

The new Congenital Heart Disease review: 9th update – John Holden

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Your feedback

Thank you for your continued feedback, on the blog and elsewhere (our email address is england.congenitalheart@nhs.net). Amongst other things, you have

- reminded us we need to listen to the views of Healthwatch (local and national);
- expressed concern about the tight deadlines for commenting on papers;
- told us that some of the services we might consider “out of scope” of the review are in fact key to its outcome, and
- asked whether we are being even-handed in our dealings with each of the surgical centres, their supporters and representatives.

I'll deal with each of these in turn below.

Healthwatch: I've been discussing with Katherine Rake, Healthwatch England's CEO, how best NHS England can engage with Healthwatch on the new review of congenital heart disease. She has impressed on me that Healthwatch is much more than the national body, and that we should take full advantage of the opportunity presented by the experience and expertise in local Healthwatch groups. We both agree there needs to be an explicit opportunity for local Healthwatch to express their views and begin a dialogue; we'll say more about how we plan to achieve that shortly. In addition we've also asked Healthwatch England how they would like to be involved in our patient and public group: this is likely to be as observers. I will provide further updates in due course.

Tight deadlines: We've been criticised for publishing the Task & Finish Group papers only a few days before that Group met. I accept that it is in everyone's interests that we give as much notice as possible. In an ideal world, the papers would have been published earlier, but as ever, we are trying to strike a balance between making rapid progress, being as open as possible, and maximising opportunities for engagement. (For example, in allowing more time for everyone to feed in their comments on the Task & Finish Group paper on scope of the review (see below), we have reduced the time available for the members of the Clinical Advisory Panel to see this paper in advance of their meeting. Trade-offs like this are inevitable). Our timing was in accordance with our publication scheme (which commits to publishing the agenda and papers) and with the Task & Finish Group's own terms of reference. Of course we can always do better and we will try. But I don't accept some of the more strident criticism which implies we are manipulating the process, or even breaking the law. On the contrary: publishing the papers for the review's working groups, and inviting comment, is a practical example of our commitment to openness and transparency.

Services outside the scope of the review: Our Task & Finish Group provided an initial steer on scope, and we have received comments from stakeholders, all of which will help shape the discussion at our Clinical Advisory Panel (CAP) on 15 October. The paper on scope will be issued only shortly before the CAP meeting, reflecting the fact that we want to take account of the feedback we have received. CAP will make recommendations to help the Task and Finish Group to reach a decision. Some concerns have been expressed that if we define scope too narrowly we might close down an important line of discussion, or fail to make sense of the complex dependencies between services. In turn, so the argument goes, this might not only disadvantage certain groups, it may also favour some centres more than others, and so we are – deliberately or inadvertently – determining the outcome of the review. In fact, what we are doing is precisely the opposite – we are trying to ensure that the review strikes a sensible balance between scope which is too broadly defined, and therefore undeliverable in any meaningful timescale, versus scope which is too narrow, and inappropriately excludes patient groups who depend on CHD services. Even if we decide that a service is “out of scope” this does not simplistically mean that we will ignore it, as if it didn’t exist. It means the review will not seek to determine how that service should be delivered, but we will take full account of the links to CHD services. So if the standards which are set for CHD require us to take account of those excluded services (for example requiring that they are co-located with CHD surgery) then we will ensure this is factored into our review’s conclusions.

Even-handed approach: I hope it is clear from these remarks that we are striving to be sensible, consistent and even-handed in the way we go about this review, but in spite of this we are regularly challenged as to whether some action or inaction by NHS England reveals a preference for one centre or another. Here’s my response to a selection of concerns from recent blogs –

- The reason NHS England’s Dr Mike Bewick met the Leeds Charity CHSF was to discuss the review of surgical safety at Leeds, which has been ongoing since Easter. He is not involved in the national CHD review, and I am not involved in his work.
- The reason I have not met other Overview & Scrutiny Committees yet is because I took expert advice from the Local Government Association and the Centre for Public Scrutiny. They told me to prioritise the three OSCs who referred *Safe and Sustainable* to the Secretary of State. We are convening a meeting of council leaders for other areas to discuss how best to involve them.
- The fact that we want to work with the Children’s Heart Federation, or Somerville Foundation, or British Heart Foundation, or CHUF, or CHSF, or Little Hearts Matter, etc., does not mean we are “taking sides”. We will talk to anyone who can help us.
- The fact that some clinicians who have reached national prominence might know each other or have trained together is hardly surprising in a relatively narrow field of activity, in a country the size of ours. It is not evidence of collusion.

And so on. We don’t have the time to mount a defence against every charge, or to dismantle complex conspiracy theories, so please don’t assume that silence means agreement. Judge us by our actions, and please get involved in the review and help to shape it.

Patients, families and their representatives

Yorkshire and Humber Joint Health Overview & Scrutiny Committee have now published their [draft minutes of the meeting](#) I attended on 13 September. The minutes will remain in draft until they are formally approved by a future meeting of the Committee.

On 9 October our Medical Director, Professor Sir Bruce Keogh, and Programme Director for the new review, Michael Wilson, attended a meeting of the All Party Parliamentary Group (of MPs and peers) in Committee Room W1 at the Houses of Parliament. For a [list of attendees see here](#). Michael gave a short [presentation which is available here](#).

We will produce a note of the meeting and post it on our webpage (with a link in the blog). It was not possible to answer all the Group members' questions in the time available at the meeting, so we have offered to provide written responses and we will also publish a link to those answers as soon as they are available.

On Friday 25 October I will attend the meeting of the Joint Scrutiny Commission for Leicester, Leicestershire and Rutland in Leicester.

We have set up a patient and public group, chaired by Professor Peter Weissberg (of the British Heart Foundation), to bring together representatives from every local and national charity with a direct interest in the review. The group's first meeting has been scheduled for November 12 in London. The full list of invitees is being finalised and will be available very shortly on [our web page](#). If you think we've missed a group or organisation that should have been invited please let us know.

Clinicians and their organisations

The Clinical Advisory Panel (CAP), chaired by Professor Sir Michael Rawlins, meets in London on 15 October. Amongst other things CAP will consider the scope of the new CHD review, and provide a recommendation to the Board's Task and Finish Group on this. The [agenda and papers are here](#). The final paper on scope will be added to our web page later and takes account of your feedback (following the publication of Task and Finish Group papers on 27 September).

The [updated paper on scope which takes account of your feedback](#) (following the publication of Task and Finish Group papers on 27 September) is now available.

We have also set up a clinicians' group, chaired by Professor Deirdre Kelly (who also chaired the group developing additional standards for paediatric congenital cardiac care), to bring together representatives from every congenital heart centre, and other relevant clinicians. The group's first meeting will be held in London in November. The full list of [organisations that have been invited to send representatives is attached here](#). If you think we've missed a group or organisation that should have been invited please let us know.

We have set up a provider executives' panel, chaired by Chris Hopson (CEO of the Foundation Trust Network), to bring together the senior managers from those provider organisations most directly affected by the new CHD review. The panel's first meeting has been scheduled for November 19 in London. The [full list of invitees is attached here](#). If you think we've missed a group or organisation that should have been invited please let us know.

NHS England and other partners

We now have a [transcript of the discussion at our Board meeting](#) on 18 July (the video has been online for some time).

The minutes of the Board Task & Finish Group, which met on 30 September, will be available very shortly on [our web page](#).

Back in August I said that I was aiming to publish a blog every fortnight and I've roughly stuck to that plan, although I interrupted the cycle on 27 September to tell you about the papers for the Task & Finish Group. I am now back in a fortnightly routine and so future publication dates are likely to be on or around:

- Monday 28 October
- Monday 11 November
- Monday 25 November
- Monday 2 December
- Monday 16 December