Paper NHS071414

BOARD PAPER - NHS ENGLAND

Title: Update from the Board Task and Finish Group on the new congenital heart disease review.

From:

Rosamond Roughton, Interim National Director: Commissioning Strategy

Purpose of paper:

- To provide an update on the work of the Board Task and Finish Group for the new congenital heart disease review.

Actions required by the Board:

The Board is asked to:

- note the key issues; and
- note the progress of the new congenital heart disease review to date ("One year on" - Annex C).

Update from the Board Task and Finish Group on the new congenital heart disease review

Background

1. The purpose of this paper is to provide an update to the NHS England Board on the progress of the new congenital heart disease (CHD) review since the last update to the Board on 24 January 2014.

Board task and finish group

2. The purpose of the Board task and finish group is to:

   - provide strategic direction to the new congenital heart disease review on behalf of the NHS England Board;
   - provide assurance to the Board that the work is aligned with the stated aims of the review and NHS England's other strategic priorities;
   - advise the Board on particular issues in relation to the review and also on any decisions which the Board may be required to make; and
   - where required, commission work and / or request further information from the review's programme board in order for the group to fulfil its function.

3. Since the paper was written for the NHS England Board meeting on 24 January 2014, the Board Task and Finish Group (the "Group") met on 7 January 2014 and 15 April 2014. The minutes of both meetings are attached as Annex A and Annex B to this paper.

Key issues

4. When the Group met on 15 April 2014, members noted that the best case scenario for public consultation on the new set of standards for the whole lifetime pathway of care was July 2014. Since that meeting and following further work, the new CHD review team have concluded that the new timeline for the start of public consultation is now September 2014. Though the Group has not met again at the time of writing this paper, members have received an update on the revised timeline and will discuss this in more detail at their next meeting on 23 June 2014.

Recommendations

5. The Board is asked to note the Task and Finish Group's report on progress of the new congenital heart disease review and in particular the paper "One Year On" at Annex C.

John Holden
Director of system policy
July 2014

Minutes of the Board Task and Finish Group held on 7 January 2014

Present:

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

Apologies:

- Professor Sir Malcolm Grant (Chair)
- Professor Sir Bruce Keogh, National Medical Director

In attendance:

- Mr John Holden, Director of System Policy
- Mr Michael Wilson, Programme Director
- Penny Allsop (Secretariat)

Item	Agenda Item
1	**Welcome and Apologies**
	The Deputy Chair welcomed everyone to the meeting and the apologies were noted.
2	**Note of the last meeting**
	The notes of the last meeting were agreed. The Group recognised the importance of transparency, and emphasised the need for papers and notes of its meetings to be made public.
3	**Action log**
	Actions in progress were considered. Action 5: The Group recognised the importance of distinguishing between evidence and judgment and was encouraged that the new review team are commissioning an independent evidence review. On this basis this action was closed. Action 7: The Group recognised the importance of this piece of work but understood that it cannot be undertaken at this stage. It was agreed that the action will be closed on this log, but will be tracked elsewhere so that it is addressed at the appropriate time. Action 8: This action related to the work as originally envisaged. The new review is focused on continual engagement and so the Group agreed to close this action. Actions 15 and 19: The Local Government Association is keen to be kept up to date about the new review, but does not consider that it would be feasible to set up a national overview and scrutiny committee. The action was closed. Action 16. See item 4. Action closed. Action 17: The review team undertook to produce guidance on completing the agreed conflict of interest declarations

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ACTION	**Update action log as per discussion.**
ACTION	**Produce guidance on completing the agreed conflict of interest declaration form.**
4	**DRAFT Policy for managing conflicts of interest**
	Action 16: The draft policy for managing conflict of interest was agreed, subject to there being a clear reference in the policy to the need to publish a register of interests.
ACTION	**A clear reference to be added to the policy for managing conflicts of interest regarding the publication of the register of interests.**
5	**Programme Stocktake**
	The Group received a presentation on progress to date (slides attached here). The Group acknowledged the size of the task and also the history involved. Specifically, the Group: • supported the focus on standards and recognised the important contributions of the Standards Group and the Clinical Implementation Advisory Group; • was pleased to hear that the new review team has commissioned an analysis of future demand of CHD services up to 2025, but recognised that there may be some limitations due to the way in which CHD is coded, particularly in adults; and • recognised the importance of the work on antenatal and neonatal detection rates. Recognising that the current focus of work is on standards and not the form of services, it was noted that it would be important to speak to Monitor in advance of any scenario planning/modelling and that it would be critical to engage with the Competition and Markets Authority. The Group discussed the importance of recruitment and retention of surgeons and asked the new review team as a matter of urgency to speak to the Royal College of Surgeons about training. The Group agreed the timetable as set out in the presentation, but urged 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. The Group asked the new review team to set out a more complete timetable as quickly as possible.
ACTION	**Engage with both Monitor and the Competition and Markets Authority in advance of any scenario planning / modelling.**
ACTION	**The new review team to speak to the Royal College of Surgeons about training, as a matter of urgency.**
ACTION	**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.**

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ACTION	**The new review team to set out a more complete timetable as quickly as possible.**
6	**Update from the Programme Board**
	Bill McCarthy noted that he has undertaken to ensure that the new review is adequately resourced. The Group supported this as a high priority programme for NHS England.
7	**Update from the Clinical Advisory Panel**
	Professor Sir Michael Rawlins (Chair of the Clinical Advisory Panel) provided a verbal update on the second meeting of the review's Clinical Advisory Panel (18 December 2013). The Clinical Advisory Panel (CAP) comprises a range of clinicians from within and outside the CHD community. The meetings to date have been a success and the members of the CAP are getting to grips with the issues. The Group recognised the importance of CAP and suggested that Professor Sir Malcolm Grant might be invited to a future meeting.
ACTION	**Professor Sir Malcolm Grant to be invited to a future meeting of the Clinical Advisory Panel.**
8	**Highlight report**
	The report was accepted.
9	**Any other business**
	There was no other business
Date of next meeting	Wednesday 12 February 2014, 10:30am – 12pm, Maple Street, LONDON ***[THIS MEETING WAS SUBSEQUENTLY CANCELLED]***

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. John introduced the item “Update and Assurance Process” which described

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	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. • It is unlikely that any current provider will be able to satisfy every

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	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.

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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

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 overlyfocused 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, Chief Executive 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 feedback 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 we have two sources of data available on current inpatient activity, but both are flawed for different reasons. Not all adult activity is reported to the national database run by the National Institute for Cardiovascular Outcomes Research (NICOR), and the generic nature of Hospital Episode Statistics (HES) means it is not easy to 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