ITEM 7

NORTH YORKSHIRE COUNTY COUNCIL

SCRUTINY OF HEALTH COMMITTEE

8 April 2011

National Review of Children's Congenital Heart Services in England

Purpose of Report

1. This report provides an opportunity for the Committee to be updated on the national review of Children's Congenital Heart Services in England.

Background

2. In 2008 the NHS Medical Director requested a review of Children's Congenital Heart Services in England. The aim of the review was to develop and bring forward recommendations for a Safe and Sustainable national service that has:
    - better results in surgical centres with fewer deaths and complications following surgery;
    - better, more accessible assessment services and follow up treatment delivered within regional and local networks;
    - reduced waiting times and fewer cancelled operations
    - improved communication between parents/guardians and all of the services in the network that see their child;
    - better training for surgeons and their teams to ensure the service is sustainable for the future;
    - a trained workforce of experts in the care and treatment of children and young people with congenital heart disease;
    - surgical centres at the forefront of modern working practices and new technologies that are leaders in research and development;
    - a network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network.

3. On behalf of the ten Specialised Commissioning Groups in England, and their constituent local Primary Care Trusts, the Safe and Sustainable review team (at NHS Specialised Services) is now managing the review process.

4. "The Need for Change" and the latest briefing paper are enclosed for your information as APPENDICES 1 and 2 respectively.

5. Why just two centres in the north?

    "Northern England (defined as Newcastle, Liverpool and Leeds centres) needs 2 centres as there are not enough patients to ensure all 3 achieve the 400 procedure minimum. These 2 should either be Liverpool and Newcastle or

Liverpool and Leeds as Newcastle and Leeds cannot achieve the 400 minimum each while maintaining strong networks and access times."

6. The patient flows from areas with a post code within North Yorkshire are attached as APPENDIX 3.

7. The proposed options have a special significance for North Yorkshire. 3 of the 4 options retain the Freeman Hospital (FH), Newcastle but not the Leeds General Infirmary (LGI). However, in the 4th option this is reversed - the LGI is retained but the FH in Newcastle is not retained.

Joint Health Overview and Scrutiny Committees

8. In cases where an NHS body consults more than one health overview and scrutiny committee (OSC) because its proposals affect the residents of each of their areas, those health OSCs that consider the proposals to be "substantial" are required to form a joint committee to deal with the consultation and respond on behalf of their communities.

9. Across the country Joint Health Overview and Scrutiny Committees are being established in each region to examine the proposals. The Yorkshire and Humber Joint Committee which comprises one member from each of the local authorities in this region and is attended by your Chairman, County Councillor Jim Clark met on Tuesday 29 March 2011. Councillor Clark will give a verbal update from that meeting.

Recommendation

10. That Members:

    a) Consider the proposals in this consultation and that the Committee's views be reported to both the Yorkshire and Humber Joint OSC and the North East Joint OSC.

    b) Confirm County Councillor Jim Clark as the representative from the North Yorkshire Scrutiny of Health Committee on the Yorkshire and the Humber Joint Health Overview and Scrutiny Committee.

Bryon Hunter
Scrutiny Team Leader
County Hall, NORTHALLERTON

Author and Presenter of Report: Bryon Hunter
Contact Details: Tel: 01609 532898
E-mail: bryon.hunter@northyorks.gov.uk
29 March 2011

Background Documents: None

APPENDIX 1

Safe and Sustainable
Childrens Heart Surgery in England

Children's Heart Surgery

The Need for Change

April 2010

Setting the scene

Having the best and safest surgery in the NHS for children's heart conditions has to strike a balance between services that are close to home and services with enough specialist expertise to allow the highest standards of care.

Heart surgery for children is complex and becoming even more sophisticated. The NHS is looking at the best way to ensure that:

- Each surgical team does an adequate number of operations a year to achieve the best results
- Units have enough volume of work to train the next generation of surgeons
- There are enough surgeons for proper team working and to provide specialist out of hours care.

This document makes it clear that to sustain current levels of care and to do even better in the future, surgeons treating heart conditions in babies and children must be concentrated in fewer, bigger centres.

As a parent of a child with a heart condition it is vital that your views are heard as this decision will affect not just your family but also many other families going through a similar experience in years to come. As surgeons, our job is to provide the very best quality surgery we can. The key decision is whether you accept the case for having to travel further to get a better service. We do not underestimate the difficulties you will have to face.

John Black
President, The Royal College of Surgeons of England

On behalf of children and families, it is important that the National Health Service reviews the appropriate number of centres for children's heart surgery in England. As technology advances and procedures become more sophisticated, it is sensible to review the size and number of centres performing children's heart surgery. A significant risk with smaller centres with fewer staff is that there may be times when cardiac surgery teams are not available. Furthermore, smaller centres may not see the same volume and variety of caseload that colleagues in a larger centre will see. What does this mean and does it matter? It means that children's cardiac surgery services need to be planned to give the best possible results for children and their families in England. Children's heart surgery is extremely complex and demanding and requires very specialist surgeons and support staff with a great deal of technological support. 'The Need for Change' document reviews how children's heart surgery services are currently provided in England and suggests new ways to deliver these services so that all children have equal access to the highest standards of care.

Professor Terence Stephenson
President, Royal College of Paediatrics and Child Health

Delivering a world class service

Safe, sustainable and world class. Not ordinary, OK or just good enough. Children and young people who need heart surgery must have excellent care.

Children's heart surgery services need to be planned and delivered to give the best possible results for critically ill babies, children and young people. Performing heart surgery on such young patients is incredibly complex and requires great technical skill. This is a highly specialised area and is becoming even more so with modern surgical skills and technology.

There are now 31 surgeons in 11 hospitals in England performing around 3,600 heart surgery procedures for children every year. The services were pioneered in a number of areas by talented and dedicated surgeons, but they were developed on an ad-hoc basis.

We need a planned and co-ordinated approach for England. This 'Need for Change' document explains how children's heart surgery services are provided at the moment and outlines how we can improve them so that all children have equal access to the same high standards of care.

By creating fewer, larger centres, while strengthening arrangements for non surgical services locally, we can deliver the best possible care for children who need heart surgery.

"Paediatric cardiac surgery is complex and demanding. It requires very specialist and highly technological support. If a child of mine needed a complex heart operation I would want the operation to be performed in a centre that regularly performed the procedure. We currently have too many hospitals offering heart surgery to children. We need fewer centres so that children are only treated by surgeons supported by skilled and experienced staff. We must put the interests of children first. If we don't address this issue we will put some of the most critically ill children at risk and fail in our duty to ensure these NHS services are fit for the future."

Professor Sir Bruce Keogh
NHS Medical Director

"The time for change is now. Concentrating heart surgery for children in fewer, larger centres is in the best interests of children, young people and their families. This approach will ensure we have experienced surgical teams that are used to performing these highly complex operations. Having larger centres will help avoid unnecessary cancellations and reduce the risk of services being suspended."

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

About Safe and Sustainable

In 2006 a panel of experts agreed that the current layout of services in England was unsustainable and recommended fewer, larger centres of excellence delivering the best possible care for children and their families. This was also the view of the Royal College of Surgeons which recommended in 2007 that 'there should be fewer but larger paediatric cardiac surgery services'. The NHS Medical Director has asked the NHS to respond to these conclusions by delivering recommendations for a safe and sustainable children's heart surgery service.

The job of the National Specialised Commissioning Group (NSCG) is to make sure that heart surgery services deliver the best possible results for today's children and for the children of tomorrow.

We have called this process Safe and Sustainable. Our work is being guided by four key principles:

- **High standards.** All children in England who need heart surgery must receive the very highest standards of NHS care, regardless of where they live or which hospital provides their care
- **Personal service.** The care that every centre provides must be based around the needs of each child and family
- **Local where possible.** Other than surgery and interventional procedures all relevant treatment should be provided as close as possible to where each family lives
- **Quality.** Standards are being developed and must be met to ensure that services deliver the best care.

This process is now well underway with changes expected in 2011.

"The Society for Cardiothoracic Surgery strongly supports the current review of children's heart surgery in England. We do not believe that the current system, which depends on a small number of surgeons in each centre, is sustainable. We believe that in order to provide a high quality, safe and sustainable service in the future surgical expertise must be concentrated in fewer larger centres. Only by doing this can we ensure that every child who needs heart surgery, regardless of where they live, has access to a high quality service that can perform the full range of specialist complex procedures 24 hours a day, 7 days a week. We believe that larger centres of expertise will deliver a better service for children and their families and will deliver the best clinical outcomes."

Mr Leslie Hamilton
President of the Society for Cardiothoracic Surgery in Great Britain and Ireland

Why do we need change?

What sounds better; having a critically ill child needing heart surgery treated by a surgical team that regularly performs heart surgery on young people? Or using a surgical team that only occasionally carries out the same complex operation for the same age group?

At the moment professional experts are concerned that some centres cannot provide the best possible service. Some centres cannot provide 24/7 care and some are not seeing a wide enough range of heart surgery cases. Experts agree that hospitals with teams that regularly perform a larger range of complex heart operations tend to have the best results. We want to ensure that our surgeons' expertise in children's heart surgery is the best it can be across England.

The current two-tier system has developed on an unplanned basis with 11 centres, both large and small. This is unsatisfactory because the centres are unable to offer the same range of services or the same levels of expertise within their medical and nursing teams.

The need for larger centres

Of the 11 heart surgery centres in England, four have two or fewer paediatric surgeons. This means that in some centres there will be times when a surgeon is not available to deal with routine cases or with emergencies. We need enough surgeons in each centre to meet the day-to-day demands of performing operations in theatre, being on call to respond to emergencies, doing ward rounds and holding outpatient clinics as well as the other core services that parents and children expect.

Fast facts

- Experts in the field are calling for change
- Some centres cannot provide appropriate 24/7 care
- There is too much variation in the expertise available from centres
- Having a varied case load means larger centres are best placed to recruit new surgeons and plan for the future

"We believe that concentrating clinical expertise for complex conditions in the right number of centres to meet the national caseload is vital for the best clinical outcomes. We support Safe and Sustainable in ensuring that children with congenital heart problems receive the best possible care from the best expert teams."

John Murray
Director, Specialised Healthcare Alliance

Limitations of smaller centres

Put simply, we believe that smaller teams have disadvantages for children and their families.

For example, surgeons and their teams need to deal with a sufficient volume and range of complex operations if they are to offer a truly excellent and comprehensive service.

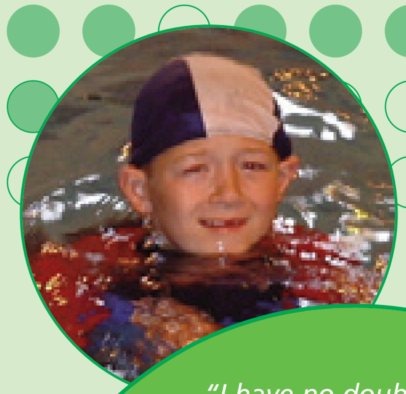
If surgeons are not available for ward rounds or to respond to emergencies, post operative care can be affected. We can't predict when emergencies will occur, but we know that it isn't possible to provide safe 24/7 care unless each hospital has enough surgeons.

Nor can we deliver an excellent service if surgeons don't have time to take part in case conferences and team meetings or to provide support to colleagues giving other specialist treatment to a child. We need surgeons to be available to meet parents well before planned surgery and we need them to have long enough to answer all the questions parents might ask.

As well as being involved in how their service is managed, surgeons also have research and development interests. How will they do all of this without the support of a larger team?

Planning for the future is also more difficult for smaller centres. We know that they can struggle to recruit and retain new surgeons who want to work in larger teams with a greater volume and range of operations.

Sometimes operations have to be cancelled on the day that they were planned. This can be very distressing for children, who will not have eaten because of surgery, and to their parents who will have taken time off work. The risk of having elective surgery cancelled on the planned day of operation currently ranges from less than 1% to 10% across the 11 centres. We have developed new standards that aim to reduce the incidence of cancelled elective operations to less than 1% across all of the centres.



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

Professor Roger Boyle CBE
National Director for Heart Disease and Stroke

A parent's experience

Theo's story – as told by Willow Langdale-Smith

"We've had just about every service going. The NHS needs to give us a 'joined up' service so that all the doctors and nurses who see our children know what to do. They need to communicate better with each other and with us parents and they need to provide us with a better and more accessible local service for all of the non-surgical treatment our children need.

One time, the paramedics came out to deal with Theo when he had respiratory problems. We wanted reassurance but they didn't have the right piece of equipment so we had to go to hospital and wait in Admissions for six hours.

Most of the time the GP service just isn't sufficient – they take one look at Theo's notes and medicine list and freak out. We're expected to come into hospital for assessment and frequently admission, even for simple things like sickness and diarrhoea.

I called a GP out once soon after Theo's discharge. The GP didn't understand how the Nippy ventilator worked and asked me about it. I was amazed that a child could be sent into the community and the family expected to cope when even the local GP practice could not have cared for him.

If the Safe and Sustainable review can give us a joined up service that makes it easier for our children to get the best care from all of the professionals that see our children, including doctors and nurses in the local hospitals and in the community, then I think it's a fantastic opportunity not to be missed."

"The majority of parents recognise that paediatric cardiac surgery is a specialist service that is best delivered on a national basis. So they support the concept of larger, but fewer centres of excellence and are willing to travel substantial distances for their child's surgery. Indeed, many are already travelling considerable distances. However, there are a number of parents who live close to a surgical centre and so experience their service as local and it is important that their views are understood."

Anne Keatley-Clarke
Chief Executive,
Children's Heart Federation

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

Dr Ian A Jenkins
President, Paediatric Intensive Care Society

How large should centres be?

Four is the magic number. The Royal College of Surgeons and other professional bodies believe that in the future a children's heart surgery centre should have a minimum of four full-time surgeons. This means they can cover theatre, emergency admissions, outpatient clinics and ward rounds. Naturally, it makes sense to plan for surgeons' holidays and periods of unplanned leave as well as their other responsibilities such as research and education.

At the moment we have 31 surgeons working in 11 centres. The surgeons are spread too thinly. The number of children needing heart surgery every year is about the same. In 2007/08 and 2008/09 the number of surgical procedures in England was around 3600 each year. The numbers are static and we do not expect them to increase significantly. So why don't we simply employ more surgeons? Unfortunately, increasing the national pool of surgeons to 44 would not solve the problem. Instead, it would result in more surgeons performing even fewer operations at each unit and we would expect the quality of the service to go downhill.

For too long we have relied on the goodwill of some surgeons, especially those working without other surgeons or in very small teams. We need to ensure that services are safe and sustainable for the long term. Having larger teams means we can eliminate the problem of the same surgeon working and being on call 24/7.

Working in a team of surgeons also provides professional support and allows senior surgeons to train and mentor junior surgeons. Surgeons should learn from each other. We also need to think about the next generation of surgeons so that the services are sustainable in the years to come. Working in teams exposes junior surgeons to the full range of surgical techniques necessary to deal with the complex and varied caseload of congenital heart disease. We need to make sure the service we deliver is fit for the future.

Safe and Sustainable has worked with professionals, parents and other experts to agree minimum standards that a children's heart surgery centre must meet in order to be designated as a specialist surgical centre.

"All of the reports since the Bristol Inquiry have identified restructuring tertiary congenital heart disease services into smaller numbers of higher volume centres as an essential pre-requisite to providing world class care for patients born with heart problems. The BCCA wholeheartedly supports the argument for properly funded and considered restructuring of congenital cardiac services not only to improve care for these patients but also to provide sustainable services in the longer term."

Dr Shakeel A Qureshi
President, British Congenital Cardiac Association

What will change look like?

The location of these children's heart surgery centres cannot be 'local' to all people in England. But, services that don't involve surgery or interventional procedures can be provided more locally. Our vision is a network of linked hospitals working together, pooling expertise and experience to ensure the best results for children and young people.

All children who need heart surgery or interventional procedures will be referred to a Specialist Surgical Centre (SSC). For some children, these centres are relatively near their home and so it will also be possible to be assessed and receive follow up care there.

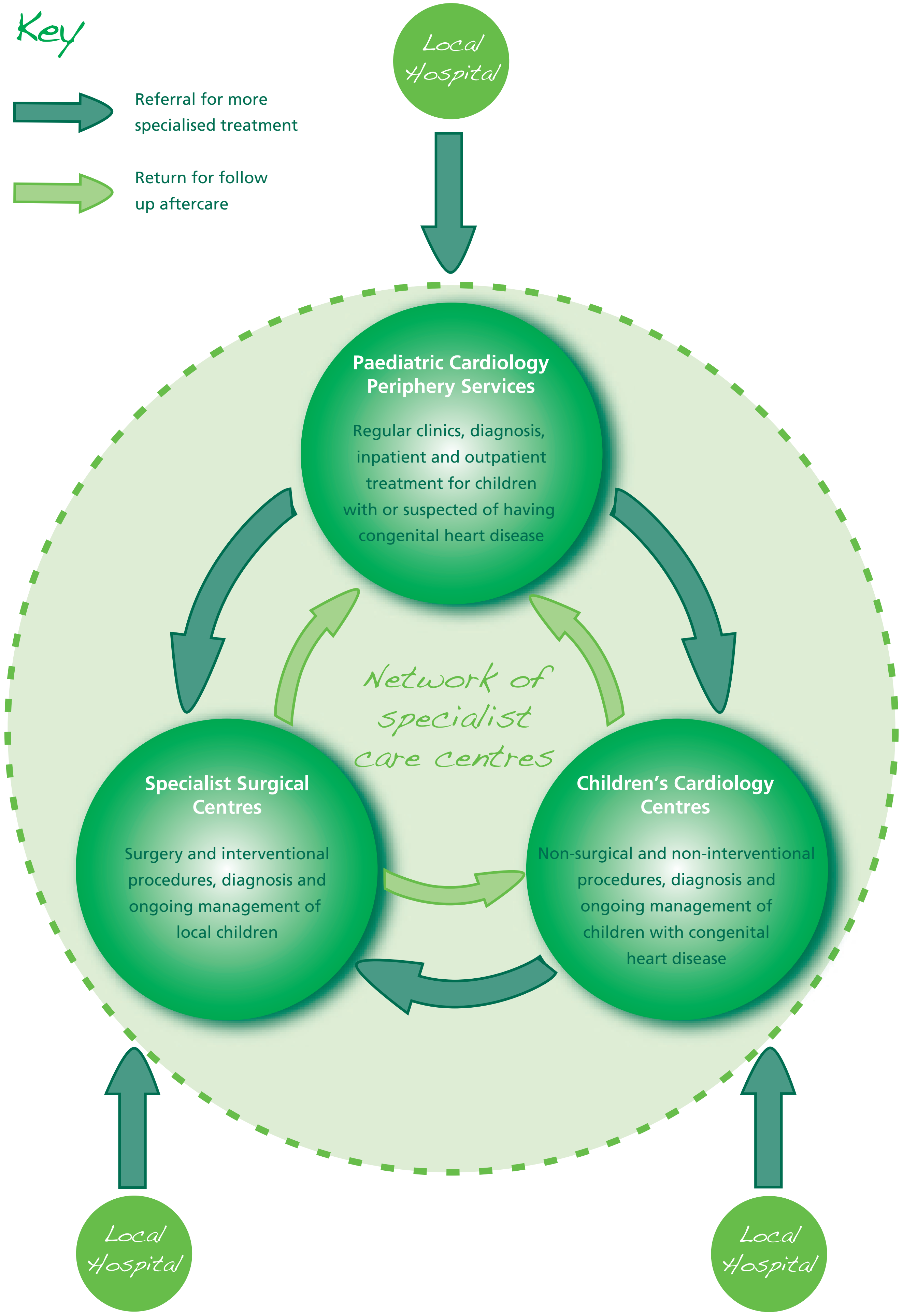
Some of the 11 centres now performing surgery and interventional procedures will stop performing operations and will become Children's Cardiology Centres (CCCs). Some children who don't need surgery will be treated in these centres. These centres will have experienced children's cardiologists who can perform non-interventional procedures and provide ongoing management of children with congenital heart disease. CCCs will team up with SSCs for combined clinics.

Paediatric Cardiology Periphery Services (PCPS) will be available in some local hospitals. The team will include a consultant paediatrician with expertise in children's cardiology. There will be a named consultant paediatric cardiologist from the CCC so that combined clinics are held regularly at the PCPS.

Children with suspected congenital heart disease will initially be referred to the PCPS where inpatient and outpatient treatment can be performed. When a higher level of expertise is needed children will be referred to the PCC or SSC.

The new model aims to deliver better and more consistent care for children and young people with heart disease. Continual review will ensure it provides the best care and support for parents and their children.

> *"On top of cardiac problems, many of these children have other complex conditions as well. That is why it is vital to have experienced and highly trained teams of nurses and surgeons. The RCN supports the idea of having fewer centres with more staff. This is the right way to retain people's experience and skills, and ensure better outcomes for children and young people."*
>
> Fiona Smith
> **Adviser in Children and Young People's Nursing, Royal College of Nursing**



Referral for more specialised treatment

Return for follow up aftercare

Paediatric Cardiology Periphery Services

Regular clinics, diagnosis, inpatient and outpatient treatment for children with or suspected of having congenital heart disease

Specialist Surgical Centres

Surgery and interventional procedures, diagnosis and ongoing management of local children

Children's Cardiology Centres

Non-surgical and non-interventional procedures, diagnosis and ongoing management of children with congenital heart disease

Benefits of the new service

We believe that a new national service will bring benefits for children and their families including:

- Better results in the surgical centres with fewer deaths and complications following surgery
- Better, more accessible diagnostic services and follow up treatment delivered within regional and local networks
- Improved communication between parents and all of the services in the network that see their child
- Better training for surgeons and their teams to ensure the sustainability of the service.

Delivering services in this way gives children better access to the right services at any time of day or night.

Our new standards ensure that the Specialist Children’s Cardiac Nurse and liaison team roles will be strengthened, improving communications with parents. Other support services such as clinical psychology and counselling will also be improved and there will be arrangements for an appropriate transition to adult services.

As a result we will have:

- A trained workforce expert in the care and treatment of children and young people with congenital heart disease
- Centres at the forefront of modern working practices and innovative technologies that are leaders in research and development
- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network.

An important indicator of the quality of care provided by a centre is the number of complications experienced by children after surgery. Currently this information, called morbidity data, is not routinely analysed. But it will be in the future, and it will be shared with parents and the public. Having larger centres will mean that we can more easily understand what the morbidity data is telling us and we will have a much better understanding of the overall quality of care in each centre.

Any questions?

What will it mean for parents who will now have to travel further?

All non-surgical and non interventional care will be provided as locally as possible. Children who need care before and after surgery will go to a local centre. We understand the concerns some parents have about travelling further when their children have heart surgery. We are trying to address these concerns by developing new standards around facilities for parents and families at the hospital. However, experts including many parents of children who have received heart surgery believe that the benefits outweigh the inconvenience. It makes good sense to travel further to ensure critically ill children receive the best possible care.

Will some staff have to relocate?

Yes, it is likely that a small number of staff will need to re-locate. We know that some of the smaller centres are having problems recruiting and retaining surgeons. It is important that we put the needs of children before the convenience of NHS staff. The hospitals that stop carrying out heart surgery will still need specialist staff as they will work within a NHS network for children with heart conditions. The NHS will put systems in place to help re-location where necessary.

Can you produce outcome data to prove that a centre should be stopped from performing surgery?

This is not possible because the volume of surgical procedures in centres is too low to enable a meaningful analysis of outcome data. So, while the available outcome data does not suggest that any centre is currently ‘unsafe’ neither does it provide us with a complete assurance that all centres are currently operating within safe limits. By creating larger centres with larger caseloads, a more meaningful analysis of outcome data will be possible in the future so that parents may be completely assured about safety and quality.

So, how we can be sure that centres are currently safe?

Existing governance and commissioning arrangements will alert NHS commissioners to any concerns about individual centres that may require immediate attention.

Is this about cost cutting?

No. We don’t anticipate cost savings from this process. Some additional money may be required to expand some centres. This is about ensuring that all children have equal access to heart surgery services and that those services are as safe and sustainable as possible. Larger services will result in more highly qualified staff which will improve quality.

If my local centre is not selected to continue providing surgery, does this mean I am going to lose the service completely?

No, the centre will continue to provide non-surgical services and these will be strengthened.

The service my child has received has always been excellent. If it ain’t broke, don’t fix it. Why bother meddling with the structure of the service?

Two previous reviews led by Sir Ian Kennedy and James Monro have recommended changes. The structure of the current service has developed on an ad hoc basis. True, many children have received excellent care. But, we should not settle for anything other than the best. Most experts agree that we need to act now to ensure the service is safe and sustainable for the long term.

Will it mean less chance of last minute cancellations?

Yes. Having larger centres with larger teams and better facilities in each will mean that there is much less chance of operations being cancelled.

What are the risks of reconfiguring the services?

There are some risks which need to be managed very carefully, for example, the possible knock on effect to other services if children’s heart surgery is removed from a hospital. The NHS is used to dealing with these issues and can help minimise these risks.

How can I give you my feedback?

We are very keen to get feedback. We will be organising a series of events to talk to parents and young people about the issues. In the autumn we will be organising a public consultation on which centres should be designated to provide surgery. We will encourage people to have their say and contribute to the consultation.

What happens now?

Service standards based on achieving the best possible care and outcomes for children have been developed by a group of experts. You can view these standards on our website. In May 2010 a panel of experts, led by Professor Sir Ian Kennedy, will visit each of the centres to assess their ability to meet the standards. The outcome of these visits and other relevant evidence will be reviewed by the National Specialised Commissioning Group (NSCG) in the summer. The NSCG will also consider issues around transport, travel and access. In autumn 2010 we will consult with young people, parents, overview and scrutiny panels, healthcare professionals, relevant unions and other interested parties on a proposed new structure of services. The consultation will provide people with an opportunity to have their say and help us develop a world class service.

May	Panel to assess centres
Summer	National Specialised Commissioning Group reviews findings
Autumn	Public consultation
Early 2011	Outcome of consultation expected

A final thought

Doing nothing is not an option. Surgeons in smaller centres do not have the same opportunities to see children requiring the range of different procedures to which larger centres have become accustomed. Children at some of the smaller centres also experience delays and cancellations that maybe dangerous and can easily be avoided. Having a service nearer to your doorstep does not necessarily make it better.

This document reminds us that this is a very complex area of specialist surgery which continues to evolve and as it does so, it gets increasingly sophisticated. Surgeons perform procedures now that would not have been dreamt of only a few years ago. The experts in this field are absolutely right to demand change, because it is vital that our surgeons and their teams perform sufficient numbers of specialist procedures to stay safe and to improve and develop their skills. Change can be uncomfortable, but if we want a world class, safe and sustainable service that we can rely on to provide the very best standards of care for these children, we must act now. The time has come to concentrate our surgical expertise in fewer centres. We understand loyalties to local hospitals, but for me, the quality of surgery and the outcomes for children come above all other considerations. The new model of services – linking expertise and hospitals together in a children's heart surgery network – is the right way forward.

Dr Patricia Hamilton CBE
Chair of the steering group for Safe and Sustainable

Further information

- Commissioning Safe and Sustainable Specialised Paediatric Services, Department of Health, 16 September 2008 www.dh.gov.uk
- www.specialisedcommissioning.nhs.uk
- www.childrens-heart-fed.org.uk

BRITISH CONGENITAL CARDIAC ASSOCIATION

Society for Cardiothoracic Surgery
in Great Britain and Ireland

children's heart
FEDERATION

DH Department
of Health

The
Royal
College *of*
Surgeons *of*
England

NHS

Royal College
of Nursing

Royal College of Paediatrics
and Child Health

PAEDIATRIC INTENSIVE CARE SOCIETY

Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

It's not just us who think change is necessary. The professional bodies and patient groups above also recognise the need for change.

For further information on Safe and Sustainable visit: www.specialisedcommissioning.nhs.uk

Safe and Sustainable
Children's congenital heart services in England

NHS
Specialised Services

Review of Children's Congenital Heart Services in England: Briefing 3

Spring 2011

1.0 Background information

This briefing provides an update on the public consultation which forms part of the NHS review of children's congenital cardiac services. This is the third briefing we have sent to all Health Overview and Scrutiny Committees in England to update them about the ongoing review of children's heart surgery services. Previous briefings were issued in August and November 2010.

It is possible that some HOSCs may consider the recommendations for change - that have now been published - to be a 'substantial variation', requiring us to formally consult with those HOSCs. The 2003 Direction from the Secretary of State requires scrutiny committees to convene a joint HOSC when two or more HOSCs consider that proposals affecting a population larger than a single HOSC to be substantial.

2.0 Aims of the review

What does the review aim to achieve?

- Better results in the surgical centres with fewer deaths and complications following surgery
- Better, more accessible diagnostic services and follow up treatment delivered within regional and local networks
- Reduced waiting times and cancelled operations
- Improved communication between parents and all of the services in the network that see their child
- Better training for surgeons and their teams to ensure the sustainability of the service
- A trained workforce expert in the care and treatment of children and young people with congenital heart disease
- Centres at the forefront of modern working practices and innovative technologies that are leaders in research and development
- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network

3.0 The review process: Where are we now?

The options for change

The Joint Committee of Primary Care Trusts (JCPCT), the decision-making body for *Safe and Sustainable* held a meeting in public on 16th February. At this meeting the recommendations for changes to the way children's congenital heart services were discussed and the options for reconfiguring the service were agreed.

What will we be consulting on?

We will be consulting on the following key areas:

- Standards of care: proposed national quality standards of care to be applied consistently across the country
- Congenital heart networks: development of networks to coordinate care and ensure more local provision (e.g. assessment, ongoing care)
- The options: the number and location of hospitals that provide children's heart surgical services in the future
- Better Monitoring: improvements for analysis and reporting of mortality and morbidity data

There are currently 11 surgical centres across England:

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

The four options that the public will be consulted on are:

Option A
Seven surgical centres at:

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

Option B
Seven surgical centres at:

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

Option C
Six surgical centres at:

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

Option D
Six surgical centres at:

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

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

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

New national quality standards to improve care
New national quality national standards have been developed as part of this review to help ensure that services produce better outcomes for children and are safe and sustainable. These are the quality criteria that experts believe must be met by any hospital that performs heart surgery on children. The proposed standards were developed in partnership with healthcare professionals, parents and patient groups and they are part of this consultation.

The development of congenital heart networks
Safe and Sustainable is proposing that surgical centres are not just responsible for the care they provide but that they lead a congenital heart network. These networks would ensure services are better coordinated and strengthen existing local assessment and ongoing care services where they exist and develop more outreach support in areas that have been neglected in the past. The standards set out the proposed roles for Specialist Surgical Centres, Children's Cardiology Centres and district level services and how the different parts of the network will work together.

4.0 The public consultation

Consultation timings:

The NHS has launched a four month public consultation. It will end on 1st July 2011.

Who will consult?

The Joint Committee of Primary Care Trusts

The NHS has established a national Joint Committee of Primary Care Trusts (JCPCT) which has legal powers for consultation and decision making. The committee includes the Chair of each of the 10 Specialised Commissioning Groups in England (each SCG Chair is a PCT Chief Executive).

The Welsh Assembly Government and the Welsh Health Specialised Services Committee were invited to join the JCPCT as Welsh children are usually referred to a heart surgical centre in England. They have chosen to attend meetings as observers to enable them to continue to ensure the interests of children in Wales are represented.

How will the NHS consult with the public?

The NHS wants as many people with an interest in children's congenital cardiac services to take part in the consultation. Everyone's view will be considered. The public will be able to take part in the consultation in the following ways.

Printed communications: We will be publishing a consultation document. This will be available to view online and printed copies will also be available upon request. We will also be producing a range of posters and leaflets to help promote the consultation events taking place around the country.

Online: Our website www.specialisedservices.nhs.uk/safeandsustainable will carry an online version of the consultation document, a link to the response form, materials (leaflets and poster) on the consultation process, and a video about the consultation.

Face to face events in England and Wales: We will hold over 15 face to face events in England and Wales, including three events specifically for young people. These events will help give people the information they need and answer any questions they may have, with the aim of encouraging people to take part in the consultation. The events will give people the opportunity to put their views to local clinicians and commissioners. More information and a link to the registration page can be found on our website.

We will be holding consultation events at:

Location	Date	Time of primary event	Proposed Venue
London (Event for young people)	Sat 19 March	11am-1pm	Charing Cross Hotel
Birmingham	Mon 4 April	6-8pm	Maple House
Cardiff	Tues 5 April	6-8pm	Cardiff City FC Stadium
Newcastle	Thurs 7 April	6:30-8:30pm	Discovery Museum
Birmingham (Event for young people)	Sat 9 April	11am-1pm	Maple House
Oxford	Wed 4 May	6-8pm	Kassam Stadium
London	Sat 7 May	11am- 1pm	Emirates Stadium
Warrington	Mon 9 May	6-8pm	Halliwell Jones Stadium
Leeds	Tues 10 May	6-8pm	Royal Armouries Museum
York (Event for young people)	Sat 14 May	11am-1pm	The Royal Hotel York
Cambridge	Wed 18 May	6-8pm	De Vere University Arms Hotel
Gatwick	Thurs 19 May	3-5pm	Copthorne Effingham Park
Southampton	Tues 24 May	6-8pm	The Guildhall (part of the Civic Centre)

Taunton	Tues 7 June	3-5pm	Taunton Racecourse
Leicester	Thurs 16 June	6-8pm	Walkers Stadium

Media relations: We are also working with the media to ensure information about the review process and the consultation appears nationally and locally.

What happens to the consultation responses?

Ipsos MORI, an independent company will collect and analyse all the responses and a comprehensive analysis of the responses will be published in a final report. The Joint Committee of Primary Care Trusts will consider the report carefully to help them evaluate the four options and make a final decision. We expect a final decision to be made in Autumn 2011. Implementation of any changes to children's congenital heart services are expected to start in 2013.

5.0 Is there support for the review?

There is strong support. The review was instigated at the request of national parent groups, NHS clinicians and their professional associations.

The review is supported by the following organisations:

Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS
Society for Cardiothoracaic Surgery in Great Britain and Ireland
NHS
Little Hearts Matter
The Royal College of Surgeons of England
Paediatric Intensive Care Society
British Heart Foundation
RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health
Royal College of Nursing
DH Department of Health
British Congenital Cardiac Association
children's heart FEDERATION

What engagement has taken place?

The review process has benefitted from the input that clinicians and parents have provided to help shape the national standards and the design of the future service. A range of engagement activity has taken place, including national and regional engagement events for parents and staff. Summaries of the meetings are on our website. The Safe and Sustainable review team has provided updates to keep parents and staff informed about the progress of the review.

The Gateway report

The Safe and Sustainable review process has itself been subject to external scrutiny. The Office of Government Commerce ‘Gateway’ report (September 2010) into the process concluded that “the Steering Group is seen as having exercised real leadership in the work to articulate the clinical case and to develop quality standards”. It also noted that “stakeholder engagement to date has been robust and impressive, and there is widespread support for the new standards and the case for reconfiguration.”

The NCAT report

The NHS National Clinical Advisory Team has also delivered a very positive independent assessment of the review. NCAT has concluded that there is a strong case for reconfiguring paediatric cardiac surgery by reducing the number of cardiac surgery centres across England, and has endorsed the proposed network model of care. Both reports have made some helpful recommendations which we are now acting on.

Have any decisions been made by the NHS?

The NHS has not yet made any decisions on the future configuration of services. No decisions will be made until the outcome of consultation has been considered.

In October we issued a statement about one of the current centres, the John Radcliffe Hospital in Oxford. The NHS review team has recommended to the Joint Committee of PCTs that this centre should not be included in any potential configuration option. This is because the service at the John Radcliffe Hospital received the lowest ranking as part of the assessment process by a significant margin and that it would be the least likely of all the centres to be able to meet the new quality standards in the future. The JCPCT has accepted this recommendation.

The NHS has not yet made any decisions on the future configuration of services. No decisions, including on the future of the service at the John Radcliffe Hospital, will be made until the outcome of consultation has been considered.

5.0 Key dates

April – June 2011: Regional public consultation events

1st July 2011: Formal public consultation ends

July – Sept 2011: Analysis of consultation by independent third party

Autumn 2011: JCPCT considers outcome of consultation

Winter 2011: Decisions expected

2013: Implementation

6.0 Would you like further information?

HOSCs have already told us how they would like to scrutinise the consultation and representatives of the regional Specialised Commissioning Groups have been in contact with local HOSCs to arrange meetings to discuss the review and the consultation with them.

Do let us know if you would like any further information and please do register to participate in forthcoming consultation events.

Contact details
The NHS review is led by NHS Specialised Services on behalf of the 10 Specialised Commissioning Groups in England.

Please contact: Zuzana Bates, Project Liaison Manager, Zuzana.Bates@nsscg.nhs.uk

NHS Specialised Services, 2nd floor, Southside, 105 Victoria Street, London SW1E 6QT

Direct Line: 020 7932 3771

For further information please contact us, or see our website:
www.specialisedservices.nhs.uk/safeandsustainable

APPENDIX 3

National Review of Children's Congenital Heart Services in England

Population Flows to Surgical Centres

Postcode/Area			Option A						Option B						Option C					Option D				
			London	Birmingham	Bristol	Newcastle	Liverpool	Leicester	London	Birmingham	Bristol	Newcastle	Liverpool	Southampton	London	Birmingham	Bristol	Newcastle	Liverpool	London	Birmingham	Bristol	Leeds	Liverpool
BD	Bradford	32					32						32						32				32	
DL	Darlington	31				31						31						31					31	
DN	Doncaster	43						43				43						43					43	
HG	Harrogate	8				8						8						8					8	
LA	Lancaster	19				11	8					11	8					11	8					19
LS	Leeds	45				45						45						45					45	
TS	Middlesbrough	51				51						51						51					51	
WF	Wakefield	30				30						30						30					30	
YO	York	33				33						33						33					33	