

# News

## The new Congenital Heart Disease review: 13th update – John Holden

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### Your feedback

We often get questions about Patient & Public representation on the CHD clinical reference group (CRG). It's become a bit of a *cause celebre* – there is a concern that some people who wished to be patient representatives on this CRG were excluded. This has been investigated, and NHS England is satisfied that there was no process failure and that no applications which had been correctly submitted were overlooked. However, this debate reinforces what we already knew, that patient and public representatives very much want to be involved in the work of NHS England, especially in those clinical reference groups which are dealing with services where major change could result. This was discussed at our recent Programme Board (see below), which includes Mr James Palmer, who is National Clinical Director for Specialised Commissioning, and Giles Wilmore, who is Director for Patient & Public Voice. It was agreed by the Programme Board that for those CRGs where this is a particular issue, we should take the opportunity to strengthen patient and public representation, with eight members rather than the usual four. So, NHS England will shortly announce a process to add another four patient and public members to the existing four on the congenital heart CRG (and the same approach will be adopted on a few other CRGs: Neurosciences; Chemotherapy; and PET-CT).

### Patients, families and their representatives

We are holding an event in Birmingham on 8 January to which we are inviting local authorities and local Healthwatch for those areas which currently host a congenital heart centre. The intention is to raise awareness amongst all these authorities and to provide an opportunity for all to discuss and debate. We will be discussing the outline plan for the event in advance, but our working plan is that it should cover the following items:

- Update on the new review – what has been done, what is in plan, what the timelines are and the plan of the year ahead.
- Summary of the outputs from clinical, provider and patient engagement groups, how we are responding to the “difficult issues”.
- Opportunity for questions from the floor and identify any items of particular concern for attendees

One of the topics I would like to discuss is the timing of local elections and the implications of “purdah” (restrictions on local authority activity during the pre-election period) for any engagement or consultation that would otherwise take place, since this presents a risk to our review’s timetable.

We are making separate arrangements to engage with the wider local authority community in England.

The date of our next Patient & Public Group meeting has been set for **21 January 2014**. Further details to follow.

### **Clinicians and their organisations**

NHS England’s analysts have been working on refreshing the data and analysis which underpins our understanding of the services currently being provided, and which may be required in future. I first provided a [summary in blog 7 \(23 September\)](#) and since that time the specification has been refined in the light of feedback from clinicians and others. We have been working with clinicians to define which procedures and diagnoses are relevant and have identified a [list of relevant procedures](#). 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. An [update of where we are with this work is attached here](#), amendments to the original specification have been shown as successive updates to the end of the note so you can follow the trail. This initial analysis is focused on the demand for specialist inpatient congenital heart disease care; at a later stage we will be carrying out a full capacity and impact analysis also. The [enclosed slide pack](#) aims to provide an overview of the review’s analytical programme. We welcome views from all stakeholders on the proposed analytical work and the procedures and diagnoses in question. If you have any comments on this work please submit them to our email address – [england.congenitalheart@nhs.net](mailto:england.congenitalheart@nhs.net)

On 19 November Michael Wilson and our review’s lead analyst Jo Glenwright met representatives of NICOR – the National Institute for Cardiovascular Outcomes Research. NICOR run the Congenital Heart Disease Audit using patient information collected by the Central Cardiac Audit Database (CCAD). NICOR are experts in using this data and producing outcomes analyses. They discussed whether the information collected could be used to further understand the relationship between certain factors and patient outcomes –whether, for example, there is any association between certain outcomes and type of procedure, patient ethnicity, distance from surgical centre, access to related services, and number of procedures carried out by a surgical centre. It was agreed that NICOR would investigate this, but also recognised that there are serious concerns that existing data on patient outcomes is limited, and any analysis could only show association not causality (and there may be some complicated inter-relationships), and the amount of data may be insufficient to give reliable (statistically significant) answers. Given these limits there are risks to be addressed in interpreting any results. The agreed next steps are that NHS England will formally describe the data questions it is most interested in, and NICOR will

respond. We will publish our formal request to NICOR, their response, and any subsequent analysis.

The date of our next Provider Group meeting has been set for **15 January 2014**. The date of the next Clinicians' Group meeting has been set for **30 January 2014**. Further details on both meetings to follow.

### **NHS England and other partners**

The new CHD review Programme Board met on 13 November; a [DRAFT note of the meeting is here](#). The note will remain draft until ratified at the next Programme Board meeting (due 16 December).

MPs and peers (members of the House of Lords) ask questions of health ministers, and the answer (or the transcript when there is a debate) is published in Hansard. [See here for a question relating to the new CHD review which was answered recently](#).

We are now overdue publishing the notes of one or two of our recent meetings. I want to avoid any excess delay so I will produce a short blog next week (Monday 16 December) to sweep up any outstanding items, so you have something to read whilst roasting chestnuts over an open fire etc. There will then be no further blog in December but I will resume again in January – most likely on 13 January (this is a change from earlier plans).