

**JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE  
(YORKSHIRE & THE HUMBER)**

**EXTRACT FROM THE DRAFT MINUTES OF THE MEETING HELD ON  
FRIDAY, 13 SEPTEMBER 2013**

**The New Review of Congenital Heart Services in England**

The Head of Scrutiny and Member Development submitted a report that sought to introduce and present a range of details associated with the new review of congenital heart services in England.

The Principal Scrutiny Adviser introduced the report that confirmed NHS England as the responsible body for undertaking a national review of congenital heart services for both children and adults. It was reported that the new review would consider the whole lifetime pathway of care for people with congenital heart disease (CHD) and aim to:

- Achieve the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- Tackle variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
- Achieve great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.

It reported that NHS England Board had established a committee (or sub-group) to provide formal governance for the new review work going forward. The membership of that committee was reported as follows:

- Sir Malcolm Grant (NHS England's Board Chairman) – Chair
- Margaret Casely-Hayford (Non-Executive Director)
- Ed Smith (Non-Executive Director)
- Sir Bruce Keogh (Medical Director)
- Bill McCarthy (National Director for Policy)

A range of further information relevant to the new review was appended to the report, as follows:

- A copy of the report setting out broad proposals for undertaking the new review, which was considered by the NHS England Board at its meeting on 18 July 2013.
- Details provided by NHS England to the Secretary of State for Health, via a letter from the Chair of NHS England (dated 31 July 2013).
- Notes from the first meeting of the Congenital Heart Disease (CHD) sub-group, held on 29 July 2013.
- Notes from a series of different stakeholder meetings, as follows:
  - National charities and patient groups – 16 July 2013;

- National clinical organisations – 16 July 2013;
- Clinicians from surgical centres – 22 July 2013; and,
- Local charities and patient groups – 7 August 2013.

Having been submitted earlier in the meeting (minute 86 refers) the following supplementary information was also considered:

- Notes of the meeting between NHS England, the Local Government Association (LGA) and the Centre for Public Scrutiny (CfPS) – 27 August 2013.
- Copy of the letter from Sir Bruce Keogh to Dr Tony Salmon – 30 August 2013.
- Copy of the letter from Sir Bruce Keogh to Professor John Deanfield – 30 August 2013.
- Copy of letter from Children’s Heart Surgery Fund to Bill McCarthy – 12 September 2013.

The following representatives were in attendance to address the joint committee and respond to appropriate questions:

- John Holden – Systems Director (NHS England);
- Sharon Cheng – Director (Children’s Heart Surgery Fund (CHSF)); and,
- Lois Brown – Parent and member of Children’s Heart Surgery Fund

In providing an introduction to the joint committee a number of specific points were highlighted, including:

#### Children’s Heart Surgery Fund (CHSF)

- Welcomed the content of the IRP report and recommendations.
- Welcomed the new review of congenital heart services in England.
- To-date, the contact and engagement work from NHS England had been good.
- There were some concerns regarding the relevant Clinical Reference Group (Congenital Heart Services) and some of its ‘patient experience members’. The recruitment/ appointment process was unclear and questions had been raised regarding the appropriateness of some of the appointed members. Reference was made to the letter from Children’s Heart Surgery Fund to Bill McCarthy (12 September 2013).
- A meeting with NHS England’s Deputy Medical Director was scheduled to take place in the near future.

#### NHS England

- NHS England was the new, single NHS organisation responsible for commissioning congenital heart services in England.
- It was hoped the discussion would represent the start of a new relationship and dialogue between the joint committee and NHS England.
- It was intended that the new review would consider:

- The 'whole lifetime pathway' of care – covering prior to birth through to end of life care.
- Achieving high quality standards and services – now and in the future.
- A national service, working to national standards, and seek to address variations across the country.
- Provision of information for patients.
- The review would be undertaken at pace, due to some services being 'vulnerable', with the aim of achieving an implementable solution within a year.
- Achieving an implementable solution within a year (that was not simply a top-down solution) represented a significant challenge.
- The new review would adopt the following principles:
  - Putting patients first – the needs of patients and families being at the heart of the review, over-riding organisational boundaries;
  - Transparency and openness – ensuring everything of substance is shared and available for public scrutiny;
  - Evidence based decisions – being clear on the nature and limitations of the evidence, and the use of 'judgement'.
  - Retaining good elements from the Safe and Sustainable review – although the precise scope was still to be determined.
- In terms of addressing any perceived 'bias' it was important to be:
  - As transparent as possible.
  - Clear about advisory and decision-making processes
  - Judged on actions and not words i.e. be held to account.
- CRGs have an important role to develop standards for all nationally commissioned services, however it was important to recognise the concerns raised and the sensitivities associated with the CRG for Congenital Heart Services: It would be important for the concerns raised to be addressed by the Chair of the CRG.

The subsequent key points of discussion included:

- Concerns over potential bias at such an early stage in the new review: It would be important to maintain an overview of such matters going forward.
- The importance of NHS England maintaining a close dialogue with all stakeholders.
- The need to avoid mistakes and learn the lessons from the previous review that produced a situation of 'winners and losers'.
- The new review needed to be undertaken in a robust manner in order to establish credibility and maintain the confidence of all stakeholders.
- Concerns regarding the proposed timescales of the new review.
- The direction of research / analysis of the impact of variables (such as ethnicity, socio-economic factors, size of unit, distance travelled) on the outcomes of cardiac surgery.
- General issues around the scope and boundary of the new review, in particular the inclusion of the treatment neonates within the review.

In summing up, the Chair acknowledged members general view that, in order to ensure any future proposals were in the best interest of patients and families across Yorkshire and the Humber, the new review was likely to require the same level of external scrutiny as the previous Safe and Sustainable review of services.

**RESOLVED –**

- (a) That the contents of the report, its appendices and the information provided at the meeting be noted.
- (b) That, subject to the outcome of the discussion around the future role of the Joint HOSC, the joint committee maintain an overview of progress of the new review of congenital heart services in England.