NHS England

PROPOSED CONGENITAL HEART DISEASE STANDARDS AND SERVICE SPECIFICATIONS

a consultation →

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Contents

Foreword

In June 2013, the board of NHS England resolved to start a fresh review of services for congenital heart disease (CHD) with the aim of achieving the best outcomes for all patients, consistently across the whole country, and with excellent patient experience. Reflecting the importance of this work, we established a board task and finish group to provide board-level oversight.

There have, of course, been previous reviews. Although we do not feel bound by what has gone before, we knew we could learn a great deal from those experiences. We embarked upon an approach of openness and engagement from the outset. We have been extremely fortunate: we have been advised and informed by a wide range of stakeholders, including patients and the public, and those who represent them; clinicians; and hospital managers. We have also had lively discussions with local authority and local Healthwatch representatives. These groups have told us that the key to our approach must be a set of national standards, consistently applied, covering the whole of a patient's life. In that way we can help ensure that wherever patients live, they will be able to access the best possible services.

In the following pages we explain more about our review. We also set out the proposed national standards, which have been drafted by expert groups, widely discussed in consultative meetings, and finally considered and approved by the review's Clinical Advisory Panel.

The proposed standards are in turn accompanied by draft service specifications which are the mechanism for incorporating the standards into our contracts with hospitals. As with every specialised service, these specifications were prepared by a Clinical Reference Group with clinical and patient membership. We have summarised the standards, setting out what we have heard, what we are proposing and what we think this will mean. Where there has not been full agreement in discussions to date we say so, and explain the arguments, setting out our judgements and asking for your views.

Of course the world does not stand still, and doubtless other initiatives will emerge in the future, but we are confident that the network-based system we have proposed for CHD services will be able to flex and adapt as needed. Everyone is aware that the NHS faces an extremely challenging financial situation, and we need to work together to deliver high quality care within the resources available to us. The work we have done to assess the financial impact of the proposed standards suggests that for CHD this is possible.

I would like to once again thank the very many people who have given their time, good will, expertise and enthusiasm, and have offered support and challenge in equal measure. The draft standards and service specifications have been greatly enhanced through their input.

In the same vein, I hope that as many as possible will respond to this consultation in the spirit of openness and engagement to which we are committed, and help us to ensure high quality care for all, now and for future generations.

Professor Sir Malcolm Grant
Chair of the Board Task and Finish Group

Executive summary

Congenital heart disease (CHD) is the most common type of congenital anomaly. It affects the normal workings of the heart. It ranges from severe life threatening conditions that need immediate surgery, at or even before birth, to minor conditions that often do not need to be treated. All will require specialist diagnosis, monitoring and care throughout the person's life.

What difference will these proposals make?

Although relatively small in terms of patient numbers, (around 9,400 children and adults had at least one specialist inpatient episode in 2012/13)[1] and expenditure (around 1% of total spending on specialised services)[2], CHD services are a matter of great public concern. Confidence in the service has been undermined by many years of repeated review and investigation. Investment in the service has been held back because of continuing uncertainty. It is, therefore, important that this review is brought to a clear conclusion. We have heard that relationships between some hospitals have become strained because previous reviews made them feel that they needed to compete against each other. Our proposals aim to ensure that CHD services work together within regions and across the country with the patient's best interests as their prime concern.

Early diagnosis

Making a diagnosis of CHD early helps with planning and can improve outcomes. As much as possible we want to detect the problems before a baby is born. The first indication usually comes from the routine scan at 18-20 weeks. We heard that detection rates vary across England and could be better. For example, according to 2011/12 data from the National Institute for Cardiovascular Outcomes Research (NICOR), of babies requiring an intervention in the first year of life, only 35% were diagnosed antenatally and there is variation by area[3]. Our proposals aim to ensure that patients receive the same high quality screening wherever they live and will receive the support, care, and information they need if an anomaly is suspected. We also heard that standards, by themselves, could not solve all the problems with low detection rates. So we are also doing some more work in this area to understand the problems in more detail and make separate proposals for improvement.

Variations in service delivery

Babies born with CHD are among the most vulnerable patients the NHS cares for. Services in England are considered to be good, but they could be even better. We know that there is variation in the way different providers deliver these services. Sometimes this reflects providers delivering services in different but equally effective ways or one hospital developing a new technique or approach to care. But sometimes there is no good explanation for the differences. Our proposals aim to ensure that every patient gets the same high quality service wherever they live and wherever they receive their care.

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[1] NHS England analysis of Hospital Episode Statistics (HES) admitted patient care data

[2] NHS England analysis of Secondary Uses Service (SUS) data for 2012/13

[3] NICOR data on antenatal diagnosis available at: **https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument**

Maintaining and improving outcomes

While surgery is only a small part of the patient's experience of CHD, it is a very important part. Everyone wants to make sure that every patient has the best chance of a good outcome. Results from surgery and catheterisation measured as survival at 30 days, are very good at 98.2% in 2012/13[4] (for providers that report to NICOR). But it is still important to do everything we can to make sure they continue to be good and if possible to continue to improve outcomes overall.

We heard[5] a lot about the optimal number of surgeons to have in a team, how many cases each surgeon should do each year to make sure they keep their skills, the importance of each surgeon only tackling cases they have the skills to do, and how to make sure that patients with the rarest and most complex conditions receive the best possible care. These discussions are set out in more detail later in this document.

Our proposals will ensure that each surgeon will do enough operations to maintain their skills. Our proposals also aim to ensure that surgeons work in teams big enough to protect against fatigue and burnout, to be able to cope with the loss of a surgeon (for example in the event of illness), to provide 24-hour clinical cover all year round and seeing enough cases to develop and maintain skills in operating on less common or more complex conditions. Finally, our proposals aim to ensure that wherever patients receive their care, they will be seen by a doctor with the right skills, will be referred to another doctor if they need more specialist care, or the hospital will bring in expert support.

We have described here the issues about surgery, but many of the same concerns affect interventional cardiology, so we have made similar proposals for this too.

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[4] NICOR data available at: http://nicor4.nicor.org.uk/CHD/an_paeds.nsf/WMortality?Openview

[5] *What we have heard*, CHD review blog 26 http://www.england.nhs.uk/2014/06/24/john-holden-26/

Patient-centred care

Patients often have other problems as well as CHD and so need care from many specialists not just heart specialists. We have been told that sometimes it can take too long to get the help of other teams, and that sometimes the different teams of doctors do not work closely together. Our proposals aim to ensure that wherever patients receive their care, all the experts they are likely to need are on site or available very quickly.

CHD is often a lifelong condition. Although much can be done to correct the problems this is not usually a complete cure. So it is important that services throughout life are joined together and have a consistent approach. Our proposals include standards covering every part of the patient's life from early diagnosis in the womb through childhood, adolescence, adult life, planning a family and onwards. We heard that moving from children's services to adult services (transition) can be particularly difficult for young people. Our proposals aim to ensure that young people and their families receive more support at this difficult time and that children's CHD services and adult CHD services work more closely together to manage transition.

Adult congenital heart disease services (ACHD)

As a complete and systematic register of patients with CHD is lacking, no reliable data exists on the prevalence of congenital cardiac anomalies. Several attempts to estimate the prevalence of CHD have been undertaken over the past decade.

However, we heard that the number of adults living with CHD is probably now greater than the number of children and young people[6]. The prevalence in adults and median age of patients with severe CHD increased in the general population from 1985 to 2000. In 2000, there were nearly equal numbers of adults and children with severe CHD – based on research from North America[7].

'Treatment of adults with congenital heart disease is relatively new as more children with congenital heart defects receive treatment and reach adulthood. As a result of the success of paediatric cardiology and cardiac surgery over the last four decades, it is thought that more adults with congenital heart disease will require medical care than children.'
British Heart Foundation[8]

So, it is particularly important that we are clear what a good service for adults looks like. Our proposals set national standards for adult congenital heart disease (ACHD) services for the first time. We heard that some problems remain in the service for adults that have already been solved for children's services. These include isolated and occasional practice. This could be where hospitals do not work in partnership with others providing CHD services as part of a network, and/or where doctors undertake only a small number of procedures that may be too low to develop and maintain the right skills.

Quality of care

The quality of care is not just about surgical skills and the use of technology. We heard that patients want to be more involved in decisions about their care, to receive all the information they need to make good decisions and to be supported better, especially at the most difficult times. Our proposals aim to ensure that patients receive better information in a way they can understand and their views are taken into account.

We have also set standards that will improve communication and support at all times, but particularly when there is a suspicion that a baby may

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[6] *Congenital Heart Disease in the General Population Changing Prevalence and Age Distribution,* Marelli et al, (2007), Circulation – Journal of the American Heart Association

[7] Delivery of care for adult patients with congenital heart disease in Europe: results from the Euro Heart Survey, Moons et al (2006) European Heart Journal 27, 1324–1330

[8] *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickramasinghe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London

have CHD, when a patient is dying and when a family is dealing with bereavement. As we have spoken with patients and families we heard again and again how important specialist (liaison) nurses were in providing support and guidance, helping people to find their way through the system. Our proposals will make sure that there are enough specialist nurses to provide that support for patients of all ages and their families. We also heard that psychologists can make a real difference for patients and families struggling to come to terms with this illness and to make tough decisions. So our proposals, for the first time, set standards for numbers of psychologists and access to the help they can give.

Although most patients do not need to be inpatients often, some will need many admissions and some stays can be long. We heard that for patients and families, spending a long time in hospital, especially if that is not near home, can be hard. So our proposals aim to help patients, families and carers to be able to live as normally as possible during times spent in hospital.

Financial impact

The aim of the review is to ensure that services achieve the highest possible quality within the available resources. The available resources are not open-ended and it is the duty of the NHS to ensure both that it lives within its means and that it achieves the maximum value for every pound it spends. So it is important to think about the cost of new proposals to ensure that they offer good value and to make sure that the NHS can afford to make the improvements we are suggesting.

Our analysis shows that if recent trends continue we can expect that activity will increase whether or not new standards are introduced. So spending on these services by commissioners can be expected to increase. Our assessment of the financial impact of introducing the standards indicates that the higher costs of providing the service to the new standards will be met from the additional funding hospitals receive as activity levels increase. Introducing the standards will ensure that this increase in spending will give us higher quality and not just more activity.

The new CHD review: an overview

The aims of the new CHD review are:

- securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives;
- tackling variations so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- improving patient experience including how information is provided to patients and their families, and consideration of access and support for families when they have to be away from home.

This consultation on draft standards and service specifications is one part of the work of the review. We are also:

- analysing current and future demand for services;
- looking at the overall shape of the service that is provided;
- considering how best to commission any required improvement and support the necessary change;
- reviewing how better, more timely information can be provided; and
- looking at ways to achieve better earlier diagnosis of CHD.

Evidence

To ensure that we had the most reliable evidence on which to base our work, we asked The University of Sheffield's School of Health Research and Related Studies (ScHARR) to undertake an independent review of the literature. Their review considered 'What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services'.

In addition NICOR was asked to examine its data and to advise on what this showed about service factors that could influence outcomes. Although the final write up of this work is not yet available, NICOR supplied a summary of the main findings.

We also benefited from a great deal of expert advice, both from clinicians and from patients and their families.

"In my experience, the amount of quantitative scientific evidence available to guide us in deciding how best to organise health services is often much less than we would like. In these circumstances we rely heavily on the views of experts, both specialist clinicians and those who are expert because of their experience of using the services in question. The views of experts, while qualitative rather than quantitative, are also valid and an important source of evidence in our deliberations."

Professor Sir Michael Rawlins, Chair, Clinical Advisory Panel

Prevalence

It is estimated that across England and Wales between five and nine in every 1,000 pregnancies are associated with some form of CHD[9]. Birth rates are very difficult to predict but recently they have been rising[10]. If this continues, the number of babies born with CHD will increase. In their 'principal' projections, the Office of National Statistics predict that birth rates will fall over the next ten years, but under their 'high' projections, they recognise that they could also continue to rise[11].

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[9] *Table 1.1 and 5.1, "Congenital Anomaly Statistics 2011, England and Wales"*, BINOCAR, September 2013, found at: **http://www.binocar.org/content/Annual%20report%202011_FINAL_040913.pdf**

[10] ONS Population Estimates 2002-2010 available at: **http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-269171**

[11] ONS Population projection 2012-2037 available at: **http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-318453**

Because of improvements in treatment, people with CHD can now expect to live longer than ever before. Between 1979-1983 and 2004-2008, the number of deaths from CHD in children under 15 years fell by 83% in the UK[12]. While the number of adults with CHD is known to be increasing there is no reliable estimate of the number of people living with CHD. However, we do know that in the future we are likely to see the service moving from one that is focussed on children, to one that is treating a growing number of young people and adults[13], who will continue to have (often complex) health needs. Even when anomalies have been treated in childhood, further problems can develop later in life that require medical care or further surgery[14]. As the number of adults living with CHD rises, it will become difficult for Specialist Surgical Centres to manage the demand. So, it is important that we develop new ways of working. Most patients, children and adults, will only receive a small part of their care at the Specialist Surgical Centre. Our proposals set standards for Specialist and Local Cardiology Centres so that more care can be given closer to home, in hospitals working closely with the Specialist Surgical Centre with agreed ways of working.

Hospital activity

Figure 1 shows how provider volume differs, with some carrying out relatively low levels of activity[15]. Our proposals would mean that all doctors undertaking interventional cardiology or surgery for CHD will be required to do a minimum number of cases each year and decisions on how to treat each case will be made by the multidisciplinary team (MDT). This is designed to bring to an end occasional and isolated practice.

Some hospitals are not reporting their results centrally for audit and monitoring. NICOR estimate

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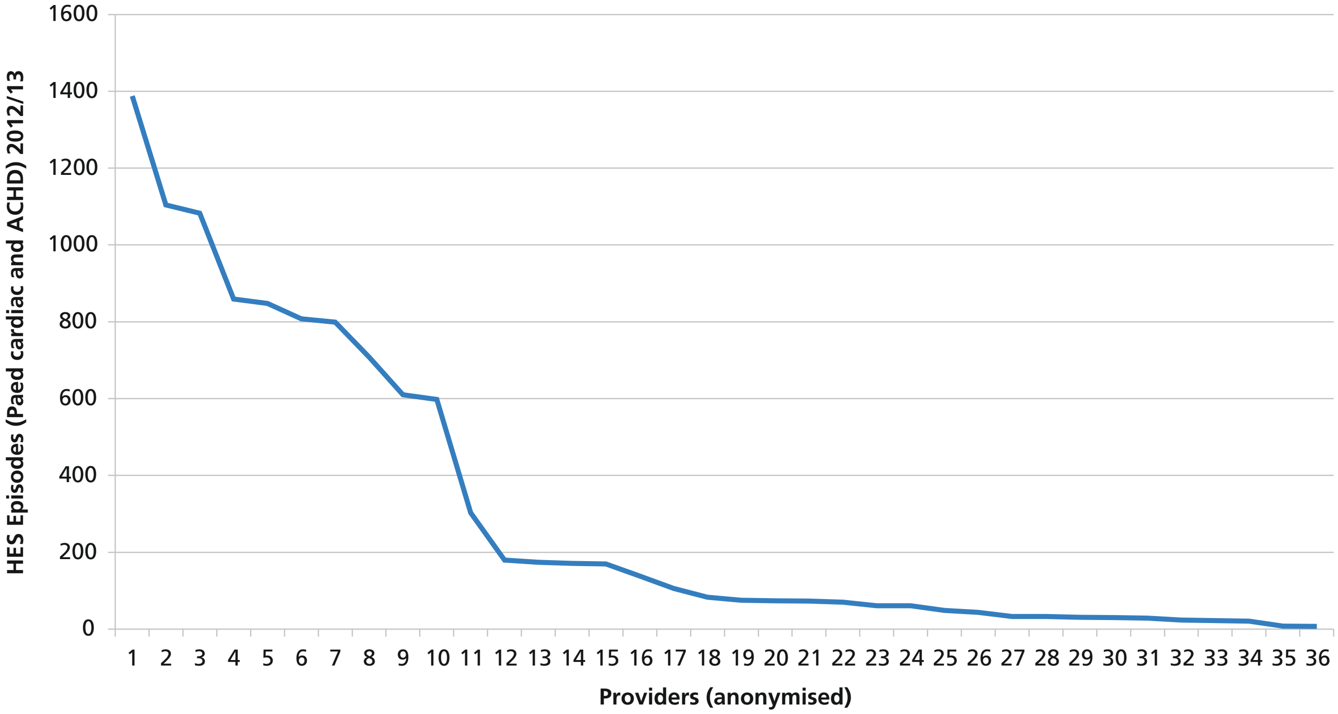
[12] *Mortality with congenital heart defects in England and Wales, 1959-2009: exploring technological change through period and birth cohort analysis* Knowles RL, Bull C, Wren C, Dezateux C (2012) Arch Dis Child, 2012 Oct: 97(10): 861-5

[13] *Delivery of care for adult patients with congenital heart disease in Europe: results from the Euro Heart Survey*, Moons et al (2006) European Heart Journal 27, 1324–1330

[14] *Care and Treatment for congenital heart defects* (2011) American Heart Association **http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/CareTreatmentforCongenitalHeartDefects/Care-and-Treatment-for-Congenital-Heart-Defects_UCM_002030_Article.jsp**

[15] NHS England analysis of HES data. The limitations of ACHD activity data are acknowledged. Providers with fewer than 20 episodes not included as very low level activity could be data coding issue

Figure 1: 2012/13 specialist inpatient episodes of care, for paediatric cardiac and ACHD services, by provider (anonymised)



that around 80% of current adult activity is reported to their congenital audit. Our proposals aim to ensure that all hospitals providing care for CHD patients are part of networks and report their results to the national audit (NICOR).

Developing the draft standards and service specifications

When we started our work, patients, the public, clinicians and providers told us that the best way to improve CHD services was through clear service standards, consistently applied.

NHS England is responsible for buying all specialised CHD services in England, so we have an opportunity to ensure consistently high standards for patients everywhere.

Professor Sir Bruce Keogh, NHS England National Medical Director noted:

"The aim of the review is to ensure that services achieve the highest possible quality within the available resources, now and for future generations… the standards [must] set out what is needed to achieve this".

Taking Sir Bruce's challenge, we have aimed to set out standards for services of the highest possible quality. People told us that this was important, even if it later proved necessary to make tough choices when considering how to put them into practice and what we can afford within the available resources.

Work on developing standards for children's and adult CHD services was already underway when the new review was set up. We have worked with groups of practising clinicians from most Specialist Surgical Centres in England and patient representatives to develop the standards and to draw the different pieces of work together into a single coherent set. During this process, we have also discussed the standards with our engagement and advisory groups (patients and public, clinicians, and providers) and with the Congenital Heart Services Clinical Reference Group (CRG), met with patients and staff in all Specialist Surgical Centres and with children and young people from all over the country. Finally the standards have been considered by a national, expert Clinical Advisory Panel. We have provided updates on our work in a fortnightly blog on the NHS England website. For the first time, we can set standards for CHD services right across the whole life-course from fetal diagnosis through children's and adult services including transition and pregnancy, to end of life care and bereavement.

The draft standards in detail

The draft standards will help ensure that CHD patients across the country receive the best possible care, within existing resources, now and in the future. The standards propose a joined-up system where care is provided through a network of services with the patient at the centre.

There are 13 sections, listed from A-M (networks to dentistry):

Section A:	The network approach
Section B:	Staffing and skills
Section C:	Facilities
Section D:	Interdependencies
Section E:	Training and education
Section F:	Organisation, governance and audit
Section G:	Research
Section H:	Communication with patients
Section I:	Transition
Section J:	Pregnancy and contraception
Section K:	Fetal diagnosis
Section L:	Palliative care and bereavement
Section M:	Dentistry

At the same time, the Congenital Heart Services CRG has developed service specifications. These make it possible for NHS England to ensure that the standards are part of its contracts with hospitals.

There is broad agreement on most of the proposed standards, but there are some issues where not everyone agrees. Where this is the case, we discuss this within the relevant sections. In each case, we make clear the approach we prefer, and why.

This consultation

In this consultation, we are seeking your views on draft standards and service specifications for the delivery of CHD services for children and adults in England.

This consultation document summarises the issues and lists the consultation questions and provides an introduction to the draft standards and service specifications. In the following pages we give an overview of what each section covers. We then sum up what we have heard so far and what we are proposing. Some sections are longer than others. This reflects the level of discussion there has been and the detail in the standards.

The standards describe how services should be organised and delivered. They do not make recommendations about what treatments should be used or which patients should receive them.

The service specifications bring the standards into the contractual arrangements between NHS England and hospitals providing CHD services.

While this consultation document provides a summary, the full draft standards and service specifications are available online at: **https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards**

There are consultation questions throughout the document and they are also listed together at Annex A. We have set out some key questions on which we are keen to hear your views, but if there are other areas you would like to comment on, we will be happy to receive those too, although we may not be able to reflect those in our analysis of consultation responses.

CHD review reference pack

The reference pack includes a selection of key documents for convenience of access, though all of these and others have previously been posted on the NHS England website.

We have also produced a draft financial impact assessment and draft equality analysis that sit alongside this consultation. All of these can be accessed via this link: **https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards**

PART 1

Model of care for CHD services

The standards are based on having three levels of CHD services for children and adults working as part of networks. These are:

- **Specialist Children's Surgical Centres and Specialist ACHD Surgical Centres (level 1);**
- **Specialist Children's Cardiology and Specialist ACHD Centres (level 2); and**
- **Local Children's Cardiology Centres and Local ACHD Centres (level 3).**

The standards set out the different requirements for each level of the service and the way in which they need to work together in a network relationship.

What we have heard

We have heard that patients and their families should be able to receive as much of their care as locally as possible. For this to be possible, networks need to ensure that local services work closely with specialist services to ensure that patients receive their care in a setting with the right skills and facilities.

We have heard that not all hospitals offering surgery or interventional cardiology to adult patients with CHD are part of networks. This can lead to isolated practice, with decisions not subject to review by the MDT, as well as occasional practice, with doctors doing only a small number of operations or procedures on adult patients with CHD each year. Patients' representatives have expressed concern about this arrangement.

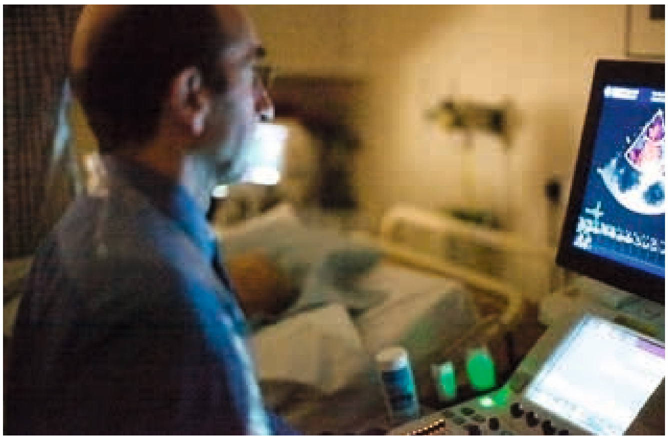
What we are proposing

We are proposing that hospitals providing care for CHD must work as part of three-level networks that bring together fetal, children's and adult services (described in more detail in section A). Patients being considered for surgery or intervention must be discussed by the MDT (described in more detail in section F) and these procedures must only be undertaken at a Specialist Surgical Centre.

Each network will have at least one Specialist Surgical Centre (level 1) working with a number of local hospitals that provide ongoing outpatient care (level 3). Specialist ACHD Centres, and Specialist Children's Cardiology Centres (level 2) are able to provide all the medical care offered at Specialist Surgical Centres except for surgery and interventional cardiology.

Some networks may function adequately without level 2 Specialist Cardiology Centres, depending on local issues and geography. The level 2 and 3 centres would allow patients to receive as much of their care as is appropriate in a centre closer to their home and allow Specialist Surgical Centres to focus on the most complex patients. Cardiologists based at level 1 Specialist Surgical Centres and level 2 Specialist Cardiology Centres would work across the network, including at outreach clinics, according to local circumstances.

Patients will not necessarily move through the three levels of care in order. Depending upon circumstances, they could move from a Specialist Surgical Centre to a local centre and back again without needing to access care at a level 2 Specialist Cardiology Centre. Adult patients enter the ACHD model of care via a general hospital or primary care, if they were not diagnosed during antenatal care or childhood.



Level 1: Specialist Surgical Centres

Specialist Surgical Centres would manage all patients with highly complex CHD. All congenital heart surgery and catheter interventions[16] will be carried out in Specialist Surgical Centres by trained congenital cardiac surgeons and interventional cardiologists with anaesthetic cover provided by those with CHD training.

Congenital heart networks would be hosted by a Specialist Surgical Centre. The Specialist Surgical Centres are likely to provide much of the leadership for networks, making sure services are better coordinated and working to common protocols. They will proactively lead training, development and research across the network.

Services delivered at the Specialist Surgical Centre

- All CHD surgery (to be delivered only by trained congenital cardiac surgeons with anaesthetic cover provided by those with appropriate CHD training).
- All CHD catheter interventions.
- Access to hybrid procedures – combined CHD surgical/CHD cardiology working.
- Joint surgical procedures – combined ACHD surgical/general cardiothoracic surgical working.
- Joint cardiology procedures – combined ACHD cardiology/general cardiology working.
- Electrophysiology. Simple procedures could be carried out at Specialist ACHD Centres but only following MDT consideration of individual cases.
- Complex pacing and implantable cardioverter defibrillator (ICD) procedures.
- Invasive and non-invasive imaging (including echo).
- Transition and transfer clinics.
- 24-hour on-call availability, 7 days per week.
- In-reach working by cardiologists from the level 2 Specialist Centre.
- Working links to other specialist specialties such as congenital transplantation services, genetics, National Pulmonary Hypertension Service.
- Very complex CHD patients requiring non-cardiac surgery to be managed in this setting in order to have access to anaesthetists with CHD experience.
- Joint management of ACHD patients with high-risk pregnancy.
- All other services delivered at level 2, Specialist Cardiology Centres.

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[16] Definitions of adult CHD surgery and interventions have been set out in the standards so that it is clear which procedures should be restricted to specialist centres and which can be undertaken by general adult cardiothoracic surgeons and cardiologists

Level 2: Specialist Cardiology Centres

Specialist Children's Cardiology and Specialist ACHD Centres would provide a broad range of medical cardiology services, to the same quality standards as the Specialist Surgical Centres, but focusing on diagnosis and ongoing management of patients and not surgery or catheter interventions.

They would be able to care for patients before and after surgery in a Specialist Surgical Centre including ongoing patient care and management. Not all networks will necessarily include level 2 centres, but because of the increasing number of adults living with CHD, Specialist ACHD Centres will be more common. Wherever they exist, Specialist Cardiology Centres must meet the standards.

We heard concerns that Specialist Children's Cardiology Centres may not be sustainable in the longer term, especially if it is not possible to attract high quality staff to work there. On the other hand, we heard that because of the expected continued rise in the number of adult patients living with CHD, Specialist ACHD Centres could have a vital role to play. Adult patients have fewer operations and interventional procedures than children and ACHD services can be delivered in hospitals with other adult (non-congenital) cardiac services. Because of this, we are particularly interested in views about the future role of Specialist Cardiology Centres.

Services delivered at the Specialist Cardiology Centre

- Fetal diagnosis (specialist diagnosis/second opinion).
- Assessment and diagnosis of new referrals (a broad range of diagnostic services, including non-invasive imaging, delivered at the same quality to those in level 1 Specialist Surgical Centres).
- Ongoing care for patients not requiring intervention or surgery.
- Simple electrophysiology work – only if agreed as part of network wide arrangements and following MDT consideration.
- Ongoing management of pacing.
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to level 1 Specialist Surgical Centres in high-risk cases.
- Specialist Cardiology Centres will not perform any CHD surgical procedures or catheter interventions (emergency balloon atrial septostomy and temporary pacing may be undertaken, if approved by the network).
- All other services delivered at level 3, Local Cardiology Centres.

Level 3: Local Cardiology Centres

Local Cardiology Centres will often be involved in the diagnosis of CHD. They will be part of the congenital heart network bringing expert care closer to home. They will refer more complex patients to the level 1 Specialist Surgical Centre or level 2 Specialist Cardiology Centre where more detailed investigations are needed when a patient may need an operation or interventional procedure. They will provide routine and follow-up care for patients with CHD, particularly those with less complex problems.

Local ACHD Centres will be staffed by a cardiologist with expertise in CHD to provide care for adults. Local Children's Cardiology Centres will be staffed by paediatricians with expertise in cardiology to provide care for children and young people. Under our proposals the numbers of doctors with this sort of expertise in local hospitals will increase, and they will be important members of the wider network team. They will work alongside specialist cardiologists from the Specialist Surgical or Specialist Cardiology Centre when they conduct outreach clinics.

Services delivered at the Local Cardiology Centre

- Delivery of shared care under protocols established within the network.
- Delivery of long-term follow-up as appropriate to need.
- Referral of patients to different network settings to meet changing clinical needs.
- Basic cardiac diagnostic services.
- Dental management, information and care.
- Monitoring of anticoagulation and blood chemistry.
- Joint working with palliative care.
- Management of low-risk pregnancies.
- Advice on lifestyle issues.

What this will mean

The proposed standard will help ensure that patients will be able to receive as much of their care as is appropriate closer to home. Each centre will have clear roles and responsibilities and will work together within a congenital heart network.

Patients are able to move between service levels as appropriate. This will not necessarily be between all three or from one to the other, but will depend on patient need.

Focus on: The role of level 2 Specialist ACHD Centres

The standards propose that all decisions regarding CHD patients are made through the MDT meeting and that congenital interventional cardiology procedures are only undertaken at Specialist Surgical Centres to assure safety, while increasing the sustainability of services. During pre-consultation some argued that this approach was too inflexible. We note here what we have heard, and what we are proposing, to deliver the best possible outcomes within existing resources.

What we have heard

We heard different views on whether, in a Specialist ACHD Centre, it should be possible to undertake interventional congenital cardiology procedures.

Some considered the standards too inflexible and that these centres should be permitted to continue to undertake congenital interventional cardiology procedures, as long as patients are appropriately selected and discussed at the MDT, the cardiologists have been appropriately trained, and meet the minimum surgical caseloads. They argue that this is safe, outcomes are good and it is more convenient for patients. They note that for some of the simpler procedures, a large proportion are currently undertaken at Specialist ACHD Centres and that it could be hard for Specialist Surgical Centres to absorb the extra workload.

Others considered that this would not be appropriate because we need to ensure that low risk procedures continue to have a near zero mortality. Concentrating this work at Specialist ACHD Surgical Centres ensures:

- appropriate surgical back-up for complications, only available at congenital Specialist Surgical Centres;
- that congenital interventional cardiologists can meet minimum activity levels, and as importantly, ensure a caseload large enough for four congenital interventional cardiologists to provide a 24/7 emergency on-call rota; and
- cases for congenital trainees.

We heard that the argument was not about the technical competence of non-congenital cardiologists. Rather the argument was that all surgery and catheterisation in CHD patients needed to be part of the network, discussed at the MDT and with the appropriate expert surgical back-up if there were complications. The requirement for specialist congenital surgical back-up in particular was considered essential by surgical members. We heard that non-congenital cardiac surgeons in other centres may not have the appropriate range of skills with the changes in surgical training now being put in place.

The standards extend the opportunity for cardiologists from level 2 Specialist ACHD Centres to continue to undertake catheterisation at the level 1 Specialist Surgical Centre.

What we are proposing

We are proposing that:

- all decisions regarding CHD patients must be made through the MDT meeting;
- congenital interventional cardiology must only be undertaken at Specialist Surgical Centres (level 1); and
- cardiologists from level 2 specialist ACHD centres will be given the opportunity to continue to undertake catheterisation at the Specialist Surgical Centre (but must meet standards for minimum numbers).

What this will mean

Patients with CHD can be assured that any decision to undertake an interventional cardiology procedure will have been agreed by the MDT and will take place in the safest environment.

Questions

Looking at the draft standards and service specifications:

Q.1. What do you think of the model of care that we are proposing?

Q.2 What do you think about our proposals for level 2 Specialist Cardiology Centres?

PART 2

Introduction to the individual sections

Section A: The network approach

Section A sets out how all hospitals treating people with CHD will work together to deliver the best possible outcomes within existing resources. Networks include all CHD services for both children and adults, at all three levels of the service.

What we have heard

We have heard that patients have a better experience and better outcomes when hospitals and clinicians are working together in a coordinated way. Networks provide a way to:

- bring hospitals together around patients with CHD to improve quality including patient experience and outcomes;
- share learning; and
- deliver efficiencies.

We have heard that CHD networks should bring together fetal, children's and adult services. We have heard that clinicians have a key leadership role to play and networks need a single clinical leader and to be properly resourced and supported.

We have heard that one of the effects of the CHD service having been under review for more than a decade is that relationships between some hospitals have become strained, because previous reviews made them feel that they needed to compete against each other. It is clearly vital for patient care that hospitals and clinicians work together.

We have heard mixed views on whether it is good for networks to have fixed, geographical boundaries. Some people think that fixed network boundaries would allow us to manage patient flows to ensure that all CHD surgeons in each Specialist Surgical Centre received enough cases to meet the standards. However, others worry that controlling patient flows in this way could reduce patient choice, prevent good centres from growing and mean that some patients would not be allowed to use their nearest centre.

What makes a good network?

We have heard that good networks need to:

- be clearly defined, including their roles and responsibilities, and need to cover children's and adult services;
- include all elements of CHD care – not just surgery;
- be large enough to be sustainable, but small enough to manage cases as individuals;
- have adequate resourcing, clear leadership and named contacts;
- develop consistent care pathways for children and adults to identify how hospitals work together: patients need to get the right care in the right place;
- invest in developing individual relationships across the network;
- ensure that there is a shared understanding of how each part of the network works with each other; and
- ensure that there are shared information systems including clinical IT systems and video conferencing.

In order to facilitate discussion about patient flows and networks, we have produced two maps. Figures 2 and 3 show historic patient flows based on our analysis of Hospital Episode Statistics (HES). The lines denote activity flows from patient residence to providers.

Figure 2: Paediatric cardiac specialist inpatient flows from 2003/4 to 2012/13

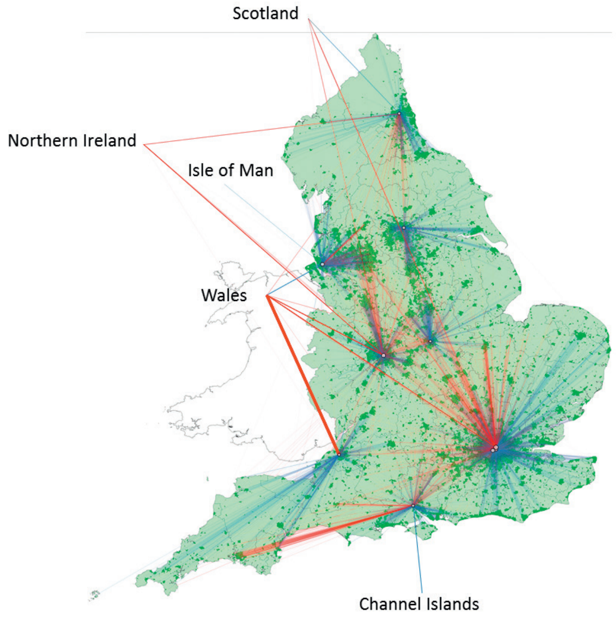
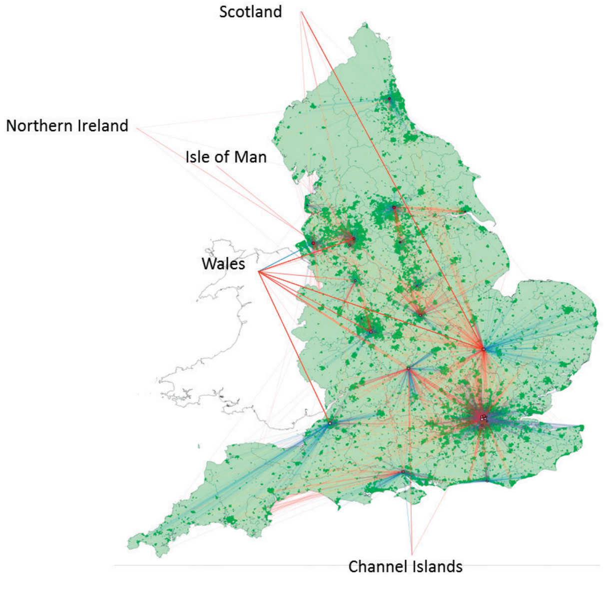


Figure 3: Adult congenital heart disease specialist inpatient flows (for 25 highest volume providers) 2006/7 to 2012/13



Thicker lines denote more episodes. Red lines show where a patient is travelling past their nearest centre, blue lines show where patients are travelling to their nearest centre. All flows are shown 'as the crow flies' – real journeys and access times would be more complex.

What we are proposing

Local networks

In section A, we propose the creation of local congenital heart networks that are a more sophisticated version of the 'hub and spoke' model usually followed. They would be based around Specialist Surgical Centres, ensuring strong links with Cardiology Centres and referring hospitals. These would ensure a consistent approach across the network, with shared information systems. They would have a particular role in quality assurance and improvement. Each would have a strong clinical leadership team and appropriate managerial support. By working together in this way, the hospitals in a network can make sure that patients get their care and treatment from the most appropriate professional in the most appropriate setting as close as possible to home.

Networks will organise weekly specialist MDT meetings to consider all patients who may need a procedure and cover second opinions and referrals. (See sections B and F for more on MDTs and Part 2 of this document for more on the model of care).

This includes an expectation that congenital heart surgery for children and adults is only undertaken in Specialist Surgical Centres.

The standards describe the relationships that CHD networks need to have with other local networks, including maternity and fetal, neonatal and paediatric intensive care. This will enable expertise to be shared in order to improve patient experience and outcomes.

Networks will also need to have formal working relationships with national specialist services for example heart and lung transplant and pulmonary hypertension services.

The precise shape of each congenital heart network will be determined by local need and local circumstances, including geography and transport. We have not proposed fixed network boundaries, but would welcome further views. There is an opportunity later on in the review to do more work on how networks are set up.

A key role for networks will be to ensure that information is shared. The standards make a number of proposals to improve information sharing across and between networks, including a new standard health records summary, a management plan and shared telemedicine and information technology across networks. In addition, the standards propose the development of a nationally consistent system of 'patient held records'.

Regional or national networks

The standards include an expectation of regional and national networking so that Specialist Surgical Centres work more closely with each other to share learning and skills and to provide important quality assurance and mutual challenge, enhanced training and research opportunities.

What this will mean

- The proposed standards will help to ensure that hospitals and clinicians work together in networks locally, regionally and nationally to provide the best possible care for patients.
- Patients, their families and their carers will have a better experience as the services they receive will be more joined-up and will work around the patients.
- Networks will ensure that the new standards are implemented in all their hospitals and lead quality improvement.

Consultation questions

Q.4 What do you think of our proposals for the development of networks?

Section B: Staffing and skills

Section B sets out the staff and skills needed in teams to deliver a world-class service across all parts of the network and to deliver excellent outcomes within existing resources.

What we have heard

We have heard that it is important to ensure that all CHD centres are adequately staffed and that staff have the skills they need. A common theme that came up in our conversations was concern about current and future staffing levels.

We have heard that there is a need to ensure that patients, families and carers have the care and support of a range of professionals. This includes making sure the emotional needs of patients of all ages are addressed. Patients and their families need help to understand the health system, but also to sort out other important areas like benefits and education.

What we are proposing

In section B we describe the staff and skills (surgeons, cardiologists, paediatricians with expertise in cardiology, cardiologists with expertise in congenital, specialist nurses, psychologists and others) needed to ensure that a world-class service is provided across the country.

We set out proposals for minimum staffing and activity levels for surgeons (covered in more detail below), interventional cardiologists and other members of the MDT, specifications for staffing of catheter labs, electrophysiology, imaging and echocardiography, anaesthesia, intensive care and nursing. This includes paediatric, adult, fetal and

transition specialist nurses. It also includes psychology and requirements for administrative support, safeguarding leads and named bereavement officers.

We describe what needs to be in place to ensure that there is all year round, 24-hour staffing, including on-call arrangements to ensure consistent high quality care.

The standards would require professionals to only provide care that they are competent to give and make clear that they must seek support from a colleague, and/or refer the patient to another centre, if they do not have the necessary skills. We also include a requirement that all centres and networks must work together to develop and support national, regional and local collaborative arrangements.

We understand that there is particular concern about staffing levels in paediatric intensive care and high dependency units. We will work with the Royal Colleges, professional associations and Health Education England to make recommendations in relation to workforce and future training strategies as a later part of the work of the review.

What this will mean

- The standards are designed to help to ensure that wherever patients receive their care, the centres will have the right staffing with the right skills, and if necessary will refer patients to another unit if they need more specialist care, or will bring in expert support.
- We expect that there will need to be an increase in the number of some staff groups at some centres and across networks to meet the standards. This includes, for example, surgeons, specialist nurses and psychologists.
- Networks will need to ensure that each centre has the right staffing levels, and the right skill mix at all times.

Questions

Q.5 What do you think of our proposals for staffing CHD services?

Focus on: Surgical caseloads and size of surgical teams

Surgery is carried out in Specialist Surgical Centres. During pre-consultation, we discussed the ideal number of operations per surgeon each year, and how many surgeons there should be in surgical teams. We note here what we have heard, and what we are proposing, to deliver the best possible outcomes within existing resources.

What we have heard

During pre-consultation there was a clear consensus about the individual caseloads needed to ensure that skills are maintained, but we heard continuing debate about the ideal number of surgeons in a team.

Maintaining skills

We have heard that it is important that each surgeon does enough operations on a regular basis to maintain their surgical skills (this is the case in all types of surgery, but is especially important in CHD because of the range and the complexity of procedures undertaken). Surgeons are clear that the number of operations they each do (level of activity) is more important for achieving the best outcomes than the number of surgeons in a team. Increasing the number of surgeons in a team must never be at the expense of minimum levels of activity. All the surgeons we have spoken to support a minimum of 125 operations a year. They told us that this must be seen as a minimum.

Some surgeons consider that maintaining skills is not just about numbers but also about the kinds of cases being done so some considered that short and long procedures should be counted differently. Most, however, did not favour a more complicated system of counting. They thought that a requirement to do at least 125 cases with internal systems for managing which surgeon does which cases would be sufficient.

Surgical teams

We have heard arguments in favour of bigger surgical teams – teams of at least four consultant congenital surgeons – to enable centres to:

- provide a concentration of expertise ensuring a team approach can be taken to managing clinical problems in a team with a greater range of skills;
- be more resilient to the loss of one surgeon (for example, in the event of illness);
- provide 24-hour clinical cover all year round while avoiding the risk of fatigued surgeons; and
- increase the opportunities for training, mentorship, dual consultant operating and professional development.

Bigger surgical teams are also associated with bigger units which some consider to provide better supporting facilities and staffing, more attractive units for recruitment and greater opportunities for training and research. These are not seen as ends in themselves but as important contributors to higher quality services that will improve outcomes.

In our discussions everyone agreed that two surgeons in a team are not enough. This is because for around 20 weeks of the year (when the other is away) there is only one surgeon available to cover all surgical requirements at the unit.

Most of the discussion we have heard has centred on whether a minimum of three surgeons in a team is enough or whether there needs to be at least four. It is generally accepted that teams of at least four surgeons is the ideal, but we have heard mixed views from the surgeons themselves about whether the minimum number should be three or four. Many surgeons consider that even though the on-call commitment is potentially onerous, teams of three are acceptable and safe, provided that all the other service standards are met. Surgeons tend to look after their own patients whether they are on-call or not. A number of centres currently have teams of three surgeons, and their results are good.

We have heard concerns that requiring teams of four surgeons could mean some centres would have to close. Not everyone agrees that this is the case. Other possible solutions include regional multi-centre networks with individual surgeons working as part of larger surgical teams and working across more than one centre, or managing caseloads at each centre to ensure sufficient activity. NICOR activity data for 2012/13 shows there were around 4,700[17] surgical

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[17] Procedures by NHS England providers for patients resident in England and Wales. Adult activity figure uplifted to account for underreporting

procedures carried out at NHS centres in England, on children and adults from England and Wales, and a further 250[18] on patients from elsewhere. If this work was spread evenly across the existing 10 Specialist Surgical Centres it would be close to the level of activity required to meet proposed standards at every centre. We expect activity to rise in the next few years.

Our Clinical Advisory Panel considered all the arguments and concluded that our proposed standards should require that congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year. They accepted the argument that ensuring each surgeon maintained their skills by undertaking enough operations was more important for patient outcomes than the number of surgeons in the team, but they did not think that it was best practice to have smaller teams than this. In coming to this conclusion they considered the pre-consultation discussions, the evidence from the literature review and also drew on their experience from other services and settings.

The rapid literature review[19] by ScHARR found that the evidence shows that bigger units are associated with better outcomes. The review identified a substantial number of studies reporting a positive relationship between volume and outcome. However, while many studies showed better patient outcomes with larger volumes of surgery, this was not consistent across all the studies, none were based in the UK and other inter-related factors could be affecting outcomes. The relationship was stronger in studies of single complex conditions or procedures. The evidence did not tell us the best size for a Specialist Surgical Centre. As a result our Clinical Advisory Panel told us that while the evidence was broadly supportive of the relationship between volumes and outcomes, by itself it did not provide a compelling argument for change.

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[18] Surgical procedures on patients from Scotland, Northern Ireland, Isle of Man, Channel Islands and Overseas (including Ireland)

[19] *What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services? A rapid review.* Turner at al. (2014) University of Sheffield School of Health Research and Related Studies

The Congenital Heart Services CRG advised that with increasing sub-specialisation, the number of surgeons was not the only issue. Each hospital needs to make arrangements to ensure the availability of surgeons with the required skills at all times including the ability to do surgery on new-born babies (the most frequent out of hours emergency), undertake complex congenital operations and to set up cardiac extracorporeal membrane oxygenation (ECMO). Emergencies out of hours are, however, rare.

What we are proposing

Taking all this into account, we are proposing that congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations a year (adults and/or children) averaged over a three year period. This will enable surgeons to maintain their skills and will ensure the best possible outcomes for patients.

We are also accepting the advice we received from the Clinical Advisory Panel that the standards should state that teams should be made up of a minimum of four surgeons. This would help secure consistently good outcomes; enable surgical teams to adequately cover children's and adult services (which may be located in different centres); and reduce the risks associated with fatigue.

We are clear that we would not want to see teams of four or more in a unit too small to provide them each with sufficient activity levels.

What this will mean

- Bigger surgical teams, with each surgeon doing enough operations to maintain their skills will provide greater assurance of quality.
- Teams that are better able to provide 24 hour clinical cover all year round, and be more resilient to events.
- Not all of the existing Specialist Surgical Centres currently have enough work for four surgeons each doing at least 125 operations per year.
- While we expect the number of operations being done to continue to rise, it is possible that this requirement will mean that the way services are provided will need to change.
- This might mean fewer Specialist Surgical Centres in future, but other solutions are possible including managing the case load at each centre to ensure sufficient activity or creating regional/national multi-centre networks with individual surgeons working as part of larger surgical teams and working across more than one centre.

Questions

Looking at the draft standards and draft service specifications,

Q.6 What do you think of our proposal that surgeons work in teams of at least four, each of whom undertakes at least 125 operations per year? Please explain your answer.

Focus on: Sub-specialisation

Our proposals for bigger surgical teams are intended to ensure that, in every team, the skills are available to perform most operations. Rare and complex cases would be managed either by referral to an appropriate specialist or by inviting a specialist to provide support at the patient's usual centre. However, some people have suggested that at least some centres should be bigger and that they should be designated to undertake more specialist work. We note here what we have heard, and what we are proposing, to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that the standards must ensure that congenital cardiac surgeons and consultant interventional cardiologists only undertake procedures for which they have the appropriate competence because not all cardiac surgeons and consultant interventional cardiologists are trained to perform all procedures.

Views are mixed on whether or not it would be appropriate to formally designate sub-specialist centres (so that they are identified as the ones that perform particular operations). While this would offer certainty in terms of competence and reassurance to patients, a two-tier service could result which would affect the service available in the other centres and might affect their long term future. It would also mean more longer journeys for patients.

Doctors told us that they preferred a system to ensure that support is brought in from within the network or another specialist surgical centre or to refer the patient to an alternative specialist surgical centre where a surgeon/interventional cardiologist has the appropriate skills. However, we heard that under current rules it can be very difficult for doctors to work in a hospital other than their own, especially at short notice, and that this needs to be resolved for this approach to work.

We heard that congenital heart networks have an important role to play in ensuring that:

- there is free movement of surgeons to mentor and work alongside other surgeons in difficult cases;
- the introduction of new techniques is managed appropriately; and

- there is mutual support and accountability for the way services are delivered across the network.

What we are proposing

These standards require that all congenital cardiac surgeons and consultant interventional cardiologists only undertake procedures for which they have appropriate competence. The proposals relating to the number of surgeons in a team aim to make sure that there is a suitable skill mix and that between the members of the team there are the skills and experience to deal with the great majority of surgical challenges.

The network standard (section A) sets out what needs to happen if a situation arises that the team does not have the skills or experience to deal with. In these cases:

- support needs to be sought within the network or another Specialist Surgical Centre or the patient must be referred to an alternative Specialist Surgical Centre where a surgeon/interventional cardiologist has the appropriate skills;
- arrangements for services out of hours must also meet the requirement that surgeons and cardiologists only undertake procedures for which they have appropriate competence;
- arrangements must be in place in each Specialist Surgical Centre both for consultant interventional cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases, within compliant rotas; and
- Specialist Surgical Centres and networks must work together to support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre to centre referrals.

We believe that these proposals will ensure that patients will always receive care from a doctor with the appropriate skills and so we are not proposing any formal sub-specialist designation for Specialist Surgical Centres.

What this will mean

- Patients can be assured that their care will only be provided by a doctor with the appropriate skills and training.
- Surgical teams will need to recognise competences.
- Surgeons and centres will need to work closely and collaboratively to ensure that all patients receive the best care possible.
- Networks will need to manage competence through peer review and audit.
- Networks will need to work together to ensure that surgeons can move between units to support each other as needed.

Question

Looking at the draft standards and service specifications:

Q.7 What do you think about our proposed approach to sub-specialisation?

Section C: Facilities

Section C sets out what facilities and equipment are needed to deliver care and treatment to people with CHD, to support families and carers, to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that having good facilities makes a huge difference to patient and family experience. While some of the things we heard only relate to CHD services, many do not. We have noted them all here, but do so on the understanding that they are not all in scope of the new CHD review. People told us:

- It would be helpful if hospitals provided a 'How to find us/About Us' booklet with information about where to park, eat and sleep.
- Facilities need to be welcoming and clean. They need to be age-appropriate.
- Playrooms need to be staffed so children can use them with separate facilities for young people and adults.
- Living in hospitals is expensive and can be unhealthy. There need to be facilities where people can make their own meals and shops/cafés where people can get inexpensive and nutritious food (taking into account intolerances, allergies and religious restrictions).
- Wi-Fi needs to be available at all times for patients to let them keep in touch with friends and family, for entertainment, education and work.
- Facilities need to be available for children and young people to keep up with schooling.
- Parking charges need to be reasonable or removed.
- Facilities need to be wheelchair friendly.

What we are proposing

In section C we set out what will be required in the different centres. These include standards that relate to the provision of hospital information booklets; age appropriate facilities; Wi-Fi; catering facilities; schooling; reasonable and affordable parking for long stays; and dedicated room space for therapeutic work.

What this will mean

- The proposed standards will help to ensure that networks and centres are able to offer the facilities that will improve the overall experience of patients, their families and carers.
- Patients, families and carers will be able to live more comfortably and independently in hospital.

Section D: Interdependencies

Section D sets out the relationships CHD services (children's and adults) need to have with each other and with other services to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that specialist congenital services need to work with many other services to provide good care for their patients. CHD patients often have other problems as well as CHD and so need care from many specialists, not just heart specialists. When services work together in this way they are referred to as 'interdependent'. Everyone agrees that some of these services must be on the same hospital site as the CHD service (we call this co-located) and that other services could be in a different nearby hospital as long as doctors could reliably get to the patient's bedside within a specified time. However, not everyone agrees which services must be co-located and which can be provided from another, neighbouring hospital. We heard that whether they are on the same site or not, good working relationships are important in making sure that services work well together in the patient's best interests.

Some people told us that the best way to ensure that the different teams all work closely together and respond appropriately is to have them all on one site.

As well as thinking about the links with other specialties, it is important to think about the relationship between children's cardiac services and adult CHD services. We heard that 'triple co-location' would be the ideal, that is, to have all the following services on the same site:

- children's congenital heart surgery with other specialist children's services;
- children's congenital heart services with adult congenital heart services; and
- adult congenital heart surgery with other specialist adult services.

While most people agreed that this is the ideal, there were different views about the importance of each. We heard that because of shared rotas, joint working and the need to minimise losses to follow up at transition, children's cardiac and adult CHD services need to be close to each other and work as a fully integrated service.

Most discussion was about the importance of the relationship between children's CHD services and other specialist children's services. Some people told us that while responsiveness is important, it is not the only thing that matters: daily interaction between teams is also important in building relationships and ensuring the best care. They considered that it was not safe to provide care for children with the most complex congenital heart problems in hospitals where other children's services are not on the same site because a high proportion of children with CHD have other conditions and need other services, especially neonatal patients.

Other people argued that as long as the other children's services could meet the required response times and there was the facility to carry out any necessary treatment at the Specialist Surgical Centre without moving the child, it was not necessary for all the children's services to be on the same site. They also suggested that when children's CHD services are in a children's hospital this may also mean that the relationship with adult CHD services may be less close.

We did not hear a similar debate about adult CHD services, although adults with CHD often also have other conditions.

We asked the ScHARR to look at the research on the benefits of co-location of services in relation to mortality and reducing health complications. They did not find many good studies to inform our thinking so the proposed standards are based on expert opinion, rather than research[20].

We heard that CHD patients need access to transplant and bridge to transplant services, and that demand for this was rising. We also heard that access to transplantation can be an issue for adults with CHD. Some felt that because of this it was wrong to develop standards for CHD services but not for transplant services.

We heard that the provision of cardiac ECMO is an essential part of a CHD service and that standards were needed to assure consistent quality.

What we are proposing

Taking all this into account, we are accepting the advice we received from the Clinical Advisory Panel that the standards should state that specialist children's cardiac services should only be delivered in settings where a wider range of other specialist children's services are also present on the same hospital site.

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[20] *What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services? A rapid review.* Turner et al (2014), University of Sheffield School of Health and Related Research

The Clinical Advisory Panel considered that this brought the standards for CHD services into line with expectations in other specialist children's services. This recognises the importance of multidisciplinary care for children with complex heart disease and addresses concerns about the safety of caring for children with complex conditions (a high proportion of whom will need input from other specialties) in settings without other children's services.

The standards also recognise triple co-location as the ideal, but where this is not possible, they set out which services for children and adults must be on the same site, and the required levels of responsiveness for all the services patients with CHD depend on. Our proposals aim to ensure that wherever patients receive their care, all the experts they are likely to need are on site or available very quickly.

The CRG for Heart and Lung Transplantation has developed a service specification for heart and lung transplantation for all ages, so we have not developed separate standards. As we take forward work on the other elements of the review and look at commissioning, we will consider the definition of patient pathways and referral routes for patients with CHD, who need transplant or bridge to transplant services.

Cardiac and respiratory ECMO for children's services is in scope. The work of the review on standards does not include ECMO standards. This will be taken forward separately.

What this will mean

- The standards will help to ensure that wherever patients receive their care, all the experts they are likely to need are on site or available very quickly.
- Not all current centres as presently arranged will be able to meet all the interdependency requirements: Centres will need to consider how to arrange services to ensure that they will meet these standards. The relationships between specialties and the way they work together for patients will also need to be examined.

Consultation questions

Looking at the draft standards and service specifications:

Q.8 What do you think of the proposed standards for service interdependencies and co-location?

Section E: Training and education

Section E sets out what continuing training and education all healthcare professionals involved in the care of those with CHD need to have, in order to deliver the best possible outcomes within existing resources.

What we have heard

We received little feedback specifically about ongoing training and education.

We heard that it is important that trainees are able to communicate effectively with patients, their families and carers and listen to the patient. We also heard that there are pressures on junior staff and training, particularly in smaller units.

We also heard that nurses in level 2 and 3 services need specific help to maintain their skills and knowledge because they do not see CHD patients all the time. We heard that this was less of an issue for level 2 cardiologists as they see CHD patients more frequently.

In our discussions about congenital heart networks we heard about the important role networks can play in enabling all MDT members to learn from each other.

What we are proposing

We are proposing that all centres need to ensure that all healthcare professionals involved in the care of people with CHD stay up to date through continuing training and education.

CHD networks will have an important role in promoting education and training and will be responsible for making sure that there is a formal annual training plan.

Networks will have cardiac clinical nurse educators to deliver standardised competency based training and education across the network. This will cover clinical knowledge and skills, as well as teaching, research, audit and management.

All members of cardiac medical and nursing teams will be required to complete mandatory training on end of life care, breaking bad news, and supporting families and carers through loss.

What this will mean

- The proposed standards will help to ensure that patients, families and carers will be cared for by staff who are appropriately trained in the skills needed to perform their jobs.
- Networks and centres will need to ensure that they have the right processes in place to train staff appropriately

Section F: Organisation, governance and audit

Section F sets out systems to ensure good decision making and quality improvement, including learning from local data and experience to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that the way information is collected and used varies. Some centres have more advanced systems than others - the best are being used to improve quality. We have heard that decisions on surgery and intervention need to be made by the MDT (except where they are covered by protocols) to ensure the best outcomes.

While recognising that there will always be emergencies, some people told us that they felt too many operations were cancelled at short notice.

We heard that systems for reporting adverse incidents are not clear.

We heard that there need to be stronger links between GPs, hospitals, workplaces and schools so that everyone has all the information they need in relation to the patient. Information sharing between agencies needs to be handled appropriately.

What we are proposing

We are proposing that Specialist Surgical Centres have an internal management group to coordinate service delivery and bring appropriate focus to this sensitive service.

The standards require networks to develop a robust and documented clinical governance framework that includes:

- clinical audit;
- regular network MDT meetings to discuss patient care pathways, guidelines and protocols;
- regular network meetings, to discuss mortality, morbidity and adverse incidents; and
- regular audit days that include discussion of adverse incidents and follow up action plans.

The standards require that all hospitals that perform operations or cardiology interventions on CHD patients must send information about their activity and results to the national audit run by NICOR and report on adverse incidents.

The standards set out systems to ensure that:

- networks keep up to date with new technologies and new treatments;
- networks and centres plan workforce needs;
- waiting times and cancellations are noted and acted upon; and
- audit is used to drive improvement.

What this will mean

- The proposed standards will help to ensure that patients, families and carers will benefit from clearly organised systems focused on patient care and improved outcomes.
- Patients and commissioners will be assured that the outcomes from surgery and interventional cardiology are being closely monitored at every hospital that offers this care to CHD patients.
- Networks will need to ensure that they have the right processes in place to deliver quality outcomes based on robust information and audit systems.

Section G: Research

Section G sets out a requirement for networks to have and regularly update a research strategy and research programme to deliver the best possible outcomes within existing resources.

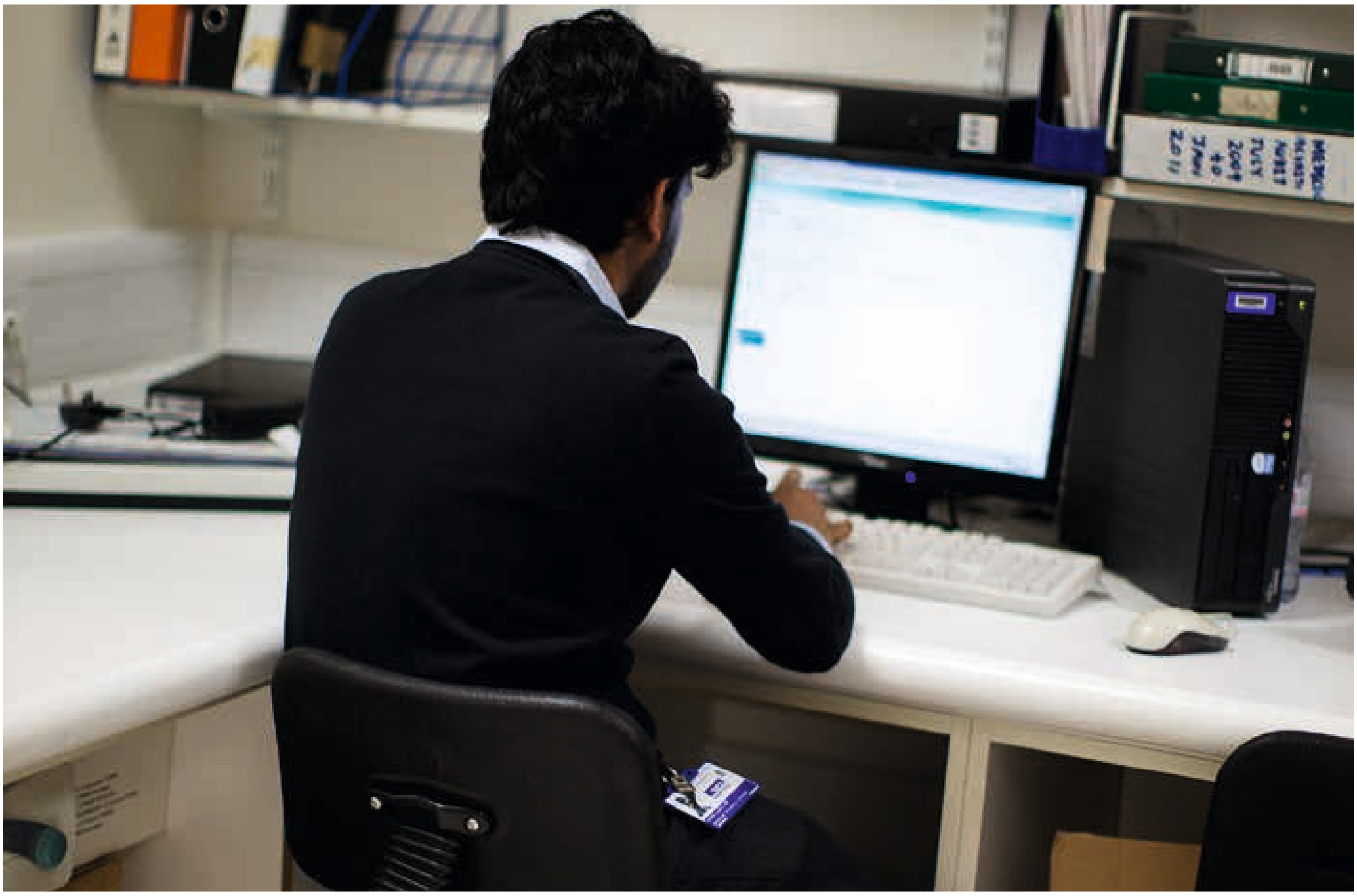
What we have heard

We have heard that many centres have close links with academic institutions.

What we are proposing

We are proposing a new commitment to research that ensures that all services are continually focused on improvement, development and innovation. Local networks will be required to have, and regularly update, a research strategy and research programme to improve clinical practice and outcomes. In addition, they will be required to demonstrate close links with one or more academic department(s) in higher education institutions.

Regional and national networks, if developed, may have a role in coordinating research.



What this will mean

- The proposed standards will help to ensure that patients, families and carers will benefit from research that adds to the understanding of CHD now and in the future.
- Networks and centres will be able to keep adding to their knowledge and understanding.

Section H: Communication with patients

Section H sets out the importance of ensuring that patients of all ages, their families and carers are able to participate actively in decision-making at every stage in their care to deliver the best possible outcomes within existing resources.

What we have heard

We have had a great deal of feedback about how important it is for staff to communicate with patients, their families and carers in a way that is sensitive and caring. We heard that patients, their families and carers want to be treated with respect and be given the information they need to make decisions.

We also heard how important it is to help patients, their families and carers deal with new experiences, explaining what is happening at all times, and providing the support needed. Research suggests that anxiety and fear can delay healing and effective communication can reduce anxiety[21].

Patients, their families and carers have told us that there needs to be a better way of sharing information across services so that they do not have to repeat their story to different health professionals.

We also heard that patients, families and carers would like information about living with CHD and what this means outside hospital.

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[21] *Costs and Benefits of Implementing a Patient Experience Strategy; Or Why Every Director of Finance Should be Investing in Patient Experience, (2012),* Patient Experience Portal available at http://patientexperienceportal.org/export/document/1056

What we are proposing

Our proposals aim to ensure that there is a renewed focus on effective and honest communication and information. The draft standards emphasise the need for two-way communication and encourage concerns and complaints to be raised and to be dealt with in an open and positive way that is followed through with the person who has raised the complaint. Patients will be supported if they request a second opinion.

The standards will require that patients, families and carers are supported to understand CHD and the effect it will have on health and future life, including social and community services; benefits; sex, contraception and pregnancy; dental care and endocarditis; and school and careers.

Our proposals would mean that patients, their families and carers are told about what is happening at all times, including what treatment is proposed – and are enabled to take part in decisions that are being made. Each patient will have an individualised care plan explaining what will happen next, the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.

Patients who are going to have surgery will be able to visit the Specialist Surgical Centre before the operation.

We propose consistent information provision so that patients, their families and carers know what different services have to offer and can make informed choices on where they will be cared for. Information needs to be available in a wide range of formats (including translation where appropriate). children's cardiac nurse specialists and adult CHD nurse specialists will liaise between the clinical team, the patient, family and carers throughout their care.

The standards also set out processes for sharing information across services (health and others). We have proposed increased sharing of information within and across centres and networks.

What this will mean

- The proposed standards will help to ensure that patients, families and carers will have a better understanding of CHD, the care provided and what the options are.
- Patients will be enabled to take part in decisions about their care. They will also be encouraged to offer feedback and complain if they need to.
- Networks and centres will work with patients, families and carers to help and support them at all times, giving them the information they need in a form that makes sense.

Section I: Transition

Section I sets out the importance of ensuring that young people can move smoothly from children's to adult CHD services in a way that respects individual circumstances and needs, to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that moving from children's services to adult services (transition) can be particularly difficult for young people. Our analysis of hospital data suggests that in 2012/13 around 1,600 patients (17%) receiving specialist inpatient care were aged 12-18[22] and are therefore in transition.

We have heard that transition needs to be planned carefully and be personalised. The time for transition will depend on the young person – some will need more support than others. Young people who have more complex needs including learning disabilities, need more support in adult CHD services as well as help to understand the health and social care systems that can be complicated.

We heard that around the age of 14 young people feel like they are stuck between the child and adult worlds. There needs to be a gradual introduction to the new staff and ward/building. Transition needs to be a time of joint-working between the children's and adult CHD services.

We have heard that there are a number of things that help young people transition well:

- dedicated transition nurses;
- transition days and meeting the new consultant and ward staff before transition;

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[22] NHS England analysis of HES data

- being able to speak to someone who has already gone through it if you want (buddy system);
- young adult clinics and teenage and young adult wards; and
- information for everyone that is clear and easy to understand and targeted specifically at young people. This could include lifestyle choices, as well as education/employment opportunities.

What we are proposing

Our proposals aim to ensure that young people and their families receive more support at this difficult time and that children's services and adult CHD services work more closely together to manage the transfer.

In section I, we propose consistent linked standards for children's and adult CHD services. All services in the local congenital heart network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult CHD cardiologists.

The standards emphasise the need for transition to be tailored to meet individual needs, but the process of transition will be started no later than age 12, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.

Approaching transition the patient will be seen at least once for consultation by an adult CHD cardiologist and an ACHD nurse specialist. Clear care plans/transition passports will be agreed and relevant records transferred. Young people, parents and carers need to be fully involved and supported in discussions about the clinical issues and the young person must be fully heard and their views considered. The particular needs of young people with learning disabilities and their parents/carers need to be considered.

What this will mean

- The proposed standards will help to ensure that young people will have the help and support they need as they grow up and move from children's into adult CHD services.
- Networks and centres will need to work together to ensure that all young people experience a seamless transition and those young people who need ongoing support and treatment continue to receive it.

Section J: Pregnancy and contraception

Section J sets out the importance of appropriate discussions about sex and family planning, starting during transition, to deliver the best possible outcomes within available resources.

What we have heard

As the care of patients with CHD has improved, pregnancy in women with CHD is becoming more commonplace, emphasising the importance of a close relationship between maternity and ACHD services, and the importance of decisions about place of delivery and the levels of CHD cardiology support available.

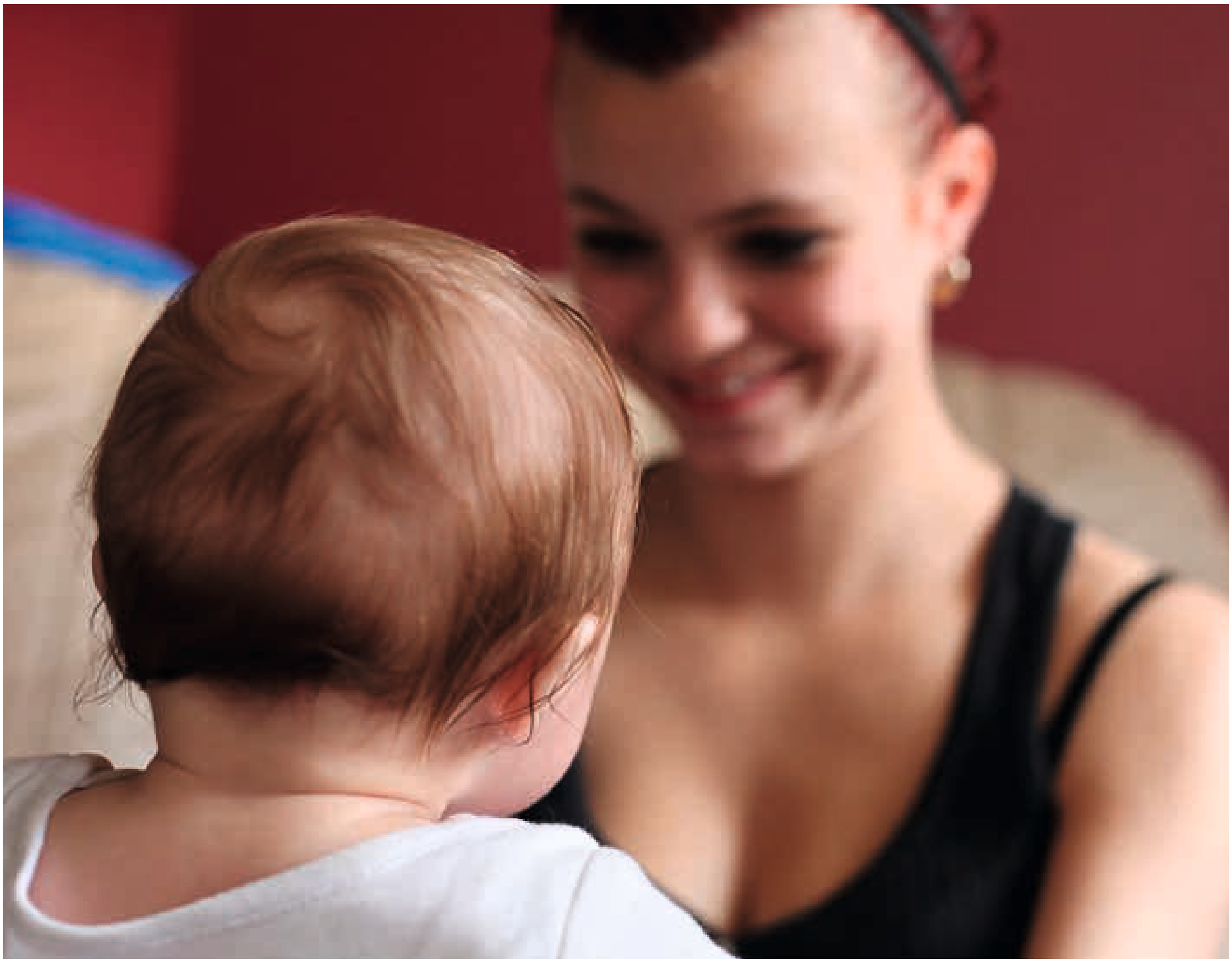
What we are proposing

In section J we propose that:

- women with CHD of child-bearing age will be given the opportunity to discuss their child-bearing potential and contraception with a consultant cardiologist and specialist nurse;
- men with CHD will also have access to, and information about, contraception and recurrence risks; and
- specialist genetic counselling will be available for those with heritable conditions.

Discussions about family planning will begin during transition (from age 12 in line with national curriculum requirements, but taking into account culture and level of understanding).

Each Specialist Surgical Centre must be linked to a specialist maternity unit staffed by a MDT. Ideally, they would be on the same site but if this is not the case, clinical advice is that the unit must be no more than 30 minutes away. They must be staffed by specialist ACHD cardiologists with expertise in pregnancy, with appropriate arrangements for cover within the centre.



Patients considering pregnancy who carry a medium/high risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with expertise in pregnancy in women with CHD. The individualised care plan must cover the antenatal and postnatal periods as well as pregnancy. It must include clear instructions for shared care with other services as needed.

Patients will be offered access to a practitioner psychologist, as appropriate, throughout family planning and pregnancy, and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment. Pregnant women with CHD must also have the opportunity for access to termination of pregnancy services.

What this will mean

- The proposed standards will help to ensure that patients will be able to make informed choices in relation to contraception, termination, pregnancy and maternity.
- Pregnant women who are at risk will be cared for in the most appropriate setting.
- Networks and centres will be able to plan services and staffing appropriately and ensure that support services are to hand in high risk pregnant women.

Section K: Fetal diagnosis

Section K aims to increase early diagnosis of CHD by ensuring that national standards are consistently applied and results reported. It also underlines the key role congenital heart networks and CHD services have in making this happen and ensuring the best possible outcomes within existing resources.

What we have heard

Early detection and diagnosis is important, but according to 2011/12 data from NICOR, only 35% of babies requiring an intervention in the first year of life were diagnosed ante-natally and this varies across the country[23].

We have heard that new standards are expected in 2015, but we have also heard that some units are struggling to meet the current requirements introduced by the Fetal Anomaly Screening Programme (FASP) in 2010 to test for CHD at 18-20 weeks.

We heard that having standards that set out the need for scans is not the full answer and that the following areas are also important:

- ongoing training for sonographers with feedback on their performance;
- a national fetal anomaly register to show performance across units; and
- more coordinated working as part of a fetal network.

We are taking a separate piece of work forward to look at what can be done alongside the standards to increase scan numbers and improve early diagnosis. This includes discussions with Public Health England

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[23] NICOR data available at: http://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument

about the development of a national congenital anomaly register.

We have heard that this is a very worrying time for parents and that everything possible needs to be done to minimise the time between the first suspicion of a problem and confirmed diagnosis. We have also heard how important it is that parents are provided with support at this time and are given all the information they need to make the best decisions. Nurse Specialists play an important role in supporting patients.

What we are proposing

The standards expect all congenital heart networks to work with all providers of maternity and paediatric cardiac services in their network to ensure that FASP and British Congenital Cardiac Association (BCCA) standards are consistently met and results reported.

Where there is a concern that a baby in the womb may have anomalies of the heart, a firm diagnosis will be made as quickly as possible and expert advice and support will be made available at this difficult time.

At diagnosis, a plan will be developed that gives information about arrangements for delivery of the baby. The plan will be updated during pregnancy. Where appropriate, the delivery will be arranged at or close to a Specialist Surgical Centre (level 1). Where the plan is for delivery at the local maternity unit, arrangements need to be put in place in case early intervention or assessment is required.

What this will mean

- The proposed standards will help to ensure that patients will receive the same high quality fetal anomaly screening wherever they live and will receive the support, care and information they need if an anomaly is suspected.
- Networks and centres will need to ensure that they are meeting FASP and BCCA standards and have the support in place for women who have a suspected or confirmed cardiac anomaly.

Section L: Palliative care and bereavement

Section L sets out how to support patients and their families when their disease is not responsive to curative or life-extending treatment.

What we have heard

We have heard that when the condition of a patient with CHD is progressive or if they are dying, patients, families and carers depend on psychological, social, spiritual and practical support at this very difficult time. Excellent and open communication is key.

We have heard that members of staff need to be trained in how to break bad news. In our discussions about bereavement and poor outcomes, we heard that the way in which this is handled is not always as sensitive as it might be.

We heard that families and staff need to be able to express grief and sadness within a supportive culture – and not one of blame/denial. Families and carers want to be able to understand what has happened and why.

What we are proposing

In section L, we describe how CHD services at all levels should support patients and families at this time with the help of other specialist teams (like palliative care, pain and bereavement specialists). The standards complement the approach of 'Priorities for Care of the Dying Person'[24].

All CHD services must be able to provide appropriate support to patients who are dying and to their families. This will include bereavement follow up and referral for ongoing emotional support of the family/carers.

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[24] *One chance to get it right: Improving people's experience of care in the last few days and hours of life* Leadership Alliance for the Care of Dying People 2014

When a patient approaches end of life, a lead doctor and named nurse will be chosen by the MDT and the patient and their family/carers. The lead doctor and named nurse will make sure that the patient and their family/carers are supported up to, and beyond death. They will also ensure that an individual end of life care plan is developed and that it is written down and agreed with all medical, nursing and psychological support team members.

A key element of these standards is the need for communication and end of life care discussions with patients and their families/carers to be open, honest and accurate.

The standards cover care in the hospital as well as the arrangements to be made if a patient wishes to be at home.

The standards also set out the support that must be given to bereaved families and carers at the time of death and afterwards.

What this will mean

- The proposed standards will help to ensure that patients, families and carers receive all the support they need at the end of life whether that be in the hospital or in the community, including at home.
- Congenital heart networks and centres will work together to agree and deliver appropriate care and support which will include care and support for families and carers after the patient's death.

Section M: Dental

Section M sets out how to ensure that CHD patients receive good dental care to deliver the best possible outcomes within existing resources.

What we have heard

We have heard that it is important for people with CHD to receive appropriate dental care because of the risk of endocarditis (infection of the lining of the heart and valves, or both) which can start as an infection of the gum.

What we are proposing

Each congenital heart network will be responsible for having a clear referral pathway for urgent dental assessments for certain patients. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.

Centres must be able to provide access to theatre facilities and appropriate anaesthetic support, or refer patients to the Specialist Surgical Centre.

What this will mean

- The proposed standards will help to ensure that patients who are at risk because of dental problems will be identified and treated.
- Networks and centres will need to ensure that they have the facilities to undertake dental surgery on CHD patients where needed.

PART 3

Introduction to the proposed service specifications

The proposed service specifications (the way in which NHS England ensures that the standards are part of its contracts with hospitals) have been developed by the Congenital Heart Services CRG[25]. Service specifications are the way in which NHS England sets out its requirements of service providers as part of its contractual arrangements. The specifications therefore sit alongside the proposed standards and are part of this consultation.

There are two draft service specifications: one covers children's services and the other, adults.

Each specification sets out how the standards link to the NHS Outcomes Framework. They explain what the standards mean in terms of overall aims and objectives of CHD services. They set out the processes that are being proposed to make this happen, as well as the number of staff being proposed. They also make links to related work.

Consultation questions

Q.9 What do you think of the proposed service specifications?

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[25] We provide information about the CHS Clinical Reference Group in the accompanying reference pack

PART 4

Delivering the standards within available resources

The aim of the new CHD review is to ensure that services achieve the highest possible quality within the available resources. As already noted, we have aimed to set out standards for services of the highest possible quality. People told us that this was important, even if it later proved necessary to make tough choices when considering how to put them into practice and what we can afford within the available resources. NHS England also has to consider the importance of investment in one service compared to another. The available resources are not open ended and it is the duty of the NHS to ensure both that it lives within its means and that it achieves the maximum value for every pound it spends. This is considered fully in the financial impact assessment.

Activity

If recent trends continue it is expected that, whether or not new standards are introduced, activity will increase and, therefore, spending by commissioners, and income to hospitals, can be expected to increase.

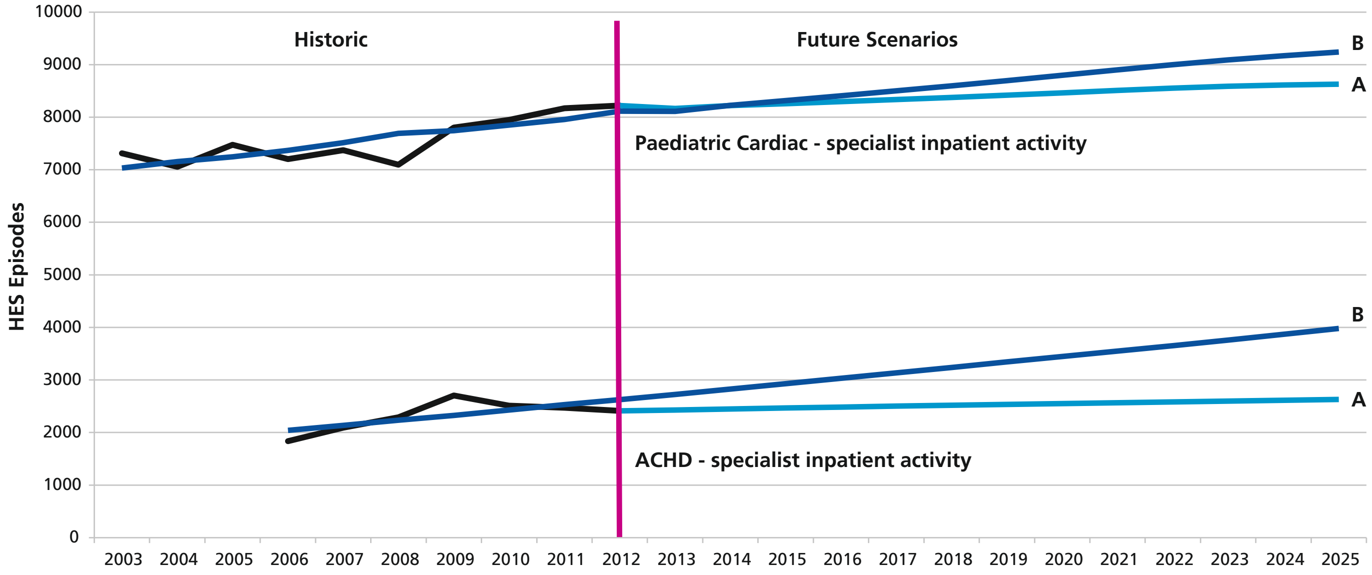
Figure 4 shows possible scenarios for future activity growth for paediatric cardiac and ACHD specialist inpatient care; Scenario A takes account of population growth only, Scenario B considers population growth and also assumes that activity per head will continue to increase as it has in the past.

This suggests that we should plan for between 0.4% and 1% more activity in paediatric cardiac services and between 0.7% and 4% more activity in adult CHD services each year. The cumulative effect of annual increases like this would be considerable. Using these levels would mean that by 2025 there would have been an increase in activity between 5% and 14% in children's cardiac services and between 10% and 67% in adult CHD services.

Cost and funding

It is clear that we face a challenging financial situation and everyone involved in CHD services will need to work together to deliver high quality care within the resources available to us. The work we have done to assess the financial impact of the proposed standards suggests that for CHD this is possible.

Figure 4: Historic and future specialist inpatient activity for paediatric cardiac and ACHD services



For the majority of these services hospitals are paid by commissioners using the national tariff (price) per unit of activity. Within this price is some funding for investment in services. Therefore, as activity rises more funding becomes available for further investment. The new standards set out how this money should be spent rather than requiring specific funding of their own.

We expect the costs of providing the service to the new standards to be met from the additional funding hospitals receive as activity levels increase, without causing the current price paid per unit of activity (tariff) to rise. This is because some of the costs of meeting the standards, particularly those arising from additional consultant surgeons, are directly linked to activity and so will only rise if there is enough activity to justify it. Further, many of the requirements are already included in the current paediatric cardiac service specification so they are considered to be reflected in the existing tariff paid. We also know some providers are already meeting the standards within the current tariff paid by commissioners so it can be achieved.

Our finance impact assessment gives further consideration to other ways of managing costs while still ensuring that the standards are achieved.

Benefits

In considering whether any increased costs represent good value it is important to consider what benefits come from the higher spending. Introducing the standards ensures that the NHS delivers higher quality and not just more activity.

There will be wide-ranging benefits for patients, their families, NHS England and other commissioners, and also to provider organisations.

The new standards will reduce variation and improve quality of care because:

- the standards define excellent care which is not currently being delivered consistently;
- commissioners will have a means of contracting with providers on a consistent basis across the country;
- the standards will be clear, defined and credible enabling commissioners to take action where they are not being met;
- occasional practice will be eliminated thereby addressing an obvious risk to patient safety;
- providers will have clarity about the requirements of them, and after 14 years of service review this

will enable them to plan for the future and direct investment appropriately;

- relationships between providers will be improved by working as part of formal managed networks and will enable shared learning and peer review; and
- patients and their families will know what they should expect from their care and be empowered to raise questions and/or to exercise patient choice.

As a result of reduced variation and improved quality of care from adopting the new standards we expect:

- improvements in health outcomes and patient experience;
- patients, their families and the public will be assured that the care they receive will be of a consistently high quality wherever they live in England;
- commissioners will be assured of the quality of care and that additional expenditure for increased activity will be directed to services of increasing quality and not just quantity; and
- providers will reduce their risk of litigation, see fewer complaints and resource consuming investigations.

Consultation questions

Q.10 To ensure that we work within the available resources, difficult decisions may need to be made. What parts of our proposals matter most to you?

PART 5

Making it happen

Preparing for change

Once the new specifications are agreed, we expect to develop the business case for change to set out what we intend to commission and how we will do this. It will bring together all of the work of the review to set out:

- the assessment of need;
- the clinical priorities;
- what service users and carers want;
- the final standards and specifications;
- the resources needed to deliver the new service; and
- the benefits that will be delivered by the new service.

As with any other service, we would expect to prepare a technical document called "commissioning intentions," to explain to current and any potential new providers how we intend to shape the healthcare system for CHD that serves the population of England. As part of this work we will consider the best approach to commissioning and how long contracts should be awarded for.[26] The business case

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[26] Technical note: NHS England will consider the right combination of commissioning tools to deliver the improvements required by the service specifications, ranging from at one end of the spectrum disinvestment and contract penalties if services fail to meet specifications, to positive financial incentives for providers such as CQUINs (commissioning for quality and innovation payments) through to a full procurement exercise which gives both existing and new providers the opportunity to create innovative solutions to solve operational challenges.

and commissioning intentions will be agreed by the NHS England board.

The "commissioning intentions" document will provide the opportunity to work with providers, and for innovative solutions to emerge that meet the requirements of the new specifications to improve patient outcomes and experience, within the fixed resources available. To support patient-centred care, we shall be working with our own area teams, local clinical commissioners, partner NHS bodies and Local Authorities to ensure that emerging solutions have wide ownership and commitment. In the standards we have tried to specify what is required without being prescriptive about how hospitals do this. Similarly, in commissioning we will encourage innovative and flexible approaches provided that they meet our requirement of delivering the service improvements required. We will seek to encourage collaboration and encourage learning through national congenital heart networks and international partnership. We will also consider the options that may arise from Sir David Dalton's review of hospital organisational models and the NHS five year forward view.

Tough choices may be involved if it seems that the best possible outcomes would require significant changes to the way the service is configured. It would then be necessary to consider whether the evidence was strong enough to suggest that the benefits to be gained would outweigh the risks of change – the upheaval, the cost, the upset, specialist care delivered further from some patients' homes, the risk of destabilising some units or other services linked to or dependent upon CHD services. At this stage it is not clear that change of this type will be needed. There may be ways for providers to meet the standards without major reconfiguration.

Commissioning the new services

Once the appropriate approach has been agreed, we expect that NHS England will work with clinical commissioners to complete the commissioning of the agreed service specification during 2015/16 and award contracts to the successful providers for delivery in 2016/17. There may need to be a period of transition during which the changes are supported and co-ordinated at a national level. However, it should be noted that many of the service improvements required to meet the new standards are already beginning to happen as a result of the work undertaken to date and that this work can and should continue.

Making sure the standards are met

Agreeing and publishing the final standards and making them a contractual requirement through the service specification will be the first step in ensuring that the standards are met. NHS England is also developing a quality dashboard, through the Congenital Heart Services CRG, which will, for the first time, bring together a range of measures that allow commissioners to monitor the service provided. This will also be a key tool for networks in their role of improving outcomes. The review will do more work to ensure that the right information is available to commissioners and to service users. The standards also propose a system of inter-unit peer review where each centre will be required to provide evidence to show that it meets the standards.

Commissioning, networks, better information about the quality of services and peer review are the corner stones of our approach to quality improvement and ensuring that the standards are met. The NHS also has systems in place to deal with concerns relating to individual cases or services, and for regulation to address potential and actual quality and service failures.

Consultation questions

Q.11 Do you have any comments on the range of approaches proposed to ensure that the standards are being met by every hospital providing CHD care?

PART 6

What happens next?

Consultation

This document launches a consultation on draft standards and service specifications for CHD services in England for children and adults, which begins on 15 September 2014. The closing date for the consultation is 5pm on 8 December 2014.

The consultation is being run in accordance with the Cabinet Office guidance **https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255180/Consultation-Principles-Oct-2013.pdf**

The consultation is open to everyone. While our focus is on services for patients resident in England, we recognise that there are children and adults living in Wales, Scotland and Northern Ireland who use CHD services in England. We have agreed with our colleagues in the other countries that they will make people aware of this consultation. We welcome all responses and will make the other health services aware of the responses we get from their countries.

During consultation we will run a number of regional events to raise awareness of the standards and to provide an opportunity for discussion. We will also support charities, patient groups, clinicians and provider units to run their own events through the provision of materials etc.

To find out where and when your nearest event will be held please refer to the new CHD review website at **http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/**

There is a full list of the questions we are asking in Annex A.

You can respond to this consultation online at: **https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards**

Alternatively you can send your response to: **CHDconsultation@dialoguebydesign.co.uk**; or

Dialogue by Design
252B Grays Inn Road
London
WC1X 8XG

Dialogue by Design are an independent organisation who are providing expert analysis of the responses to this consultation for NHS England.

When you are replying, please let us know whether you are replying as an individual or whether you are representing the views of an organisation. If you are replying on behalf of an organisation, please make it clear who the organisation represents, and where appropriate, how the views of members were assembled.

Hard copies of the consultation document and response form are available by contacting **england.congenitalheart@nhs.net**. We have also produced a video version that explains the main elements which can be found on NHS England's YouTube channel. **http://www.youtube.com/user/TheNHSEngland**

The consultation coordinator is Michael Wilson, Programme Director. If you have any queries or complaints on the consultation process, please write to him at:

New Congenital Heart Disease Review Team (5th Floor)
NHS England
Quarry House
Quarry Hill
Leeds
West Yorkshire
LS2 7UE

or by emailing:
england.congenitalheart@nhs.net

Once consultation ends

We are asking an independent company (Dialogue by Design) to collate all the responses and to produce an analysis of what respondents have said. The analysis will be published in due course and will include information about the number, type and other characteristics of the responses giving us a good picture of the views expressed. But it is important to note that the consultation is not a vote. NHS England will consider all the responses to the consultation and where appropriate will amend the draft standards and specifications. These will then be agreed through the relevant committees and approved by our Board.

Annex A: Consultation questions

STATEMENT

In order to help us analyse and consider all responses as quickly as possible, we are asking you to consider limiting the length of your responses. We are grateful for your understanding.

The aims of the new CHD review are to ensure:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for a better quality of life for survivors
- that variation is tackled so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care;
- excellent patient experience is delivered, which includes how information is provided to patients and their families and consideration of access and support for families when they have to be away from home

1. Will the draft standards and service specifications meet these aims?

   Strongly agree
   Agree
   Neither agree nor disagree
   Disagree
   Strongly disagree
   Don’t know

   Please explain your answer

Model of care

2. What do you think of the model of care that we are proposing?

3. What do you think about our proposals for level 2 Specialist Cardiology Centres?

Networks (Section A)

4. What do you think of our proposals for the development of networks?

Staffing and skills (Section B)

5. What do you think of our proposals for staffing CHD services?

6. What do you think of our proposal that surgeons work in teams of at least four, each of whom undertakes at least 125 operations per year? Please explain your answer

7. What do you think about our proposed approach to sub-specialisation?

Interdependencies (Section D)

8. What do you think of the proposed standards for service interdependencies and co-location?

Introduction to the proposed service specifications (Part 3)

9. What do you think of the proposed service specifications.

Delivering the standards within existing resources (Part 4)

10. To ensure that we work within the available resources, difficult decisions may need to be made. What parts of our proposals matter most to you?

Making it happen (Part 5)

11. Do you have any comments on the range of approaches proposed to ensure that the standards are being met by every hospital providing CHD care?

Any other thoughts

12. Is there anything else that you want to tell us or to ask us to consider? If your comments relate to a particular standard or section please specify which you are referring to.