New Congenital Heart Disease Review



Engagement events November 2013











Update

- The challenge
- Objectives
- Engagement & communications
- Governance decision making, advice & engagement
- Scope
- Standard setting

New Congenital Heart Disease Review

The Challenge

- The best outcomes
- Consistently meeting standards
- The best patient experience
- Standards driven
- No pre-conceived answers
- The health of the service
- Delivery at pace vs. inclusivity
- Scope

Objectives... we aim to

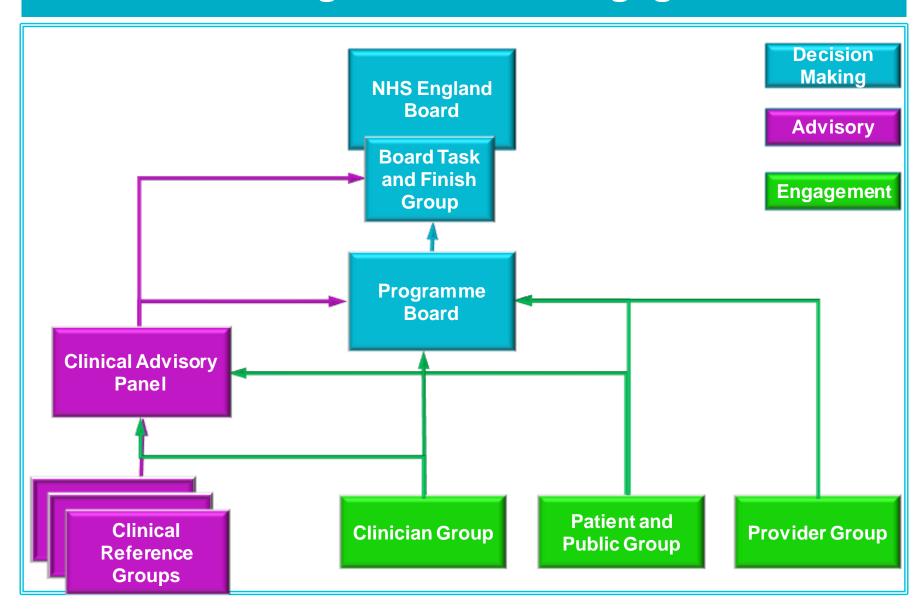
- Develop standards to improve outcomes, minimise variation & improve patient experience
- Analyse demand for specialist inpatient care now and in future
- Make recommendations about function, form and capacity of services to meet demand and quality standards, taking account of accessibility and health impact
- Make recommendations on commissioning and change management approach including workforce & training needs
- Establish a system for provision of information about performance to inform commissioning and patient choice
- Improve antenatal and neonatal detection rates

Engagement and communication

- Openness/transparency
- Blog & webpages
- Publication Scheme
- Managing interests
- Seeking input as we go, continue to refine approach

- Engagement groups
- Targeted engagement
- Consultation on specification
- ?Children & young people; seldom heard groups

Decision making, advice and engagement



New Congenital Heart Disease Review

Scope of review

- a) Improving the quality of care for people with suspected or diagnosed congenital heart disease (CHD) along the whole patient pathway
- b) The review covers all care for CHD commissioned by the NHS for people living in England
- c) Conditions which aren't CHD but receive services wholly or mainly from CHD pathway – won't set standards for these conditions but full involvement in review
- d) Services which aren't CHD-specific but often used by CHD patients review won't set their standards but full involvement and consideration of dependencies

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.

Standard setting timeline

- Ongoing work to align children's and adults' standards
- End November 2013 aligned standards will be passed to CRG to be included in a proposed updated specification
- December 2013 CRG to discuss new specification
- January 2014 Programme Board will discuss, agree and sign-off proposals for engagement during 12 week public consultation (Feb-April 2014)
- May 2014 analysis of consultation responses, financial/affordability assessment, workforce assessment
- Late 2014 CRG will revise and agree specification then make recommendations on the final specification