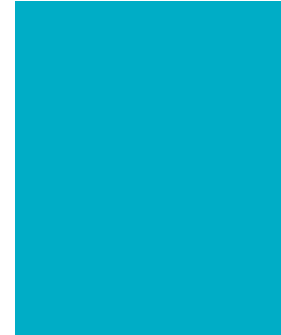


Local Government Meeting

8 January 2014



Welcome and Introductions



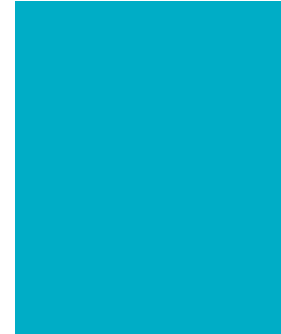
Claire McDonald



Agenda for the afternoon

- Update on activity so far and plans for coming activity
- What we have been hearing back and how we are responding
- Opportunity for questions and comments

Update on the progress of the review



John Holden
Director of System Policy



Update

- **The challenge**
- **Objectives**
- **Engagement and communications**
- **Governance:** decision making, advice and engagement
- **Scope**
- **Standard setting**

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 and 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 and training needs.
- Establish a system for provision of information about performance to inform commissioning and patient choice.
- Improve antenatal and neonatal detection rates.

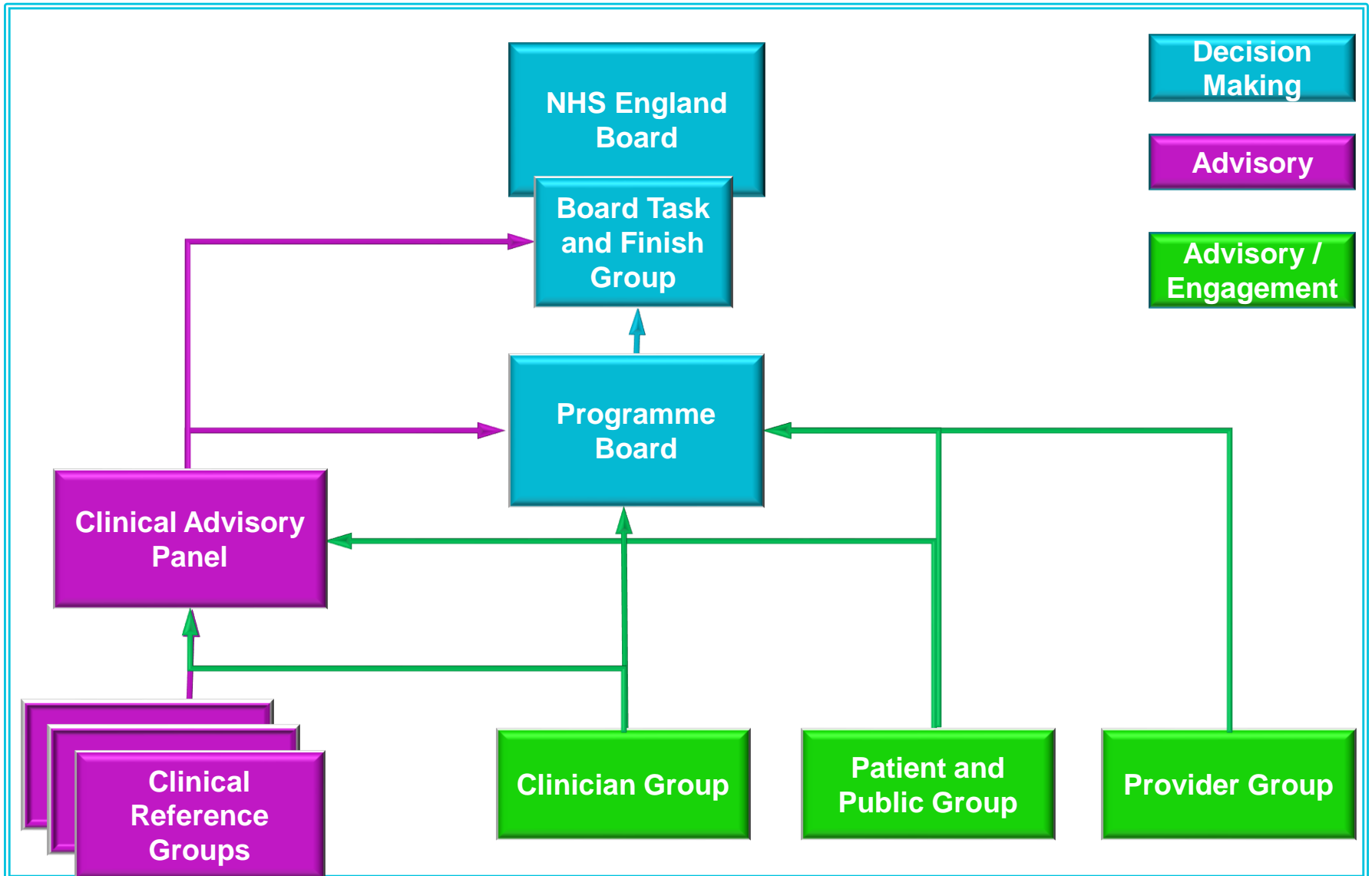
Engagement and communication

- Openness/transparency
- Blog and webpages
- Publication Scheme
- Managing interests
- Seeking input as we go, continue to refine approach
- Engagement groups
- Targeted engagement
- Consultation on specification
- ?Children and young people; seldom heard groups

Communication and engagement activity

- 14 blogs published to date
- Agenda, papers and minutes of all meetings published
- Meetings of Clinician Group, Provider Group and Public and Patient Group held in November 2013. Next round of meetings planned for January/February 2014
- Direct engagement with children and young people in development
- Policy on managing conflicts of interest signed off on 7 January 2014
- Preparation beginning for consultation on service specifications (children and adults)

Decision making, advice and engagement



In Scope

- a) Improving the quality of care for people with suspected or diagnosed congenital heart disease (CHD) 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 the 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 or poor outcomes
- b) The review covers all care for CHD commissioned by the NHS for people living in England.**

In Scope

In addition there are some conditions which while not CHD receive their care wholly or mainly from congenital heart service. 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.

In Scope

There are some services which are not congenital heart disease (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.

Out of Scope

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.

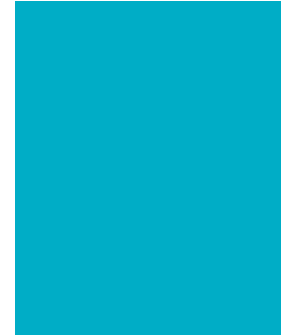
Standard setting timeline

- **January 2014** – paediatric standards group signs off work
- **February 2014** – CAP agree aligned standards for consultation
- **From March 2014** - work with CRG to develop and run consultation on proposed specifications (child and adult)
 - CRG sense checks standards with registered stakeholders
 - Undertake impact assessments (finance/workforce)
 - Seek CPAG recommendation/DCSC approval for consultation
- **Late spring 2014**: 12 week public consultation
- **Early autumn 2014**: Analyse and consider consultation responses
- **Late 2014** - CRG will revise and agree specification then make recommendations on the final specification
- **2015** – Commission against the new specifications

Commissioning and change

- No decisions yet on approach
- Need to develop and evaluate options
- Features of new specialised commissioning system:
 - Single national specification and pricing
 - Trajectory for convergence through use of derogation and future standards
- Important role for providers working collaboratively (networked)

What have we heard so far



Michael Wilson
Programme Director



Engagement to date: what we have heard so far

Three independently chaired meetings with:

- **Patients and public** including national, regional and local charities;
- **Providers** including Chief Executives or their nominees from all providers of congenital heart disease services; and
- **Clinicians** including providers of congenital heart disease services and linked specialties.

How we are working

- We have been asked to ensure that we communicate effectively.
- We need to explain simply and persuasively the case for change and to have wider communication with all groups.
- We need to ensure that we do not reinvent the wheel.
- We need to learn from other specialties and other countries.
- We need to be aware of conflicts of interest.

Views on the scope of the review

- There is support for the scope of the review and bringing children's and adults' standards together (not just surgery);
- There is a shared commitment to planning, developing and commissioning a world class service that is safe, sustainable and future proof and puts the child first but recognition in the clinical group that this might come in steps – not all at once; and
- A request to move quickly to ensure that services are not damaged in the meantime.

Objective 1 : Standards

- A need to have clarity when setting standards about what number of clinicians is required to ensure safe cover and a resilient service; and
- The need to recognise co-dependencies in service provision – services need to work together when providing different elements of care.

Objective 2 : Analysing demand for specialist inpatient CHD care

- Need to develop a local and national understanding of delivery of care;
- Need to be clear about activity levels now and in the future;
- Consider impact of growing population and how we identify and meet demand for services; and
- Ensure that there are adequate adult services as more children survive.

Objective 3: Function, form and capacity

- Access – need for services to be within reasonable and safe distances;
- Potential for sub-specialisation - all centres not doing all procedures;
- Occasional practice – need to manage risk;
- Co-dependencies in service provision – services may need to work together when providing different elements of care;
- Funding – need to identify additional costs including workforce/training; and
- Need to develop outcome measures that go beyond mortality.

Objective 4 : Commissioning and change management approach

- Importance of keeping workforce, training and research in mind;
- Importance of commissioning services which are sustainable and resilient to events specifically, but not only, the financial implications; and
- Need to resource change.

Objective 5 : Performance information

Call for expansion of data collection so focus is:

- not only on surgery
- but also on morbidity and quality of life as well as mortality

Objective 6 : Improve antenatal and neonatal detection rates

- Support for the pathway to include antenatal care and the focus on improving early detection and diagnosis.
- Recognition in clinician group that antenatal detection is abysmal and needs to be improved.

Questions and comments



Thank you and contact details

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