



# The new Congenital Heart Disease review: 15th update – John Holden

13 January 2014 - 16:01

It's the first blog of 2014 and so I'd like to wish my reader(s) a Happy New Year.

## Your feedback

A question was raised with us about membership of the Clinical Advisory Panel. The specific question was about representation for paediatric intensivists, but it raises a more general point about how the review gets comprehensive clinical advice. Members of the Clinical Advisory Panel have been selected to bring a breadth and depth of experience from the whole range of medical practice, so that we can benefit from an understanding of how similar issues are tackled not just in CHD but also in other specialities, and to ensure that we never consider CHD completely in isolation.

The Panel's role is to provide clear advice to the review, taking account of the best evidence available and also the wide range of clinical opinion. We have judged that to best achieve this, the Panel's membership must be limited to a manageable size.

Of course this creates a risk that some specialties or groups may feel they don't have a seat at the table. To ensure that every clinical group with an interest in the review's work has the opportunity to hear about the work and to contribute, the review has also established a clinician group with a very broad membership that includes representatives from:

- every English provider trust identified as providing any congenital heart surgery or cardiology intervention or with a specialist congenital cardiology centre
- Welsh, Scottish and Northern Irish hospitals providing specialist congenital heart services
- relevant professional colleges and societies covering the main clinical professions and specialist groups involved in delivering care for congenital heart disease.

We also had a meeting with Local Government (see below) at which, amongst other things, attendees pointed out to us that we don't say much about the role of Health & Wellbeing Boards (HWB). There is one HWB for every Local Authority, and its purpose is to bring together the relevant health, public health, social care professionals and other stakeholders to ensure a joined

up approach to meeting the needs of the local population. We will reflect on this feedback, and explain how we propose to make sure that HWBs can play their full part in the review.

### **Patients, families and their representatives**

John Holden, Michael Wilson and Claire McDonald (our engagement adviser) held a meeting in Birmingham on 8 January 2014 to which we invited all those Local Authorities who host a congenital heart surgical centre, and representatives from national and local Healthwatch. The [agenda is here](#) and the [slides we used for the meeting are here](#). We will provide a write up of the meeting shortly.

The next meeting of our Patient and Public Group is on **10 February 2014** in London. This is a change from the originally advertised date.

### **Clinicians and their organisations**

The next meeting of our Provider Group (engagement with Chief Executives and other senior leaders of provider organisations) is on 15 January 2014 in London. The [agenda for the meeting is here](#).

The next meeting of our Clinicians' Group is on **30 January 2014** in London.

We want to look at all possible sources of evidence that can aid our understanding of how best to deliver future congenital heart disease care. As part of this, we want to explore what evidence there may be in existing data and academic literature (including international comparisons). Therefore, we need to a) commission an analysis of the existing data and b) undertake a literature review.

For the analysis of existing data, I outlined in [Blog 13](#) the work we are commissioning from NICOR, to see whether the information they collect could be used to help understand the relationship between certain factors and patient outcomes. For example, this might show whether there is any association between 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. This work is in progress we will provide further updates in due course.

In addition, we have asked the NHS National Institute for Health Research (NIHR) to commission a literature review under their Health Services & Delivery Research (HS&DR) Programme. The NIHR is a large, multi-faceted and nationally distributed organisation, funded through the Department of Health to improve the health and wealth of the nation through research. The NIHR Health Services and Delivery Research (HS&DR) Programme funds research to produce evidence on the quality, accessibility and organisation of health services. This includes evaluations of how the NHS might improve delivery of services.

This programme is contracting with The University of Sheffield, School of Health and Related Research (SchARR) who have expertise in academic literature reviews of health care service design and this team, on our behalf, will undertake a systematic review of the literature to understand how organisational factors may affect patient outcomes.

We have asked the reviewers to complete a conflicts of interest form. More information on NIHR, their HS&DR Programme and SchARR can be found at the following links.

- [The National Institute for Health Research \(NIHR\)](#)
- [The NIHR Health Services and Delivery Research \(HS&DR\) Programme](#)

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

On 7 January NHS England published on its website an “invitation to [change proposals for specialised services](#)”.

The invitation is for patients, public and professionals to submit [ideas of how changes could be made to specialised services](#). Clearly, as we are already well underway with this review, it would be a little odd to run a parallel process for congenital heart disease services, and so any ideas **regarding CHD services** which are submitted in response to invitation above will be forwarded to the new CHD review team to deal with

On 7 January 2014 the Board’s Task & Finish Group met in London. The [agenda and papers for the meeting are enclosed here](#). A note of the meeting will be available shortly.

The next meeting of our Programme Board is on 14 January 2014 in London. The [papers for the meeting are now available to view here](#).

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