*New Congenital Heart Disease Review*

# Patient and Public Engagement Group

## New Congenital Heart Disease review

**14th January 2015**

# Agenda

- Welcome and overview of the afternoon
- Since we last met – update
- Consultation update and what happens next
- Continuing to work with each other – inc restricted period
- Contributions from meeting attendees
- Update on other review objectives
- AOB

*New Congenital Heart Disease Review*

# Since we last met – update

## John Holden

*New Congenital Heart Disease Review*

# Consultation update and what happens next

## Michael Wilson

# Consultation update

- 12 weeks of consultation – many events across UK delivered by the review team and by partners
- Aim was to make people aware of the proposed standards, the questions and how they could respond
- Met patients, families, staff from units, clinicians from others services, charities and local community groups, politicians
- Around 500 responses
- Variety of responses in detail, subject matter, length of response

# Responding to consultation

- All responses will be read both by team members and Dialogue by Design (DbD)
- DbD will produce an independent analysis of consultation responses - final report expected by February 6th
- Standards Groups and Clinical Reference Group will advise CAP
- CAP will make recommendations on any changes to made to the standards
- Final decision on the standards made by the NHS England board

# Decision making

**CAP**

- Recommends any changes needed

**TAFG**

- Approves revised standards / specification entering assurance process

**Assure**

- Specialised commissioning assurance
- *Equalities; Engagement; Governance; Affordability; Strategic Fit*

**Board**

- Considers whole review
- Makes final decisions

# Business plan

| Headings | Content overview |
|---|---|
| **Executive summary** | key findings and recommendations |
| **Background** | history; scope of the report; objectives |
| **Methodology** | approach; governance; communication and engagement |
| **Needs assessment** | analytical data demonstrating prevalence and trends; morbidity and mortality (Objective 2) |
| **Current system** | service delivery; gaps in service capacity; performance management; current provision of care; networks currently in operation; current commissioning arrangements |
| **Standards and service specification** | development, review, consultation, revision; recommendations (Objective 1) |
| **New model of care** | tiers of provision and associated network model of care delivery; early diagnosis; workforce (Objective 1, Objective 3, Objective 6) |
| **New commissioning model** | recommended approach to commissioning; provider development; financial impact assessment; metrics; performance management (Objective 4 and 5) |
| **Implementation** | resources; governance; communication and engagement |
| **Evaluation** | (Objective 5) |
| **Discussion** | |
| **Recommendations** | |
| **References** | |

# Timetable: 2015/16

**2015-16**

*April – July 2015*

**Commissioning development**

**Decision**

PMO support

*August 2015 – March 2016*

**Procurement**

Specialised commissioning; finance; comms & engagement; analytics

*April 2016 onwards*

**Live**

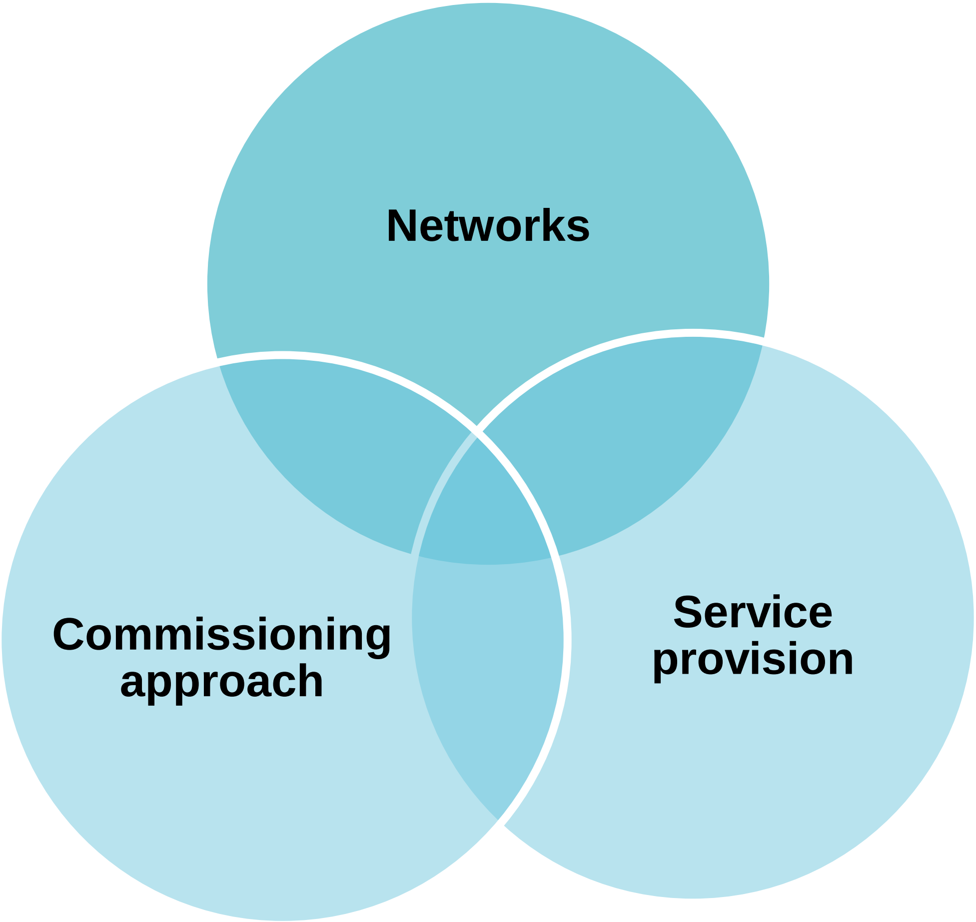
Contract & performance management

**Transition from review to SpecCom**

# Commissioning Challenges

- Time of rapid policy development
- New and emerging specialised commissioning team
- Developing appropriate approach for commissioning this service
- Working with CCGs on commissioning of tier 3

# Work with providers and SpecCom



Networks

Commissioning approach

Service provision

# Networks

- What needs to be done to enable networks to function effectively?
- What should then be developed by each network?
- What ought to be developed at a national level to ensure :
  - necessary consistency and sustainability?
  - effective collaboration?

NHS England

# Continuing to work with each other – in restricted period and beyond

## John Holden & Michael Wilson

# Contributions from meeting attendees

# Break

# Update on other review objectives

**Michael Wilson**

# Review objectives

- Objective 3 and 4 – Function, form & capacity and Commissioning & change
  Working with national and local commissioners and our provider engagement group to establish a timely and appropriate commissioning process to enable effective delivery of services

- Objective 5 – Provision of information
  Following the meeting on the 10th Dec we are establishing a system for the provision of information about the performance of CHD services, to help patients make informed choices and to give valuable feedback to NHS England as the commissioner of the service

- Objective 6 – Antenatal and neonatal detection
  We are preparing an options appraisal report with recommendations for the Programme Board in February, which will discuss the actions required to help improve antenatal and neonatal detection rates.

# Objective 2: activity analysis

- Update existing analysis to include 2013/14 data, comments etc
- Develop subnational activity analysis
- Develop diagnosis (rather than procedure) based activity analysis
- Develop analysis of current travel times (modelled)
- Develop analysis of comparative lengths of stay
- Translate existing analysis into different currencies - ops or interventions, admissions, bed days, beds required etc
- Analysis of NICOR ACHD mortality data
- Support further affordability analysis

# Objective 5: Better Information

To establish a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice.

1. Activity and Finance
2. Outcomes
   - Mortality
   - Morbidities
   - Quality of life
   - Patient Experience
3. Standards Compliance

# Objective 5: Progress so far

Met and discussed with:

- Provider Trusts
- NICOR
- UCL – Clinical Operational Research Unit
- CRG
- Specialised Commissioners
- International Colleagues
- Patient and Public Group Representatives

# Objective 5: PPEAG views

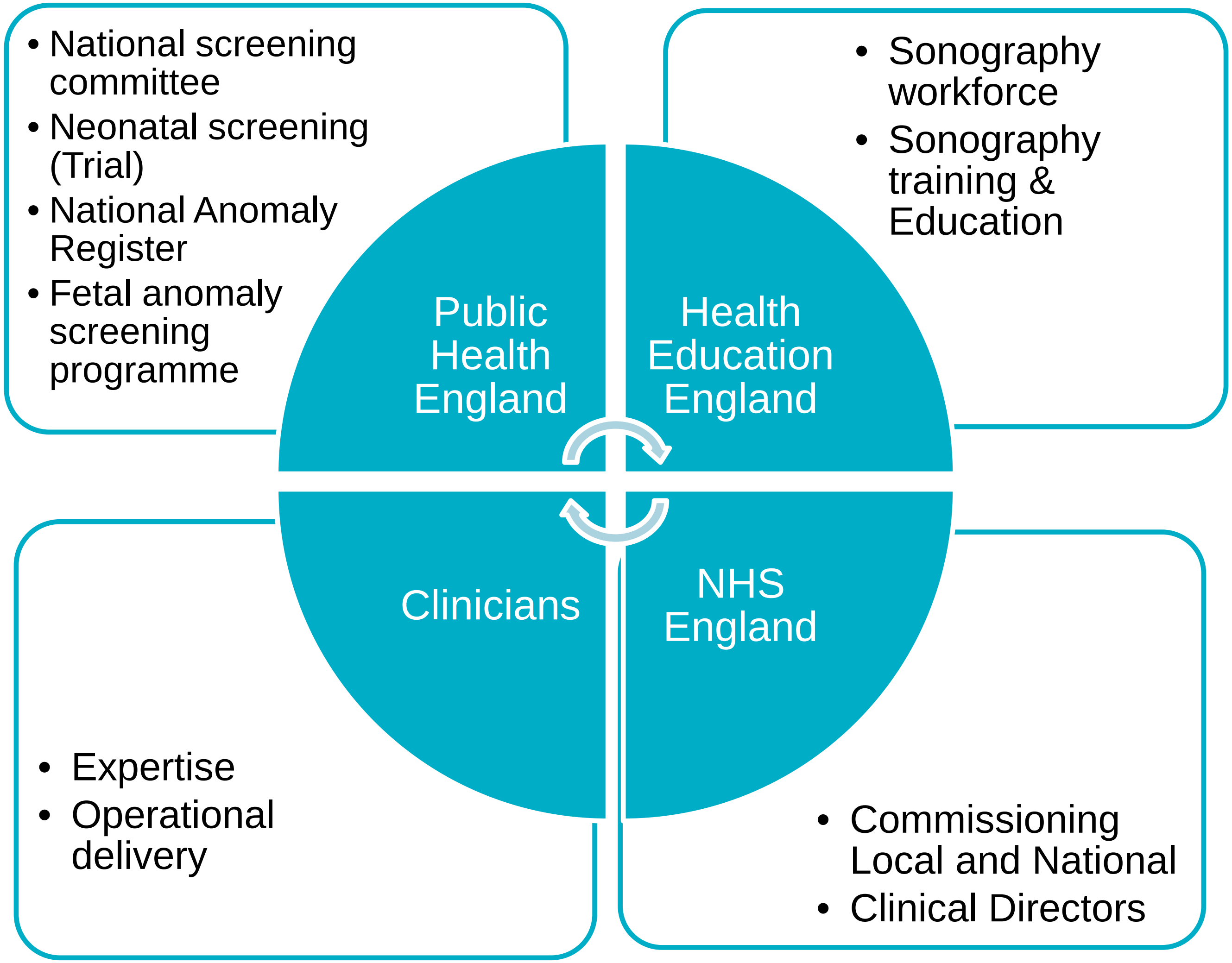
There was support for:

- Diagnosis based outcome measures
- A register of all congenital heart disease patients that should include everybody no matter when diagnosed.
- A more comprehensive range of procedures to be included in the CCAD database
- Measures of a wide range of morbidities
- Developmental measures
- Measures that would capture mental health and behavioural problems
- Patient experience (though many caveats about how hard it is to capture this)
- Cancellations and reasons for cancellation

# Objective 5: Next Steps

- Produce a report on the discussions to date and key areas of information which could be developed, and use as a basis to:
  - Seek views on prioritisation
  - Discuss practicalities
  - Agree plan

# Objective 6: Early Diagnosis



**Public Health England**

- National screening committee
- Neonatal screening (Trial)
- National Anomaly Register
- Fetal anomaly screening programme

**Health Education England**

- Sonography workforce
- Sonography training & Education

**Clinicians**

- Expertise
- Operational delivery

**NHS England**

- Commissioning Local and National
- Clinical Directors

# Objective 6: Developments

- **National anomaly register** – rare disease and congenital anomalies
- **Sonographer  workforce development**
  - Workforce– linked with HEE to deliver a workforce analysis.
  - Training – working with FASP to deliver sustainability in the system.
- **Commissioning**  – devise easy guide to commissioning of screening and the changes expected.
- **Neonatal detection** – from May 2015 a 6 month trial on pulse oximetry, within 14 trusts. (7 new and 7 already trialling it)

Item

*New Congenital Heart Disease Review*

# AOB

*New Congenital Heart Disease Review*

NHS England

# Thanks & close