were the same.

The rankings of the parents and clinicians very closely match the assessment of the Steering Group and SCGs. There is a slight difference

in the rankings of 'deliverability' and 'sustainability' but the weightings for these criteria are fairly close. For these reasons the following weightings were used to score the non-financial criteria and to double check whether 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

Respondents were also asked to suggest any other criteria they thought should be applied but no further relevant criteria were suggested.

EVALUATION	
<p>ACCESS AND TRAVEL</p> <ul style="list-style-type: none"> 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 Paediatric Intensive Care Society 'Standards for the Care of Critically Ill Children, 2010' 	14
<p>QUALITY</p> <ul style="list-style-type: none"> 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 	39
<p>DELIVERABILITY</p> <ul style="list-style-type: none"> The NHS in England will continue to provide high quality: <ul style="list-style-type: none"> 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 	22
<p>SUSTAINABILITY</p> <ul style="list-style-type: none"> 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 	25

THE RESULTS OF THE SCORING PROCESS

PROPOSED SCORING WAS CARRIED OUT ON A FIVE POINT SCALE, AS SHOWN BELOW:

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 RESULTS OF THE PROPOSED SCORING ARE SHOWN IN THE TABLE BELOW:

	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

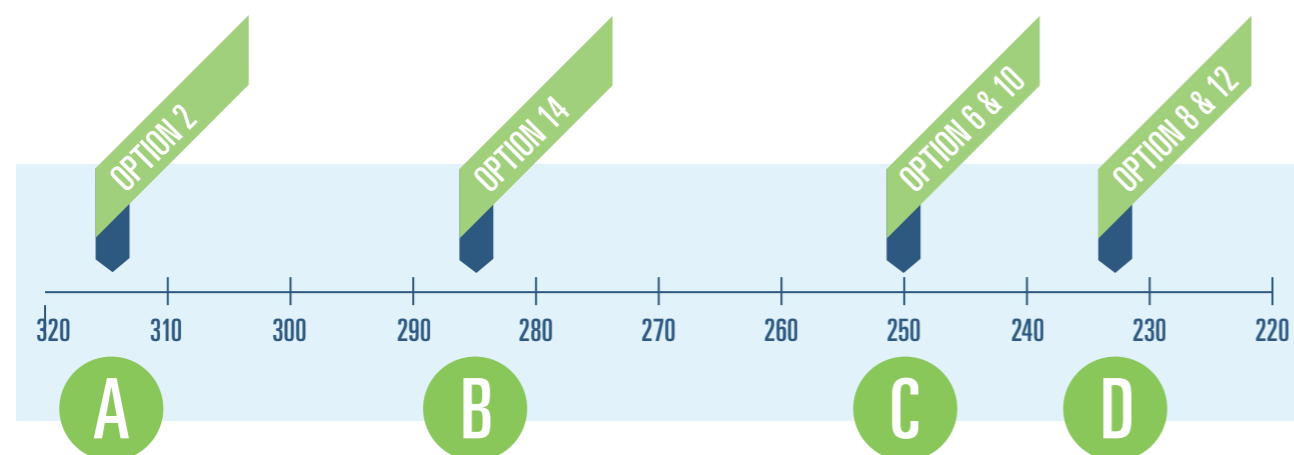
The weightings were then applied to arrive at total proposed scores per option.

THESE PROPOSED SCORES ARE SHOWN ON THE SCALE BELOW:

	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	75	75	50	75	50	50
TOTAL	314	250	213	250	213	286

For more information on the scoring process please see Appendix 7.

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 four versions Option 2 was the highest scoring option and Options 8 and 12 were the lowest scoring options.

THE FINAL RECOMMENDED OPTIONS FOR CONSULTATION ARE:

- 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 depending

on the testing of assumptions about future patient flows in South Central and South West England as a result of the suspension of the service at the John Radcliffe Hospital. It also lessens the potential risk of reconfiguration of national paediatric intensive care provision

- Option 6 is viable
- Option 8 is viable

During the process to identify and score the options each option was numbered. For ease of reference we have now re-labelled the four remaining options with a letter from A - D.

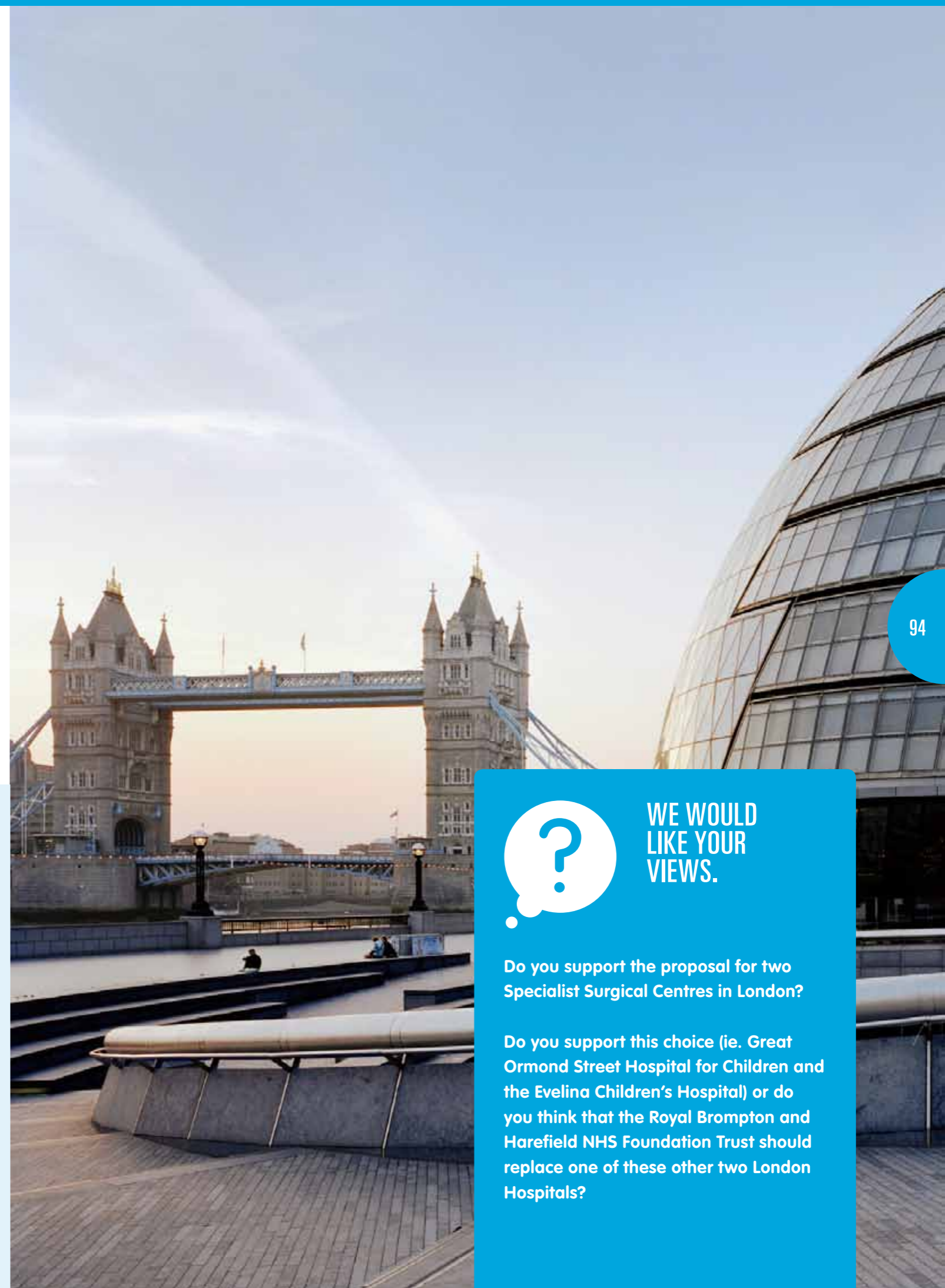
LONDON

It was recommended to the Joint Committee of Primary Care Trusts that Options 10 and 12 (which included 3 centres in London) should not form part of the public consultation for the following reasons:

- The Joint Committee of Primary Care Trusts recommends that two designated centres is the ideal configuration for the population of London, East of England and South East England. The question of whether two centres in London is the right number will be asked during consultation
- The forecast activity levels for London and its catchment area (currently around 1,250 paediatric procedures per year) mean that two centres would

be well placed to meet the proposed ideal number of 500 procedures a year. This could only happen with three London centres if patients were diverted from neighbouring catchment areas into London. Our analysis shows this would significantly, and unjustifiably, increase travel times and impact on access for patients outside of London, South East and East of England

- 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 East of England according to the *SAFE AND SUSTAINABLE* model of care



WE WOULD LIKE YOUR VIEWS.

Do you support the proposal for two Specialist Surgical Centres in London?

Do you support this choice (ie. Great Ormond Street Hospital for Children and the Evelina Children's Hospital) or do you think that the Royal Brompton and Harefield NHS Foundation Trust should replace one of these other two London Hospitals?

WHICH 2 CENTRES IN LONDON?

The Joint Committee of Primary Care Trusts has identified its preferred two centres in London: the Evelina Children’s Hospital and Great Ormond Street Hospital for Children. This is being specifically addressed in the consultation.

On the following pages you will find the Joint Committee of Primary Care Trusts’ recommendation which is based on the results of applying the same criteria used to score the potential options for the three centres. The results are:

ACCESS AND TRAVEL TIMES

Because all the current centres are close together there is unlikely to be a significant increase in travel times for parents and children whichever centres are chosen. For the same reason all centres are equally capable of meeting the Paediatric Intensive Care Society standards around retrieval times.

QUALITY

The proposed score for the Evelina Children’s Hospital reflects the results of Sir Ian Kennedy’s panel assessment of its capacity for ‘research and innovation’ (refer to map on page 103).

Similarly Great Ormond Street Hospital and the Royal Brompton Hospital were ranked equally by the panel, but the higher score for Great Ormond Street is due to its capacity for ‘research and innovation’. Because they are already close together, there is unlikely to be an impact on the sub-criterion of ‘manageable networks’.

DELIVERABILITY

As Great Ormond Street Hospital would retain three nationally commissioned services in their current location (cardiothoracic transplantation, ECMO and complex tracheal surgery) we recommend it scores higher in potential configuration options. Because the PICU at the

Royal Brompton Hospital exists predominantly to support cardiac surgery, we propose it is scored lower than the Evelina Children’s Hospital on the sub-criterion involving ‘the negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum’.

SUSTAINABILITY

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 them would receive too great a caseload.

SCORING THE LONDON SITES: SCORES

CRITERIA				WEIGHTING								
				GOSH	EVELINA	RBH	Weighting applied to each criteria	GOSH Weighted Score	EVELINA Weighted Score	RBH Weighted Score		
ACCESS AND TRAVEL TIMES	The negative impact on travel times for elective admissions is kept to a minimum.	The negative impact on retrieval travel times for emergency admissions is kept to a minimum, taking account of expert views on emergency transportation.		3	3	3	14	42	42	42		
QUALITY	Designated surgical centres will deliver high quality service.	Innovation and research is present across networks and the national service.	Clinical networks are manageable, taking account of population and geography and the need for clear leadership and communication.		3	4	2	39	117	156	78	
DELIVERABILITY	The NHS in England will continue to provide the relevant high quality Nationally Commissioned Services.	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 a minimum.	Transitional plans for implementation are in place by April 2013.		4	3	2	22	88	66	44
SUSTAINABILITY	All designated centres are likely to perform at least 400 procedures each year, ideally 500 paediatric procedures each year.	No one designated surgical centre will receive too onerous a caseload that would exceed the 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 succession plans.		4	4	4	25	100	100	100	
TOTAL SCORE								347	364	264		

6. OPTIONS FOR CHANGE

Below we outline the key factors that have been considered by the Joint Committee of Primary Care Trusts.



FACTOR: ACCESS AND JOURNEY TIMES

This is an important issue for many families travelling to surgical centres.

! RISK

Some families already travel long distances to surgical centres. The Joint Committee of Primary Care Trusts has considered the impact that fewer, larger centres may have on journey times.

ANALYSIS

We have analysed travel times for the different potential reconfigurations. Some options have been discounted because they would mean much longer journeys for some families. The table below shows that there is a minimal impact on journey times for most families for the four options you are being asked to consider. Most children don't have to stay in hospital very often. As the table on page 22 shows over the past ten years around 90% of children needing heart surgery or interventional cardiology only required one stay in hospital.

OPTION	% OF POPULATION EXPERIENCING AN INCREASE IN TRAVEL TIME OF MORE THAN 1.5 HOURS
A	3.6%
B	6.2%
C	6.2%
D	3.6%





DISTANCES FOR URGENT ADMISSIONS (RETRIEVAL)

Specialist Surgical Centres must be able to ensure an ambulance with suitably qualified staff can reach a child within three hours.

! RISK

Removing surgery from some centres could have a disproportionate impact on children in some remote areas because ambulances would not be able to reach the child in three hours or less.

ANALYSIS

We have carried out a detailed study to assess 'retrieval times' by road. Air travel has not been considered because it cannot always be relied upon, for instance because of poor weather and the lack of appropriate landing sites. Most areas of the country are within three hours of two or more centres. The people of South West Cornwall and South Wales would be adversely affected if the Bristol centre no longer carried out surgery as it is over three hours to Southampton or Birmingham. So Bristol has been included in all viable options.



NUMBER OF PROCEDURES

The proposed standards require each Specialist Surgical Centre to carry out a minimum of 400 surgical procedures each year. The ideal is 500.

! RISK

Options present risk if some centres would struggle to see 400 children. However there is also a risk if a configuration option would mean centres were required to treat more children than they have said they can manage.

ANALYSIS

In considering viable options the Joint Committee of Primary Care Trusts has examined extensive data based on estimated patient numbers for each centre under each option. The Joint Committee of Primary Care Trusts has also considered the potential for populations to grow in each area. All the options put forward for public consultation are potentially viable. Several options that would require centres to treat more children than they have said they could manage have been ruled out.



MANAGED CLINICAL NETWORKS

Each congenital heart network must be manageable.

! RISK

In line with the proposed standards Specialist Surgical Centres would lead the new congenital heart networks. However centres' ability to lead these networks did vary. Networks also rely on patients flowing through the system in the assumed way.

ANALYSIS

The key issue here is whether each proposed congenital heart network would generate a minimum of 400 children requiring heart surgery. Parents generally choose a surgical centre following advice from their clinicians however the NHS must accommodate patient choice. The proposed networks will need to be tested further during the consultation to check whether patients will flow in the way assumed. For instance under Option B we will examine whether it is feasible for families with Brighton and Redhill postcodes to travel to Southampton for surgery rather than to London. At the same time we will test whether the changes at the Oxford centre mean that the Southampton centre is already performing 400 heart operations on children a year and what, if any, impact there has been on the Bristol centre.



STAFFING AND SKILLS

! RISK

Trusts need to have enough skilled surgeons, nurses and other key staff. Trusts must be able to recruit excellent staff, including newly qualified surgeons, and retain them. The main risk is that the NHS may lose the skills and expertise of cardiac staff who work in centres that are not designated as Specialist Surgical Centres in future.

ANALYSIS

The proposed options mean that there would be an impact on the workforce at some centres. However, detailed analysis shows that the impact is about equal for all centres. This means that all centres are roughly equally affected in this area.



FACTOR: QUALITY

Trusts were assessed on how well they were currently meeting the standards and their capacity to meet them in the future.

! RISK

The highest standards of care are vital if we are to continue to improve children's outcomes. Removing surgery from a high ranking centre could mean lower quality overall.

ANALYSIS

Professor Sir Ian Kennedy and his panel of experts assessed each centre. The panel's conclusion was that all centres except the John Radcliffe Hospital in Oxford could meet the minimum proposed national quality standards in the future although there is variation in how they could meet all of the standards to the full extent in the future.



FACTOR: RESEARCH AND INNOVATION

Breakthroughs in the treatment of congenital heart disease mean that some children's lives are now saved which would have been lost in previous years.

! RISK

The key risk is that some options would mean that high ranking centres in this area may not continue to carry out surgery.

ANALYSIS

Each centre's capability was assessed and scored. Professor Sir Ian Kennedy's panel found significant variation in the quality of research and innovation at the different centres as set out opposite.





FACTOR: THE LOCATION OF THREE HIGHLY SPECIALISED NATIONALLY COMMISSIONED SERVICES

The NHS in England will continue to provide high quality:

- Children's heart transplantation in two centres
- Extra Corporeal Membrane Oxygenation services for children with severe respiratory failure in at least three centres
- Complex tracheal surgery in one centre

! RISK

The heart surgery centres at Great Ormond Street Hospital, the Freeman Hospital in Newcastle and Glenfield Hospital in Leicester provide nationally commissioned services. If these centres are not selected to provide children's heart surgery in future, the national services would need to be re-located.

🔍 ANALYSIS

All centres were asked during the assessment process whether they would be able to provide nationally commissioned services. The Joint Committee has been advised by an expert panel which was asked to look at the impact to nationally commissioned services. The panel recommended that nationally commissioned services should remain in their current locations if possible. When developing configuration options the Joint Committee was advised by the panel to consider the following:

Children's heart transplantation in two centres.

There must be a minimum of 2 centres providing transplant services in each option and that these could be either:

- Great Ormond Street Hospital and the Freeman Hospital
- Great Ormond Street Hospital and Birmingham Children's Hospital
- Birmingham Children's Hospital and the Freeman Hospital

Potential options scored higher under this criterion if they retained these centres.

ECMO services for children with severe respiratory failure in at least three centres.

There must be a minimum of 3 centres providing ECMO included in the configuration options. These could be either at:

- Great Ormond Street for Children
- Birmingham Children's Hospital
- Freeman Hospital, Newcastle
- Glenfield Hospital, Leicester

Potential options scored higher under this criterion if they retained these centres.

Complex tracheal surgery in one centre

There must be a maximum of one centre providing this service in every option. The one centre currently providing this is Great Ormond Street Hospital. 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.

As 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, all decisions about where they are provided can only be made by the Secretary of

State for Health, after taking advice from the independent committee, the Advisory Group on National Specialised Services [AGNSS].

Following public consultation, if the Joint Committee of Primary Care Trusts' decision was dependent on a change to the provision of any of these national services, this would need to be ratified by the Secretary of State for Health, taking account of the advice from AGNSS. Were he not to support the proposed change to national services, then the Joint Committee of Primary Care Trusts would have to make a fresh decision about the location of Specialist Surgical Centres that did not require such a change

When this analysis is applied to the shortlisted options it results in the following ranking of the options (table below):

OPTION A ● OPTION CONTAINING BOTH NEWCASTLE AND LEICESTER

OPTION B ● OPTION CONTAINING NEWCASTLE BUT NOT LEICESTER

OPTION C ● OPTION CONTAINING NEWCASTLE BUT NOT LEICESTER

OPTION D ● OPTION CONTAINING NEITHER NEWCASTLE NOR LEICESTER

For further information on the Joint Committee of Primary Care Trusts' consideration of Nationally Commissioned Services please refer to Appendix 2



FACTOR: PAEDIATRIC INTENSIVE CARE UNITS

To what extent would these services be affected?

! RISK

If children's heart surgery is removed from current centres it would mean the current paediatric intensive care units would see a reduction in the number of children they treat because heart patients account for approximately 40% of all children that are treated in a paediatric intensive care unit. Some centres have voiced concerns that it may be difficult to retain experienced paediatric intensive care staff if children's heart surgery is no longer carried out and the implications for retrieval services would also need to be addressed during consultation.

🔍 ANALYSIS

We have assessed the risk to paediatric intensive care units. Some paediatric intensive care units would become unviable as a consequence of losing paediatric cardiac surgery (the Glenfield Hospital in Leicester, the Freeman Hospital in Newcastle and the Royal Brompton Hospital in London). However, as these paediatric intensive care units exist predominately to support cardiac surgery (and because all three cities have existing alternative paediatric intensive care provision for non-cardiac admissions) this presents limited risk to local and national paediatric intensive care provision.

All the other paediatric intensive care units in the other hospitals would remain viable. The John Radcliffe Hospital in Oxford would continue to meet the critical mass necessary

for a Level 2 paediatric intensive care unit (200 to 350 admissions); the centres in Bristol and Leeds would sustain the critical mass necessary for a Level 3 unit (350 to 500 admissions); the remaining centres would treat enough children to ensure they would meet Lead paediatric intensive care unit status (500+ admissions).

Bristol Royal Hospital for Children is considered to be most at risk due to the higher volume of cardiac cases using paediatric intensive care units, followed by Leeds General Infirmary and Southampton General Hospital.

During consultation we will explore with all units affected the impact of reconfiguration to other children who use the paediatric intensive care units.

The table below shows the amount as a percentage of children who are cardiac patients using paediatric intensive care units. The higher the percentage, the more cardiac patients a unit treats. The lower the percentage, the less reliant a unit is on treating cardiac patients.

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 Hospitals	39%
John Radcliffe Hospital, Oxford	33%
Southampton General Hospital	29%



OTHER INTER-DEPENDENT SERVICES

! RISK

SAFE AND SUSTAINABLE has explored the impact to relevant interdependent services within local health economies in the event that a current provider of is not selected to carry out children's heart surgery in the future.

🔍 ANALYSIS

The Critical Interdependencies Framework³⁰ identifies four clinical services (other than children's 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 children's heart surgery to be a core service upon which any of the four services is reliant, SAFE AND SUSTAINABLE has concluded that the removal of children's heart 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 mandatory the conclusion is that there are no significant issues to report.

During public consultation we will work with the current surgical centres and NHS commissioners to explore the impact of reconfiguration to other services that may be affected so that this information may be considered by the Joint Committee of Primary Care Trusts before a final decision is made.

³⁰ Department of Health, 'Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies', September 2008

OPTION A

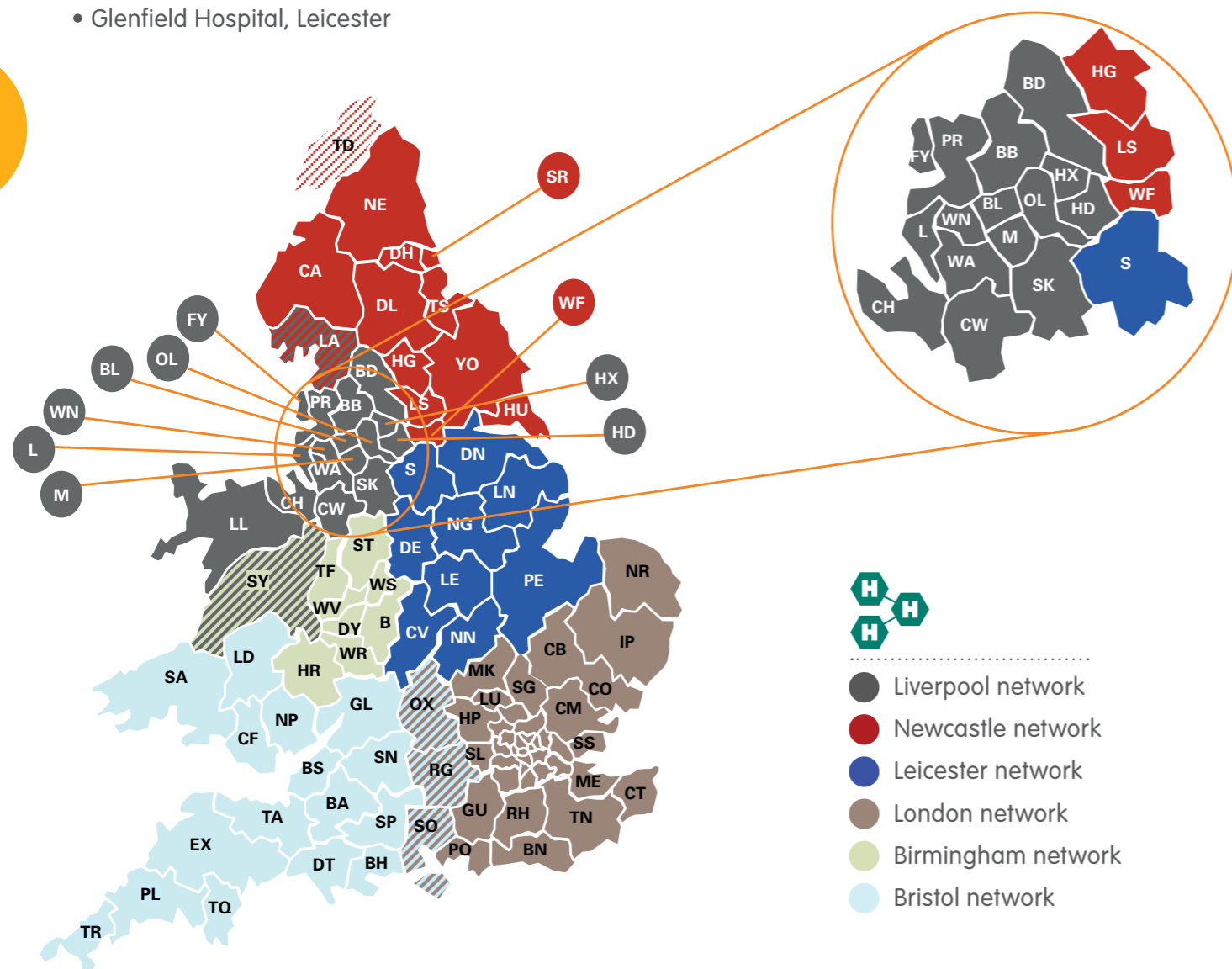
Option A includes seven Specialist Surgical Centres and four potential Children's Cardiology Centres.

PROPOSED SPECIALIST SURGICAL CENTRES

- Great Ormond Street Hospital, London
- Evelina Children's Hospital, London
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- Freeman Hospital, Newcastle
- Alder Hey Children's Hospital, Liverpool
- Glenfield Hospital, Leicester

POTENTIAL CHILDREN'S CARDIOLOGY CENTRES

- Royal Brompton Hospital, London
- Southampton General Hospital
- Leeds General Infirmary
- John Radcliffe Hospital, Oxford



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

+ BENEFITS UNDER OPTION A

- The Joint Committee of Primary Care Trusts believes that Option A and Option D would be the best options for travel and access. Under Option A most families would experience minimal or no impact to their journey to the Specialist Surgical Centre for planned care. Only 3.6% of families would see an increase in travel time of 1.5 hours compared to Option B and C where the number of families would increase to 6.2%
- Option A would ensure every Specialist Surgical Centre reaches the minimum of 400 procedures a year
- Option A includes Great Ormond Street Hospital, Evelina Children's Hospital, Bristol Royal Hospital for Children and Birmingham Children's Hospital as Specialist Surgical Centres which were ranked highest for innovation and research
- No nationally commissioned services would need to be relocated under this option. Therefore Option A scored highest for minimising the impact to nationally commissioned services
- All the networks appear to be viable

! RISKS UNDER OPTION A

- Option A does not retain higher scoring surgical centres
- Under Option A Leeds General Infirmary and Southampton General Hospital would no longer carry out surgery which may impact upon the paediatric intensive care units at both hospitals but they nevertheless remain viable (please see previous section for details)

OPTION D

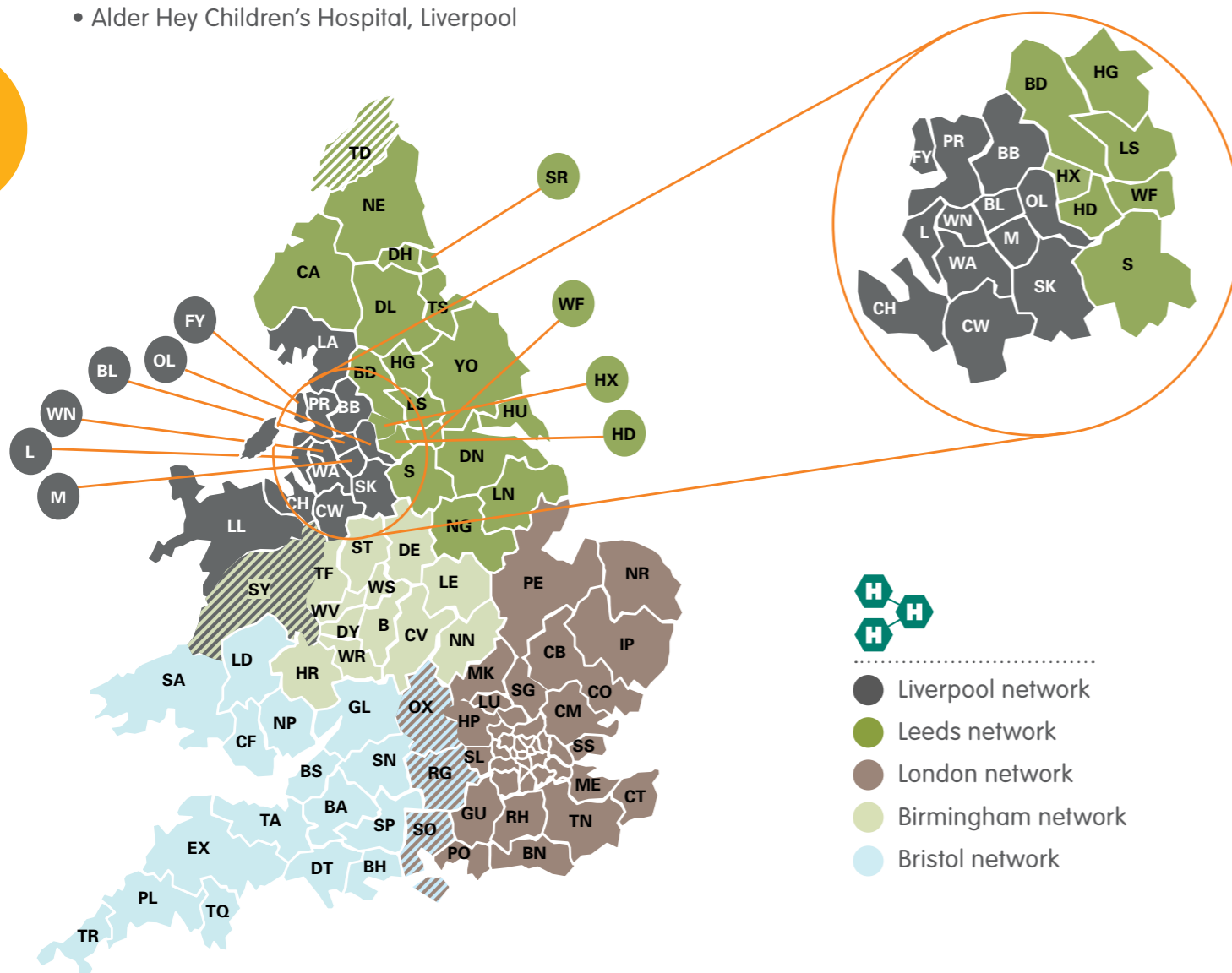
Option D includes six Specialist Surgical Centres and five potential Children's Cardiology Centres. It is the second six centre option chosen for public consultation.

PROPOSED SPECIALIST SURGICAL CENTRES

- Great Ormond Street Hospital, London
- Evelina Children's Hospital, London
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- Leeds General Infirmary
- Alder Hey Children's Hospital, Liverpool

POTENTIAL CHILDREN'S CARDIOLOGY CENTRES

- Royal Brompton Hospital, London
- Freeman Hospital, Newcastle
- Glenfield Hospital, Leicester
- John Radcliffe Hospital, Oxford
- Southampton General Hospital















































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

+ BENEFITS UNDER OPTION D

- Only 3.6% of families would see an increase in travel time to their nearest Specialist Surgical Centres of 1.5 hours compared to Option B and C where the number of families would increase to 6.2%
- Under Option D all of the centres have interdependent services co-located on one site
- Each Specialist Surgical Centre under Option D would comfortably meet the minimum of 400 procedures per year

! RISKS UNDER OPTION D

- Option D was the worst scoring option for impact on nationally commissioned services because the centres in Newcastle and Leicester are not included
- A minimum of two Specialist Surgical Centres are needed to deliver transplantation services nationally. Under Option D the Freeman Hospital in Newcastle would no longer carry out surgery meaning transplantation services would need to be relocated to Birmingham Children's Hospital
- Extracorporeal Membrane Oxygenation services would need to be relocated from the Glenfield Hospital in Leicester and the Freeman Hospital in Newcastle to Birmingham Children's Hospital and Bristol Royal Hospital for Children

FACTORS		OPTION A	OPTION B	OPTION C	OPTION D	
	ACCESS AND JOURNEY TIMES % who would see an increase in travel time of more than 1.5 hours	 3.6%	 6.2%	 6.2%	 3.6%	
	RETRIEVAL TIMES	 Compliant with Paediatric Intensive Care Society standards	 Compliant with Paediatric Intensive Care Society standards	 Compliant with Paediatric Intensive Care Society standards	 Compliant with Paediatric Intensive Care Society standards	
	NUMBER OF PROCEDURES	 400+	 Testing viability of networks	 400+	 400+	
	MANAGED CLINICAL NETWORKS		All networks are potentially viable subject to further analysis of networks under option B			
	QUALITY	 Does not retain higher ranked centres	 Best option for retaining centres ranked highest for quality	 Does not retain higher ranked centres	 Does not retain higher ranked centres	
	RESEARCH AND INNOVATION	 Includes the highest ranking centres with the exception of Southampton General Hospital	 Includes the five highest ranking centres	 Includes the highest ranking centres with the exception of Southampton General Hospital	 Includes the highest ranking centres with the exception of Southampton General Hospital	
	RELOCATION OF THREE HIGHLY SPECIALISED NATIONALLY COMMISSIONED SERVICES	Children's heart transplantation in two centres	 Services retained in current location	 Services retained in current location	 Services retained in current location	 The transplantation service would need to be relocated from the Freeman Hospital in Newcastle
		Complex tracheal surgery in one centre	 Services retained in current location	 Services retained in current location	 Services retained in current location	 Services retained in current location
		ECMO services for children with severe respiratory failure in at least three centres	 Services retained in current location	 ECMO services would need to be relocated from the Glenfield Hospital in Leicester	 ECMO services would need to be relocated from the Glenfield Hospital in Leicester	 ECMO services would need to be relocated from the Glenfield Hospital in Leicester and the Freeman Hospital in Newcastle
	PAEDIATRIC INTENSIVE CARE UNITS	 Impact on two centres: Leeds General Infirmary and Southampton General Hospital would see a reduction in PICU admissions	 Impact lessened	 Impact on two centres: Leeds General Infirmary and Southampton General Hospital would see a reduction in PICU admissions	 Impact on two centres: Leeds General Infirmary and Southampton General Hospital would see a reduction in PICU admissions	

GUCH IMPLICATIONS - CURRENT SURGERY PROCEDURES 2008/9

As we set out on page 64 there is a separate designation process for the delivery of adult congenital services.

CENTRES	CURRENT	OPTION A	OPTION B	OPTION C	OPTION D
London	200	241	205	241	246
Birmingham	19	19	75	60	40
Bristol	65	106	73	106	106
Liverpool	7	7	7	7	7
Leicester	41	61			
Leeds	56				159
Newcastle	88	124	124	144	
Southampton	66		74		
Oxford	16				
Subtotal	558	558	558	558	558
Other centres	300	300	300	300	300
Total	858	858	858	858	858



The table above sets out the options around how GUCH patients may use services in the same areas where children with congenital heart disease receive surgical care. We have set this out for illustration only. The NHS will fully consult on any changes to GUCH services that are proposed in the future.

The second column shows the number of people that centres see currently. The information is based on 2008/2009 figures validated by the Central Cardiac Audit Database. The table also shows the potential flow of patients following reconfiguration of surgical centres under each potential option.



WE WOULD LIKE YOUR VIEWS.

To what extent do you support or oppose EACH of the FOUR alternative proposed options for the location of the Specialist Surgical Centres?

IN THIS SECTION YOU WILL FIND INFORMATION ABOUT

- How new legislation may affect the development of the service
- The way in which congenital heart networks will be developed
- How we will deal with the risks involved in making changes to services
- Information about the additional costs involved in the proposals



CHANGE AHEAD ?

7. IMPLEMENTING CHANGE

MANAGING CHANGE

The NHS has robust plans in place to ensure congenital heart networks could be operational from 2013 subject to the outcome of the public consultation. The NHS will coordinate the implementation of proposed changes via a National Implementation Team but change will be driven and implemented locally. The NHS recognises that there are challenges to implementation but continues to plan how to overcome them.

NEW LEGISLATION

NHS specialised commissioners are responsible for commissioning children's congenital heart services. We anticipate that from April 2012 the new NHS Commissioning Board will start to take on this role. The NHS will need to ensure a smooth transition and we are starting the process for preparing for implementation now.

ENSURING STABILITY DURING CHANGE

During the period of implementation the NHS will continue to communicate with stakeholders and the public so that people are properly informed and updated. NHS specialised commissioners will work in partnership with hospitals to:

- Ensure stability at all parts of the patient pathway, including compliance with access and waiting time requirements
- Ensure high quality services at all parts of the patient pathway
- Minimise workforce risks
- Minimise financial risk to hospitals and commissioners

But when the NHS Commissioning Board is established, commissioning the service would be streamlined because:

- The NHS Commissioning Board would commission the service (rather than ten different commissioners)
- There would be a single specification for services to drive up standards of care and equity across the country
- A consistent approach to funding the costs of NHS care would be applied
- The NHS Commissioning Board would be a single point of responsibility and could facilitate a swift and flexible response to any emerging challenges or issues

PRACTICALITIES

THE COMMISSIONING LEADS OF EACH CONGENITAL HEART NETWORK WOULD:



Ensure Specialist Surgical Centres 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 for the Specialist Surgical Centres



Identify resource issues (such as staff and equipment) in Specialist Surgical Centres



Plan and oversee the de-commissioning of surgical services in centres that are not designated for surgery, including the implementation of service standards for Children's Cardiology Centres and District Children's Cardiology Services



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



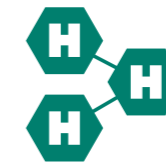
Establish a managed congenital heart network



Agree contracts with the hospitals that will provide the Specialist Surgical Centres and lead the congenital heart networks.

DEVELOPING THE CONGENITAL HEART NETWORK

The organisations that lead the congenital heart networks would also need to set up a group to develop the clinical services, bringing clinicians together from across the network.



EACH CONGENITAL HEART NETWORK GROUP WOULD BE EXPECTED TO ENSURE:

- Consistent high quality information is available for parents and children
- Ongoing active engagement with local parent/patient groups
- All the vital services work together to ensure children's care is coordinated
- Ambulance transfers (retrieval) are coordinated appropriately
- Common clinical protocols and guidelines are applied across each network, including the transfer of children requiring interventional treatment
- A strong network of specialist nursing support
- Effective communication guidelines are in place between services in the network
- Consistent record keeping and regular team meetings for the range of staff involved in children's care
- Agreed plans are in place to measure outcomes
- Consistency in the way data on children's outcomes is collected, reported and analysed, and that serious incidents are shared with colleagues
- Tele-medicine is developed
- Plans are in place for staff training and instil best practice in research activities
- An annual report on the effectiveness of the network is published



PROPOSED MEMBERSHIP OF CONGENITAL HEART NETWORK GROUPS:

- A senior clinician would chair the group
- Clinicians
- Parents
- Young people
- NHS commissioners would also attend



IMPLEMENTATION ADVICE

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

An implementation advisory group would oversee progress from a national perspective. This group would be established to assist the specialised commissioners during the implementation phase and to ensure networks develop appropriately. It would also set up arrangements to develop quality standards for Children's Cardiology Centres and District Children's Cardiology Services.



PROPOSED MEMBERSHIP OF THE IMPLEMENTATION ADVISORY GROUP WOULD INCLUDE:

- 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
- 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



ADULT CONGENITAL HEART SERVICES

Each relevant Specialised Commissioning Group will also establish a separate group to provide advice on the process for, and oversee implementation of, the designation of GUCH services in accordance with the proposed standards for GUCH services. A National Oversight Group will also be convened. This group will provide advice on the process for the designation of GUCH services in accordance with the proposed standards for GUCH services.

CAN WE AFFORD THE PROPOSED CHANGES?

The changes proposed by *SAFE AND SUSTAINABLE* would improve the services for children with congenital heart problems. They are not about saving money. We do however need to double check that the proposed changes are affordable and provide value for money.

In 2009/10 the existing surgical centres spent a total of £98m on children's congenital heart services including the costs of surgery, interventional cardiology and critical care. This represents less than 0.2% of the total amount of money spent on NHS services.

Under the proposed changes there would be additional costs for those Specialist Surgical Centres that are required to increase the number of children they treat. The options indicate that the total investment required ranges from £12m to £23m for the six or seven Specialist Surgical Centres. These costs are one off capital costs which would be funded by the centres' capital programmes.



PROPOSED MEMBERSHIP OF THE NATIONAL OVERSIGHT GROUP

- President of the British Congenital Cardiac Association or nominated representative
- A clinical lead from each of the centres currently providing GUCH services
- A representative of the GUCH Patients' Association
- NHS commissioners

There are also some costs which would be incurred by the centres which would become Children's Cardiology Centres. We envisage that the costs range from a total of £12m to £16m for four or five hospitals. These costs represent very small percentages of each centre's income and will marginally increase each centre's savings target.

An additional one off cost of around £2m would be required to enable NHS commissioners to implement the changes. In terms of ongoing costs the proposal to develop congenital heart networks would increase costs by up to £4m per year. However there will be some savings from delivering the same number of surgical procedures in fewer centres. We envisage that the costs will balance.

The conclusion is that the proposed changes would be manageable for hospitals and affordable for commissioners and option A offers best value for money.



8. MONITORING QUALITY

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 website³¹. 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 results³².

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.

³¹ Congenital Heart Disease website (or CCAD website).

³² Congenital Heart Disease website (or CCAD website).
Available at: <http://www.ccad.org.uk/002/congenital.nsf/vwContent/Information%20for%20Patients?Opendocument>

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 2010³³.

In their respective reports to the Joint Committee of Primary Care Trusts following the additional

review by *SAFE AND SUSTAINABLE* of three centres following an independent analysis of mortality data, Professor Sir Ian Kennedy and Mr James Pollock have made a number of recommendations around the future collection, validation, analysis and reporting of outcome data. The recommendations are concordant with the advice of the *SAFE AND SUSTAINABLE* Steering Group.

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

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 'real time' alert system for monitoring clinical outcomes in this speciality 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 charts³⁴.

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 Specialist 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.

³³ NHS South Central SHA, *Review of paediatric cardiac services at the Oxford Radcliffe Hospitals NHS Trust*, July 2010.

³⁴ Recommendation 10 - *'Review of Paediatric Cardiac Services at the Oxford Radcliffe Hospitals NHS Trust'*, July 2010, South Central Strategic Health Authority



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9. THE JOINT COMMITTEE OF PRIMARY CARE TRUSTS WOULD LIKE YOUR VIEWS ON THESE RECOMMENDATIONS

This public consultation is the most important opportunity you will have to directly influence the outcome of this review.



YOUR VIEWS COUNT

This four month public consultation on the future of children's heart services is your chance to have your opinions heard by the people responsible for making a final decision on the future of the service. The NHS would like as many people as possible to respond. Everyone's view will be considered.

EVERYONE'S INVITED TO TAKE PART

The consultation is open to everyone - from parents and staff to interested members of the public. This is your opportunity to influence how children's heart services are provided in England and Wales.

WHAT WE WOULD LIKE YOUR VIEWS ON

We are consulting on three key areas:

- the suggested new approach to providing children's congenital heart services. Please refer to page 38 for more information
- the proposed standards that have been developed to ensure quality across the service regardless of where you live. Please refer to page 34 for more information
- the proposed options for change. The details of these options and what they may mean for children, parents and staff are set out on page 102
- improvements in the way quality is measured as set out in section 8



ALL RESPONSES MUST BE RECEIVED NO LATER THAN 1 JULY 2011

An electronic version and hard copies of the consultation document and response form are available in English and Welsh. Braille, and copies in other languages can also be provided on request. Please contact the communications team.

Telephone: 020 7025 7520

Email: nhsspecialisedservices@grayling.com

FOR FURTHER INFORMATION

The *SAFE AND SUSTAINABLE* consultation coordinator is Jeremy Glyde, Programme Director. Any queries or complaints on the consultation process please:

- Write to *SAFE AND SUSTAINABLE*, NHS Specialised Services, 2nd floor, Southside, 105 Victoria Street, London, SW1E 6QT
- Call on 020 7932 3958
- Email ChildHeart@nsscg.nhs.uk

Please note that comments submitted via this process cannot be counted as part of the formal consultation.

HOW TO GIVE US YOUR VIEWS

- Complete the response form accompanying this consultation document.
- Or: go to www.specialisedservices.nhs.uk/safeandsustainable and complete an electronic version of the response form and submit online.

WHAT HAPPENS TO YOUR RESPONSES?

This consultation will run from 1 March 2011 to 1 July 2011. An independent third party will collect all the responses and a comprehensive analysis will be published in a final report.

The Joint Committee of Primary Care Trusts will consider the report carefully to help them evaluate the four options and make a final decision. We expect a final decision to be made later in 2011. Any changes to children's congenital heart services are expected in 2013.

CONSULTATION EVENTS

Some people will have questions about what the different options mean for you in your area. We will be holding consultation events across England and Wales throughout the consultation period to give you an opportunity to put your questions to local clinicians and commissioners. If you are a young person you may want to come to one of the events for young people.

To find out where and when your nearest consultation event will be held please go to: www.specialisedservices.nhs.uk/safeandsustainable



Birmingham	Mon 4 April
Cardiff	Tues 5 April
Newcastle	Thurs 7 April
Oxford	Wed 4 May
London	Sat 7 May
Warrington	Mon 9 May
Leeds	Tues 10 May
Cambridge	Wed 18 May
Gatwick	Thurs 19 May
Southampton	Tues 24 May
Taunton	Tues 7 June
Leicester	Thurs 16 June

GLOSSARY

A

Adult Congenital Heart Disease (ACHD): An abnormality of the heart or great vessels present at birth, but having health implications for individuals over the age of 16-18. This is also known as “grown-up congenital heart disease”, or “GUCH”

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

Artery/Arteries: A blood vessel carrying blood from the heart to another part of the body

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

B

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

C

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

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

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 (PCT's) currently 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 Patient: A patient with a condition present at birth

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

D

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

District Children's Cardiology Services: see page 42

E

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

F

Foetus: An unborn baby

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

G

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

GUCH: “Grown-Up Congenital Heart Disease”. This refers to an adult with congenital heart disease (see above). A GUCH cardiologist is a doctor trained to look after adults with congenital heart disease. A GUCH unit is a centre where care is offered to patients with congenital heart disease

H

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

I

Interventional cardiology: 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 central circulation and then into the heart

J

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

M

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

N

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

O

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

P

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

Prenatal 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

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

R

Referral: Sending a patient to a specialist for expert care

S

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

U

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

V

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

APPENDICES

Appendix 1: *SAFE AND SUSTAINABLE* Steering Group members

Appendix 2: Nationally Commissioned Services

Appendix 3: Joint Committee of Primary Care Trusts members

Appendix 4: Proposed National Quality Standards

Appendix 4.1 Membership Of Standards Working Group

Appendix 4.2 Role of the Lead Nurse

Appendix 4.3 Excluded Procedures

Appendix 4.4 References

Appendix 4.5 The 'Cardiac transition nurse' role

Appendix 4.6 The role of the Children's Cardiac Specialist Nurse within the Cardiac Liaison Team

Appendix 5: Assessment Panel Biographies

Appendix 6: Future activity projections

Appendix 7: Scoring process

Appendix 8: District General Hospitals (DGHs) that currently have more than 3,000 births per year

Appendix :9 List of Trusts with Cardiac Surgery Centres

Appendix :10 Expert staff who provide care for children

Appendix :11 Meeting best practice

APPENDIX 1: SAFE AND SUSTAINABLE STEERING GROUP MEMBERS

The Steering Group has actively steered the review, ensuring that it complies with the quality assurance requirements (Gateway and National Clinical Audit Team reviews), commented on and approved the proposed governance arrangements, timeline for the programme, and the progress and plans for engagement with the public. The Steering Group has also contributed to developing the process of assessment, including the self-assessment documentation for the centres and the panel assessment visits.

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	January 2010 - June 2010
Professor Martin Elliott	British Congenital Cardiac Association		Consultant Paediatric Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust	April 2009 - present

NAME	CONSTITUENCY		ROLE	DATES
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		<i>SAFE AND SUSTAINABLE</i> 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
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
Dr Sally Nelson	Public Health		Medical Adviser, South Central SCG	Continuous

NAME	CONSTITUENCY		ROLE	DATES
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 PCTs / 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 2: 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 Organisation (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 Primary Care Trusts 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 opposite 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)
- advise on overall viability and risks associated with re-location
- identify other relevant issues that JCPCT should address

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

SCORING

In order to quantitatively evaluate the potential of each provider that submitted an application to provide one or more of the NCS, each application was scored by the NCS 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 3: JOINT COMMITTEE OF PRIMARY CARE TRUSTS MEMBERS

The Joint Committee of Primary Care Trusts comprises the Chair of each of the 10 Specialised Commissioning Groups 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.

The establishment of a Joint Committee of Primary Care Trusts ensures that each region and each PCT in England is represented on

the decision-making body via the relevant Specialised Commissioning Group Chair.

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 4: PROPOSED NATIONAL QUALITY STANDARDS



‘You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved organisation that meets required levels of safety and quality’

Section 2a, NHS Constitution 2009

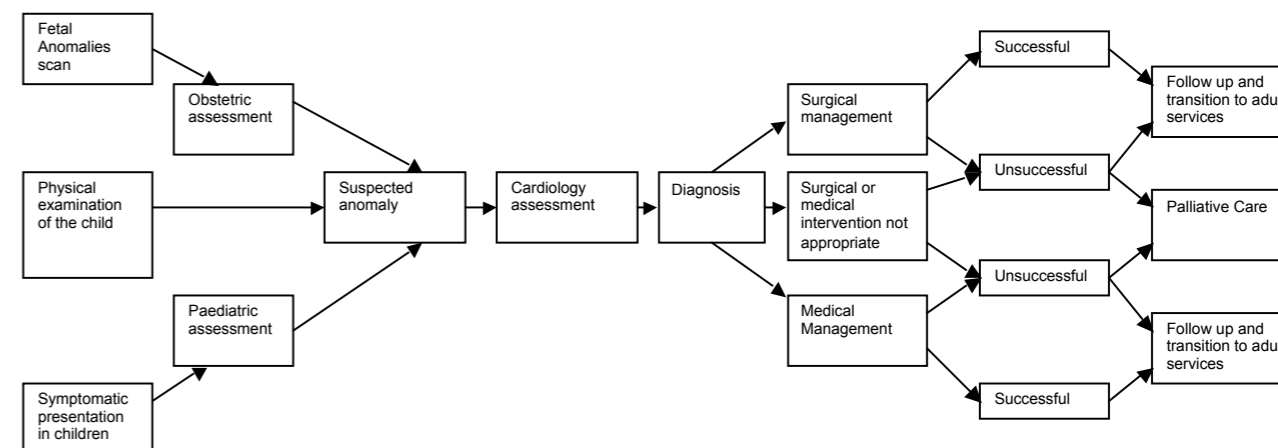
INTRODUCTION

SAFE AND SUSTAINABLE 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

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.



MANDATORY FOLLOWING DESIGNATION

- Must be in place immediately once designated
- Any failure or change in status would prompt immediate review of designation status
- 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 	Written protocols and policies Documented pathways Outcome of audits Evidence of formal contracts accompanied by Service Agreements between commissioners and all providers in the Congenital Heart Network	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' 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
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	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 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	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
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	Name of Lead Job and role description	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service' Report of the Paediatric Congenital Cardiac Services Review Group (2003)	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 4.2	Name of Lead Job and role description Advice from Royal College of Nursing (2010) Report of the Paediatric Congenital Cardiac Services Review Group (2003)	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	Written protocols Documented pathways Standards for Providers of Services for Adults with Congenital Heart Disease (2010) British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service' 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
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	Audit of referral and waiting time data Access data Report of the Paediatric Congenital Cardiac Services Review Group (2003) Department of Health Waiting Time Standards NHS Operational Framework	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 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' Report of the Paediatric Congenital Cardiac Services Review Group (2003)	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	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	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 Service 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			
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	Written protocols Audit of service activity	British Congenital Cardiac Association (2009) 'Requirements for Provision of Outreach Cardiology Service'	MANDATORY AMBER
	<p>a) Prenatally Diagnosed Congenital Heart Defects.</p> <p>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>			

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	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'	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	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'	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	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'	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 feto-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan should be updated throughout pregnancy	Written protocols and audit of compliance	British Congenital Cardiac Association (2010) '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	Posts in place Evidence of qualifications, experience and training	NHS Constitution 2009 RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People' 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' 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
C2	All paediatric cardiac surgical cases should be carried out by a dedicated paediatric cardiac surgical team	Posts in place Audit of operating logs	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	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	Posts in place Named individuals Record of nurse staffing	RCN (2003) 'Defining Staffing Levels for Children's and Young People's Services' RCN (2010) 'Health Care Service Standards in Caring for Neonates, Children and Young People' National Service Framework for Children, Young People and Maternity Services (2003 and as modified)	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	Named individuals Job descriptions Evidence of qualifications, experience and training	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service' Consensus reached at <i>SAFE AND SUSTAINABLE</i> national stakeholder event, October 2009	MANDATORY AMBER

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C THE SPECIALIST SURGICAL CENTRE PROFESSIONAL COMPETENCE				
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	Written protocols and audit of compliance	Royal College of Surgeons (2007) 'Surgery for Children: Delivering a First Class Service'	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 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 4.3)	Posts in place Audit of operating logs Submission of data to CCAD	This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons Appendix 4.4 for relevant papers	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 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 4.3)	Submission of data to CCAD	This figure has been determined with reference to the need to avoid occasional surgical practice in a centre staffed by 4 full time surgeons Appendix 4.4 for relevant papers	HIGHLY DESIRABLE
C8	Each Specialist Surgical Centre must be staffed by a minimum of 1 consultant paediatric cardiologist per half million population served	Named individuals Job descriptions	Report of the Paediatric Congenital Cardiac Services Review Group (2003)	HIGHLY DESIRABLE

DESIGNATION STANDARD	MEASURES	COMPATIBLE EVIDENCE BASE	STATUS	
C THE SPECIALIST SURGICAL CENTRE PROFESSIONAL COMPETENCE				
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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008)	MANDATORY
C19	Neonatology: access as stipulated in the Framework of Critical Inter-Dependencies	Description of services available Audit of compliance with CID Framework	Commissioning <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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 <i>SAFE AND SUSTAINABLE</i> 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	Dietitian	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			
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
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 <i>SAFE AND SUSTAINABLE</i> Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008) Department of Health (2009) 'Toolkit for High Quality Neonatal Services'	MANDATORY
C37	Fetal 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 <i>SAFE AND SUSTAINABLE</i> 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 (macroscopic and microscopic)	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	Description of services 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 0.8%	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% of admissions	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
D6	Young people must have the opportunity to be seen by a Clinical Psychologist on their own. Psychological support should also be offered to parents and carers	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 12 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>	MANDATORY AMBER

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>	MANDATORY
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 4.6)	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	Publication of audits	<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 sufficient to 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>	Advice from Royal College of Nursing (2010)	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 4.1: MEMBERSHIP OF STANDARDS WORKING GROUP

NAME	CONSTITUENCY	ROLE		DATES
Mr William Brawn (Chair)	Chair of the Standards Working Group and President of British Congenital Cardiac Association	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust		April 2009 - February 2010
Dr Martin Ashton-Key	National Specialised Commissioning Team	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
Professor Martin Elliott	British Congenital Cardiac association	Consultant Congenital Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust		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
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
Dr Sue Hobbins	Royal College of Paediatrics & Child Health	Consultant Paediatrician with Expertise in Cardiology, South London Healthcare NHS Trust		April 2009 - February 2010
Dr Ian Jenkins	Paediatric Intensive Care Society (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 - February 2010
Dr Sally Nelson	Public Health	Medical Adviser, South Central SCG		December 2009 - February 2010
Dr Shakeel Qureshi	British Congenital Cardiac Association (President Elect)	Consultant Paediatric Cardiologist, Guy's and St Thomas' NHS Foundation Trust		April 2009 - February 2010
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		April 2009 - February 2010
Louise Tranmer	SCG Directors Group	Director, South West SCG		December 2009 - February 2010

APPENDIX 4.2: 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 4.3: 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

APPENDIX 4.4: REFERENCES

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APPENDIX 4.5: 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 4.6: 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

APPENDIX 5: 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 6: 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 CCAD³⁵ 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 opposite. The 2009/10 data (representing 1 April 2009 to 31 March 2010) has been used to underpin most of the analysis given 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 of the Pre-Consultation Business Case.

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 findings³⁶.

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 Statistics³⁷ suggest an increase in the paediatric population of England and Wales by 13.7% from 2006 to 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 this is 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 groups³⁸. 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.

³⁵ 2009/10 CCAD validated data, surgical procedures only

³⁶ Commission for Paediatric Heart Interventions, *Concentration of congenital heart surgery and catheter interventions*, June 2009 Document translated from Dutch by Ubiquis, London

³⁷ UK National Statistics website - Available at: <http://www.statistics.gov.uk/hub/index.html>

³⁸ 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 CCAD³⁹ 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 Statistics⁴⁰. 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.

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

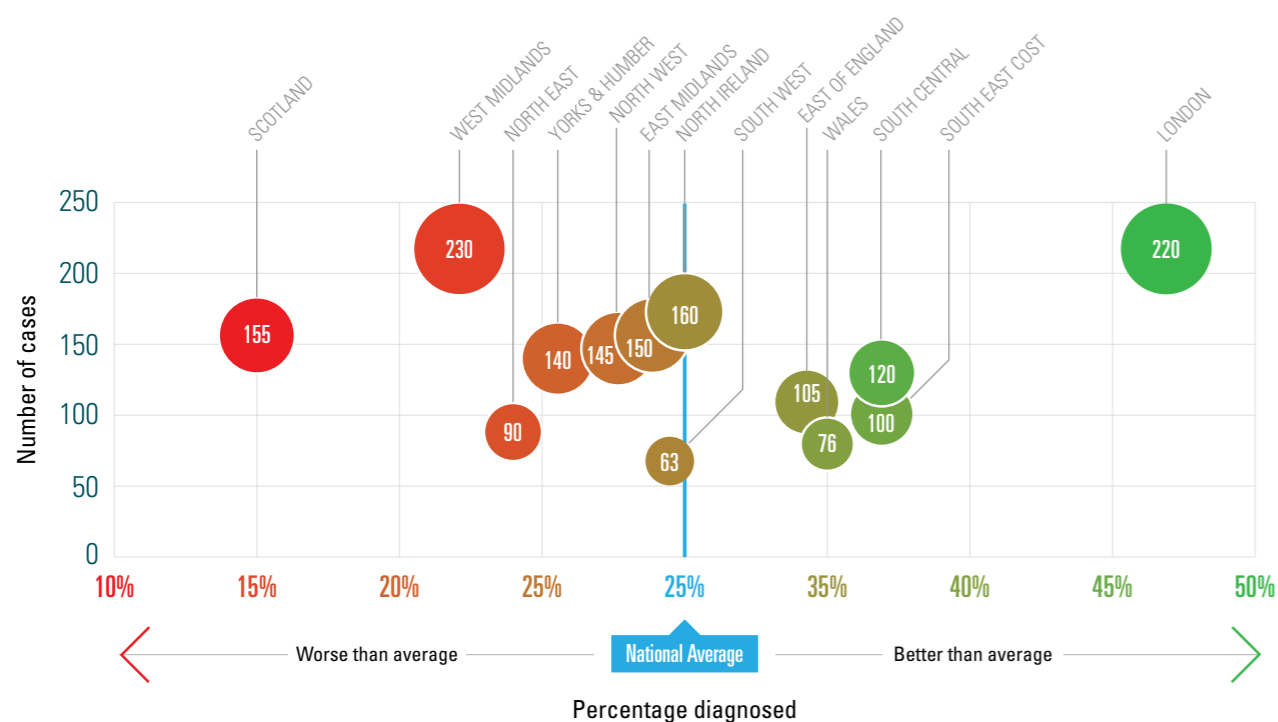


Table 1

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 %

³⁹ Congenital Heart Disease website (or CCAD website) - Available at: <http://www.ccad.org.uk/congenital>

⁴⁰ 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

The latest CCAD data confirms that current paediatric cardiac surgery activity has been relatively 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% from 2006 to 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 of the Pre-Consultation Business Case. However the increase may be tempered by technological advances and increased rates of screening.

APPENDIX 7: SCORING PROCESS

The following material is taken from the Pre-Consultation Business Case and was used to help the Joint Committee of Primary Care Trusts arrive at their recommendations. Please note options have been re-labeled A-D (Option 2=A, 14=B, 6=C, 8=D)

SCORES FOR ACCESS AND TRAVEL TIMES

Suggested scoring of options presented to Joint Committee of Primary Care Trusts (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

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 of the Pre-Consultation Business Case.

- 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 of the Pre-Consultation Business Case.

- 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 Sir Ian Kennedy’s Assessment Panel scores shown in Appendix K1 of the Pre-Consultation Business Case.

- 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, at 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 of the Pre-Consultation Business Case

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 a minimum of 2 centres providing transplant services and this must be met by any 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 of the Pre-Consultation Business Case.

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 predominantly supports 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 as in 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

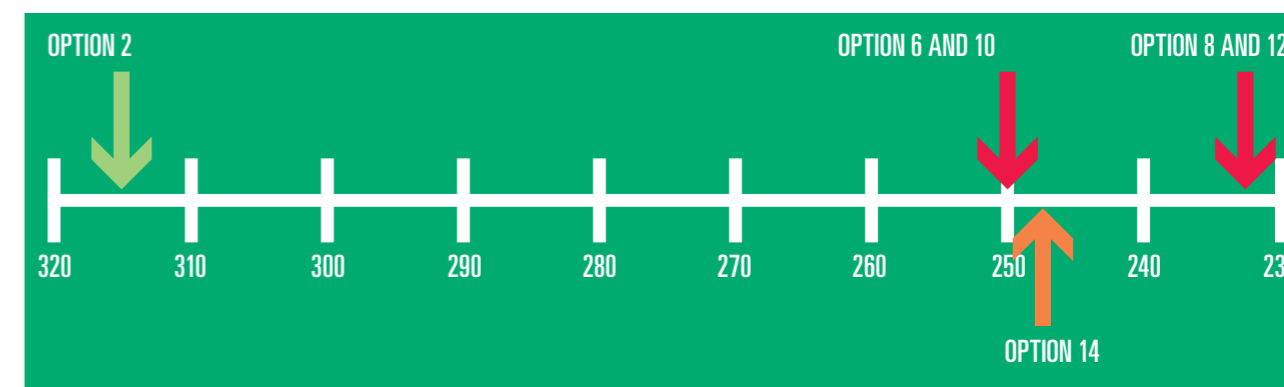
A sensitivity testing has been applied to show what the outcome of the scoring would be under various different scoring scenarios. These scenarios are outlined on the next page.

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.

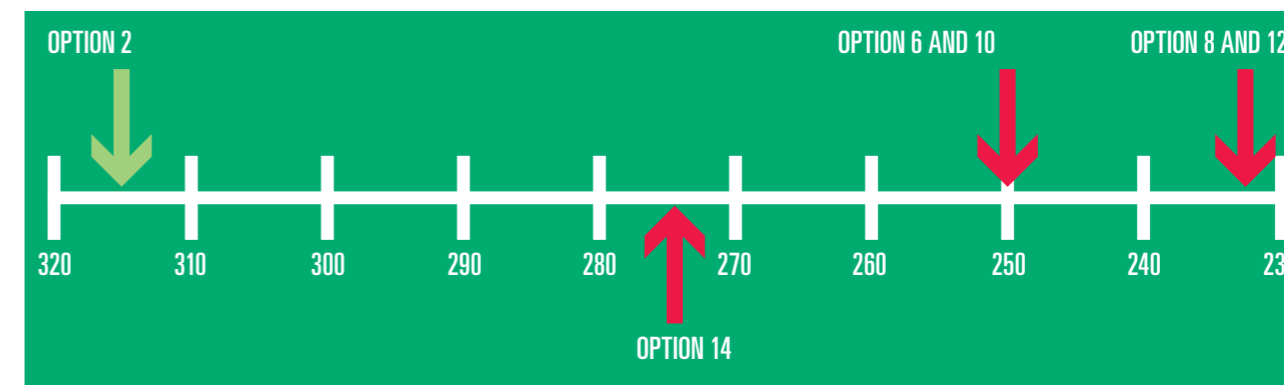
The outcome of running scenario 1 when compared to the suggested scoring as set out in section 7 would be that option 14 moves from second position down to second last position and options 6 and 10 move from second last position to second position as can be seen on the ranking indicator above. All other 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.

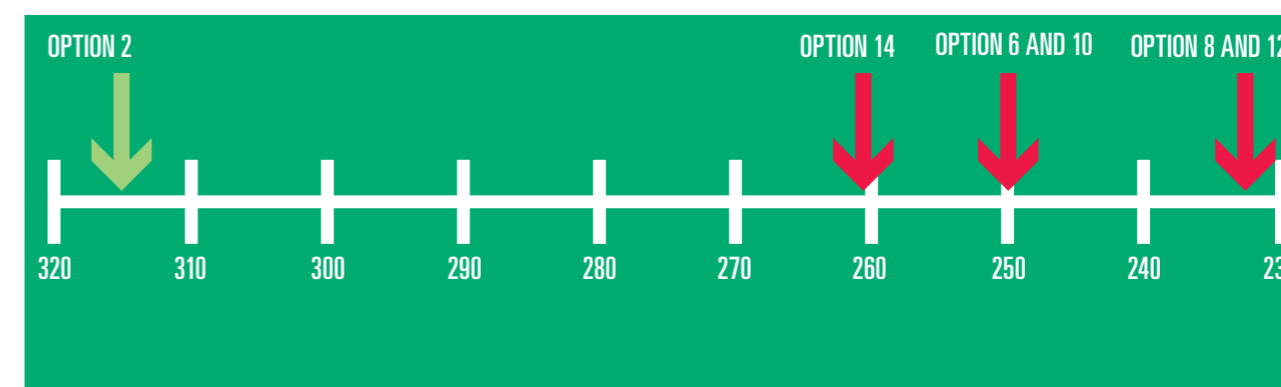
The outcome of running scenario 2 when compared to scenario 1 above is that option 14 comes back up the ratings. Option 2 would still be highest ranked and options 8 and 12 would remain lowest ranked.

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 Society⁴¹.

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.

⁴¹ 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 2	OPTION 6		OPTION 8	OPTION 14
1	Access and travel times	14	4	1		3	1
2	Quality	39	3	3		3	4
3	Deliverability	12	3	2		1	3
4	Sustainability	25	3	3		2	2
		TOTAL	13	9		9	10
		RANKING	1	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 2	OPTION 6		OPTION 8	OPTION 14
1	Access and travel times	14	56	14		42	14
2	Quality	39	117	117		117	156
3	Deliverability	12	75	50		25	75
4	Sustainability	25	66	66		44	44
		TOTAL	314	247		228	289
		RANKING	1	6		7	2

Option 2 remains the top ranked and option 14 second ranked.

**APPENDIX 8: NHS TRUSTS 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
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 9: LIST OF NHS TRUSTS PROVIDING CHILDREN'S HEART SURGERY

TRUST	CENTRE
Guys and St Thomas' NHS Foundation Trust	Evelina Children's Hospital
Southampton University Hospitals NHS Foundation Trust	Southampton General Hospital
Birmingham Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital
Great Ormond Street Hospital NHS Trust	Great Ormond Street Hospital for Children
Royal Brompton and Harefield NHS Foundation Trust	Royal Brompton Hospital, London
University Hospitals Bristol NHS Foundation Trust	Bristol Royal Hospital for Children
Newcastle Upon Tyne Hospitals NHS Foundation Trust	The Freeman Hospital
Alder Hey Children's NHS Foundation Trust	Alder Hey Children's Hospital
University Hospitals of Leicester NHS Trust	Glenfield Hospital
Leeds Teaching Hospital NHS Trust	Leeds General Infirmary
Oxford Radcliffe Hospitals NHS Trust	Oxford John Radcliffe Hospital

APPENDIX 10: EXPERT STAFF WHO PROVIDE CARE FOR CHILDREN

The parents of babies and children with congenital heart disease depend on the excellent care delivered by many different expert health professionals from children's cardiac specialist nurses and dieticians to the consultant cardiac surgeon and their surgical teams. These experts play a vital role at different stages of a child's development. This consultation proposes that health professionals would work within a congenital heart network in line with the new proposed national quality standards. Here are the roles of some of the most important professionals a child and their family may see.

SONOGRAPHER

A sonographer is a specially trained ultrasound technician. A sonographer uses ultrasound to check the unborn baby's heart. If they see or hear anything that suggests there may be a problem with the baby's heart, they refer the pregnant woman to a specialist fetal cardiologist. Cardiac sonographers (known as echo technicians) undertake ultrasound scans on babies and children with heart problems.

OBSTETRICIAN

An obstetrician is a doctor who specialises in the care of pregnant women. If an obstetrician suspects a baby has a heart condition, he/she refers the mother to a fetal cardiologist. Obstetricians will also be involved in planning the birth of a baby with congenital heart disease.

MIDWIFE

A midwife is usually the first and main contact for the expectant mother during her pregnancy, and throughout the labour and postnatal period. The midwife will be involved in planning the birth of a baby with congenital heart disease.

PAEDIATRICIAN WITH EXPERTISE IN CARDIOLOGY

A paediatrician is a doctor who specialises in the care of infants, children and young people. A Paediatrician with Expertise in Cardiology is a consultant paediatrician who has developed additional expertise in the care of children with heart conditions. They can provide non-interventional care in a local hospital setting, including diagnosing a congenital heart defect and treating and managing children on an ongoing basis in liaison with specialist units. The role of the paediatrician with expertise in cardiology would be strengthened to ensure vital care can be provided closer to more children's homes.

CONSULTANT PAEDIATRIC CARDIOLOGIST

A doctor who specialises in investigating and treating diseases of the heart in infants, children and young people. Cardiologists can often diagnose and treat congenital heart problems early on when the baby is still in the mother's womb ('fetal cardiology'). Cardiologists based at surgical centres also carry out invasive interventional cardiology procedures, such as inserting a catheter or other device through the skin into the heart. Cardiologists provide ongoing care for children.

CONSULTANT CONGENITAL CARDIAC SURGEON

This type of surgeon performs surgical procedures on infants, children and adults with congenital heart disease. Surgical operations are generally planned in advance but there can also be emergencies. In addition to operating in theatre, surgeons have other important duties including daily ward rounds and attending outpatient clinics.

CHILDREN'S CARDIAC SPECIALIST NURSE

The Children's Cardiac Specialist Nurse plays a vital role within a Cardiac Liaison Team. They provide practical information, educational and emotional support on a range of issues that can impact on the day-to-day life of children and their families. These nurses visit children and families in their homes and provide a link with the community healthcare team.

They provide continuity between the services a child will see as well as communication across health services and with the family. Children's Cardiac Specialist Nurses also act as an expert resource for the wider multidisciplinary team across cardiology networks.

CONSULTANT INTENSIVIST

A medically qualified doctor who specialises in the treatment of patients in intensive care. Some children with CHD will be kept in intensive care (known as a PICU) when their condition is life-threatening and they require continuous observation and management, before or after surgery.

The Intensivist is also responsible for transporting seriously ill children with CHD from a local hospital to a specialist intensive care unit (this journey is called a 'retrieval'). The Intensivist provides expert care to the child in the specially equipped ambulance. Most are trained in paediatrics or anaesthesia as well as intensive care.

CONSULTANT ANAESTHETISTS

These are medically qualified doctors who put the child to sleep for the heart operation and insert the necessary catheters into the veins and arteries for this procedure. They then look after all the child's body systems (brain, heart, lungs and kidneys) during the operation. They are experts in monitoring and responding to difficult situations as well as pain management. Many are also qualified in intensive care.

CLINICAL PSYCHOLOGIST

These people specialise in the understanding of human behaviour. They may work with children with congenital heart disease – and their families – to reduce psychological distress or behavioural problems caused by anxiety, stress, depression, phobias or trauma. Clinical psychologists may work in hospitals, health centres and community settings, and work closely with the multidisciplinary team.

DIETICIAN

It is important that children with congenital heart disease have a nutritious diet particularly as they often experience difficulties in feeding. Poor growth is common in infants with congenital heart disease. Dieticians assess a child's nutritional needs and develop specific treatment plans, which in some cases will include feeding through tubes.

APPENDIX 11: MEETING BEST PRACTICE

In developing the consultation plan, we have considered consultation best practice. Below we set out the key issues and how we have addressed them.

WHEN TO CONSULT

The consultation will start in March 2011 and will run for at least four months. It will end on 1st July. This period is an ideal stage for people to contribute to the review process, to have their say on the published recommendations and to influence the final decision. The final decision is not expected until late 2011.

DURATION

The length of the consultation is longer than the normal 12 weeks because it is a national consultation which coincides with the Easter break and several other public holidays.

CLARITY OF SCOPE AND IMPACT

The consultation document will contain information about the key recommendations, including the potential impact of the proposals. The consultation will highlight that the review has taken congenital heart services for children into account – rather than just surgery services.

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.

ACCESSIBILITY

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

The document will be written in plain language. Technical terms will be explained and a glossary will also be provided. The document will be available in English and Welsh and alternative formats will be made available on request. 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 learn more about the consultation and ask questions. Events designed for parents, staff and young people will be hosted across the country.

We need to ensure that people's views are heard, including those whose views are harder to reach. We will encourage all parents with children with heart conditions to engage in the process, regardless of how many surgical procedures they have experienced.

BURDEN

We are seeking to avoid burdening people as much as possible by making the consultation process as straightforward as possible.

RESPONSIVENESS

Capturing people's feedback is vital and all comments submitted, including those at events, will be recorded carefully. An independent third party will oversee this process. Feedback will be made available via the *SAFE AND SUSTAINABLE* website.

CAPACITY TO CONSULT

The consultation process follows a period of extensive stakeholder engagement. We have tested materials to ensure they are fit for purpose.

FOUR TESTS FOR PUBLIC CONSULTATION.

In June 2010 the government revised the NHS Operating Framework for 2010/11 including new rules on reconfiguration. The document highlights that the *SAFE AND SUSTAINABLE* review should proceed and that all proposals for consultation should take account of four new tests for reconfiguration.

The tests will require reconfiguration proposals to demonstrate:

- support from GP commissioners
- strengthened public and patient engagement
- clarity on the clinical evidence base
- consistency with current and prospective patient choice

NHS London, who are quality assuring the *SAFE AND SUSTAINABLE* review on behalf of all Strategic Health Authorities in England, advise that the four tests have been met