New Congenital Heart Disease Review

Overview and proposed approach to assurance

Women and Children Programme of Care Board

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Introduction

- This slide set describes the work of the new Congenital Heart Disease review
- Members of the Women and Children Programme of Care Board are asked to:
  - Consider and comment on the proposed approach to:
    - Involvement
    - Governance approval
    - Funding implications
  - Advise on other aspects of the review’s work that they would wish to examine

Key Facts

- Around eight out of every 1,000 babies born have some form of congenital heart disease (CHD) – around 5 000 a year for the UK.
- Number of children born with CHD is expected to rise, as the birth rate rises.
- More babies with complex problems including CHD are now surviving into adulthood.
- One year survival rate after surgery = 94%; for catheters = 99%.
- CHD surgery for children carried out in 10 hospitals in England with three other centres offering specialist paediatric cardiology.
- Up to 25 hospitals in England report that they provide surgical procedures and interventional cardiology for CHD in adults.

The “new CHD review”

The challenge for NHS England is how to ensure that services for people with CHD achieve the highest possible quality, within the available resources, now and for future generations:

- Securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- Tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care.
- Delivering 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.

Our approach

- Openness and transparency.
- Building on previous work/reviews.
- Clinical and patient leadership.
- No pre-conceived answers.
- Evidence driven.
- Extensive engagement/communication.
- Delivery at pace vs. doing it right.

Communication: what are we doing

- Strong emphasis on **transparency, openness and participation.**
- **Fortnightly blog -** provides an update on the work of the new CHD review – comments and discussion is encouraged. 21 blogs to date.
- **Papers** of all meetings **published** on website.
- **Twitter** presence.
- Looking at communications products and channels ‘beyond the blog’ to reach other audiences.
- High levels of **media interest** in CHD services generally and review in particular. Media briefings, lines to take and reactive communications all supported.
- Regular **Department of Health (DH)** briefings.
- Face to face briefings for **MPs** and support for handling of Parliamentary Questions (PQs).

Who’s involved?

- **Clinicians**: through review’s Clinical Advisory Panel; Clinicians’ Group; Congenital Heart Services Clinical Reference Group (CRG); visits to specialist units.
- **Service users**: through review’s Patient and Public Group; visits to specialist units, children and young people’s events.
- **Service providers**: through the review’s Provider Group; visits to specialist units.
- **Local government**: face to face meeting with health lead members, scrutiny committee members and Health and Wellbeing Board members (one held, one scheduled); WebEx interactive briefing; attendance at Overview and Scrutiny Committees as requested.
- **Healthwatch**: face to face meeting with local Healthwatch members (one held, one scheduled); WebEx interactive briefing; briefing for national Healthwatch.

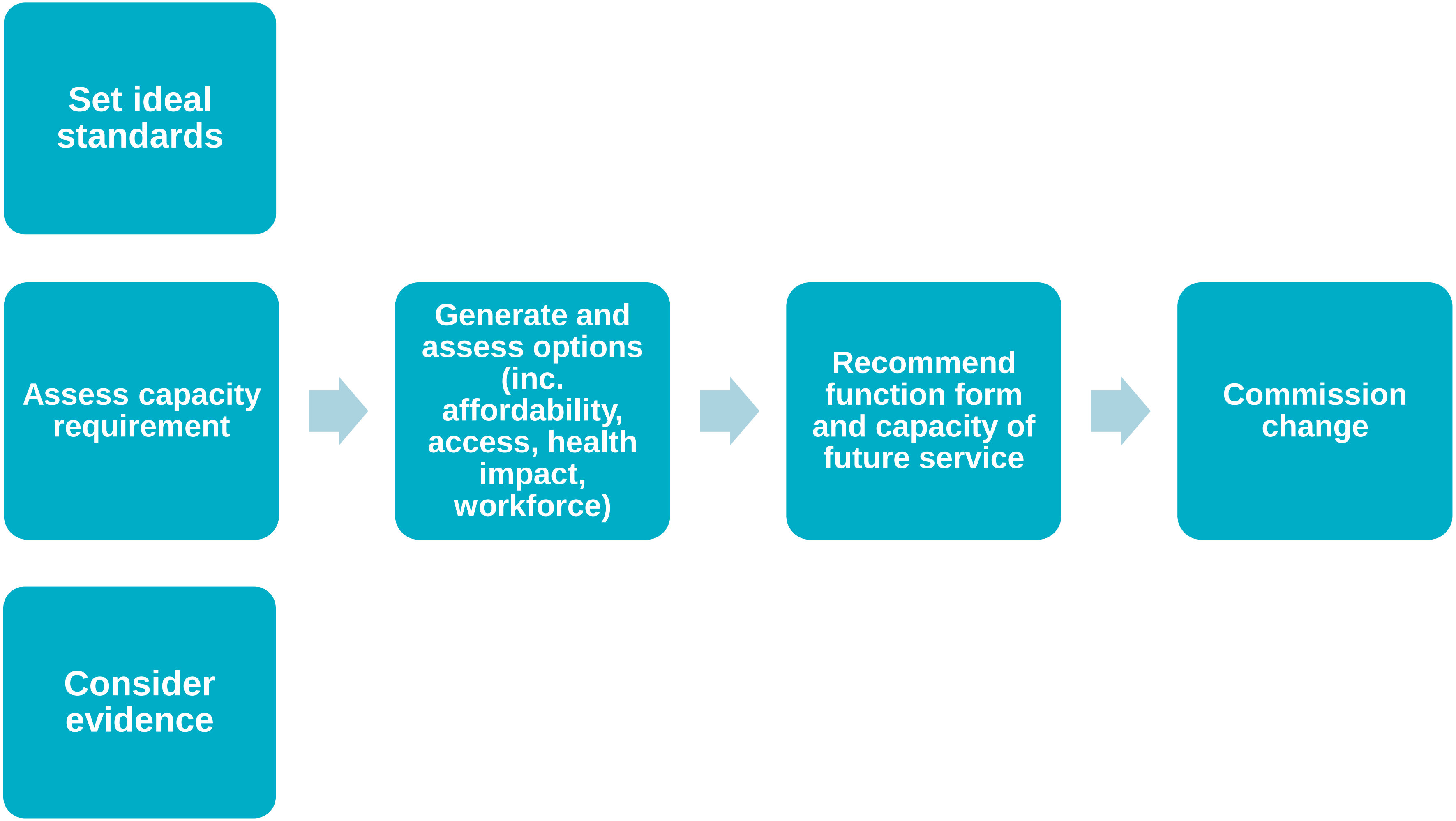
Engagement and advisory groups: what we have heard so far

- "Services are good but can become better."
- "Standards will play an important role in making this happen."
- "Important to recognise and take account of interdependencies."
- "Support for the patient pathway approach, but a recognition that one pathway does not fit all."
- "Networks and teams are important in delivering high quality services."
- "This needs effective communications and supportive relationships across networks and nationally."
- "Indecision and uncertainty present a risk to the service."

The review's six objectives

1. To develop **standards** to give improved outcomes, minimal variation and improved patient experience.
2. To **analyse demand** for specialist inpatient CHD care, now and in the future.
3. To make recommendations on **function, form and capacity** of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact.
4. To make recommendations on the **commissioning and change** management approach including an assessment of workforce and training needs.
5. 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.
6. To improve **antenatal and neonatal detection** rates.

Review methodology



Set ideal standards

Assess capacity requirement

Consider evidence

Generate and assess options (inc. affordability, access, health impact, workforce)

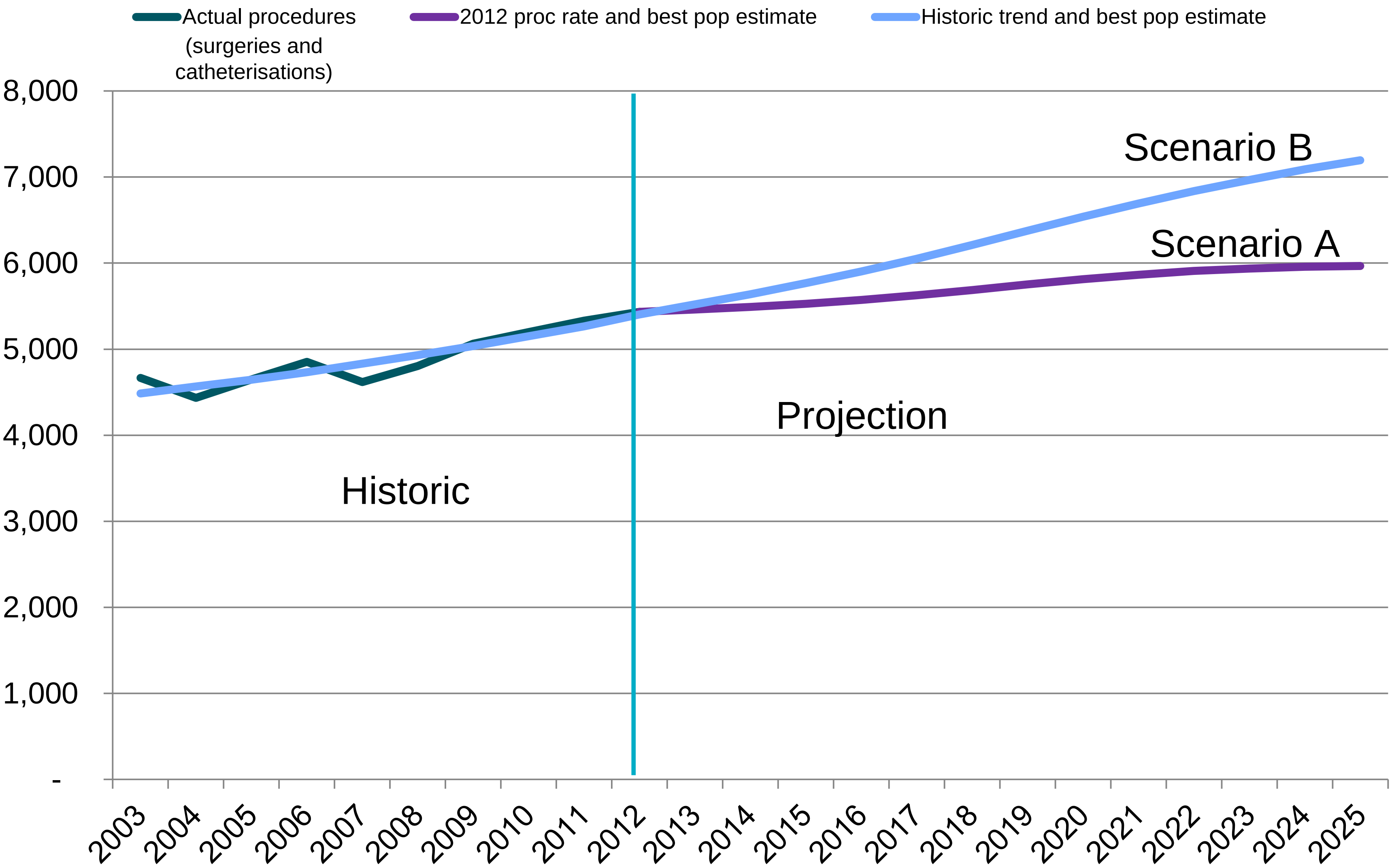
Recommend function form and capacity of future service

Commission change

Evidence

- A key source of evidence for this review is advice from experts; patients; providers and clinicians.
- We are gathering this from our groups and wider engagement.
- To look at service organisation factors that may influence outcomes, we have:
    - commissioned a systematic **literature review**; and
    - asked **National Institute for Cardiovascular Outcomes Research (NICOR)** to investigate their data.
- We are developing a completely refreshed analysis of current activity and future demand.

Assessing the capacity requirement – early (unconfirmed) data



Stakeholder led standards development

- Developed by groups that included clinicians from every specialist provider, with input from congenital surgeons, congenital cardiologists (paediatric and adult), paediatricians with expertise in cardiology and cardiologists with an interest in congenital disease, nurses, psychologists and patient representatives.
- Controversial issues discussed by stakeholders:
  - The Review's clinician, patient and public and provider groups;
  - Professional societies;
  - The Clinical Reference Group; and
  - The Review's Clinical Advisory Panel.
- The Clinical Reference Group will advise on which standards should be developmental and the appropriate timescale.

Standards at the heart…

- For the first time as a single national commissioner we are producing standards to be consistently applied across England.
- Stakeholders agreed standards should be at the heart of our approach.
- Sir Bruce Keogh called for comprehensive standards covering the whole pathway to ensure that services achieve the highest possible quality within the available resources.
- Describe how services should be set up and run.
- Also include patient experience, how information is provided to patients and families and support around end of life.
- Some standards likely to be challenging for existing providers.

Standards: what do they cover?

- Section A: The network approach
- Section B: Staffing and skills
- Section C: Facilities
- Section D: Interdependencies
- Section E: Training and education
- Section F: Organisation, governance and audit
- Section G: Research
- Section H: Communication with patients
- Section I: Transition
- Section J: Pregnancy and contraception
- Section K: Fetal diagnosis
- Section L: Palliative care and bereavement (new)
- Section M: Dental (new)

What’s different about the paediatric standards?

Safe and Sustainable standards have been reflected in the NHS England service specification since 1 April 2013. Proposed revisions include:

- new sections on ‘Pregnancy & contraception’; ‘Palliative care, end of life and bereavement’; ‘Dental Care’ ;
- substantial changes throughout the standards - most have either been amended or are new;
- standards for Specialist and Local Children’s Cardiology Centres revised and expanded;
- standards for cardiology more developed across all three tiers of the service;
- standards describing interdependencies completely re-worked; and
- revised proposals for surgeon numbers and surgical activity.

What's different about the adult standards?

Draft standards were developed for ACHD services and underwent two periods of extensive engagement so they widely known and understood. However, there is no current NHS England specification for this service. Compared to the draft standards, proposed revisions include:

- new sections on 'Palliative care, end of life and bereavement'; 'Dental Care' ;
- many minor changes to wording to ensure harmonisation with paediatric standards and many standards added to match paediatric standards;
- standards describing interdependencies re-worked; and
- revised proposals for surgeon numbers and surgical activity.

Standards built on model of care

- CHD surgery/intervention only by CHD specialists in recognised specialist CHD centres.
- Surgical centres able to manage the vast majority of CHD.
- Designation of sub-specialist units not proposed; rather a system to ensure that every patient receives care from an appropriate surgeon/interventionist.
- Three tier service delivers care as locally as possible
- Hub and spoke provider networks that:
  - have a number of local cardiology centres;
  - may have specialist cardiology centres depending on local circumstances including demand and geography;
  - ensure standards met;
  - agree joint pathways/ protocols; and
  - fully integrate paediatric and adult CHD services.

Clinical Advisory Panel (CAP) review of standards

- CAP reviewed the complete set of proposed standards.
- Particular attention was paid to the ‘knotty issues’.
- In each case, CAP considered:
    - the proposed standard;
    - the reasons for the approach taken;
    - supporting evidence; and
    - the views of stakeholders.
- After discussion, CAP approved the standards, in some cases with some amendments.
- The standards relating to the knotty issues are summarised on the following slides.

Views on interdependencies

- “Co-location of paediatric congenital heart surgery with other paediatric services; and adult congenital heart surgery with other adult tertiary services is ideal; paediatric congenital heart surgery with adult congenital heart surgery is also ideal.”

- “Other arrangements may be acceptable with appropriate responsiveness and integration.”

- “Joint rotas and the need to minimise losses to follow up at transition mean that paediatric congenital heart surgery and adult congenital heart surgery need to be in close proximity if not co-located.”

- “Excellent and timely communication and information sharing between specialties is essential.”

Standards recommended by CAP: interdependencies

- A range of other paediatric services should be located on the same hospital site as Specialist Children's Surgical Centres.
- A range of other adult services should be located on the same hospital site as Specialist ACHD Surgical Centres.
- In each case they must be part of the extended multidisciplinary team.
- Consultants in these services must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7.
- Specialist Children's Surgical Centres and Specialist ACHD Surgical Centres should ideally be on the same site, and consultants serving both must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7 at both.

Views on surgeon numbers

- “Agreement with the principle that teams of four surgeons are ideal but concern about the practicalities of implementation and the impact on units.”
- “All surgeons agree that a 1 in 2 rota is not acceptable.”
- “Some surgeons believe that a 1 in 3 rota is acceptable.”
- “Some surgeons believe that a 1 in 4 rota should be the minimum that all centres aim for, not least because a 1 in 3 rota is 1 in 2 for 30 weeks of the year.”
- “On-call is not usually onerous except in transplant centres, where a 1 in 5 rota (or better) may be appropriate.”

Standards recommended by CAP: surgeon numbers

- Noting the differing views of congenital surgeons, and following considerable discussion, CAP recommended that the standard to be proposed for pre-consultation discussion should be that Consultant Congenital Cardiac Surgeons must not partake in an on-call rota more frequent than 1:4 (requiring a minimum of four surgeons).

Views on surgical volumes

- "Surgeons consider this standard vital to ensure quality and regard 125 cases as the absolute minimum."

- "Surgeons consider this a more important determinant of quality than the number of surgeons per unit - if there was a choice for a 400 procedure unit between 3 surgeons achieving 125 cases and 4 surgeons not achieving 125 cases, the former is preferred."

Standards recommended by CAP: surgical volumes

- Congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period.

Views on sub-specialisation

- “Surgical centres should be able to do the vast majority of CHD surgery with no further formal sub-specialisation.”
- “A two tier service could emerge if some centres were designated for sub-specialist work. There is evidence that second tier centres would contract and decline.”
- “Individuals and units must recognise their limitations”
- “Standards should consider the need for competent teams not just individual surgeons/interventionists.”
- “Networks should manage competence through peer review and audit.”
- “The service should support:
    - the free movement of surgeons to mentor and work alongside other surgeons for difficult cases; and
    - the managed introduction of new techniques.”

Standards recommended by CAP: sub-specialisation

- Consultant interventional paediatric cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either:
  - the support of a competent second operator or interventionist must be obtained from within the network or another SSC; or
  - the patient must be referred to an alternative SSC where a surgeon/interventionist has the appropriate skills.

- Arrangements must be in place for interventional cardiologists and surgeons to operate together on complex or rare cases.

- Specialist CHD Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre to centre referrals.

Views on congenital surgery only by specialist congenital surgeons

- “CHD specialists strongly support this approach and consider it non-controversial , so are puzzled that it is identified as a knotty issue.”

- “Representatives of ACHD patients tell us that this is their number one concern.”

- “Cardiothoracic surgeons who are not specialist in CHD consider that they should be permitted to continue to undertake some CHD procedures. They consider their results good and that patients would be inconvenienced by change. They doubt that CHD specialist surgical centres could cope with the additional volume.”

Standards recommended by CAP: congenital surgery only by specialist congenital surgeons

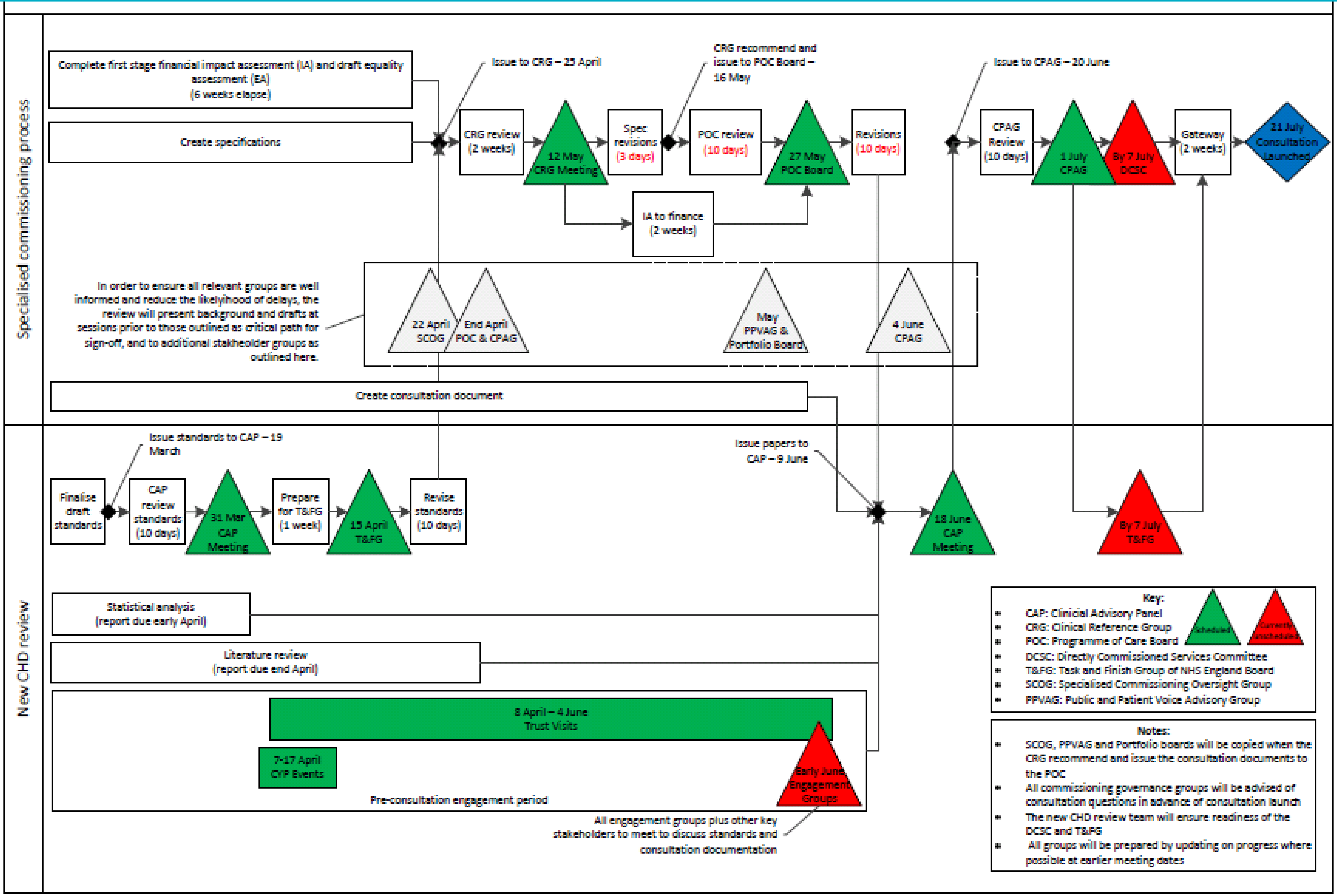
- All paediatric cardiac surgical cases must be carried out by a specialist paediatric congenital cardiac surgical team with expertise and experience in paediatric cardiac disease.
- All paediatric congenital cardiology must be carried out by specialist paediatric cardiologists.
- All adult congenital cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in ACHD.
- All adult congenital cardiology must be carried out by specialist ACHD cardiologists.
- Specialist CHD Surgical Centres in partnership with the network and commissioners will establish a model of care that will ensure that all congenital cardiac care is carried out only by congenital cardiac specialists (inc. investigation, cardiology and surgery).

Proposed consultation

- Consulting on two service specifications – one for the paediatric service, one for the adult service – with standards as an appendix.
- Designing approach to consultation with stakeholders.
- Currently undertaking pre-consultation engagement and assurance of the proposals.
- Expected timetable:
    - **Summer –** 12 week full public consultation
    - **Autumn/Winter** – analyse and consider consultation responses
    - **2015** – commission against the new specifications
- The detailed consultation timeline is shown on the next slide.

New Congenital Heart Disease Review

Consultation timeline: baseline dates pre-consultation



Specialised commissioning process

Complete first stage financial impact assessment (IA) and draft equality assessment (EA)
(6 weeks elapse)

Create specifications

Issue to CRG – 25 April

CRG review
(2 weeks)

12 May
CRG Meeting

Spec revisions
(3 days)

CRG recommend and issue to POC Board – 16 May

POC review
(10 days)

27 May
POC Board

Revisions
(10 days)

IA to finance
(2 weeks)

Issue to CPAG – 20 June

CPAG Review
(10 days)

1 July
CPAG

By 7 July
DCSC

Gateway
(2 weeks)

21 July
Consultation launched

In order to ensure all relevant groups are well informed and reduce the likelihood of delays, the review will present background and drafts at sessions prior to those outlined as critical path for sign-off, and to additional stakeholder groups as outlined here.

22 April
SCOG

End April
POC & CPAG

May
PPVAG &
Portfolio Board

4 June
CPAG

Create consultation document

New CHD review

Issue standards to CAP – 19 March

Finalise draft standards

CAP review standards
(10 days)

31 Mar
CAP
Meeting

Prepare for T&FG
(1 week)

15 April
T&FG

Revise standards
(10 days)

Issue papers to CAP – 9 June

18 June
CAP
Meeting

By 7 July
T&FG

Statistical analysis
(report due early April)

Literature review
(report due end April)

8 April – 4 June
Trust Visits

7-17 April
CYP Events

Early June
Engagement
Groups

Pre-consultation engagement period

All engagement groups plus other key stakeholders to meet to discuss standards and consultation documentation

Key:

- CAP: Clinicial Advisory Panel
- CRG: Clinical Reference Group
- POC: Programme of Care Board
- DCSC: Directly Commissioned Services Committee
- T&FG: Task and Finish Group of NHS England Board
- SCOG: Specialised Commissioning Oversight Group
- PPVAG: Public and Patient Voice Advisory Group

🟩 Scheduled

🟥 Currently unscheduled

Notes:

- SCOG, PPVAG and Portfolio boards will be copied when the CRG recommend and issue the consultation documents to the POC
- All commissioning governance groups will be advised of consultation questions in advance of consultation launch
- The new CHD review team will ensure readiness of the DCSC and T&FG
- All groups will be prepared by updating on progress where possible at earlier meeting dates

Proposed pre-consultation engagement activity

- Children and young people's events (underway).
- Visits to specialist units (underway).
- Briefing for MPs (breakfast meeting on 9 April 2014).
- Briefing for local government / Healthwatch (WebEx planned 29 April 2014).
- CRG review standards and agree specification (12 May 2014).
- Combined meeting of review engagement and advisory groups and CRG registered stakeholders (date tbc).

Consultation on service standards: proposed suite of documents

- The proposed service specifications – full version and plain English summary.
- The proposed service standards.
- A consultation document – full version, easy read summary version, video version presented on the NHS England YouTube site.
- An extended range of response routes including standard response form (electronic and print) as well as options for responding via alternative channels including letter, social media or text.
- An overarching draft first stage impact assessment (partial).
- An overarching draft first stage equality assessment (partial).

Consultation on service standards: proposed consultation activities

- Four regional events.
- Meetings of each of the review's engagement/advisory groups focused on the service specification and standards.
- A national meeting for local government representatives (Health and Wellbeing Boards and Overview and Scrutiny members) and HealthWatch.
- A meeting with MPs.
- Event(s) for adults with CHD.
- Briefings for local government.
- Targeted engagement with relevant protected characteristic groups.
- We will need to work with the NHS in Wales to consider appropriate involvement in the consultation for residents of Wales.

POC Assurance Process

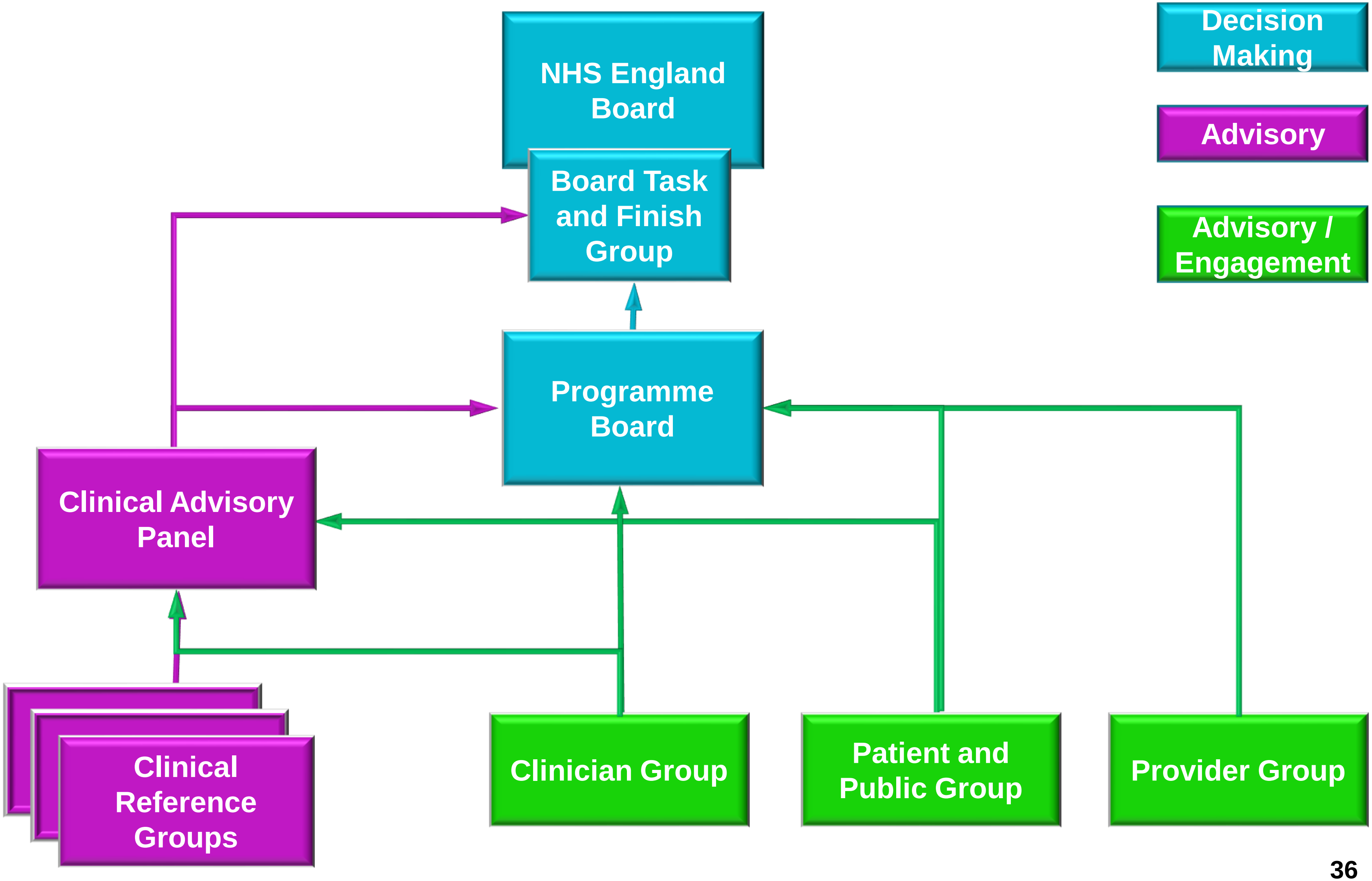
In this presentation to you, we are seeking to:

- clarify your assurance requirements; and
- explain and test our proposed approach.

We have used a standard POC template as our starting point in the following slides. Key elements include:

1. Involvement (operations, finance, patients and information and medical);
2. Governance approval (working with the CRG);
3. Funding implications

1. Involvement: Review decision making, advice and engagement structure



NHS England Board

Board Task and Finish Group

Programme Board

Clinical Advisory Panel

Clinical Reference Groups

Clinician Group

Patient and Public Group

Provider Group

Decision Making

Advisory

Advisory / Engagement

1. Involvement

	Task and Finish Group	Programme Board	Clinical Advisory Panel
Operations		Y	
Finance			
Patients and information		Y	
Medical	Y	Y	Y

We are currently working with the analytical team, and will work with finance colleagues as part of the assurance process

2. Governance approval

The proposed service specification is being developed by the Clinical Reference Group; the standards will be appended to the specification.

The specification and the proposal to consult will be reviewed and assured by:

- **Specialised**: This POC; CPAG; DCSC
- **Review**: Programme Board; Board Task and Finish Group.

We will be providing programme updates to:

- This POC , Portfolio group, SCOG, PPVAG, NHS England Board.

The standards will be reviewed and amended by the review's Clinical Advisory Panel prior to consultation, taking account of:

- Views expressed during pre-consultation engagement (inc. CRG)
- Evidence review (ScHARR and NICOR).

3. Funding implications

- We are consulting on the ideal and aspirational standards that set out best practice for congenital heart disease services.
- We are trying to establish a consensus on best practice in line with the review's agreed remit and ways of working.
- The Review's senior governance groups have discussed the challenge of affordability and agreed:
  - There is no blank cheque.
  - We will undertake financial impact assessment
  - In consultation we will:
    - Be clear that improving quality will have some cost implications;
    - Say that affordability will be taken into account in our decisions;
    - Seek views on appropriate trade offs; and
    - Avoid making commitments that falsely raise expectations.

3. Funding implications

- Financial impact and affordability are critical considerations but cannot be fully assessed until later in the process.
- In order to produce a full assessment of affordability and value for money we would need to understand:
  - The cost impact of the standards;
  - Pricing/payment systems;
  - Predicted future activity levels; and
  - The proposed form and function of the service including the number and size of centres.
- All of these are variables, not just the standards, and our final decisions will consider a range of options and trade offs.

3. First stage financial impact analysis

- We will provide a first stage assessment to accompany the consultation - this assessment will:
  - set the financial context (current spending and expected future growth);
  - highlight potential drivers of cost in the proposed specification compared with the existing specification; and
  - highlight potential benefits / savings from the proposed specification compared with the existing specification.

After consultation: analysis of responses

- It is difficult to estimate the number of responses that will be received.
- Previous consultations on service specifications may be a poor guide given the high level of interest in the review and the higher level of consultation activity proposed
- It is proposed that a specialist external agency be engaged to analyse and report on consultation responses
- The review's Clinical Advisory Panel will consider how to respond, agreeing any necessary revisions to the standards.
- The CRG will consider and respond to responses specifically relating to the specification.
- The review will produce a report on the response to the views expressed in consultation.

After consultation: second stage financial impact assessment

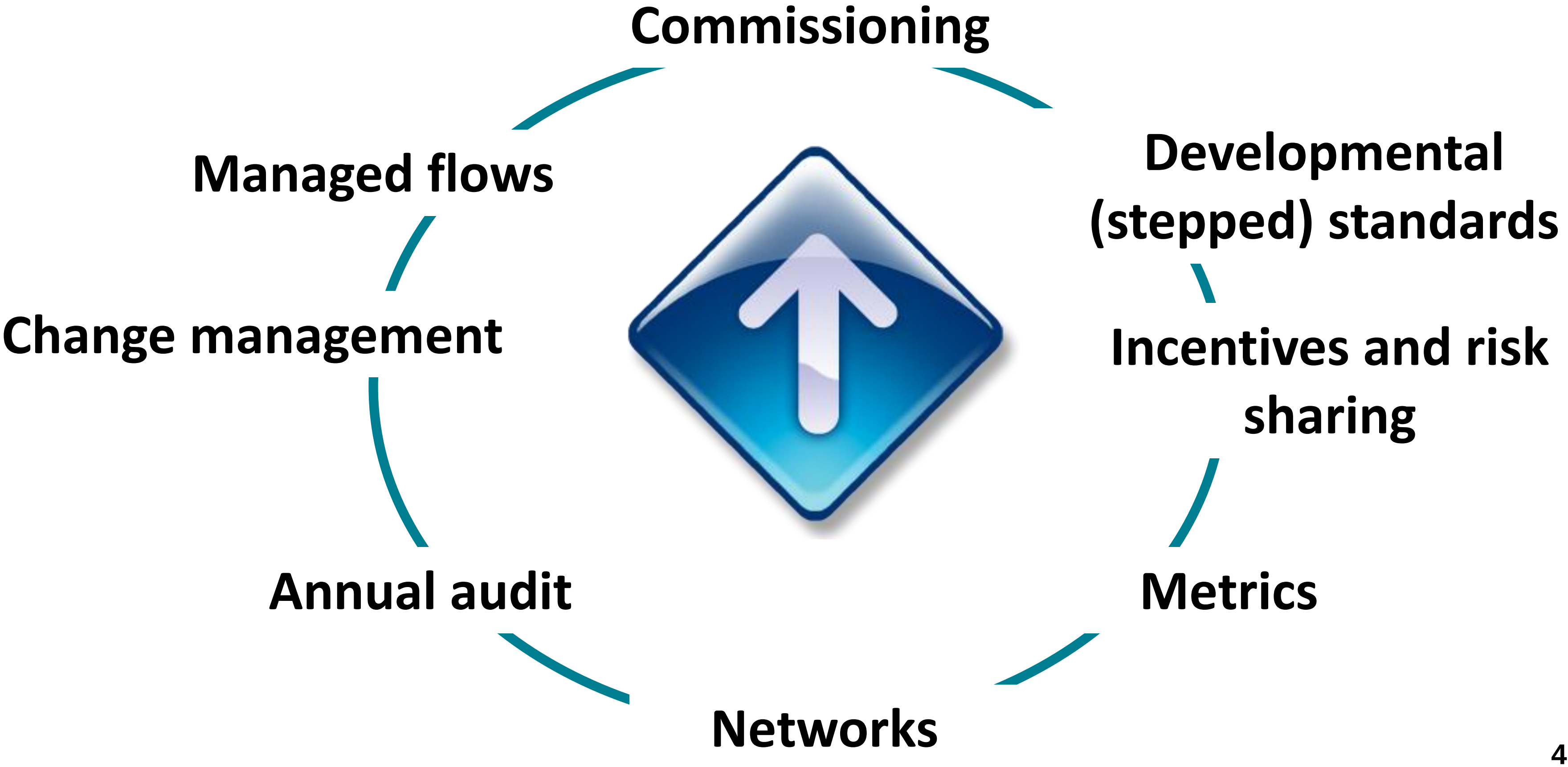
- During consultation we will seek information from providers on current practice and the gap between this and the standards.
- We will provide a second stage, quantitative financial assessment before the standards are agreed for commissioning.
- This assessment will consider:
  - Proposed final specification / standards
  - Pricing/payment systems
  - Predicted future activity
  - Future configuration of services.
- This will be central to the review's third objective *'To make recommendations on function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact.'*

After consultation: decision making

- The review has made a commitment that all decisions directly affecting the CHD service will be taken by the full NHS England Board in public.
- Prior to this proposals will be subject to the review's and specialised commissioning's assurance process.
- Further consideration needs to be given to this process to avoid undue delay and duplication.

How do we propose to make change happen?

Effective implementation will require a multi-dimensional approach



Commissioning

Developmental (stepped) standards

Incentives and risk sharing

Metrics

Networks

Annual audit

Change management

Managed flows