

Update on National Congenital Heart Disease Review April 2015

The independent report of the public consultation on draft standards and service specifications for the congenital heart disease service was published 2.3.15. Meetings of the Clinicians Group (3.2.15) and Joint Engagement and Advisory Groups (9.3.15) enabled members to discuss the report and start developing plans to move into the next phase of the review, in particular commissioning and implementation.

The consultation reported broad positive agreement with the standards suggesting they will promote high quality, accessible and networked patient-centred care. However, the majority of respondents identified specific advantages or concerns with particular features of the proposals, or describe challenges of implementation, particularly adequate funding and staffing.

Specific comments about transplant services included:

- Disappointment that the current review does not include transplant services, which are seen as an integral part of the care pathway for a number of Congenital Heart patients. Therefore some suggest that the review cannot be seen as comprehensive.
- Concern about proposed standard for co-location of all paediatric services having an adverse impact on centres that carry out transplant services.
- Centres that perform transplantation and ECMO should not be subject to the same standards.
- Transplant services should be provided following the same approach suggested for sub-specialisation – providing the service in all centres with the help of peripatetic surgeons;
- Standards on transplantation for CHD patients need to be evolved further.
- Designated patient pathways to transplantation for both adults and children with CHD should be developed now, with the involvement of patients and their families.
- The pathway for end stage heart failure should be strengthened.
- Transplant medicine is perceived to be disproportionately funded and needs to be rationalised.

The Clinical Reference Group had requested a joint meeting with the Cardiothoracic Transplant CRG to discuss transplantation for patients with congenital heart disease before this group was disbanded. A joint meeting has instead been requested with CTAG representatives.

Current Review work streams and developments:

- Supporting Objective 5: Better Information to establish a system for the provision of information about the performance of CHD services to inform commissioning and patient choice.
- Supporting Objective 6 of the review: Better earlier diagnosis
- Shaping the NHS England Response

- Delivery models: NHS Providers meeting 29.4.15 to implement care that meets the standards in a way that is deliverable, affordable and sustainable.
- Congenital Network arrangements
- Quality Dashboards for outcome metrics
- Peer review mechanisms
- Appropriate commissioning approach including transition from review to Standards and Specification implementation
- Preparing for decision making (including the assurance process).

Timetable for Review activities:

- April – September 2015:
 - Deliver review objectives
 - Agree standards (CRG with Standards Group will review (May) need to change Standards and Specification with advice considered by Clinical Advisory Panel. Recommendations made to the Review's Board Task and Finish Group.
 - Co-design commissioning model (NHS Providers)
 - Proposals considered by groups that make up the Specialised Commissioning assurance process, prior to final decisions by the NHS England Board in July.
- October 2015 – March 2016: Procurement; specialised commissioning; finance; communications and engagement; analytics
- April 2016 onwards: Live; Contract and performance management

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