# The new Congenital Heart Disease review: 30th update – John Holden

3 September 2014 - 13:39

To those of you who have been on holiday – welcome back, I hope you had an enjoyable break.

In the CHD review team we have packed away our flip-flops and our attention is now focused entirely on the remaining things we have to do prior to the launch of 12 weeks' consultation on standards and service specifications. The target date for launch is Monday 15 September 2014, and although we cannot take for granted that we will get all the approvals we need, we are confident that we are ready to proceed.

### Your feedback

In response to blog 29 we were asked about the distinction between paediatric and adult services, and whether this was sufficiently clear in the review. In short, what is a child?

We rely on data from different sources (for example NICOR and HES) and these data sometimes use different ages to describe children (for example "up to 16", and "up to 18"). This is evident in our work on CHD activity levels, where we put the HES and NICOR data side by side. But as far as the review is concerned, it doesn't matter what age is used, so long as we understand the different numbers in order to draw sensible conclusions about current activity, future demand etc.

What matters is that hospitals have services for children and services for adults, and we are publishing one specification for each. The children's service must comply with the children's specification, and the adults' service with the adult specification. Children will migrate to adult services – so called "transition" – and the age this happens will vary depending on the child and on the service provided at the hospital where they receive their care. Most will have undergone transition by the time they are 18, many earlier than that, but there is no fixed point, and it's not necessary for us to establish a single definition for the purpose of the review.

## Patients, families and their representatives

In my last blog I told you about the joint meeting of all three of our engagement and advisory groups (Patients & Public, Clinicians' and Providers) that took place in London on 25 July 2014. A draft write up of the meeting, including a list of attendees is now available here.

We are making plans for a series of local events during the consultation period. The enclosed timetable sets out our current thinking, though we have not finalised all the details. On the advice of our stakeholder groups these will not be "town hall meetings" with speakers delivering their message from a platform. The events will be "drop-in" style, run during the afternoon and early evening, with displays and other information available as well as one or more review team members to answer questions.

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Another date for your diary: on 9 October 2014 there will be a national engagement event in Birmingham specifically aimed at Local Government and Healthwatch organisations. We will provide more detail in due course. Just to be clear – this is in addition to the local events we are hosting during the consultation period – there will be a separate event in Birmingham on 22 October 2014 for all interested local stakeholders.

### Clinicians and their organisations

The latest iterations of the draft standards are available via the links below. There have been no significant changes since we updated on the outcome of the last Clinical Advisory Panel, but the formatting has been, and will be continue to be tidied up ready for consultation.

- Paediatric standards
- Adult standards

Of course the consultation document itself (due to be published on 15 September 2014) will provide the necessary context and set out questions on which we are seeking views.

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Professor Deirdre Kelly (Chair of the review's Clinicians' Group) along with members of the review team made visits to Brighton on 13 August 2014, and Papworth on 15 August 2014. These were the last of three planned visits to a representative sample of units providing ACHD procedures outside the specialist congenital surgery centres.

# NHS England and other partners

As the August 2014 meeting of NHS England's Directly Commissioned Services Committee (DCSC) was cancelled, this paper (and annexes) was circulated by correspondence on 15 August 2014.

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On 20 August 2014, Michael Wilson (the review's Programme Director) attended a meeting of the Women and Children's Programme of Care (PoC) Board to formally present the draft service specifications and impact assessments for a recommendation to progress to the Clinical Priorities Advisory Group (CPAG). This is a key step in the specialised commissioning governance process to gain approval for us to consult on the proposed standards and service specification. You can read the papers we submitted to the meeting here.

At this meeting, the PoC Board recommended submission to CPAG for consideration at their meeting on 2 September 2014, subject to some changes to the documents. The papers were updated and submitted to the CPAG and can be viewed here.

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NHS England's Board Task and Finish Group met on 1 September 2014 – you can read the meeting agenda and papers here. As you can imagine, the main focus of the meeting was the ongoing preparation for the launch of consultation. A draft note of the meeting will be available in due course, but in the meantime please note that the Task and Finish Group delegated authority to the review's Programme Board to approve the launch of consultation.

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The review's Programme Board is due to meet on 8 September 2014 and the agenda and papers for the meeting can be viewed here.

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Issue 3 of NHS England's Specialised Commissioning Newsletter is now available here.