Board Task and Finish Group

23 June 2014

AGENDA

1pm – 2:30pm

(Malcolm Grant's Office, Room 6A1, 6th Floor, Skipton House, London)

Members in attendance: Professor Sir Malcolm Grant, Board Chair, (Chair)
Margaret Casely-Hayford, Non-Executive Director
Professor Sir Bruce Keogh, National Medical Director
Rosamond Roughton, Interim National Director: Commissioning Strategy *(joining via VC from Quarry House)*

Apologies: Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel
Ed Smith, Non-Executive Director

Additional attendees: John Holden, Director of System Policy
Lauren Phillips, Programme Development Manager (Secretariat)

Item	Agenda Item	Action	Lead
1	**Welcome and Apologies**	To note	Chair
2	**Minutes of the last meeting (15 April 2014)**	To agree	Chair
3	**Declarations of Interest**	To note	Chair
4	**Action Log**	To discuss	Chair
5	**Board Task and Finish Group Membership** (verbal)	To agree	Chair
6	**Update to the NHS England Board - One year on**	To discuss	John Holden
7	**Update from the Programme Board** (verbal)	To note	John Holden
8	**Timeline update**	To discuss	John Holden
9	**Preparing for consultation**	To note	John Holden
10	**Transition Dashboard**	To discuss	John Holden
11	**Programme Board Membership**	To agree	John Holden
12	**Update from the Clinical Advisory Panel** (verbal)	To note	Professor Sir Bruce Keogh
13	**Highlight report**	To note	John Holden
14	**Any other business**	To discuss	All

Minutes of the Board Task and Finish Group held on 15 April 2014

Present:

- Professor Sir Malcolm Grant (Chair)
- Professor Sir Bruce Keogh, National Medical Director
- Mr Ed Smith, Non-Executive Director
- Ms Margaret Casely-Hayford, Non-Executive Director
- Mr Bill McCarthy, National Director: Policy
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel

In attendance:

- Mr John Holden, Director of System Policy
- Lauren Phillips (Secretariat)

Item	Agenda Item
1	**Welcome and Apologies**
	The Chair welcomed everyone to the meeting.
2	**Note of the last meeting**
	The notes of the last meeting were agreed (7 January 2014).
3	**Declarations of Interest**
	The Chair advised the Board Task and Finish Group that at the time that the National Institute for Cardiovascular Outcomes Research (NICOR) was established he was the President and Provost of University College London (UCL). Professor Sir Bruce Keogh advised the Board Task and Finish Group that at the time NICOR was established he was the Professor of Cardiac surgery at UCL.
4	**Action log**
	All actions in progress were considered. Professor Sir Malcolm Grant confirmed that he would be attending part of the next meeting of the Clinical Advisory Panel on 18 June 2014. (Action 28)
5	**Update and Assurance Process**
	John Holden pointed out that though the Board Task and Finish Group had not met since 7 January 2014, as the meeting scheduled for February 2014 had been cancelled, John had circulated a note to members of the Group in the interim period to update them on progress.

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	John introduced the item "Update and Assurance Process" which described the review's work and proposed approach for the key NHS England assurance groups. John explained that this is the slide set / paper that would be considered at the both the Women and Children's Programme of Care Board meeting on 29 April 2014 and the Clinical Priorities Advisory Group (CPAG) meeting on 30 April 2014. John drew the Task and Finish Group's attention to the following slides: **Slide 8: Engagement and Advisory Groups** The Board Task and Finish Group discussed what could be interpreted by "interdependencies", for example integrated, co-located, networked and agreed it was important to be really clear about what the review meant when it used the term. John confirmed that to date there had been a lot of consensus from the engagement and advisory groups about the importance of the standards based approach. He also explained that the review was now operating on a more stable basis than the situation which had been inherited. The Board Task and Finish Group noted that the large amount of engagement with those groups had put the review into a good position to move onto the next phase. John explained that through discussions with Local Government, NHS England's patient voice team and representative faith groups, there had been some further suggestions for engagement with people from Black, Asian and Minority Ethnic (BAME) groups who are disproportionately affected by congenital heart disease. The Board Task and Finish Group noted that further engagement work was required was required for BAME groups. **Slides 10, 11 and 12: Review methodology, evidence and assessing capacity** John explained that the review's intention was to develop a single set of standards for the whole pathway of care which sets out the ideal. Alongside that the team is currently carrying out analytical work to understand current and future demand and the implications for capacity requirements. This will be used with the other evidence, for example the work with NICOR, intelligence from the Trust Visits and the literature review. The Board Task and Finish Group requested that further detail and options relating to the recommendations on function, form and capacity of future services and the commissioning model should be brought back to a future meeting for a more detailed discussion. **Slides 29 and 30: Consultation timeline** John explained that the current best-case scenario is that the 12 week full public consultation could begin in July 2014.

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	John noted that it was impossible to know how many responses to consultation would be received, though noted that the *Safe and Sustainable* consultation received approx. 75,000. As such, the current timeline had allowed 3 months for the analysis of any consultation responses, to amend the standards / specifications and, if necessary go back through the NHS England specialised commissioning governance. John explained that under the current arrangements, 6 months notice was to be given to Providers which would mean that the new specification would not be commissioned until 2015/16. The Board Task and Finish Group acknowledged that this did not necessarily prevent NHS England encouraging providers to implement some changes and improvement to services during the notice period. **Slide 31: Proposed pre-consultation engagement activity** The Board Task and Finish Group noted with approval the proposed pre-consultation engagement activity. **Slides 34 – 40: (CPAG) assurance process** John explained that the review team intended to attend a meeting of CPAG at the end of April 2014 to provide a briefing on the work to date, clarify their assurance requirements and explain and test the review's proposed approach. John explained that slides 35 – 40 were framed around the standard CPAG template (those assurances the review must satisfy CPAG on) as follows: 1. **Governance and decision-making** CPAG requires assurance that the review had been though the appropriate governance (both the review's own 'governance and also the NHS England specialised commissioning governance). 2. **Stakeholder testing** CPAG requires assurance that the review's stakeholders are familiar with the standards and that they believe a consultation is necessary. 3. **Financial impact** (see below) 4. **Equality analysis** CPAG requires a statement outlining the review's approach to equalities. Following discussion, the Board Task and Finish Group confirmed that it supported the review's proposed approach to assuring the CPAG on governance and decision-making, stakeholder testing and equality analysis. John drew the Board Task and Finish Group's attention to the work in relation to the **financial impact** (slides 38 and 39) and made the following points: • The review is consulting on ideal and aspirational standards.

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	• It is unlikely that any current provider will be able to satisfy every single part of the new standards. • Affordability, value for money and deliverability are important considerations, however a full / detailed financial impact analysis which takes into account potential changes to delivery of service, cannot be completed at this stage. The intention however is to provide some high level analysis now about the potential impact of this work, including a baseline of current spend and likely future cost drivers. The Board Task and Finish Group discussed and agreed that ideally the high-level financial impact analysis should set out: • the best sense of the overall financial envelope at the present; • those standards which, because they are extending the scope, will inevitably cost more (for example pre-natal screening); and • those standards which are about improvements to existing services and therefore may potentially incur additional cost or even create reductions in cost due to better organisation or smarter processes. Standards must describe a high quality service but this did not of itself guarantee a "blank cheque" for every possible change. The Board Task and Finish Group discussed the relationship between costs and tariff and John confirmed that the current time lag between cost collection and tariff change is 3 years. The Board Task and Finish Group agreed that a meeting should be scheduled between Malcolm Grant, Bill McCarthy and John Holden to further discuss the approach to assurance. The Task and Finish Group agreed that it was important to provide a line of sight to the NHS England Board via an update to the meeting on 3 July 2014, including all the progress to date and current expected timescales for the review.
ACTION	**Further engagement required with Black, Asian and Minority Ethic (BAME) groups.**
ACTION	**Discussion to be scheduled at a future meeting of the Board Task and Finish Group regarding the recommendations of function, form and capacity of future services and the commissioning model.**
ACTION	**Malcom Grant, Bill McCarthy and John Holden to meet to discuss assurance requirements.**
ACTION	**An update to be provided to the NHS England Board in July 2014, detailing the progress to date.**
6	**Feedback from the engagement and advisory groups**
	The feedback from the review's engagement and advisory groups was noted.

Item	Agenda Item
7	**Update from the Programme Board**
	Bill McCarthy (Chair of the review's Programme Board) provided a verbal update on the last meeting of the review's Programme Board. Bill confirmed that following the recent business planning round, further financial resourcing had been secured for the new CHD review programme for 2014/15. Bill noted that in response to requests from the review's Patient and Public Group for a specific session on safety concerns, John Stewart (NHS England), Ted Baker (Care Quality Commission) and Nigel Acheson (NHS England) had attended the last meeting of the Patient and Public Group on 27 March 2014 to discuss this. The Board Task and Finish Group noted that the next meeting of the review's Programme Board was scheduled for 16 April 2014.
8	**Update from the Clinical Advisory Panel**
	Professor Sir Michael Rawlins (Chair of the review's Clinical Advisory Panel) provided a verbal update on the third meeting of the review's Clinical Advisory Panel (31 March 2014). This meeting had focussed on the latest iteration of the draft standards and the associated "knotty issues". The Board Task and Finish Group noted that the next meeting of the review's Clinical Advisory Panel was scheduled for 18 June 2014.
9	**Highlight report**
	The Board Task and Finish Group noted the highlight report and requested sight of the risk mitigation associated with the key risks on the highlight report.
ACTION	**Latest iteration of review's Programme Board risk register to be circulated to the Board Task and Finish Group.**
10	**Any other business**
	There was no other business.
Date of next meeting	TBC

Action Log: Task and Finish Group

Action no.	Meeting date	Action description	Responsibility	Progress details	STATUS	Date closed
5	29.07.13	**Clearly differentiate between evidence and judgement.**	Bruce Keogh	28 August 2013: Letters sent to both Dr Tony Salmon and Professor John Deanfield who lead the respective groups working on standards. 07 January 2014: commissioning an independent evidence review.	CLOSED	07.01.14
7	29.07.13	**Consider how to support those affected by change – for example patients and families who might potentially need to use different services, and clinicians and staff whose units might be affected.**	Bill McCarthy	Engagement / advisory groups established to facilitate dialogue with those potentially affected by change.	CLOSED	07.01.14
8	29.07.13	**Continue engagement and discussion with a view to developing an initial proposition for discussion in the autumn.**	Bill McCarthy	Engagement is ongoing	CLOSED	07.01.14
15	30.09.13	**Discuss the potential for joint local government engagement, overview and scrutiny.**	Malcolm Grant	To be discussed with the Chair of the Local Government Association (LGA).	CLOSED	07.01.14
16	29.10.13	**The DRAFT policy for managing conflict of interest to be updated as per the amendments agreed during the meeting and brought back to the next meeting of the Task and Finish group for sign-off.**	Michael Wilson	Agreed at Task and Finish Group meeting on 7 January 2014 .	CLOSED	07.01.14
17	29.10.13	**Guidance to be produced to support group members in completing their declarations.**	Michael Wilson	Pending outcome of discussion of policy at meeting on 7 January 2014	CLOSED	17.02.14
19	29.10.13	**Ensure that the Local Government Association (Sir Merrick Cockell, Chair and Carolyn Downs, Chief Executive) are regularly briefed on the review.**	Bill McCarthy		CLOSED	07.01.14
21	07.01.14	**Update action log as per discussion.**	Michael Wilson	Complete	CLOSED	08.01.14
22	07.01.14	**Produce guidance on completing the agreed conflict of interest declaration form.**	Michael Wilson	Guidance produced	CLOSED	17.02.14
23	07.01.14	**A clear reference to be added to the policy for managing conflicts of interest regarding the publication of the register of interests.**	Michael Wilson	Reference added	CLOSED	08.01.14
24	07.01.14	**Engage with both Monitor and the Competition and Markets Authority in advance of any scenario planning / modelling.**	John Holden	Discussions planned as part of work of Objective 3.	IN PROGRESS	
25	07.01.14	**The new review team to speak to the Royal College of Surgeons about training, as a matter of urgency.**	Michael Wilson	Discussed by Clinical Advisory Panel on 31 March 2014 - resaasurance received regarding effectiveness of the pipeline of congenital surgeons.	IN PROGRESS	

26	07.01.14	**The new review team to look at what work could be done in parallel, including scenario planning on what form services could take, without prejudice to any future public consultation.**	Michael Wilson	Plans to be developed during consultation period.	IN PROGRESS	
27	07.01.14	**The new review team to set out a more complete timetable as quickly as possible.**	Michael Wilson	To be discussed at the Task and Finish Group on 15 April 2014.	CLOSED	15.04.14
28	07.01.14	**Professor Sir Malcolm Grant to be invited to a future meeting of the Clinical Advisory Panel.**	Professor Sir Michael Rawlins	Professor Sir Malcolm Grant attended a meeting of the Clinical Advisory Panel on 18 June 2014.	CLOSED	18.06.14
29	15.04.14	**Further engagement required with Black, Asian and Minority Ethic (BAME) groups.**	John Holden	Specific engagement planned with BAME communities during consultation. To be discussed at Task and Finish Group meeting on 23.06.14.	IN PROGRESS	
30	15.04.14	**Discussion to be scheduled at a future meeting of the Board Task and Finish Group regarding the recommendations of function, form and capacity of future services and the commissioning model.**	John Holden	On the forward plan for discussion at a future meeting of the Board Task and Finish Group	IN PROGRESS	
31	15.04.14	**Malcom Grant, Bill McCarthy and John Holden to meet to discuss assurance requirements.**	Malcolm Grant / Bill McCarthy / John Holden	Meeting took place on 21 May 2014.	CLOSED	21.05.14
32	15.04.14	**An update to be provided to the NHS England Board in July 2014, detailing the progress since June 2013.**	John Holden	To be discussed at the Task and Finish Group on 23 June 2014.	IN PROGRESS	
33	15.04.14	**Latest iteration of review's Programme Board risk register to be circulated to the Board Task and Finish Group.**	John Holden	Risk and Issue Registers circulated electronically to those Board Task and Finish Group members who are not also members of the review's Programme Board.	CLOSED	15.04.14

DRAFT – Update to the NHS England Board

One Year On: progress of the new congenital heart disease (CHD) review

Executive summary

The review has made progress against all of its objectives. In particular, the development of a single coherent set of standards provides the platform for commissioning an excellent service, and will help determine whether providers are able to meet our requirements. But commissioning an excellent service is not just about the location of surgical units. Our work to date will enable us to describe expectations of the service for the whole lifetime pathway of care; to set out a detailed understanding of current and future demand and the drivers which affect it; to make information readily available on the quality of service; and to improve outcomes by ensuring earlier and better diagnosis.

We had hoped to be consulting on standards by this point, but we have more work to do. The review has managed a constant tension between acting with enough pace to mitigate the risks of "limbo" (whereby investment is withheld, recruitment is difficult, service developments are stalled) versus taking enough time to give all stakeholders the opportunity to shape the future. "Safe and Sustainable" took four years and had a net cost of £6m, but in the end the conclusions were not implemented because of concerns about the process. We are mindful of this and - despite the clamour for a quick solution – have resisted the temptation to take short-cuts in our process, our engagement or in our own internal assurance.

The next steps in this work are to consult on and agree the standards and specification, complete the analytical work, and develop the functions & form and commissioning & change model. At that point we will be able to make recommendations to the NHS England Board. We expect that by the end of the 2014/15 financial year this will cease to be a dedicated "task and finish" project, and implementation will be mainstreamed as part of NHS England's wider commissioning of specialised services.

Introduction – an "implementable solution within a year"

In June 2013 the Secretary of State announced that he accepted the recommendations of the Independent Reconfiguration Panel (IRP), and was therefore setting aside the outcome of the "Safe and Sustainable" review of children's congenital heart surgery. The work had been led by a committee, acting on behalf of all primary care trusts, which no longer existed. He therefore asked NHS England, as the organisation now responsible for commissioning these services, to undertake a new review, learning the lessons of experience to date, including Judicial Review findings and the report of the IRP.

The Board of NHS England, meeting in public in July 2013, discussed the issue (see link to paper). It was recognised that the new review was a vital opportunity to secure lasting improvements for some of the most vulnerable NHS patients. Reviewing such a high profile and sensitive service would be seen as a test of the way in which the emergent

NHS England conducted itself, and our commitment to patient and public engagement, clinical leadership in every aspect of our work, and evidence-based decision making. The Board recognised the difficulties of conducting the review in a climate where trust had broken down and relationships needed to be rebuilt, but was nonetheless concerned about the risks to the congenital heart service due to continuing uncertainty and "limbo". Therefore the Board set an ambition that there should be an "implementable solution within a year". We have now reached the one year anniversary of the Board's challenge, and this paper describes the progress that has been made and what remains to be done.

Overall approach – six objectives

Stakeholders – especially patient groups and clinicians - told us from the start that to have any kind of constructive dialogue, we should "take closure off the table". In other words, we must find a way to discuss the issues without pre-supposing that some units must cease to provide services. Many told us that the threat of closure had led to an adversarial approach during the previous review, both in terms of engagement in the review, and even in the way that surgical centres behaved towards each other, to the detriment of patients. More positively, many stakeholders told us that the key to a successful outcome would be to build consensus around a set of standards, but that the standards should not be "fudged" – i.e. they should objectively describe the optimal model of care, without regard for the current service arrangements.

At the same time, it became apparent to us that we needed a comprehensive understanding of historic activity, and the current and anticipated volume of services. Alongside a new set of standards for the whole pathway care - from fetal through children and adults - this would help us to understand the capacity requirements and the cost implications. Analysis of the historic data could help us to identify any relationship between the way services are organised and the outcomes for patients. In turn, the standards and capacity requirements would allow us to start to describe the functions and form of a congenital heart disease service for all patients in England, including issues not dealt with by the standards like access and geographical distribution. Taking all these points together, we were satisfied that we could legitimately "take closure off the table". We considered that in the absence of compelling, prima facie evidence that closing units was the only way to secure high quality services for the future, that the new review should have an open mind, develop standards of care and follow the evidence as it emerged. Once we had agreed the standards, examined the data and other evidence, and considered functions & form, only then could we have a meaningful dialogue with potential providers about how to meet our requirements, and whether any reconfiguration would be necessary.

NHS England is a commissioning organisation and this strategic review is the front end of a commissioning process – defining the need, and considering the options. Provider organisations told us they wanted to understand and to help shape the approach to commissioning and change – any reconfiguration resulting from the review would affect all those involved and have implications for workforce, teaching, and of course for interdependent clinical services. Even if reconfiguration were not required, it was highly likely that providers would need to make changes to be compliant, and to network effectively.

Finally, patient and public stakeholders, strongly endorsed by clinicians, told us they wanted better real time information to understand how the service was faring, to provide a quality safeguard and to inform patient choice. They argued that current data was overly-focused on one metric, for "30 day mortality" (i.e. post-operative survival), which showed that in the past decade (since the Kennedy Inquiry at Bristol in 2000) surgical outcomes had levelled up significantly so that across England these outcomes were now world-leading. But mortality is not the only indicator of good care, and does not reveal enough about other outcomes. They also told us that a really good service does not begin at the point that surgery takes place; it begins with early and accurate detection and diagnosis, through improved rates of antenatal detection, supplemented by improved neonatal detection.

In January 2014 our Board was asked to consider and agree a set of six objectives for the review, which captured all of these different strands of work (see link to paper). Progress against the six objectives would be the measure by which we could demonstrate progress against the Board's ambition for an "implementable solution".

The following six objectives were agreed:

Objective 1: to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;

Objective 2: to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;

Objective 3: to make recommendations about the function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact;

Objective 4: to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;

Objective 5: to establish a system for the provision of information about the performance of congenital heart disease services to inform the commissioning of these services and patient choice; and

Objective 6: to improve antenatal and neonatal detection rates.

Range of services covered by the review

Our Board had already decided, in July 2013, that the new review should encompass both adults and children's services, recognising that in practice they were inextricably linked, through shared staff including surgeons. Stakeholders – especially clinicians - told us this "child and adult" approach was essential, but it was a significant departure from "Safe and Sustainable", which had been asked to look at children's services only. This meant that without doing anything else, our work was already much broader in scope than the previous review. And there were more detailed questions of scope to be answered, for example whether and how to take account of interdependencies between services. It was important to get the balance right before asking the Clinical Advisory Panel (Chaired by Professor Sir Michael Rawlins) to consider and advise on the review's scope, because too broad a scope would make the review undeliverable; too narrow might mean that important dependencies were overlooked. Therefore we consulted our stakeholders for

comment, and through this process we formally agreed the scope of our work on standards.

Similarly, one of the most powerful messages we heard from our early meetings with patient groups was that the CHD service sometimes failed patients and families at their lowest ebb, when there was a poor outcome, or during palliative care, or following bereavement. This was about treating people with compassion and dignity, rather than a question of the technical skills of the clinicians involved. So, almost from our first meeting with patients, we decided that there should be a dedicated chapter in our new standards to deal with palliative care and bereavement. And throughout the standards there are references to the importance of open, honest communication. Finally, we have been clear that NHS England's focus is on commissioning services for the population normally resident in England. However, congenital heart surgery for patients resident in Wales invariably takes place in England, and so we have been factoring this in to our work, and considering where appropriate the relatively smaller cross-border flows with the other devolved administrations.

Openness, engagement and decision making

We began our work in June 2013 by meeting the national patients' charities, to get an overall perspective on the challenge. This immediately triggered concerns amongst local charities and patient support groups that their views were not being sought and would not be respected by the national charities. It was clear that relationships between some of the charities and patient groups had been left strained following the "Safe and Sustainable" process.

Our early meetings with stakeholders were focused on giving everyone a chance to say what they felt about the recent history and their hopes for the future. This was essential to the constructive working relationship we have now, based on a programme of regular engagement events with three different groups each chaired by an independent representative of the group concerned. (Patient and Public Group chaired by Professor Peter Weissberg, Medical Director at the British Heart Foundation; Clinicians' Group chaired by Professor Deirdre Kelly, Consultant Paediatric Hepatologist at Birmingham Children's Hospital NHS Foundation Trust; and Provider Group chaired by Chris Hopson, CEO of the Foundation Trust Network). We have sought to involve every constituency in these groups – every charity and patient support group, clinicians and managers from every hospital delivering specialist congenital heart care, and every linked speciality. We make sure that we offer all three groups a broadly similar programme so that there is consistent and comprehensive sharing of information, but we also adapt the agendas to reflect whatever those groups wish to discuss. Every meeting has its own character. All are robust in their debates and appropriately challenging to NHS England. They never allow us to forget that these are real issues that need to be resolved.

For local government and Healthwatch representatives we have held a national plenary meeting (in Birmingham) and subsequently an update via WebEx; we have also attended Overview and Scrutiny Committee hearings around the country to explain the work of the review. We have attended two all-party parliamentary briefing sessions, and supported Department of Health ministers to answer numerous Parliamentary Questions. We have also attended various professional conferences – for example the national association of critical care managers. Over the Easter School Holidays in April 2014 we ran nine

regional events around the country, specifically designed to hear from children and young people. Over 100 young people and their families told us their stories. And we have just completed a series of visits to every specialist congenital heart unit in the country, led by the chair of our clinicians' engagement and advisory group. As part of these visits we were able to hear from and talk to front-line clinicians, patients and their families and hospital managers, giving us a much richer understanding of their achievements and challenges. There is more work to do – especially to hear from adults with CHD, from black, asian and minority ethnic groups, from people with learning disabilities and from bereaved families, all of whom have been relatively under-represented in our work to date. But as a result of this extensive engagement we feel we are in a good position to consult on a set of standards, and that there will be no surprises for any of our constituencies.

The IRP report into "Safe and Sustainable" observed that there were perceptions of a lack of openness, and a suspicion that outcomes were pre-determined. The diagram at Figure 1 shows the governance arrangements we have established for this review, and in particular how our decisions are made, and how the different engagement and advisory groups feed in to the decision making process. We have shared this widely so that there is no confusion about the route by which the ultimate decisions are made – in particular, the pre-eminence of the NHS England Board and its "Task and Finish Group" (chaired by Professor Sir Malcolm Grant) dedicated to this project. But for reasons of simplicity and clarity the diagram does not attempt to show the full complexity of the governance arrangements which must be satisfied in order to consult on the new service standards, which require the involvement of a Programme of Care Board; the Specialised Commissioning Oversight Group; the Clinical Priorities Advisory Group; and the Directly Commissioned Services Committee of the main Board. Successfully navigating this governance without undue delay is one of the main challenges we face in consulting on standards in September 2014.

One of the defining features of our work over the last year has been the approach we have taken to openness and transparency. In addition to involving the widest possible range of stakeholders, we have tried to make sure that everything we do is open to scrutiny, with a conflicts of interest declaration being widely rolled out, and a publications policy where the default is always that we publish everything. This is logistically difficult and can create tensions – often we are doing our "thinking out loud", and in public, and we are robustly challenged on ideas which have merely been floated, not finalised. But on balance the approach has been quite liberating. We publish all significant material, whether it is correspondence, agendas, meeting papers or minutes. We produce a blog every fortnight (there have been 25 in the year from June 2013) in which we describe what is happening and what is forthcoming, and we always feed back what we have heard and what we have done about it.

Progress update against the objectives

- **Objective 1 - standards**

  From the beginning of the review's work, stakeholders told us that the best way to improve services was through clear service standards, uniformly applied. The creation of NHS England as a single national commissioner of specialised services presents an opportunity to drive high standards consistently in a way not open to our predecessors. Under the leadership of Professor Deirdre Kelly and with extensive cooperation from a range of clinical experts and patient representatives, a single

coherent set of standards has been developed that describes the whole patient pathway from fetal diagnosis through children's services and adult services including transition and pregnancy. This builds on two discrete sets of pre-existing standards, and a third which was underway; all have been fully reviewed, refreshed and further developed. There is an increased emphasis on good communication with patients and their families and a new section covering end of life care and bereavement. Responding to the challenge set by Professor Sir Bruce Keogh, the standards aim to describe an excellent service, not just best fit with current practice. This has been a lengthy, complex and testing exercise, to harmonise a large number of standards which had previously been organised and expressed in different ways, and grappling with some of the most “knotty” issues. The draft standards will be subject to full public consultation later this year: our target date has slipped from July 2014 to September 2014 and we have been criticised for the delay, which is due to the production of the consultation materials, and the challenge of clearing the internal assurance process referred to above. One issue to be tested in consultation will be the potential trade-offs required if, in meeting the standards at all specialist units, the standards were to be considered unaffordable. Possible approaches could include a longer timetable, commissioning from fewer units (to achieve economies of scale), lowered expectations for those standards associated with higher costs, or focusing on a smaller set of “must do” standards.

The standards, once agreed, will form the basis of NHS England's service specification which we use for contracting. The standards will be challenging and it is not expected that any provider meets all the standards currently. Some of the standards will be developmental, so a timetable for reaching them will be set out. The Clinical Reference Group (CRG) responsible for congenital heart services has worked with the new CHD review team to develop the draft service specification and timetable for developmental standards. Once agreed, the specification will become the basis for NHS England's commissioning of CHD services and all providers will be expected to meet the standards.

In addition to the work described on developing standards for CHD services, the review will work with colleagues from NHS England and the relevant CRGs to develop standards for extra corporeal life support services (including extracorporeal membrane oxygenation) and referral pathways and criteria for CHD patients who could benefit from cardiac transplant.

- **Objective 2 - analysis**

In order to commission CHD services effectively, NHS England needs to understand the demand for services now and in future. Clinicians and hospitals providing CHD services have told us that they expect the growth in paediatric activity seen over the last ten years to continue in future. The number of adult patients with CHD is now believed to exceed the number of children with CHD for the first time, and the number of adult patients is expected to continue to rise.

For adult services some information is available on current inpatient activity, but this information is incomplete because not all adult activity is reported to the national database run by the National Institute for Cardiovascular Outcomes Research (NICOR), and the coding used in Hospital Episode Statistics (HES) does not easily distinguish CHD activity from other cardiac services. No comprehensive assessment of expected changes in future years has previously been available for both children

and adults. The review's analytical team has worked with clinicians, NICOR and NHS England's lead commissioners from national and area teams to define a set of procedure codes that most accurately describe CHD inpatient activity. Data from the NICOR database and the HES data set are being analysed and compared to give the best understanding possible of current activity as well as trends over the last ten years. By the end of July 2014 we aim to have the first evidence-based projections of activity for children's and adults' services, modelling two different scenarios for growth (population only, and population plus other factors). The emerging analysis already confirms our understanding that beyond those centres providing specialist CHD services, a larger number are involved in providing care for adult patients, mostly undertaking lower numbers of procedures, which raises questions about the incidence of "occasional practice". Our public and patient stakeholders representing adult patients have told us this is a significant concern for them.

- **Objectives 3 and 4 – function, form & capacity and commissioning & change**

  The review will move beyond standard-setting and activity analysis to make recommendations for the shape of the CHD service of the future. It will also consider possible approaches to commissioning those services to ensure that everyone has access to excellent services that meet the service standards, and that occasional practice is eliminated. The preparatory work is already underway, but we cannot pre-judge the outcome of the standards and analytical work. The review is working with colleagues from across NHS England to develop an approach that helps to inform similar work on other specialised services.

  Engagement with our provider leaders' group has highlighted the importance of any change programme taking account of research, training and workforce implications, and the need to have some explicit recognition of the cost of any substantial change. We intend to describe the necessary components of a commissioning approach to facilitate the emergence of regional, collaborative, provider-led solutions, including the potential for the development of formal joint approaches that also meet the necessary requirements of competition and choice.

  The standards will establish some important parameters for future services including the minimum levels of surgical and interventional activity required (because of the requirements for teams of surgeons and interventionists and minimum activity requirements for each of these groups to assure continued competence). This will be taken into account along with considerations of access, changing demand, affordability and other parameters in making these recommendations.

- **Objective 5 – better information**

  The IRP in its review of the work of "Safe and Sustainable" noted that high quality, accessible and understandable information to inform decision making was lacking. The review will therefore ensure that better information is available for commissioners and to inform patient choice.

  As a first step, we have worked with lead commissioners from regional teams to institute the use of a children's congenital heart "transition dashboard". This was originally specified to manage risks in the period when it was expected that "Safe and Sustainable" would be implemented. Despite implementation not taking place, the transition dashboard still provides a mechanism to test the current health of the

system, by collecting specific information on defined aspects of the children's congenital heart services in England. And in line with other specialised services, the CRG for Congenital Heart Service has developed a quality dashboard covering a range of measures, which will be the enduring approach to real time quality monitoring. Although the quality dashboard has been introduced for 2014/15, it has been agreed that the transition dashboard will remain in situ until further notice.

The review is also working with NICOR to consider how the information it produces can be improved. We will work with them to consider how a wider range of outcomes (beyond mortality) could be reported. We will also work with them to develop ways of presenting the information which would be easier for patients to interpret and allow them to make informed choices.

- **Objective 6 – early detection**

  Abnormalities of the heart are the most common congenital defect and yet rates of diagnosis before and immediately after the baby is born are not as high as they could be. Clinicians tell us that earlier diagnosis can lead to better outcomes throughout a patient's lifetime, more informed choice, better managed births and better experience for families.

  The review has brought together a wide range of stakeholders with an interest in early diagnosis to better understand the reasons for current low antenatal detection rates and to develop plans for addressing these. Early work suggests that better training and support for ultra-sonographers undertaking antenatal scans will be important. We will work with Health Education England (HEE), providers and third sector partners to consider how this, and other potential issues, could be addressed.

  Stakeholders have also told us that the lack of a consistent, national database for recording all congenital defects is a further significant problem. Without this it is not possible to be sure about the rate of antenatal diagnosis. We are in discussion with Public Health England (PHE) who will be developing and implementing a new national database which is expected to be functional by April 2015.

  The National Screening Council (NSC), now part of PHE, recently consulted on the efficiency of pulse oximetry, a simple test to measure oxygen saturation levels in new born infants which can help to identify potential congenital heart problems. The evidence was not conclusive and so the NSC has announced that it will be running a pilot programme to better assess the effectiveness of pulse oximetry and the related implications if it were to be specified as part of the new-born infant physical examination (NIPE). This will help to address longstanding concerns in this area, and the review will stay close to this work as we are very supportive of the evidence-based approach.

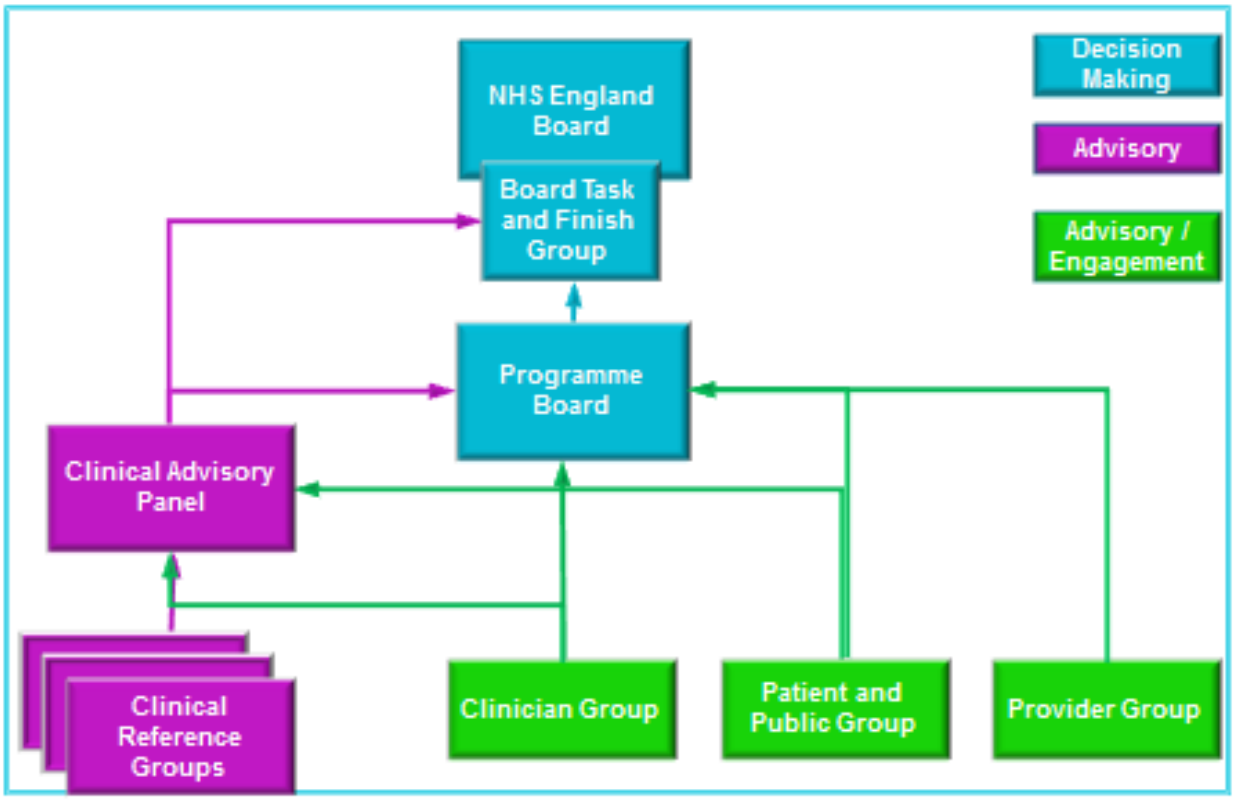
Conclusion and next steps

The review has taken seriously the Boards' ambition for an implementable solution to be delivered within one year. Early work with stakeholders made clear that the scope of the review needed to be wider than originally envisaged and that a new approach would need to be developed, retaining what was useful from earlier processes (e.g. the work on standards for children's surgical centres) but with no pre-conceptions about a particular

"answer". The review also needed to rebuild trust, and this has been successful because in large part it was not rushed. In the year since we were asked to take on this challenge, NHS England has invested significant time and effort in working with public and patients (and their representatives), clinicians from provider organisations and national bodies, and provider leaders. We have been very open in our processes and maintained a constant account of what we are doing, publishing all relevant documentation at every step of the way. Taken together, these factors have made it hard to meet the ambitious timeline originally envisaged.

Good progress has however been made on all of the review's objectives, especially in the development of standards for the whole lifetime pathway. Plans are well advanced to consult on these standards, but there remain significant risks, and our current expectation is that consultation could commence in September 2014, subject to approval by NHS England's internal assurances processes. This could then mean that the review would be able to make recommendations to the NHS England Board on all six objectives at the end of the financial year.

Figure 1: Decision making, advice and engagement



New Congenital Heart Disease Review

NHS England

Timeline update

John Holden
Director of System Policy
23 June 2014

Timeline: summary

- In March 2014 the Programme Board approved a 'best case' scenario timeline that would have led to consultation launch at the end of July 2014.
- In order to meet the best case scenario for consultation launch the review team advised the Programme Board that a number of conditions needed to be met.
- Some of these conditions have not been met, and along with other factors this means that a July 2014 launch will not now be achieved.
- A revised timeline was therefore presented to the Programme Board on 10 June 2014. Risks to achieving the new timeline were also identified, along with mitigating actions.

Timeline: factors leading to the delay

In order to mitigate the risk of legal challenge against the review it is imperative that due process is followed.

- As advised at the May 2014 Programme Board meeting, the scale of the financial impact assessment required for Programme of Care (POC) Board and Clinical Priorities Advisory Group (CPAG) is much more significant than had been anticipated.
- Aspects of the financial impact assessment now require specialist finance input.
- The required financial impact assessment can only be completed once the standards and service specifications are agreed.
- The Clinical Advisory Panel (CAP) has reviewed the standards in light of what has been heard during pre-consultation engagement (and the evidence from ScHARR and NICOR). The drafting of the service specifications by the Clinical Reference Group (CRG) is not yet complete.
- Completing the financial impact assessment is dependent on accurate activity data and projections and there have been both delays in obtaining activity data from HES and additional complexity in estimating activity.

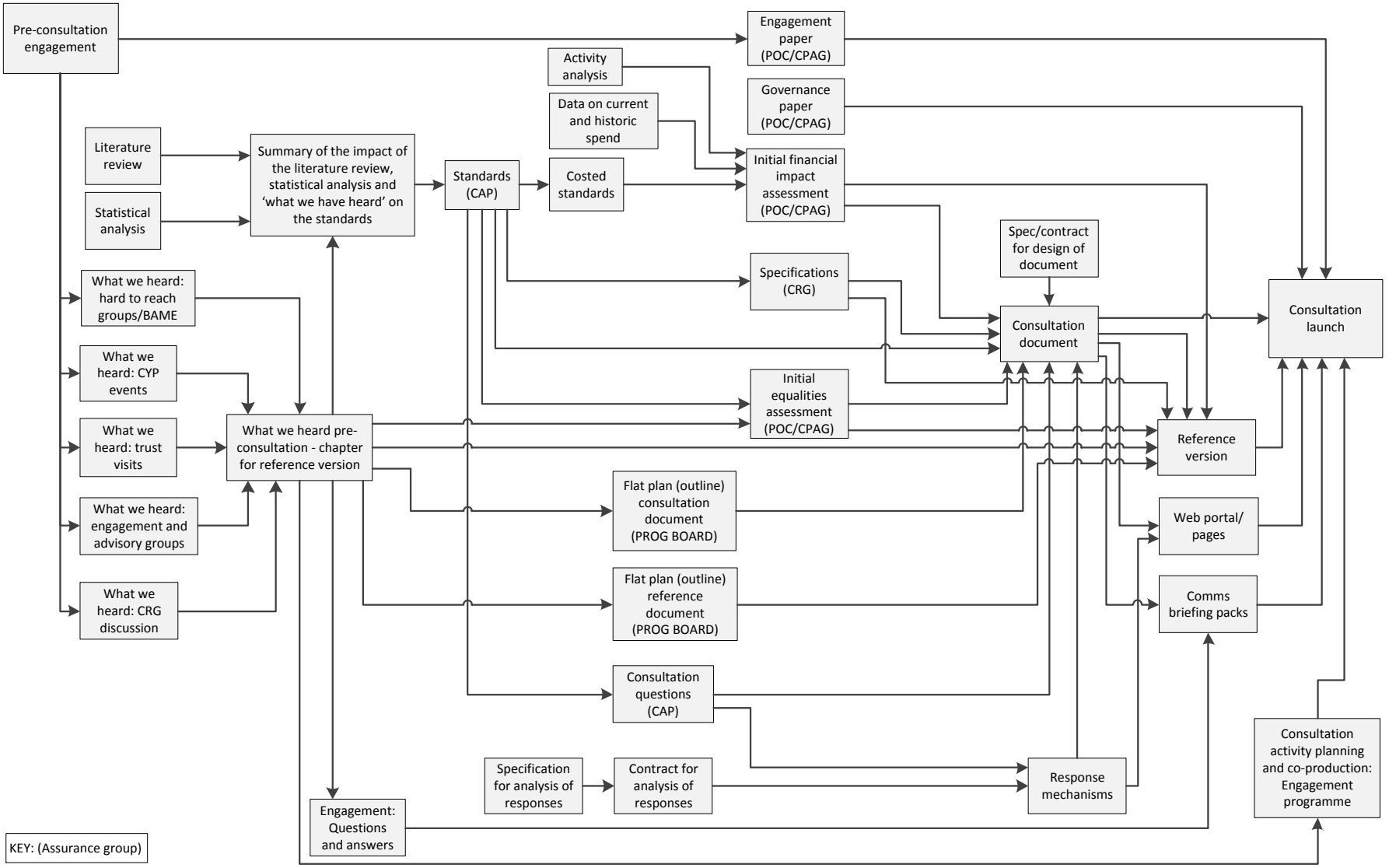
Timeline: planning

- In order to develop a clear work plan and a deliverable timeline the programme team has identified all the products that need to be delivered in order to launch consultation.

- Where appropriate the relevant approving body has also been identified.

- The inter-relationships and dependencies between these products has been mapped and is shown on the next slide.

Detailed product dependency map



The current expected timeline

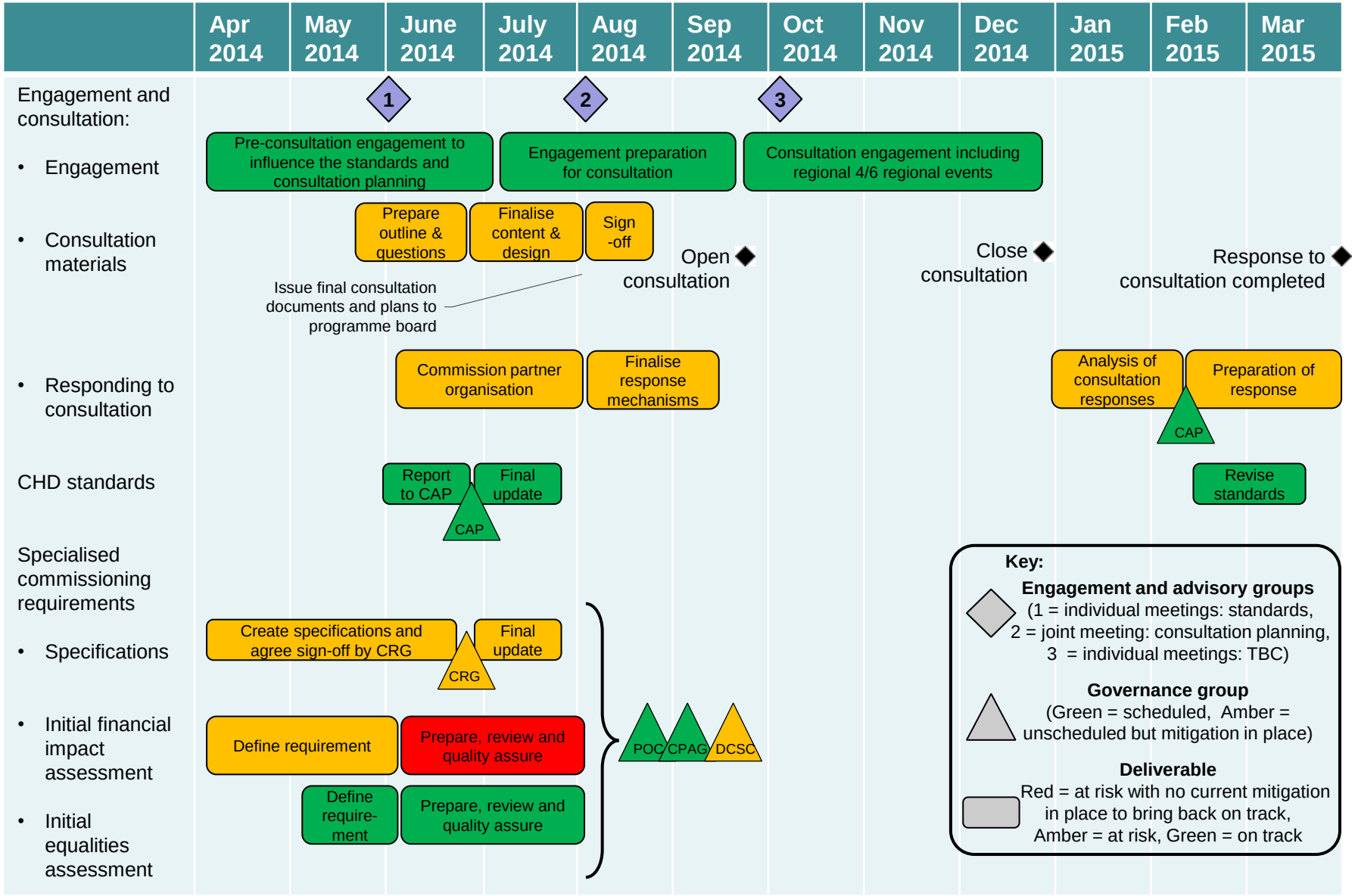
- The following slide shows the current expected timeline, aligned to one of the possible scenarios presented to the Programme Board in March 2014.

- This takes into account:
  - the products that need to be delivered and their dependencies;
  - the work needed to deliver these products;
  - the need to bring in additional expert support; and
  - the assurance process and the timing of key groups.

- This suggests that the **best case scenario** for consultation launch is now mid/late September 2014.

New Congenital Heart Disease Review

Current expected timetable (June 2014)



Risks to achieving the proposed timeline

- Risks to achieving this launch date include:
  - continued risk around the ability to deliver all the required products, particularly the financial impact assessment, due to both volume and complexity;
  - the need to identify finance expertise;
  - POC and CPAG would need to review and respond within tight, identified time limits, including meeting as currently scheduled in August 2014;
  - all assurance groups (including Gateway) would need to approve the proposals at the first consideration.
- The Programme Board asks the Board Task and Finish Group for its support in mobilising the required resource within NHS England to ensure the launch of consultation during September 2014.

Recommendations

- The Programme Board asks the Board Task and Finish Group to approve the new proposed timeline for consultation, to note that this will mean that the NHS England Board's ambition of an implementable solution within one year will not now be achieved and to seek the support of the NHS England Board for this.

- The Programme Board asks the Board Task and Finish Group for its support in ensuring that successful launch of consultation at the earliest possible date is a shared priority across the whole organisation.

Item 9

New Congenital Heart Disease Review

NHS England

Preparing for consultation

John Holden
Director of System Policy
23 June 2014

THE NHS CONSTITUTION
the NHS belongs to us all

Pre-consultation: engagement

- Bi-monthly meetings of the review's engagement and advisory groups (Providers; Clinicians; and Patients and Public)
- Clinical Reference Group (CRG)
- Children and young people events
- Visits to specialist units
- Briefing for MPs and peers
- WebEx with local government and Healthwatch
- Preparing for consultation

Pre-consultation: assurance

- The role of assurance

- What are we being asked about?

  - ✓Governance
  - ✓Engagement
  - ✓Equalities
  - ✓Affordability

Preparing for consultation

- Clinical Reference Group developing the service specifications and agreeing recommendations for phasing introduction.
- Workshop with members of the Patient and Public group to discuss what a ‘good consultation’ looks like.
- Testing proposed approach with engagement and advisory groups.
- NHS England’s Patient and Public Voice Assurance Group.
- Will work with the NHS in Wales, Scotland and Northern Ireland to consider their requirements.

Consultation materials

Our proposed consultation materials are:

- a plain English consultation document;
- an audio visual version of the consultation document;
- an easy read version of the consultation document;
- a full reference document;
- draft standards and specifications; and
- initial financial impact and equality assessments.

Consultation activities

Four regional events.

Specific engagement with adult patients; Black, Asian and Minority Ethnic (BAME) communities; bereaved families and patients with learning disabilities and their families.

Plans to encourage partners to hold their own events as part of a wider approach to engagement.

- NHS England regional and area teams
- Charities and support groups
- Professional associations
- Provider organisations

Develop materials for use by partners including FAQs.

Consultation questions and responses

Expect to ask questions across a whole spectrum:

- **Simple** – what about the service matters most to you?
- **Moderate** – do you agree with our proposals for network working?
- **Complex** – please comment on each standard

Expect it to have a mix of response types – Y/N, rating, free text

Expect to receive responses both on the structured response form and as letters. Do not expect to be able to include text or social media as routes for responding.

Expect to commission a specialist independent agency to analyse the responses.

Transition Dashboard

Purpose

The purpose of this report is to provide an update to the new CHD review's Board Task and Finish Group on the adoption and reporting process for the Children's Congenital Heart Transition Dashboard.

Background

The purpose of the Transition Dashboard is to provide a mechanism to test the current health of the system by collecting specific information on defined operational delivery aspects of the Children's Congenital Heart Services in England. The metrics were developed in the Midlands and East with input from Provider Units. The Transition Dashboard was rolled out to all units during the course of 2013/14 and is now fully operational in all Area Teams.

A copy of the dashboard is attached at Annex A. All activity monitoring is collected using the same definitions as already used for submission to the National Institute for Cardiovascular Outcomes Research (NICOR).

The Accountable Commissioner for the Congenital Heart Services Clinical Reference Group (CRG) takes a lead on the Transition Dashboard and answers queries from the 10 Area Teams leading on Specialised Commissioning.

Process

The Dashboard is completed by the 10 current service providers on a monthly basis. The Dashboard is submitted to the relevant Area Team Service Specialists each month with information relating to the preceding month. The area team review the Dashboard and have discussions with the providers either as part of their normal contract review meetings or as a specific Transition Dashboard discussion.

The aim is for the Area Team to confirm and challenge the data with providers in order to gain assurance that the service is functioning appropriately and that any risks to patient care and safety are identified, mitigated and escalated where appropriate.

In addition, following feedback from the Congenital Heart Services CRG, a SitRep process has been established, led by the Congenital Heart Accountable Commissioner. The purpose of the call is to ensure that there is national triangulation of any issues which may be emerging from the Transition Dashboard, to verify that the Dashboard has been returned and reviewed by the Area Team and to identify any issues which require escalation. Any issues requiring escalation will be referred to Specialised Commissioning Oversight Group (SCOG) in the first instance.

The SitRep calls, chaired by the Accountable Commissioner are scheduled to take place monthly via telephone conference. Membership includes an AT Commissioner for all of the current units. The first SitRep call took place on the 30 May 2014 and at this time no issues which require escalation have been identified. Area Teams reported some data errors which have been addressed and one Area Team reported that they are investigating two formal complaints which have been reported.

Discussion took place on the SitRep call regarding clinical validation of the data received and what support is available to Commissioners. It was agreed that where Area Team Commissioners needed additional support to confirm/challenge the data that they will in the first instance engage their Public Health Lead and if further specialist input is required the CRG will be approached for advice as appropriate.

Next steps

It has been agreed that although the Quality Dashboard for Congenital Heart has been introduced for 2014/15 that the Transition Dashboard will remain in situ until further notice. There will be regular checks to avoid duplication of data across the dashboards.

Dates for the monthly SitRep call have been confirmed through to the end of the year.

Julia Grace
Accountable Commissioner for Congenital Heart Services
NHS England

Annex A: Children's Congenital Heart Services - Transition Dashboard (insert year)												
Reporting Period	Q1 April to June			Q2 July to Sep			Q3 Oct to Dec			Q4 Jan to Mar		
Deadline for Submission	TBC			TBC			TBC			TBC		
	Current Year			Current Year			Current Year			Current Year		
	Quarter 1			Quarter 2			Quarter 3			Quarter 4		
	April	**May**	**June**	**July**	**Aug**	**Sept**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**March**
Activity Monitoring												
1. Number of paediatric cardiac elective patient admissions cancelled on the planned day of surgery (breakdown required see narrative section below)												
2. Number of **out of area** PIC transfers (outside of agreed care pathway)												
3. Number of out of area PIC transfers **into area** (outside of agreed care pathway)												
4. Number of patients on the paediatric cardiac waiting list for cardiac surgery (breakdown required see narrative section below)												
5.Number of congenital heart surgery procedures performed - open & closed plus interventional catheters												
6. Number of un-planned re-interventions within 30 days												
7. Number of cardiac patients treated out of region (please provide reason and place treated)												
Incident Reporting												
9. Number of SI's or Never Events Reported Linked to Paediatric Congenital Heart patients (breakdown required see narrative section below)												
10. Number of Formal Complaints												
11. Congenital Heart Friends and Family Figures report showing number of returns recommend/not recommend & breakdown of comments received (please provide a written summary)	written summary	written summary	written summary	written summary	written summary	written summary	written summary	written summary	written summary	written summary	written summary	written summary
12. % sickenss rate of medical, nursing and other staff (target 3%)												
Medical (target 3%)												
Nursing (target 3%)												
Other Staff (target 3%)												
12a. Please provide a **written summary** of your current vacancy position. Where relevant, Include information on any particular recruitment or retention issues which are impacting on patient care, capacity, or interruption to service												
13. Infection Rates												
Cdiff (provide number of cases)												
MRSA (provide number of cases)												
14. Mortality	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
All patient deaths have gone to the child death review panel												
Monthly in-house real-time VLAD plots accessed and nothing of concern to report												
Narratives												
1 - a. For each cancellation provide a written summary of outcome for patient - i.e. when was patient re-scheduled - what was the subsequent delay b. Provide details behind the reason for cancellation 2. Accompanying report with details of reason for transfer out and impact on child 4. a. Monthly breakdown of date of referral and date added to the list include number of days waiti b. Removals from waiting list and reasons why 9. Copies of SI reports required												
Additional Comments (please provide details of any other soft intelligence)												

Programme Board Membership

In order to ensure that the new congenital heart disease (CHD) review Programme Board can maintain appropriate governance of the review programme, it is necessary at this time to adjust the membership.

As the Chair of the Programme Board, Bill McCarthy (National Director: Policy) leaves NHS England in June 2014, he will be replaced as Chair by the Interim National Director: Commissioning Strategy, Rosamond Roughton, with the vice-chair remaining as Director of System Policy, John Holden.

In order to give the appropriate focus to both the financial impact of the changes that will be brought about as a result of the review and to ensure appropriate involvement within NHS England specialised commissioning, a number of new members will be invited to join the Programme Board.

The **current** core membership of the Programme Board is as follows:

- National Director: Policy (Chair);
- Director of System Policy (Vice Chair);
- Chair of the review's Provider Group;
- National Medical Director;
- Chair of the review's Clinicians' Group;
- National Clinical Director, Specialised Services;
- Chair of the Clinical Advisory Panel;
- Director of NHS Commissioning (Corporate);
- Chair of the review's Patient and Public Group;
- Director for Patient & Public Voice & Information; and
- New CHD Review Programme Director.

The **proposed** core membership of the Programme Board is as follows:

- Interim National Director: Commissioning Strategy (Chair);
- Director of System Policy (Vice Chair);
- National Medical Director;
- Chair of the review's Provider Group;
- Chair of the review's Clinicians' Group;
- Chair of the review's Patient and Public Group;
- Chair of the Clinical Advisory Panel;
- Director for Patient & Public Voice & Information;
- Director of NHS Commissioning (Corporate);
- National Clinical Director, Specialised Services; (Medical Directorate)
- Head of Strategy; (Specialised Commissioning Taskforce);
- Finance representative
- Regional or Area team commissioner; and
- New CHD Review Programme Director.

All members are asked to send an appropriate delegate when their absence is unavoidable and it is proposed that the meeting will be quorate where **8** members are in attendance, inclusive of named deputies.

The Board Task and Finish group is to agree the proposed changes.

HIGHLIGHT REPORT to the TASK AND FINISH GROUP

SRO: Professor Sir Bruce Keogh, National Medical Director
Programme Director: Michael Wilson

KEY UPDATES SINCE LAST MEETING OF TASK AND FINISH GROUP:

- Programme Board meetings: 16 April 2014, 13 May 2014 and 10 June 2014
- Further 2 children and young people's engagement events in Newcastle (16 April 2014) and Cambridge (17 April 2014)
- WebEx with Local Government and Healthwatch: 29 April 2014
- Attendance at the Women and Children's Programme of Care Board (29 April 2014) and at the Clinical Priorities Advisory Group (30 April 2014)
- Trust Visits by Professor Deirdre Kelly and members of the review team between 30 April 2014 and 4 June 2014 to the following trusts: Southampton, Brompton, Guy's and St Thomas', Newcastle, Leeds, Birmingham, Bristol, UCL, Great Ormond Street Hospital, the Heart Hospital, Leicester, and Cardiff
- Congenital Heart Services Clinical Reference Group Meeting: 12 May 2014
- Workshop Session for Patient and Public Group members re: consultation: 12 May 2014
- Provider Group Meeting on 21 May 2014
- Michael Wilson and Claire McDonald met with Families of Ocean Ward on 31 May 2014
- Clinicians' Group Meeting on 2 June 2014
- 25th Blog entry published: 9 June 2014
- Patient and Public Group Meeting on 13 June 2014
- Clinical Advisory Panel meeting on 18 June 2014

KEY RISK

Description	Current residual risk rating
There is a risk that consultation is delayed because approval to consult is not achieved through NHS England's internal assurance process (Programme of Care Board / Clinical Priorities Advisory Group). (MITIGATION: *Board Task and Finish Group asked to ensure that successful launch of consultation at the earliest possible date is a shared priority across the whole organisation.*)	**Amber / Red**

ISSUES

Description
The initial financial impact assessment has not been delivered as per the target timeline. At present no resource is available to deliver the impact assessment and it is therefore on hold. (*MITIGATION: NHS England Finance directorate have allocated resource to quality assure the output and are actively engaged in seeking resource to deliver.)*

NEXT STEPS:

COMMS AND ENGAGEMENT: A joint meeting of the review' 3 engagement and advisory groups (Patients and Public, Clinicians' and Providers) has been scheduled for 25 July 2014.

FUTURE KEY MEETINGS: Programme Board: 10 July 2014

SUPPORT REQUIRED:

The Board Task and Finish Group is asked to approve the new proposed timeline for consultation, to note that this will mean that the NHS England Board's ambition of an implementable solution within one year will not now be achieved and to seek the support of the NHS England Board for this.