

# News

## The new Congenital Heart Disease review: 12th update – John Holden

25 November 2013 - 18:15

### Your feedback

In the last couple of weeks we've had a series of face to face meetings with three different engagement groups, which have helped us to understand what's important to them, and how we work together in a way that's challenging, honest, and productive. I gave the same ["Update" presentation to all three groups – you can see it here](#). There will be notes of the meetings in due course and I have given a flavour of each of the three meetings further down this blog. The general point I'd want to make is that every meeting had a mix of general discussion, constructive suggestions and direct criticism – about the current (and previous!) processes, timetable, next steps, weariness, case for change, patient safety, and so on. From our perspective this is invaluable and the challenge now is to use what we've learnt to improve what we do. All three groups said they'd like to meet again in the new year.

One issue that I've been asked to highlight in my blog is the use of pulse oximetry – a simple test on new-borns which can help pick up heart problems that might otherwise go undetected. The National Screening Committee (part of [Public Health England](#)) is currently running a consultation on the evidence for using this technique. Although their work is separate from NHS England's review, we're very interested in better detection of heart problems, so I'm drawing this to your attention in case you wish to respond. The link is here to the [UK NSC policy on Congenital heart disease screening in newborns](#). There is a "comments form" to complete, but I'm told by those running the consultation that it's not essential to use this. Responses should be sent to [screening.evidence@nhs.net](mailto:screening.evidence@nhs.net) by 13 December.

### Patients, families and their representatives

On 12 November Michael Wilson and I attended the Patients & Public Group, which brings together local and national charities. The meeting was chaired by Peter Weissberg from the British Heart Foundation, and NHS England's "Patient Voice" team helped to facilitate the event. I felt that we had a really productive session, in large part because attendees were very open about what they wanted out of it, and what wasn't working for them. [The slide pack for the meeting – which includes questions added during the meeting – is attached here](#). Amongst other things we tried a [live twitter feed](#), which didn't generate a lot of tweets but did give us an insight into how we can reach out beyond the confines of a meeting room in London. We will keep learning from this and other events to help improve our engagement. Bill McCarthy, NHS

England's national policy director, joined us for the group discussion and Q&A. Amongst other things, the Group highlighted:

- Managing the risk of occasional practice – especially (but not only) in the care of adults
- The need for clarity, when setting standards, about the minimum number of cases for surgeons or interventional cardiologists, about case mix (of complexity, and adults/children), and what number of clinicians is required in a centre to ensure safe cover and a resilient service
- The perversity of any proposals which would require patients to travel past a congenital centre to be treated elsewhere – i.e. not for good clinical reasons, but simply to “make up the numbers”
- The potential for “sub specialisation” – whether every centre should undertake every procedure
- What exactly would it mean to have a national congenital heart service operating to national standards?

\*\*\*\*\*

The Patient Safety team in NHS England are currently recruiting a number of patient and public voice (PPV) representatives to sit on six Patient Safety Expert Groups and on the national Patient Safety Steering Group. For further information and application packs for these roles please see the [Patient Safety First website](#).

The six Expert Groups are:

- Mental Health
- Primary Care
- Surgical Services
- Children and Young People
- Medical Specialties
- Women's Health

The closing date to apply for either/or both the Steering Group and the Expert Groups is 9am, 2nd December 2013. Interviews for the national Patient Safety Steering Group only will be held on the 9th January 2014.

### **Clinicians and their organisations**

The [draft minutes of the Clinical Advisory Panel meeting on 15 October](#) are available here. The minutes will be formally agreed at the next meeting of the Panel.

On 19 November Michael Wilson and I attended the Provider Group, which brings together the Chief Executives or other senior leaders of hospitals providing congenital heart services. The meeting was chaired by Chris Hopson from the Foundation Trust Network. Amongst other things, the Group highlighted:

- Their interest in the substance of the issue (the pattern of service provision) and not just the process of review
- The importance of commissioning services which are sustainable and resilient to events – specifically, but not only, the financial implications.
- Whether all options really are “on the table” and up for debate – for example might one or only a few congenital centres undertake the most complex work?
- The risk of “chronic stagnation” – and therefore the importance of accelerating change where this was appropriate.
- Providers’ legitimate desire to help co-design the options for implementing change, without pre-judging the outcome of the review
- The importance of keeping workforce, training and research in mind whilst planning the future pattern of service provision

On 22 November, Michael Wilson and I attended the Clinicians’ Group, which brings together clinicians representing English providers of congenital heart surgery or cardiology intervention; Welsh, Scottish and Northern Irish representatives; and relevant professional colleges and societies. The meeting was chaired by Professor Deirdre Kelly who also chairs the work to align service standards. Professor Sir Bruce Keogh, NHS England’s national medical director, joined us for the group discussion and Q&A. Amongst other things, the Group highlighted:

- The need to explain simply and persuasively the case for change
- Support for the scope of the review and bringing adults’ and children’s standards together – but not going “back to square one” on standards which are largely uncontentious
- How will any proposals for change survive the inevitable challenges/objections?
- The need to make rapid progress – surgeons in some centres are under great pressure and yet delivering great results – this is not sustainable
- Reconfiguration has an unavoidable cost (double running etc) – any expectation of “cost neutrality” will be unacceptable
- How to “future proof” the service?

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

A list of dates of [future meetings of the Task & Finish Group, Programme Board, and NHS England’s main Board meeting in public](#), is attached here.

This blog is published fortnightly on a Monday. Planned publication dates are as follows:

- 9 December
- 16 December
- no blog on 30 December due to the Christmas holidays
- 6 January
- 20 January
- etc.

We have been asked whether it would be possible to issue an email alert whenever a new blog is published. We are happy to oblige, but we're conscious that some of you won't want any more emails. So, we will compile a mailing list based on our current records, and will send out alerts every fortnight with an option for you to "unsubscribe". If you don't think you're on the mailing list, but you'd like to be, please let us know at [england.congenitalheart@nhs.net](mailto:england.congenitalheart@nhs.net).