

News

The new Congenital Heart Disease review: 7th update – John Holden

23 September 2013

Your feedback

Thank you for your continued feedback. There are two issues I wanted to highlight this week:

- Membership of Clinical Reference Groups (CRGs)
- The work of the CRGs and how this links to the work of the review

Membership of CRGs: Concerns have been raised about public/patient representation on the Clinical Reference Group (CRG) responsible for congenital heart disease, and in particular the process by which members were appointed. Each CRG has four patient experience representatives. Members were recruited through an open process ([described in full here – CRG information pack](#)). And – as with every other CRG – public and patient involvement can be achieved in other ways. All patients and their representatives may also register as stakeholders of the CRG(s). In my [5th blog \(23 August\)](#) I highlighted the opportunity to [become a stakeholder](#) and to tailor your involvement according to your level of interest.

The work of this review, and the work of the CRGs (responsible for developing commissioning products such as service specifications) are separate. The review has no role in making appointments to CRGs. So – we have drawn the concerns raised with us to the attention of the chair of the CHD group and James Palmer, NHS England’s Clinical Director for Specialised Services (who has responsibility for all the CRGs). They will consider and decide any further action that may now be required. This issue will be dealt with in the same way as for any other CRG, and the resolution of any issues will be decided in accordance with the same rules which would apply to any other CRG.

The work of the CRGs and how this links to the work of the review: CRGs provide NHS England with clinical leadership and user engagement in support of specialised commissioning. CRGs develop commissioning “products”, including scope of services, policies, service specifications, and quality measures and “dashboards”. Service specifications set out what is

expected from service providers, and define access to a service. The work of the new CHD review is related to a number of CRGs, but most closely to CRG E05: Congenital Heart Services.

In my last blog I included Sir Bruce Keogh's letters in which he wrote to the clinicians who are leading two strands of work on the development of standards. In parallel I have also written to ask Professor Deirdre Kelly to oversee the completion of the review's work on additional standards for children's congenital heart services, and – working with the other standards groups – to make a joint recommendation on a single combined set of standards. The correspondence is here - [letter to Professor Deirdre Kelly](#), [letter to John Holden](#). Once the work of developing proposed standards for congenital heart disease services has been concluded, these standards will be passed to the congenital heart CRG to be included in a proposed updated specification. This specification will then be subject to a full 12 week public consultation. **This will allow everyone, not just members of the CRG, to have their say on the specification and its standards.** Following this the CRG will make recommendations to NHS England on the final specification for children's and adult congenital heart services. More information on [clinical reference groups can be found here](#).

The review will manage its links with the CRGs through the National Clinical Directors for i) Specialist Services, ii) Children, Young People & Transition to Adulthood, and iii) Cardiac Care.

Patients, families and their representatives

On 13 September I attended a meeting of the Yorkshire & Humber Joint Health Overview and Scrutiny Committee, in Leeds. On 18 September I attended the monthly meeting of the Health Scrutiny Committee for Lincolnshire, in Lincoln. Notes of these meetings will be prepared by the relevant bodies, and when they are available I will share them here. I found both events to be really helpful and constructive; an opportunity for me to explain how we are approaching the new review, and for Councillors to raise concerns and emphasise the importance they attach to early and continuing engagement.

On 9 October NHS England will attend a meeting of the [All-Party Parliamentary Group on Heart Disease](#) – to discuss the provision of congenital heart disease services and the new CHD review. The group is chaired by Chris Ruane MP and is an opportunity for MPs and peers (members of the House of Lords) to hear the latest developments and to express their views. The meeting has been arranged by the British Heart Foundation who act as secretariat to the All-Party Group. For more information about viewing the meeting please contact Rachel Almeida almeidar@bhf.org.uk.

Clinicians and their organisations

The first meeting of our Clinical Advisory Panel will be on 15 October. We will provide more information nearer the time.

We would like the new review to have some external, international perspective. **Professor Pedro del Nido**, Chief of Paediatric Cardiac Surgery at Boston Children’s Hospital, USA, has kindly agreed to provide advice and support to Professor Sir Mike Rawlins (chair of the Clinical Advisory Panel).

NHS England and other partners

I have previously referred to some of the work we have underway, eg, to describe our proposals for advisory & decision-making processes, to resolve questions about the scope of the review, and so on. This remains a work in progress and we will provide an opportunity for everyone to see it and to give us their views. But experience tells us that if we don’t set everything in context and instead just reveal part of the picture then – not unreasonably – it sets lots of hares running and generates lots of questions. So our preferred approach is to pull together the different strands, which we will be doing at the next meeting of our Board’s task and finish group (I’ve previously referred to this as a “sub group”, or “committee”). The task and finish group is due to meet on 30 September and will be asked to consider and provide an initial steer on:

1. draft governance, advisory, participation and involvement arrangements (including proposed terms of reference),
2. draft publication scheme (what correspondence and documents we will routinely publish)
3. proposals for the scope of the new CHD review (which services are included in the review and which are not)
4. proposals for how we will develop a “proposition” (about the options for future CHD service delivery, on which we can engage with stakeholders from Autumn onwards).

Papers will be published on **our web pages** and we will invite comments from all interested parties.

We have asked NHS England’s analysts to develop a proposal for refreshing the data which underpins our understanding of the services currently being provided, and which may be required in future. The draft specification they have drawn up for the first stage of this work is attached here – **CHD analysis scope note**. We welcome views on the approach described. We are asking clinicians which procedures and diagnoses are relevant to this analysis. To start the discussion our analysts have identified the attached list of diagnoses and procedures – **CHD diagnoses and procedures** as possibly relevant to the data refresh. This work will provide us with a basic data set, including the most recently available data on volume of activity by procedure (for both adults and children, at all providers), and will help shape assumptions about future demand in the light of demographic change, clinical developments and other factors. We do not think that this is the only analysis we will need; we will need further analytical work to examine specific issues as part of this review. We welcome views from all stakeholders on the proposed analytical work and the procedures and diagnoses in question. If you have any comments please submit them to our email address – england.congenitalheart@nhs.net