

# Heartnews



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[www.specialisedservices.nhs.uk/safeandsustainable](http://www.specialisedservices.nhs.uk/safeandsustainable)

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## Welcome

You are probably all aware of the landmark decision the NHS made last year on the future of children's heart services. The Joint Committee of Primary Care Trusts (JCPCT), the decision-making body, announced the development of seven congenital heart networks – a decision which was welcomed by professional associations, royal colleges and parent groups. It announced that these networks would provide services through partnerships between local centres and seven Specialist Surgical Centres.

### Why implementing change as soon as possible is vital

*"Whilst I respect the need to scrutinise the JCPCT's decision, I think it's important that we all remember why these changes were called for in the first place. Put simply, the way that children's heart services are provided is not sustainable for the future. I am a heart surgeon and am only too aware of the immense pressures that surgeons currently face. Surgical expertise has been spread too thinly for far too long. Children's heart surgeons need to work in larger teams in fewer centres - not only will this allow us to see enough patients to maintain the highest level of surgical skills but it will also make it easier to innovate and develop new life-saving techniques. Larger surgical teams will mean care around the clock, fewer cancelled operations and enough cover for emergencies. Ultimately this will improve outcomes and will help save lives."*

**Mr William Brawn CBE, Past President of the British Congenital Cardiac Association, Chair of the *Safe and Sustainable Standards Working Group* and member of the *Safe and Sustainable Steering Group***

Of course implementing these changes is a complex job, requiring detailed and careful planning and that is what the NHS has turned its attention to since the decision was made. That is the right thing to do, so that once the challenges to the decision have been resolved, the NHS is in the best position possible to move quickly to deliver these long planned improvements. In this newsletter you will find an update on the planning for implementation that has taken place so far as well as news on the review being carried out by the Independent Reconfiguration Panel (IRP) and the current legal challenge.

# Planning for implementation

The NHS has started planning the way it will develop children's congenital heart networks to bring more services closer to families' homes and to pool surgical expertise. These are extensive changes so it's important that the NHS starts to plan now so that the long-awaited improvements can be made effectively. The changes will be coordinated nationally and managed through local commissioners.

Of course implementation is subject to the outcomes of the judicial review, brought by the Leeds-based campaign group Save Our Surgery, and the Secretary of State's decision on whether the JCPCT's decision may stand. The Secretary of State is awaiting advice from the IRP - the independent experts on NHS health service change. In the meantime, planning and preparation for implementation will continue where possible to ensure that the NHS is well-placed to make these changes once these questions are resolved. There's an update on these on page five of this newsletter.

## Implementation Programme Board

The NHS has established an implementation programme board to oversee the implementation process. Caroline Taylor, Chief Executive of NHS North Central London, chairs the Programme Board. Caroline has been in the NHS for over thirty years (a Chief Executive for over sixteen), as both a commissioner and provider in primary, secondary and tertiary care.

The task for the Implementation Programme Board is to implement the JCPCT's decision. Its objectives are to ensure:

1. Excellent care with a focus on the child and their family will be achieved by developing standards of care for the whole patient pathway from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease) through infancy, childhood and through transition to transfer into adult services, implemented through commissioning and monitored and managed by the networks.
2. Seven managed children's congenital heart networks are established covering the whole population of England, each with a specialist surgical centre.
3. The new model of care including local and regional cardiology services for children with congenital heart disease and a reduced number of specialist surgical centres is established.
4. Nationally commissioned ECMO services for children with respiratory failure are provided by Birmingham Children's Hospital NHS Foundation Trust in place of University Hospitals of Leicester NHS Trust.
5. Transition to the new system is managed safely and efficiently, and in such a way as to realise the desired benefits, and clinical interdependencies and linkages are managed.

*"I'm proud to have been asked to use my experience in shaping NHS services to lead the process of planning for implementation of improvements to children's heart services. The NHS' work on stroke care is now saving up to 400 lives a year in the capital and that is the kind of transformation we can bring to NHS services. It's incredibly important that we plan now so that children's congenital heart networks can be established as quickly and efficiently as possible and I'm pleased to say that a significant amount of planning has already taken place. My approach is collaborative in style; I will work closely with clinicians, providers, parents, patients and commissioners and seek their advice to help us deliver a successful framework for future services."*

Caroline Taylor, Implementation Lead

## Implementation planning

The process of planning for implementation is well underway and several initial workshops and meetings have been held with national charities, clinicians and the hospitals currently providing surgery.

## Clinical Implementation Advisory Group

Specialist doctors and nurses will continue to play an extremely important advisory role during the implementation phase. A Clinical Implementation Advisory Group, which is made up of senior clinicians and patient and parent representatives, has been formed and has met three times. Its role is to provide expert clinical advice to the Implementation Programme Board. The Group is chaired by Professor Deirdre Kelly, Professor of Paediatric Hepatology at Birmingham Children's Hospital. A list of its members is available on the NHS Specialised Services website.

*"Members are very positive and committed to developing patient focused, high quality networks. I have established a number of reference groups covering important issues such as networks, standards and paediatric transport. We are all aware of the need for good communication with our stakeholders, patients and their families and of the importance of ensuring patient safety and the continuity of services during the transition phase."*

Professor Kelly, Chair of the Clinical Implementation Advisory Group

## Charity workshop

A number of charities including the Children's Heart Federation, Little Hearts Matter, Down's Heart Group, ARC, Max Appeal and Tiny Tickers took part in a workshop to discuss implementation issues that were raised during and since the public consultation.

## Workshop with clinicians and NHS managers

The eleven hospital trusts involved in the review were invited to attend a workshop where NHS colleagues could work together to identify the key priorities for implementation and how best they can work together to overcome challenges on a national, regional and local level. Clinicians, hospital chief executives, other senior leaders, commissioners and members of the national implementation team attended.

The workshops identified several key issues which participants highlighted must be addressed during implementation:

- **Setting standards for regional and local paediatric cardiology services**
- **Defining the networks with precision**
- **Strong leadership of the networks**
- **Staff engagement and retaining talent within the NHS**
- **Consistent approaches for commissioning, investment and governance**
- **Managing risks during the transition phase**
- **Maintaining momentum**
- **Clear messages about the progress of the review**
- **Integrated care and interdependent services**
- **Working together**
- **Consistent data collection**

For more information please go to the NHS Specialised Services website.

Updates on the implementation programme and the deliberations of the Clinical Implementation Advisory Group will be available in future newsletters. Alternatively, if you wish to contact the implementation team please refer to the contact details on page six.

**On 1 April 2013 the new NHS Commissioning Board (NHS CB) will assume responsibility for planning for implementation of the decision to reconfigure children's congenital heart services in England. The current Clinical Implementation Advisory Group will continue to advise the NHS CB on relevant clinical issues. The main aim of the NHS CB is to improve health outcomes for people in England. You can learn more about the NHS CB at <http://www.commissioningboard.nhs.uk>**

# Children's congenital heart networks

## Support for developing networks of specialist care

The JCPCT announced in July that children's heart surgery would be pooled into seven centres and that each of those centres would work in partnership with local clinicians and commissioners to ensure families can access specialist care closer to home in future. A number of professional bodies and royal colleges of medicine wrote to *The Times* to express their support for the decision. Signatories included presidents of the Royal College of Paediatrics and Child Health, the Royal College of Surgeons of England and the British Congenital Cardiac Association.

## Improving access to local specialist care

Local clinicians and commissioners will work in partnership with Specialist Surgical Centres at Bristol Royal Hospital for Children, Southampton General Hospital, Birmingham Children's Hospital, Great Ormond Street Hospital, Evelina Children's Hospital,

## Treating CHD

Sir, This week marked an important turning point in the future care of children with congenital heart disease (CHD) in England. We strongly believe that the decision taken by the Joint Committee of Primary Care Trusts (JCPCT) will improve clinical outcomes and help to save more children's lives in the future.

Maintaining the status quo was simply not an option. For too long surgical expertise has been spread too thinly across too many hospitals, and services need to be better co-ordinated to deliver expert care closer to where families live. The decision will mean that children's heart surgery will be provided in fewer larger centres with the expertise and volume of cases to ensure that outcomes for children improve. New congenital heart networks of care will be developed to ensure that services for children are more joined up, meet new national quality standards and deliver better monitoring of outcomes, allowing for services to be continually reviewed and improved.

We have stood firmly behind this review as we believe it will create a more sustainable service that is safe for the future.

It is vital that we now move forward and make sure that the process of change is embraced with no delays. Our organisations will help to ensure these changes are implemented so that children have access to world-class care in the future.

PROFESSOR TERENCE STEPHENSON  
Academy of Medical Royal Colleges  
DR PETER CARTER  
Chief Executive and General Secretary, Royal College of Nursing  
DR HILARY CASS  
President, Royal College of Paediatrics and Child Health  
PROFESSOR NORMAN WILLIAMS  
President, Royal College of Surgeons  
JAMES ROXBURGH  
President, Society for Cardiothoracic Surgery in Great Britain and Ireland  
DR TONY SALMON  
President, British Congenital Cardiac Association

Alder Hey Children's Hospital in Liverpool and the Freeman Hospital in Newcastle. Services such as assessment and ongoing care will be available closer to home - not just in some areas as is currently the case but consistently across the country. Families will have access to more expert nurses and paediatricians with expertise in cardiology as these roles are expanded and the numbers of staff are increased. Families often need support with their child's sleeping pattern and eating difficulties, and more families will benefit by having access to psychologists and dietitians. The congenital heart networks will minimise the current problem of too many families travelling long distances to surgical centres for ongoing care appointments. Ongoing care will now be provided closer to home for more families.

A working group of senior clinicians (doctors, nurses and others) has made recommendations on the way networks should work. This covers the role, scope and membership of networks as well as advice on key leadership positions within networks. These recommendations have been used by the NHS Commissioning Board to set out a specification for the new Children's Congenital Heart Networks that will be rolled out during the coming financial year (April 2013 to March 2014).



# The chance to give your views

## Independent Reconfiguration Panel

The Independent Reconfiguration Panel (IRP) is carrying out a full review of the decision made on 4 July 2012, which was requested by the Secretary of State. The IRP is the independent expert on NHS service change and provides advice to the Secretary of State for Health on proposals for health service change in England.

The review was prompted by referrals to the Secretary of State from Lincolnshire County Council Health Scrutiny Committee, Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee and Yorkshire and Humber Joint Health Overview and Scrutiny Committee. More information on these referrals are available at [www.irpanel.org.uk](http://www.irpanel.org.uk)

The JCPCT and several advisers have met with the IRP to explain the rationale for the decision and to answer members' questions. *Safe and Sustainable* will assist the IRP in whatever way possible to help the panel's review. However, it is important that the IRP understands from patients and families the reasons why children's heart services need to change. The IRP encourages anyone wishing to provide new evidence as part of the review to submit their views to them. The IRP has visited all the current surgical centres and is due to provide its advice to the Secretary of State by 28 March 2013. The Secretary of State will make the final decision following his consideration of the IRP's advice.

*Here's how you can share your views with the IRP.*

**E-mail:** [info@irpanel.org.uk](mailto:info@irpanel.org.uk)

**Post:** Independent Reconfiguration Panel,  
6th Floor, 157 - 197 Buckingham Palace  
Road, London, SW1W 9SP

**By leaving a voice message on**  
020 7389 8046

**The IRP is keen to hear all views by**  
28 February 2013.



## An update on legal proceedings

Last October Save Our Surgery Ltd, a group with close connections to the Leeds based campaign group Children's Heart Surgery Fund (CHSF), issued legal proceedings against the JCPCT's decision on the best way to improve children's heart services. They are seeking to quash the JCPCT's decision in its entirety.

The campaign group argues that the decision is unfair – an argument which relies on one ground: that the JCPCT should have disclosed Sir Ian Kennedy's independent expert panel's sub-scores to a) the JCPCT and b) the general public during the consultation process. Save Our Surgery Ltd claims that this would have enabled the JCPCT and the public to analyse the sub scores to ensure that they were correct and enabled consultees such as Leeds Teaching Hospitals NHS Trust and the CHSF the opportunity to challenge the accuracy of the scores.

The NHS mounted a strong defence of its decision and the review process during a three day hearing in February at the High Court. The NHS' case was that the campaign group's criticism of the process is misconceived and that the JCPCT's decision not to analyse the panel's 450 sub-scores was proper and appropriate. The JCPCT neither had – nor could have had – all the information relied upon by the Kennedy Panel, nor its expertise. Therefore, the NHS believes the JCPCT was entirely right to conclude that it was not in a position to 'second guess' the Kennedy Panel sub-scores and nor could consultees for the same reason. These scores can be reviewed on the NHS Specialised Services website.

Commenting on the legal proceedings, Sir Neil McKay CB, Chair of the Joint Committee of Primary Care Trusts, said:

"I believe that the NHS decision to expand access to local care and pool surgical expertise is right for children with congenital heart disease and their families. If we want to save more children's lives and reduce complications such as brain damage, we believe it's the right decision for the country. The UK's medical royal colleges which represent the doctors and nurses support the NHS decision.

"We believe that the consultation was transparent, fair and lawful however I do not deny citizens' right to challenge NHS decision makers when appropriate to do so and we have defended the very detailed process in the High Court.

"It is incumbent on all those in the NHS to strive to deliver excellent standards of care with the highest possible outcomes for patients and families. Save Our Surgery has argued that we should keep heart surgery in both Leeds and Newcastle. We considered this carefully but maintaining the status quo is not the answer as it would leave children in Yorkshire and Humberside with an inferior service than children in the rest of country would receive."

A decision is due to be made by the courts in the coming weeks.

# Contact



If you have any questions about the implementation programme, please contact the Implementation Programme Board by writing to:

[CCHS.Implementation@london.nhs.uk](mailto:CCHS.Implementation@london.nhs.uk)

