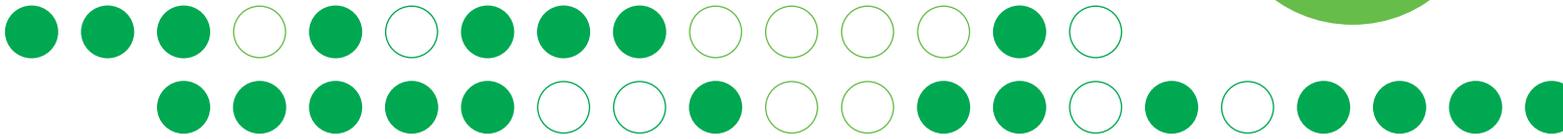


# Heartnews

issue three

May 2010



## Welcome

Welcome to the newsletter for Safe and Sustainable: Children's Heart Surgery in England. This newsletter aims to provide you with the latest update on our journey towards providing the best possible care for children and young people with heart conditions.



We want a world class, safe and sustainable service that we can rely on to provide the very best standards of care. From May an independent panel of experts led by Sir Ian Kennedy will begin a thorough assessment of the 11 NHS centres that currently deliver children's heart surgery services in England. In this newsletter we introduce you to the panel, the assessment process and the standards each centre will be assessed against before any decision is made regarding which hospitals will become designated surgical centres.

We now have a new proposed model of care, as outlined in 'The Need for Change' published in April, but how will this work for parents, clinicians and support staff at a regional level? We'd love to hear your views, which is why we will be holding a number of regional engagement events for parents and stakeholders in the coming months. Further information on what to expect from the events, how to get involved and a contribution from the Children's Heart Federation can be found later in the newsletter.

We do hope you take the opportunity to attend your local engagement event as your input is important to the development of regional services. In the meantime, we hope this newsletter answers any questions you may have about what will happen next as we move towards a safe and sustainable service.

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

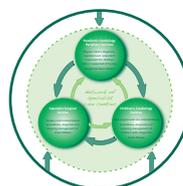
Copies can be ordered  
by calling **0207 025 7520**  
or emailing  
[specialisedcommissioning@grayling.com](mailto:specialisedcommissioning@grayling.com)



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

### *In this newsletter*

- The assessment process explained
- Meet the assessment panel
- Get involved
- News from the Children's Heart Federation



# The assessment process explained

## *What part do the centres play in the assessment process?*

Before the assessment panel begin their visits to the 11 centres in May, the centres were asked to assess themselves against a range of agreed standards that have been developed by experts in congenital heart disease. You can view the standards below and they are also on our website [www.specialisedcommissioning.nhs.uk](http://www.specialisedcommissioning.nhs.uk)

The information provided by each centre will also help the panel to ensure that any suggested configurations of services capture the excellent work already being carried out around the country.



## *What will the centres be assessed against?*

All centres will be assessed against standards that were developed by experts using parent and stakeholder feedback from events held last year:

- Centres should have appropriate and robust links with other hospitals that provide children's cardiology services within the regional and local network. These other hospitals will provide inpatient and outpatient care before and after surgery, as appropriate, so it is essential for us to ensure that these network arrangements can work as effectively as possible
- All surgical centres should employ a minimum of 4 consultant congenital cardiac surgeons, and should perform no fewer than 400 paediatric procedures and ideally no fewer than 500 paediatric procedures each year. This is to ensure that "occasional practice" is avoided, so that each surgeon and their teams have an adequate workload to ensure that their experience is maintained
- Each surgical centre should provide a full 24 hour emergency service and paediatric cardiac cover at all times
- There should be dedicated clinical facilities that are designed around the needs of children
- All care should be tailored to the specific needs of each patient, particularly taking account of their developmental age
- Arrangements should be in place to allow parents, carers, children and young people to participate actively in decision making at every stage in their child's care
- Centres should have clear quality plans in place, which show how they will continually monitor the outcomes of their service, and use research, audit and education to continually improve into the future.



# Meet the assessment panel

## Biographies

### *Sir Ian Kennedy*

Sir Ian Kennedy is Chairman of the multi-disciplinary panel of experts chosen to visit the 11 NHS centres in England currently providing children's heart surgery services.

Sir Ian chaired the public inquiry into the care of children receiving heart surgery at the Bristol Royal Infirmary between 1984 and 1995. The subsequent report in 2001 made a number of recommendations around safety, medical competency and public involvement relevant to the NHS as a whole. He was Chair of the Healthcare Commission from 2003 to 2009, after which he became Chair of the Kings Fund inquiry into the quality of general practice in England.

### *Dr Michael Godman*

Dr Godman is a retired Consultant Paediatric Cardiologist. He worked in the Royal Hospital for Sick Children in Edinburgh until 1999, during which time he was also a Senior Lecturer in the Department of Child Life and Health, and the Medical Director for the hospital. From 1999 to 2008 he worked in Riyadh, Saudi Arabia as Co-Chairman of the Department of Cardiac Sciences. He is Chairman of the Association of European Paediatric Cardiologists, and also President of the British Paediatric Cardiac Association.

### *Maria von Hildebrand*

Maria von Hildebrand has been working in patient and public involvement since 1995. She is the founder of Constructive Dialogue for Clinical Accountability, a national charity set up in partnership with patients, the public and clinicians. The objective of her work has been to improve the information exchange between health care professionals and patients, to ensure knowledge and the responsibility of informed consent is shared to enable improved quality and safety outcomes for public benefit. In June 2009 she took up her current post as Patient and Public Stakeholder Engagement Manager for the Research Capability Programme.

### *Dr David Mabin*

Dr Mabin is a Consultant Paediatrician specialist in paediatric cardiology working for the Royal Devon & Exeter NHS Foundation Trust. He is the Convenor for Paediatric Cardiology at the Royal College of Paediatrics and Child Health. He also sits on the British Congenital Cardiac Association Council and is Clinical Sub-Dean at the Peninsular Medical School in Exeter.

## *What part does the panel play in the assessment process?*

During May an independent panel of experts, led by Sir Ian Kennedy, will visit each centre to assess their ability to meet the agreed standards in the future. The panel will have the opportunity to speak to parents and to each specialist team and to view working practices. It will then combine the information gathered from these visits with the information provided by each centre as part of the self assessment process. The results of each assessment will be passed to the NHS so that it may use them to test potential configurations with the aim of creating the very best service to suit children and their parents.

## *What next?*

Recommendations for which centres should become designated surgical centres will be published in October 2010 for public consultation. We will be calling on parents, young people and stakeholders to give us their views on the proposed changes.

### *Mr James Monro*

Mr Monro was a Consultant Cardiac Surgeon in the NHS until 2004. He was President of the Society of Cardiothoracic Surgeons of Great Britain and Ireland from 2000–2002, and during this time was co-chairman of the committee that produced the "Report of the Paediatric and Congenital Cardiac Services Review Group". He was also closely involved with the UK Central Cardiac Audit Database (CCAD). Mr Monro was President of the European Association for Cardiothoracic Surgery in 2003 and 2004 and founding Chairman of the EACTS Congenital Cardiac Surgical Committee.

### *Dr Neil Morton*

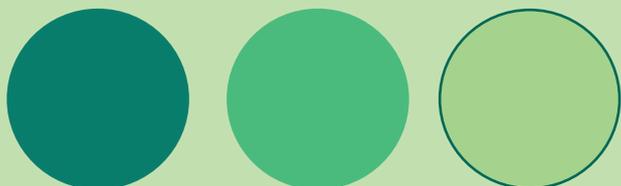
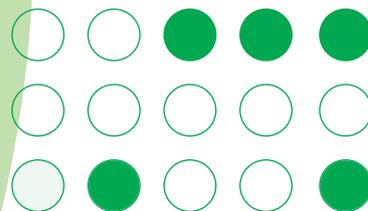
Dr Morton is a Consultant in Paediatric Anaesthesia and Pain Management at Royal Hospital for Sick Children in Glasgow and a Senior Lecturer at University of Glasgow. He has specialised in paediatric cardiac anaesthesia since 1989. He is currently President of the Association of Paediatric Anaesthetists of Great Britain and Ireland and Editor-in-Chief of the international Journal of Paediatric Anaesthesia.

### *Sally Ramsay*

Sally Ramsay is registered as a children's nurse. Her NHS career culminated in eight years as Director of Nursing in a children's hospital. For the past seven years she has worked independently. Her work has included service and education reviews, preparing expert reports and writing standards and clinical guidance documents for the Royal College of Nursing.

### *Julia Stallibrass MBE*

For the last 20 years Julia Stallibrass has worked in the NHS in various public health and commissioning roles, most recently as Head of Specialised Services Commissioning in the National Specialised Commissioning Team. She has also worked for the Department of Health where she was the policy lead for commissioning specialised services. Whilst at the Department of Health she produced the Carter Report in 2006 on the 'Review of Commissioning Arrangements for Specialised Services'. She retired in 2009 and in that year she received an MBE for services to the NHS.

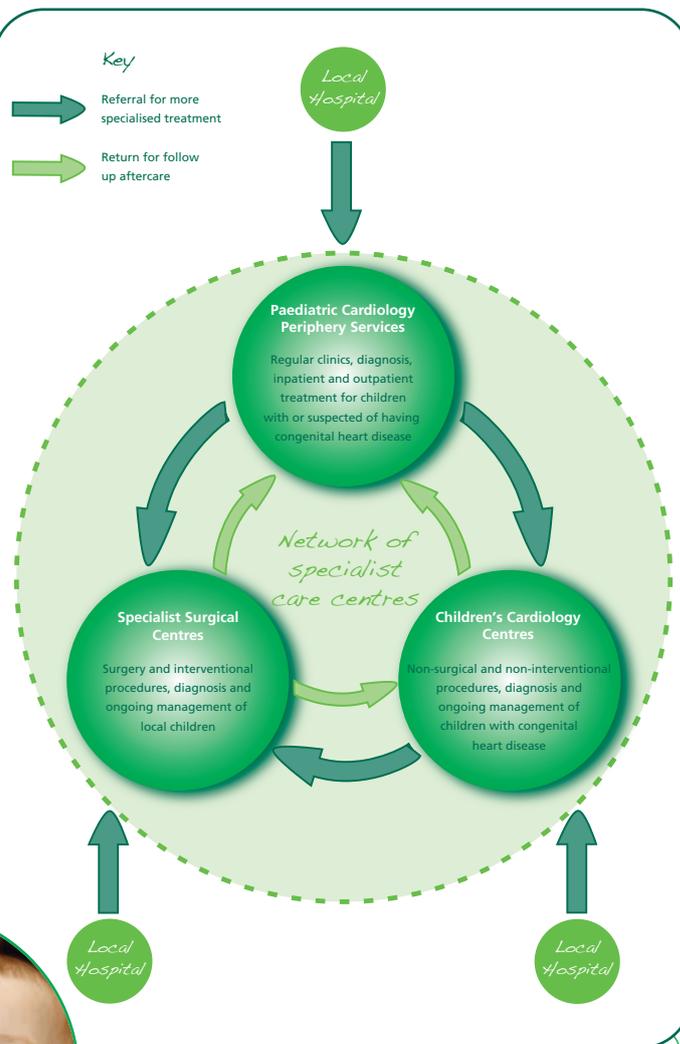


## Get involved . . .

The new proposed model of care, set out in 'The Need for Change' document, will help us to ensure that children get the best possible care. We know that surgery is usually only a small part of a child's treatment. However, the ongoing management of conditions means that children and their parents often need to make regular visits for cardiology services. The proposed new model is designed so that these regular visits are carried out at a hospital near you and by experienced clinicians and support staff working in an expert network of services.

Therefore, we want you to help us shape the future of regional services in your area. We will be holding a number of engagement events across England with the aim of getting your feedback on what you need from your regional cardiology services, what works well and what needs to change.

These events are an opportunity for you to help us to understand what a regional service might look like under the proposed new model for care.



## Join us at one of these events

Leicester	Wednesday 9 June	17.00-20.00	Leicester Tigers Stadium
Birmingham	Monday 14 June	18.00-21.00	Maple House
Oxford	Tuesday 15 June	17.00-20.00	The Oxford Centre
Warrington	Wednesday 16 June	18.00-21.00	Halliwel Jones Stadium
Leeds	Thursday 17 June	17.30-20.30	Leeds Town Hall
Southampton	Monday 21 June	18.00-21.00	Southampton General Hospital
Plymouth	Monday 28 June	11.00-14.00	Holiday Inn, Armada Way
Bristol	Tuesday 29 June	11.00-14.00	Marriott Hotel
Newcastle	Tuesday 1 July	18.00-21.00	St James' Park Stadium
London	Saturday 3 July	10.30-14.30	Science Museum

## To register

Visit: [www.eventsforce.net/specialisedcommissioningevents](http://www.eventsforce.net/specialisedcommissioningevents) and register for your nearest event



## A note from the Children's Heart Federation

At CHF over the past year, conversations about the Safe and Sustainable children's heart surgery review have sometimes reminded us of the man who asks for directions and is told, "To get there, I wouldn't start from here." Parents have pressed for a broadening of the agenda from a focus on surgery to include cardiology, support in the community and transition to adult services.

I'm delighted to say that those concerns have been picked up in the proposed model of care in the new 'Need for Change' document. We do have to start from where we are, from the NHS commitment to improve surgical services – something for which families have been campaigning for some time. At the same time as focusing on the surgical care pathway, we now have an outline blueprint that allows us to consider the whole system of children's heart care.

This is the time for parents to talk in more detail with commissioners about how the proposed model of care could work in practice: 'what good looks like' from a parent and patient point of view.

The NHS has created an opportunity for that sharing of priorities in a series of engagement events around the country in the coming two months. I would urge any parent to take part. You are an 'expert by experience' of what helps heart children and their families when they face the huge

stresses and challenges of life with a heart condition. You will have a chance to talk about what works well and what needs changing for the children's heart care system of the future, testing the proposed system against the realities of your experience.

It is a real opportunity for parents to have a direct line to NHS commissioners while so much is still open to influence. CHF has pressed for as much parent involvement as possible – now is your chance to shape the system for families in the future. Please book your place, because no one else can share your experience like you can.



**Anne Keatley-Clarke**  
CHF Chief Executive

### Have your say

We are always keen to hear from anyone who may have questions or feedback on the future delivery of children's heart surgery services in England. You can do this in the following ways:

- Write to Jeremy Glyde, Programme Director, National Specialised Commissioning Team, 2nd floor, Southside, 105 Victoria Street, London, SW1E 6QT
- Call Jeremy on 0207 932 3958
- Email [ChildHeart@nsscg.nhs.uk](mailto:ChildHeart@nsscg.nhs.uk)