

Heartnews

Welcome



Sir Neil McKay
Chair of the Joint
Committee of Primary
Care Trusts

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“Welcome to issue six of Heartnews, which provides an update on the *Safe and Sustainable* review of children's congenital heart services in England.

This month the Joint Committee of Primary Care Trusts (JCPCT) prepares to appeal the High Court ruling which quashed the public consultation. We recognise that further delay is undesirable particularly for families and NHS staff who have waited so long for change. The statements at the back of this newsletter from professional associations and parent groups clearly show the continued support for an urgent decision to be made. I would like to reassure you that no matter what the outcome of the appeal, we will make a final decision on the future of children's heart services by the end of 2012 at the latest.

In February 2012 *the Safe and Sustainable* steering group held its final planned meeting. On behalf of the JCPCT I would like to take this opportunity to thank all of the steering group members for their expert advice over the course of the review, and in particular to Dr Patricia Hamilton for the leadership that she has shown in chairing the group since 2008.

In this newsletter you will find information on a public engagement exercise being held by London Specialised Commissioning Group on the possible closure of the paediatric intensive care unit at the Royal Brompton Hospital. The SCG will be encouraging you to submit your views if you have an interest in paediatric intensive care services or paediatric respiratory services at the Royal Brompton.

Don't forget, you can stay up to date with the review and the forthcoming appeal hearing by visiting www.specialisedservices.nhs.uk/news “

Update on the appeal hearing

JCPCT granted leave to appeal in March

On 7 November 2011 the High Court ruled that the four month public consultation carried out last year should be quashed. The Judge's ruling was based on the score given to the Royal Brompton and Harefield NHS Foundation Trust for research and innovation. Importantly the Judge rejected all other allegations made by the Royal Brompton Hospital.

The JCPCT has appealed the ruling as it respectfully believes the consultation was carried out lawfully. It is also aware that the Royal Brompton Hospital's revised score for research and innovation has no material bearing on the four options that went out for public consultation. (See page 3 for further details on the scores).

The Court agrees that this is an urgent matter and has therefore granted leave to appeal September's high court ruling, on 20 March. At the hearing the court will hear from both the JCPCT and from the Trust.

What happens after the appeal hearing?

If the JCPCT wins the appeal

This will enable us to consider your submissions to the consultation we held in 2011. If the ruling is overturned, the JCPCT will move quickly to make a decision on the future of children's heart services in July. The decision will be made at a meeting held in public. Details about the meeting will be made available on the *Safe and Sustainable* website: www.specialisedservices.nhs.uk/safeandsustainable

If the JCPCT loses the appeal

This would prevent us from considering your submissions to consultation. This is one of the reasons why we think it is important to appeal. Your voice should be heard. The JCPCT will hold a meeting in public during which they will agree the options for a new public consultation, which we anticipate would start in the summer.



Implementation of the JCPCT's final decision

If the JCPCT's appeal against the judicial review is successful a final decision on the future configuration of services will be made in July 2012. NHS commissioners are already preparing for the period of implementation.

Implementation will be coordinated nationally but it is proposed that change will be driven locally via multi-professional Congenital Heart Network Groups across England. Establishing clinical and lay membership of these groups will be a priority for the NHS as soon as a decision is made.

A detailed plan is being developed including the establishment of a clinically-led Implementation Advisory Group whose remit will be to advise NHS commissioners on relevant clinical issues including how to minimise workforce risks and ensure stability and high quality services at all parts of the patient pathway. Soon, professional associations and national patient groups will receive invitations to nominate members to join the group. Terms of reference and the group's membership will be published on the *Safe and Sustainable* website in due course.

Research and innovation scores

On 24 February *Safe and Sustainable* published a report by Sir Ian Kennedy's independent panel about the additional innovation and research information submitted by eight Trusts.

Following last year's judicial review hearing involving the Royal Brompton Hospital, the Joint Committee of Primary Care Trusts (JCPCT) invited all 11 centres providing children's congenital heart services to submit new evidence demonstrating their 'innovation and research' in relation to the national quality standards.

Eight Trusts chose to submit new evidence and only two have seen a change to their score for research and innovation with Oxford Radcliffe Hospitals NHS Trust moving from 1 (inadequate) to 2 (poor) and the Royal Brompton and Harefield NHS Foundation Trust moving from 2 (poor) to 3 (adequate).

The full report is accessible through the news bulletin on the website: www.specialisedservices.nhs.uk/safeandsustainable

Work continues on the review...

An update for families of children with respiratory conditions, treated at the Royal Brompton Hospital

During public consultation the JCPCT received a number of submissions around the impact to paediatric respiratory services at the Royal Brompton Hospital. The NHS has written to Asthma UK, the Cystic Fibrosis Trust, the Muscular Dystrophy Campaign and the Primary Ciliary Dyskinesia Family Support Group to reassure families that children with respiratory conditions can continue to be treated at the Royal Brompton Hospital should its children's heart surgery service be discontinued. *Safe and Sustainable* has met with Asthma UK and Cystic Fibrosis Trust and we have listened carefully to their concerns.

The NHS has invited the four charities and individuals with an interest in paediatric respiratory services in London to work with the London Specialised Commissioning Group and the National Specialised Commissioning Team to ensure services are planned appropriately across London. The NHS will keep families updated over the coming months with the latest developments. More information about the findings of an independent panel which concluded that respiratory services would be able to continue at the Royal Brompton

Hospital (the Pollitt report) can be found here: www.specialisedservices.nhs.uk/news/view/international-experts-reject-royal-brompton-s-allegations and correspondence between the Chair of the JCPCT and the four charities can be found here: <http://www.specialisedservices.nhs.uk/document/correspondence-between-sir-neil-mckay-chair-jcpct-cystic-fibrosis-trust-asthma-uk-pcd-family-support-1/>

Engagement on paediatric intensive care services and paediatric respiratory services at the Royal Brompton Hospital

London SCG is inviting all those with an interest in paediatric intensive care services and paediatric respiratory services at the Royal Brompton Hospital to give an opinion. London SCG will use your comments to inform a report to the JCPCT and this will be taken into account by the JCPCT before any decisions are made. The background to this work, the questions being asked by London SCG and details of how to make your views known will be available from the week of 12 March 2012 at: www.londonscg.nhs.uk

Developing the standards: An update on the British Congenital Cardiac Association's (BCCA) collaborative work with the NHS Fetal Anomaly Screening Programme (FASP) and the NHS Newborn and Infant Physical Examination Programme (NIPE)

"Both the BCCA and *Safe and Sustainable* want to see an increase in the number of babies diagnosed with CHD while they are still in the womb so that doctors can work with the mother to ensure safe delivery in a hospital where clinicians are experienced in caring for new born children with congenital heart conditions. At the moment there is significant variation in pre-natal diagnosis rates across the country.

The BCCA has been working closely with the NHS Fetal Anomaly Screening Programme (FASP) and the NHS Newborn and Infant Physical Examination Programme (NIPE) during recent months to develop a new care pathway that will help to drive up the early detection of a congenital heart condition by enabling fetal and paediatric experts to work better together to provide more joined up care both before and after the mother gives birth. A draft pathway was presented to key stakeholders at a meeting on 1st March attended by members of *Safe and Sustainable*, the BCCA, FASP, NIPE and patient groups."

Why is pre-natal diagnosis so important?

It is vital that CHD is diagnosed as early as possible during pregnancy to ensure both mothers and babies get the support they need during and after birth. More timely diagnosis leads to a better outcome for the child.

If CHD is diagnosed during the pregnancy then arrangements can be made for a mother to be closely monitored for the rest of her pregnancy by clinicians with the specialist expertise needed. If the mother is giving birth at a local maternity hospital then arrangements will be put in place to transfer the mother and baby to a specialist surgical centre in case the baby needs specialist treatment soon after birth.

Dr Tony Salmon,
president of the BCCA

Concentrating excellence brings benefits....

Concentrating specialist expertise within a network that would also bring more routine care closer to the child's home is not a new concept in the NHS. A number of recent reports and reconfigurations highlight the benefits of this type of model of care for patients and their families.

Volume vs outcomes

A study by the Duke University Medical Centre in America has found that busier health centres in the US were better able to identify and treat complications that occur after heart surgery. Researchers looked at more than 35,000 children who underwent heart surgery at 68 different hospitals. The risk of complications after surgery remained the same across the board. However, the risk of dying after a major complication differed among patients in high-volume and low-volume hospitals. In centres that performed fewer than 150 heart surgeries in children each year, the risk of dying was much greater. More information can be found here: http://www.dukemedicine.org/news_and_publications/news_office

The study also suggests that good clinical outcomes in a surgical centre cannot be explained by the volume of activity alone. This finding is consistent with the model of care and standards proposed by the JCPCT, which give emphasis to a number of factors that contribute to improved outcomes:

- managed clinical networks that result in more 'joined up' approach by the various NHS services that see heart children
- improved access to expert support services including nursing and psychology support
- more timely diagnosis.

South London Cardiac and Stroke Network annual report

Further evidence of the success of concentrating specialist expertise can be seen in the case of the London Stroke Networks. After concentrating very specialist expertise for urgent cases and developing services for recovery and ongoing care, stroke sufferers in London now have better access to the necessary treatment needed to break up clots than people in any other major city in the world. More information can be found here: www.london.nhs.uk/

King's Fund report

The King's Fund has published a briefing 'Reconfiguring hospital services', calling for the concentration of some specialist services into fewer, larger centres to provide better outcomes for patients. Candace Imison, Deputy Director of Policy at the King's Fund, wrote the briefing and believes that "changes to the way hospital services are organised in some parts of the country are now a necessity, not an option, if the NHS is to deliver safe, high-quality care." More information can be found here: www.kingsfund.org.uk

Latest reports

IRP publishes its independent advice

On 23 February the Independent Reconfiguration Panel (IRP) published its assessment of the referral from Yorkshire and Humber Joint Health Overview and Scrutiny Committee concerning the review. The IRP found that there is no case for a full review. The Secretary of State for Health has accepted the IRP's advice.

Sir Neil McKay CB, Chairman of the Joint Committee of Primary Care Trusts, commented:

"I really welcome the IRP's independent advice. I am pleased that the external assessment shows that we have consulted appropriately with Yorkshire and Humber Joint Overview Scrutiny Committee. As this is a complex national review we provided all overview and scrutiny bodies seven months to consider our proposals and to provide their feedback, however I fully recognise that individual OSCs (and joint committees where they were formed on a regional basis) face considerable pressures in responding to consultations of this nature. We are considering the IRP's advice carefully and will implement the suggestions they make in full."

The IRP's assessment can be found here: www.irpanel.org.uk

The IRP suggested that any comments which stakeholders may wish to make with regard to the report on travel patterns report should be considered by the JCPCT alongside the report itself as part of its decision making process.

The JCPCT requests that any such comments are received in writing by 16 April 2012 (contact details at the back of this newsletter).



Support for the review remains strong

Support for change to children's heart services from leading heart charities and professional bodies remains strong.

Royal College of Nursing (RCN) Children and Young People's Nursing Adviser & Safe and Sustainable Steering Group member, Fiona Smith, said:

"I know that many nurses and doctors are eager for the proposed developments to proceed as quickly as possible to ensure effective NHS services for children with congenital heart disease. It is hoped that outstanding issues will be resolved as soon as possible so that improvements in services for children and their families can move forward. The Royal College of Nursing continues to support *Safe and Sustainable's* vital work to improve the provision of children's heart services across the country. Nurses will be key to providing the necessary ongoing support and care for children and their families under the new model of care. There will be lots of opportunities for nurses, as well as other clinical staff, looking to specialise in the care of children with complex congenital heart conditions. The RCN and the Children's Cardiac Nurses Association (CCNA) have been working together to develop a clear vision for future roles for nurses within the cardiac networks. As well as helping to bridge the gap between the home and the specialist cardiac centres, it is vital to have experienced and highly trained teams of nurses and other clinicians in specialist centres, ensuring better outcomes for children and young people."



Three professional associations signed a letter calling for a decision to be made on the future of children's congenital heart services to ensure urgent changes are made:

"The decision by the High Court to find the review of children's heart surgery services 'unlawful' is disappointing. This review was not undertaken lightly and never before have we been so close to achieving real change and it is frustrating that we find ourselves facing a further wait. The fact of the matter is we have too many surgeons spread too thinly across numerous hospitals. Concentrating clinical expertise into larger, specialist centres and developing networks of expert cardiology care will give children born with complex heart conditions the best quality of care. These children shouldn't have to wait any longer for urgent changes to be made to services."

Dr David Shortland, Vice Presidents of the Royal College of Paediatrics and Child Health

Dr Peter Carter, Chief Executive & General Secretary of the Royal College of Nursing

Professor Norman Williams, President of the Royal College of Surgeons

Heart charities also want to see changes made as quickly as possible.

"The reconfiguration of congenital cardiac services is long overdue having been recommended over ten years ago following the Bristol enquiry. Any further delay to the conclusion of this process could lead to the lives of children being put at risk as the current service is unable to offer the highest standard of care to all."

Suzie Hutchinson Chief Executive, Little Hearts Matter

"We must move forward as quickly as we can to ensure that all units are able to offer a 24 hour service, seven days a week, because at the moment there's not the staff capacity to cope with emergency and planned operations at every centre. We are convinced that reorganising children's heart care along the lines proposed by the *Safe and Sustainable* review would lead to a better quality of service across the country. These are goals worth striving for and we urge everyone to press forward to achieve them."

Anne Keatley-Clarke, CEO, Children's Heart Federation

Further information

Further information

You can contact the *Safe and Sustainable* team in the following ways:

✉ Write to *Safe and Sustainable*

Christy Rowley
National Specialised Commissioning Team
NHS Specialised Services
2nd floor
Southside
105 Victoria Street
London
SW1E 6QT

📞 Call the review team on 020 7932 3958

@ Email Childheart@nsscgs.nhs.uk

Are you on our email list?

Please email nhsspecialisedservices@grayling.com if you would like to receive information about the review.

Go to our website to find out more:

www.specialisedservices.nhs.uk/safeandsustainable

Review of adult congenital heart services

The NHS is currently reviewing the way congenital heart services are provided nationally for adults with congenital heart disease. This is a separate process to *Safe and Sustainable*. More information on the ACHD (Adults with Congenital Heart Disease) review can be found here:

www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease