

News

The new Congenital Heart Disease review: 11th update – John Holden

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Your feedback

The main topic you've been commenting on has been the scope of the review, which was discussed by our Board's Task and Finish Group on 29 October 2013. They considered a recommendation from our Clinical Advisory Panel, who in turn had the benefit of over 40 contributions from public, patient and other stakeholders.

One of the lessons we learnt was that in our desire to talk plain English (proposing which services are "in" or "out" of scope") we over-simplified and, as often seems to be the case, set some hares running about what we were up to. So we realised quite quickly that the approach needs to be more than just "in or out" – for example we needed to describe how we will take account of services which have a dependency with CHD but aren't solely for CHD patients. The notes of the Board Task and Finish Group and the Clinical Advisory Panel meetings will be published shortly. But to cut to the chase, our Task & Finish Group agreed that the heart of the review should be the whole lifetime pathway of care for people with congenital heart disease (CHD):

- Improving quality of care for people with suspected or diagnosed CHD (including congenital heart arrhythmias or arrhythmias in the context of congenital heart disease) along the whole patient pathway:
- Fetal and neonatal diagnosis of CHD
- Specialist obstetric care (including both the care of women whose unborn child has suspected or confirmed CHD, and care of pregnant women with CHD)
- Care for babies children and young people
- Transition from children's services to adult services
- Care for adults
- End of life care.
- Extracorporeal life support (ECLS) for children and young people including cardiac and respiratory ECMO
- Care and support for families suffering bereavement and/or poor outcomes following surgery or other intervention for CHD
- The review covers all care for CHD commissioned by the NHS for people living in England

In addition there are some conditions which while not CHD receive their care wholly or mainly from congenital heart services. Though we won't set standards for these conditions, patients with these conditions should be able to participate in the review because whatever happens to CHD services will affect them. This includes:

- children and young people with acquired heart disease
- children and young people with inherited heart disease

There are some services which are not CHD specific but which are nonetheless used by congenital heart patients. The standards for these services won't be set as part of the new CHD review, but the use of these services by CHD patients will be considered by the review, including definition of patient pathways and referral routes. Patients and specialists from these services should be able to participate in the review; this includes:

- neonatal, paediatric and adult intensive care, transport and retrieval services;
- other interdependent clinical services (e.g. other tertiary paediatric services);
- mechanical circulatory support for adults (e.g. cardiac ECMO and VAD);
- complex tracheal surgery;
- heart transplant and bridge to transplant for children and young people; and
- heart transplant for adults.

Services which are explicitly out of scope of this review are:

- adults with inherited heart disease;
- adult respiratory ECMO;
- local maternity services; and
- pulmonary hypertension services.

Patients, families and their representatives

The Health Scrutiny Committee for Lincolnshire, which I attended on 18 September 2013, [has provided an extract of their minutes, which you can read here](#). The Committee invited me to attend again on 20 November 2013, however I could not justify another visit so soon when there are many other engagement priorities. I promised to send a written update in advance of their 20 November 2013 meeting – I will publish the update here.

On 9 October 2013, Professor Sir Bruce Keogh and Michael Wilson attended the All Party Parliamentary Group (of MPs and peers) to discuss the new CHD review. They provided a [brief overview using slides, enclosed here](#). There were no minutes of the meeting but we took our own [informal note which is attached here](#). There was not enough time at the APPG to answer every question, so we have [written this letter to attendees to answer their outstanding queries](#).

On 4 November 2013 I attended the North East Regional Health Scrutiny Meeting (the chairs of local government Overview and Scrutiny Committees), in Gateshead. I will share a note of the discussion when it becomes available.

The meeting of the new CHD review patient and public group, chaired by Professor Peter Weissberg (British Heart Foundation) will be held on Tuesday 12 November 2013 in London. A list of those [organisations invited to attend is here](#).

Clinicians and their organisations

The meeting of the new CHD review provider executives' group, chaired by Chris Hopson (FT Network) will be held on Tuesday 19 November 2013 in London, you can view a [list of the organisations invited to this meeting here](#).

The meeting of the new CHD review clinicians' group, chaired by professor Deirdre Kelly, will be held on Friday 22 November 2013 in London, you can view a [list of the organisations invited to this meeting here](#).

Professor Kelly is also overseeing the process of bringing to a conclusion the work on additional standards for children's congenital heart services and is working with the adult congenital heart disease advisory group to make a joint recommendation on a single combined set of standards (for consideration and full consultation by the congenital heart services Clinical Reference Group). A note of the recent [Standards Alignment Working Group meeting held on 21 October 2013 is attached here](#).

NHS England and other partners

Our Programme Board meets on 13 November 2013 in London. The papers for that meeting (including the [draft minutes of the last discussion on 21 October 2013](#)) are attached here.

NHS England's Board met on Friday 8 November 2013, and amongst other things considered an update from each of its sub-committees and groups. Item 7e on the agenda was an update on the work of the "Task and finish group on the new CHD review". The [Board papers have been available on the NHS England website since 1 November 2013 and the link to the paper is here](#). The meeting was broadcast live on the internet and a recording will be available shortly on YouTube, with a link from the [NHS England website](#).