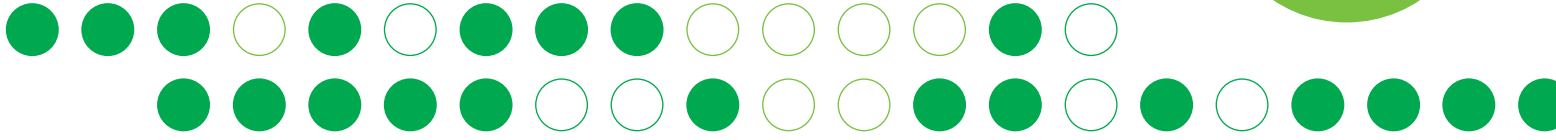


# Heartnews

issue four

Dec 2010



## Welcome

Welcome. This newsletter is packed with the latest information about the NHS Safe and Sustainable review into children's congenital heart services. It is our job to keep you updated and if you have any questions about the review, please do not hesitate to contact us.



I am very pleased that we now have the proposed decision making committee in place. I chair this group, known as the Joint Committee of Primary Care Trusts (JCPCT), and on pages 4 and 5 we introduce you to the members and the work currently underway. The group includes specialist commissioners from across every region in England. Our role includes assessing all the evidence and listening to all sides of the debate. In early 2011 we will agree the options for the configuration of fewer, larger surgical centres as part of a new proposed network of services for children with congenital heart disease. As you know, we will be formally consulting with you on these options before making any decision.

You may be aware that a new analysis of data about mortality rates for children undergoing heart surgery in England has been published. Turn to page 7 to find out more about our response. It's important for everyone to know that the analysis does not suggest that there are immediate safety concerns about any centres currently performing surgery. However, we want to ensure that we take into consideration all evidence available before making recommendations on the configuration of the surgical centres. As a result, we will now be consulting with you on the recommendations in early 2011.

*Continued overleaf*

Keep up to date with the latest information on the review at our website  
[www.specialisedservices.nhs.uk/safeandsustainable](http://www.specialisedservices.nhs.uk/safeandsustainable)

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

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## Welcome continued

Part of our work so far has included reviewing the results from the visits to all the surgical centres. On page 6 we set out why the review team will recommend to the JCPCT that the John Radcliffe hospital in Oxford will not be included in the options for future configuration. All ten other centres remain part of the options being considered at the moment.

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 has 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" and that 'the governance structure has been robust and fit for purpose.' 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 reviews have made some helpful recommendations which we are now acting on."

Sir Neil McKay CBE



## Your views

**A big thank you** - to over 1200 of you - for attending local engagement events across England earlier this year. Parents, young people, NHS staff and stakeholders attended 10 events from Southampton to Newcastle. You shared your experiences and the issues that matter to you: comments, concerns and suggestions for the future. All the events were recorded so that we could capture people's views accurately. Your comments and questions were part of the evidence presented to the JCPCT to help develop configuration options.

Some people had views about the proposed new model of care and how services can be developed more locally. During the events the review team listened to some strong views, not only from parents, but from the highly trained professionals who have provided expert care for children around the network.

*Some of the issues you have raised*

**Transition to adult services**  
**Increasing skilled staff**  
**The clinical pathway**  
**Accommodation**      **Quality**  
**Continuity of care**  
**Travel costs**      **Access to local services**  
**The cost of implementing change**  
**Non-surgical care**      **Travel**  
**Evidence**

If you were unable to attend an event near you, or if you want to know more about what was said at other events across the country, please go to [www.specialisedservices.nhs.uk](http://www.specialisedservices.nhs.uk). Opposite we have set out some of the views people expressed and issues that people raised.

## Your views continued

**//** My experiences of A&E with a cardiology child are absolutely horrendous and people running scared around the place and not wanting to know anything about it and willing to dump you wherever they want to go, that is a horrendous experience for me. **//**

**Safe and Sustainable response:** We heard many parents describe their concerns about the levels of expertise and understanding of congenital heart disease in local hospitals and have heard their calls for a more 'joined up' NHS. The Safe and Sustainable standards propose the development of congenital heart networks for children that will strengthen the role of Consultant Paediatricians with Expertise in Cardiology and Cardiac Liaison Teams, and that will improve communication across NHS services for children with CHD.

**//** When we spent two months between March and May with our child who was in for surgery, we spent four weeks on a waiting list for Ronald McDonald House...before [the family] could come up and visit. They had to go a month without mummy and baby sister being with them. If you reduce the amount of centres, have you taken into account charities such as Ronald McDonald so they can expand their facilities to help the parents and families? **//**

**Safe and Sustainable response:** The Safe and Sustainable standards require designated centres to ensure sufficient accommodation for family members, including at the child's bedside. The assessment visits undertaken by Sir Ian Kennedy and the expert panel in the summer included each centre's ability to provide accommodation for families.

Asif Hasan, Consultant Congenital Cardiac Surgeon at the Freeman Hospital, Newcastle, recounted his experience of performing on call operations three nights in a row – which he summarises here:

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



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

**//** We are very dependent on the goodwill of surgeons and the fact that many of them are working excessive hours. At the Children's Heart Federation, through the calls coming into our help line, I hear problems about cancelled operations. We are talking about units where there are one, two or sometimes three surgeons but, because an emergency has come in, the planned operations for the next day have had to be cancelled. I am still hearing from parents telling me that their children have had their operations cancelled five, six or seven times – sometimes after they have already been prepped for the operation but, again, it is cancelled at the last minute. Teams of surgeons should be working together, so you can provide a service able to cope with emergency and planned surgery while, at the same time, you can release surgeons to develop and learn about new procedures as well. **//**



# The decision makers

NHS Commissioners from every region in England will produce options for congenital heart services for children. This group is known as the Joint Committee of Primary Care Trusts (JCPCT). A Primary Care Trust is the NHS body that commissions NHS services for its local population.

The JCPCT includes representatives from each Specialised Commissioning Group in England. This means that all regions in England are represented on the committee.

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.



## *Who sits on the JCPCT?*

**Sir Neil McKay** – Chair, JCPCT and Chief Executive, East of England SHA

**Teresa Moss** – Director of National Specialised Commissioning, NHS Specialised Services

**Sophia Christie** – Chair, West Midlands SCG and Chief Executive, Birmingham East and North PCT

**Jon Develing** – Chief Officer, North West SCG

**Ailsa Claire** – Chair, Yorkshire and Humber SCG and Chief Executive, Barnsley PCT

**Deborah Evans** – Chair, South West SCG and Chief Executive, Bristol PCT

**Catherine Griffiths** – Chair, East Midlands SCG and Chief Executive, Leicestershire and Rutland PCT

**Lise Llewellyn** – Chair, South Central SCG and Chief Executive, Berkshire East PCT

**Steve Phoenix** – Chair, South East Coast SCG and Chief Executive West Kent PCT

**Chris Reed** – Chair, North East SCG and Chief Executive North of Tyne PCT

**Caroline Taylor** – Chair, London SCG and Chief Executive, Croydon PCT

**Paul Watson** – Chair, East of England SCG and Chief Executive, North East Essex PCT

**Dr Patricia Hamilton** – Chair, Paediatric Cardiac Surgery Steering Group and Director, Medical Education England. Dr Patricia Hamilton advises the JCPCT on behalf of the Safe and Sustainable steering group



## Safe and Sustainable steering group

The Safe and Sustainable steering group comprises representatives of the relevant professional associations, and parent and patient representatives. It is an expert advisory group, but does not have a role in the decision making process. It is chaired by Dr Patricia Hamilton in her role as Immediate Past President of the Royal College of Paediatrics and Child Health.

The role of the steering group has been to:

- Develop and communicate the clinical 'Case for Change'
- Consider the available research evidence around the relationship between larger surgical centres and clinical outcomes

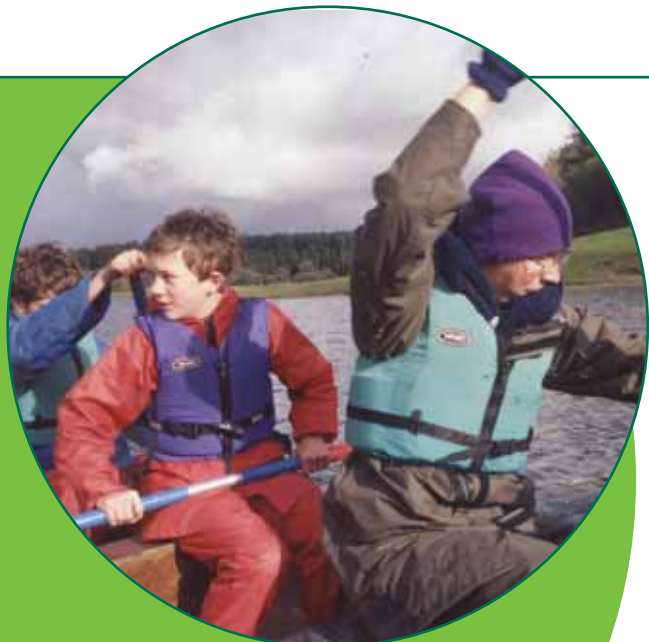
- Develop clinical standards that surgical centres must meet in the future
- Develop a proposed model of care for regional paediatric cardiology networks
- Advise on stakeholder engagement and communication

In January the steering group will advise the JCPCT on the clinical viability of short-listed options so that the JCPCT is assured that the potential options are clinically safe.

## Making the recommendations

The JCPCT will receive evidence from the expert panel chaired by Sir Ian Kennedy. It will use this evidence and the factors below to develop recommendations for public consultation:

- The need for quality services
- Clinical networks
- Population density
- Travel times
- The potential impact on other services including Paediatric Intensive Care, children's heart transplantation and children's ECMO
- Workforce implications
- Affordability



# An update on emerging recommendations

## - John Radcliffe Hospital, Oxford

On behalf of the review, Sir Ian Kennedy led a panel of independent experts to visit each surgical centre. Sir Ian Kennedy is well known for his expertise in this area; he chaired the public inquiry into children's heart surgery services in the NHS and published his landmark report in 2001 on the care required for children needing complex heart surgery.

The panel included a lay member and experts in paediatric cardiology, heart surgery, anaesthesia and intensive care, nursing and commissioning. As well as meeting the staff at each centre, they also met parents and young people. The task: to assess the ability of each surgical centre to meet the new quality standards in the future. The panel had a number of concerns about the John Radcliffe hospital and the centre received the lowest ranking of all the centres by a significant margin. This made the Oxford centre the least likely of the centres to meet all the new quality standards for children's heart surgery in the future.

The Safe and Sustainable review team explored whether the location of the John Radcliffe hospital could justify its inclusion in potential options on the grounds that this would improve access for children and families. However, it was found that access would not be improved by including the centre in the potential options.

Having considered the evidence, the Safe and Sustainable review team will recommend to the JCPCT that the John Radcliffe hospital should not be included in any potential configuration options for surgery. Instead it will recommend to the JCPCT that the centre should provide non-interventional specialised cardiology services for children. These recommendations are supported by the John Radcliffe Hospital's local commissioners, the South Central Specialised Commissioning Group. We appreciate that this is an anxious time for parents, patients and staff which is why it was agreed that it would be appropriate to announce these emerging recommendations as soon as possible.

In the next few months the JCPCT will agree recommendations for the configuration of the surgical centres. At this stage every other centre currently performing children's heart surgery forms part of the options being considered. A final decision about the future of the current services, including at the John Radcliffe Hospital, will not be made until the outcome of the public consultation has been considered by the JCPCT. You will have the opportunity to take part in the consultation and we will be encouraging as many people as possible to share their comments on the future of the services, including the service at the John Radcliffe Hospital.

### Comment from Andrew Stevens

Andrew Stevens, Director of Planning for the Oxford Radcliffe Hospitals NHS Trust, issued a response to the media that said **"It is perhaps not surprising that Oxford was felt to have the highest mountain to climb".** He said that **"Oxford is one of the smallest centres and the main thrust of the review is that there should be fewer, larger paediatric cardiac centres in the future."**



## Checking new findings

Some new information about mortality has recently been made available to the review team. The analysis - prepared as part of the separate investigation into the children's heart surgical service at the John Radcliffe Hospital - suggests that the levels of mortality for some procedures was reported as higher than expected. Whilst the analysis does not suggest that there are immediate safety concerns about any centres currently operating, we believe it is in everybody's interest

that this new information is considered appropriately and carefully. Therefore a group of independent experts in paediatric cardiac surgery, paediatric cardiology, paediatric anaesthesia / intensive care and nursing has been established to carry out some more detailed analysis.

### *The group's role*

The group of clinicians will review case summaries and will advise the JCPCT on its findings by December. The JCPCT will ask Sir Ian Kennedy and his expert panel to consider whether it is appropriate to revise its assessment of any of the three centres in light of any new evidence presented to it. The report's findings and recommendations will be made public.

### *A comment from Dr Martin Ashton-Key, Medical Advisor for Safe and Sustainable*

"South Central SHA's initial analysis of outcome data was made available to us on 14 September. This analysis identified four children's heart surgical centres, where the mortality level was reported as higher than expected. However, it is important to note that the analysis did not suggest that there are immediate concerns about any of the centres currently operating. Since receiving the initial analysis, we have asked the statistician to carry out some further analyses and it is now clear that that we should confine some further work to just four specific procedures across three centres within specific time periods. The team will work collaboratively with clinical and management staff at the three centres to understand the reasons for these reported differences."



## The procedures

From the evidence available, it is evident that we should confine further analysis to just four procedures across the three centres (Guys and St Thomas' Hospital NHS Foundation Trust, Leeds Teaching Hospitals NHS Trust and University Hospitals Leicester NHS Trust) within specific time periods. The fourth centre identified by the analysis, John Radcliffe Hospital in Oxford, is currently suspended as a result of an independent investigation.

# The consultation

No final decisions about children's congenital heart services have been made. Early next year recommendations for configuring the service will be made and we will formally consult with you about them. You will have the opportunity to comment on the national standards, which centres are designated as surgical centres and how local care should be planned and delivered. If you are a young person, a parent, a clinician or stakeholder – we will be encouraging you to take part and respond to the consultation. There will be a number of options for you to consider, including a 'preferred' option if appropriate.

We are committed to making the consultation process accessible. So we will be making sure you can participate in a number of ways:

- Face to face at a series of events for young people, parents and staff. These events will provide a forum for you to discuss the options and ask questions
- In writing to set out your views on the recommendations in the consultation document
- You will also be able to respond online at the consultation  
[www.specialisedservices.nhs.uk/safeandsustainable](http://www.specialisedservices.nhs.uk/safeandsustainable)

We will also be making sure that everyone with an interest in children's congenital heart services has an opportunity to find out more about the review and respond to the consultation. We will be working with the media, local groups and stakeholders to ensure the consultation process is widely publicised.

The responses that we get to the consultation will be analysed by an independent third party, who will report to the JCPCT in the summer of 2011.

## Further information

If you have any questions, comments or suggestions about the review, please do get in touch with us. You can contact the Safe and Sustainable team in the following ways:

- Write to Safe and Sustainable, NHS Specialised Services, 2nd floor, Southside, 105 Victoria Street, London, SW1E 6QT
- Call the review team on 020 7932 3958
- Email [ChildHeart@nsscg.nhs.uk](mailto:ChildHeart@nsscg.nhs.uk)

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

Have you received your copy of  
**'The Need for Change'?**

Order a copy on **020 7025 7520** email [nhsspecialisedservices@grayling.com](mailto:nhsspecialisedservices@grayling.com) or download from [www.specialisedservices.nhs.uk/safeandsustainable](http://www.specialisedservices.nhs.uk/safeandsustainable)

Are you on our email list? Please email [nhsspecialisedservices@grayling.com](mailto:nhsspecialisedservices@grayling.com) if you would like to receive information about the review

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## Safe and Sustainable

Children's Heart Surgery in England