

## Board Task and Finish Group

29 October 2013

## AGENDA

2:30pm – 4pm

(Meeting Room 1, Maple Street, London)

**Members in attendance:** Professor Sir Malcolm Grant, Board Chair, (Chair)  
 Professor Sir Bruce Keogh, National Medical Director  
 Bill McCarthy, National Director: Policy  
 Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel

**Member apologies:** Margaret Casely-Hayford, Non-Executive Director  
 Ed Smith, Non-Executive Director

**Additional attendees:** Michael Wilson, Programme Director

Item	Agenda Item	Action	Lead
1	Welcome and Apologies	To note	Professor Sir Malcolm Grant
2	Minutes of the last meeting – 30 Sept 2013	To agree	Professor Sir Malcolm Grant
3	Action Log	To discuss	Professor Sir Malcolm Grant
4	DRAFT Policy for managing conflicts of interest	To approve	Bill McCarthy / Professor Sir Bruce Keogh
5	Update from Programme Board ( <i>verbal item</i> )	To note	Bill McCarthy
6	Objectives of the review	To approve	Bill McCarthy
7	Communications and engagement update	To note	Bill McCarthy
8	Update from the Clinical Advisory Panel ( <i>verbal item</i> )	To note	Professor Sir Michael Rawlins
9	Scope and Interdependencies	To approve	Professor Sir Michael Rawlins / Professor Sir Bruce Keogh
10	Standards Update	To note	Professor Sir Michael Rawlins / Professor Sir Bruce Keogh
11	Highlight report	To note	Bill McCarthy
12	Any other business		All

**Minutes of the Board Task and Finish Group  
held on 30 September 2013**

**Present:**

- Professor Sir Malcolm Grant (Chair)
- Mr Ed Smith, Non-Executive Director
- Professor Sir Bruce Keogh, National Medical Director
- Mr Bill McCarthy, National Director: Policy

**Apologies:**

- Ms Margaret Casely-Hayford, Non-Executive Director

**In attendance:**

- Mr John Holden, Director of System Policy
- Mr Michael Wilson, Programme Director

Item	Agenda Item
<b>1</b>	<b>Welcome and Apologies</b>
	<p>The Chair welcomed everyone to the meeting. Apologies were noted.</p> <p>The Chair commended Mr Holden's blog as an innovative means of communicating progress. Mr Holden reported that it was being read by both patient groups and clinicians.</p>
<b>2</b>	<b>Note of the last meeting</b>
	<p>The Chair noted that this was a note rather than formal minutes reflecting the nature of the meeting at that time but that in future formal minutes would be produced.</p> <p>The notes of the meeting on 22 July 2013 were accepted as an accurate record.</p>
<b>3</b>	<b>Action log</b>
	<p>The Chair noted that all items on the Action Log were either completed or in progress.</p> <p>The Chair requested more information about the engagement groups referred to in action 7. Mr McCarthy replied that a first round of meetings with charities, clinical leaders, front line clinicians and organisational leaders had taken place. These had acknowledged concerns from the judicial review and the Independent Reconfiguration Panel. They had been helpful in explaining that the new review was not simply a re-run of Safe and Sustainable, and reinforcing our commitment that it would put patients first. It would not compromise on standards. He considered that it was the beginning of a process to build trust which was also supported by the blog and other expressions of openness and transparency. These groups were now being incorporated into a more structured system of participation and involvement which would be described under item 7.</p>

Item	Agenda Item
4	<b>Terms of reference</b>
	<p>The Chair stressed that the qualities of transparency and openness were paramount for this exercise. Mr Holden confirmed that the agenda, papers and minutes of this and other meetings would be published, as detailed in the publication scheme to be considered under item 6. In addition the blog, with its facility for comment, was an important part of achieving transparency and openness. The task and finish group would report regularly to the NHS England Board (which met in public) and all decisions that affected the commissioning and delivery of CHD services would be taken by the main board in public.</p> <p>The Chair invited the Group to consider whether it was important in the interests of transparency and openness for it to conduct its meetings in public. The Group was of the opinion that it would be normal for a working group of any organisation to hold its meetings in private, subject to it always reporting publicly the substance of its discussions. The Group's meetings would be about the nuts and bolts of the review and transparency and openness would be amply achieved in the ways Mr Holden had described. The proper management of any possible conflicts of interest would be critically important.</p> <p>Mr Holden introduced the terms of reference (TOR) and emphasised that there was a need to be clear about the role of a decision-making group like this one. The Group was a Task and Finish Group acting on behalf of the Board of NHS England in steering and shaping the review, and taking the decisions necessary for that purpose. The Board would receive regular reports, oversee the process and take the necessary substantive decisions. The review's programme board would make decisions on the day to day running of the review and report back to, and make recommendations to the Task and Finish Group. No other groups would make decisions within the review – their roles were advisory and to ensure that a wide range of stakeholders had a voice in the process.</p> <p>It was noted that the membership of the Group was not symmetrical – the chair of the programme board was a member but the chair of the clinical advisory panel was not. If the chair of the clinical advisory panel (CAP) was a member it would then be clear how the CAP's advice was considered by the Group. The Chair agreed that Professor Sir Michael Rawlins should be asked to join the group.</p> <p>With this amendment the terms of reference were agreed.</p>
Action	The chair of the CAP, Professor Sir Michael Rawlins to be invited to join the Group.
5	<b>Scope and interdependencies</b>
	<p>Professor Sir Bruce Keogh introduced the paper on scope and interdependencies. He explained that the paper sets out what is being done to resolve the remaining questions. This was for information rather than a decision. Advice would be sought from the CAP and a final decision would be made at the next Group meeting.</p> <p>He explained that the paper showed what is already known about the scope of the review, for example that it should cover the whole pathway, and that some services were out of scope but were still significantly connected to congenital heart disease (CHD) services. An example was paediatric intensive care (PIC). If paediatric CHD surgery were to cease at a hospital this could impact on the viability of the PIC unit and thus affect other clinical services. Michael Wilson explained that such services were not considered to be in scope – it was important to limit the review to the subject at</p>

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	<p>hand, but it would be important for the review to recognise the interdependency and be clear how the connections would be managed.</p> <p>Sir Bruce explained that there were other areas where it is less clear whether a service or aspect of a service should be considered to be in scope. It would be important to consider the interdependencies and any knock on effects of change on other services.</p> <p>The Group considered that criteria needed to be developed to shape decisions about what was in and why.</p> <p>The proposed process involved seeking the advice of the Congenital Heart Services clinical reference group (CRG). Also the papers for this meeting of the Group had been published on the web site and views were being sought from any interested party by this route. A number of stakeholders had already expressed opinions. These responses would be collated and used to inform the CAP as it considered its advice for the Group. The CAP's advice would be shared publicly before TAFG took its decision.</p> <p>The review needed to ensure an appropriate balance between clinical expertise and public opinion. It was important that the CAP was clinically led.</p> <p>The Chair noted that the paper presented the question of scope as a binary choice – in scope or not. But the reality was more of a spectrum.</p>
Action	CAP advice on programme scope to be published on the NHS England website and views invited before Group makes its decision.
6	<b>Proposed governance and decision making</b>
	<p>Mr McCarthy explained that the paper and diagram showed how the proposed arrangements link together and the proposed reporting line. Decisions affecting the commissioning and delivery of CHD services would be taken by the main Board at its public meetings. The Chair asked for the review to be a standing item on the Board agenda.</p> <p>Mr Holden stated that it was important to note that only three groups made decisions – the Board of NHS England, the Group and the programme board.</p> <p>Mr McCarthy drew attention to the governance diagram. The CAP and the CRG were the formal advisory groups. The clinician group, the patient and public group and the provider group were a systematic means of ensuring input from these key stakeholders; they ensured that the review had the necessary channels for regular engagement and gave the review team an opportunity to test its thinking.</p> <p>Mr Holden explained that NHS England had nominated independent chairs for each group, who could act as an honest broker as well as represent the views of the group.</p> <p>Questions were raised:</p> <ol style="list-style-type: none"> <li>(1) whether the provider group should feed into the clinical advisory panel as well as the programme board. This was not considered essential given the specific focus of the provider group (eg on organisational, financial and workforce issues) and the provider group's direct representation on the programme board.</li> <li>(2) what the relationship between the three engagement groups would be, and whether it could be helpful for there to be some joint working. Mr Holden replied that some attendees at the various stakeholder groups which had met to date were aware of each others' meetings (through reading meeting notes etc) and had in some instances referred to the notes/outputs of each other's</li> </ol>

Item	Agenda Item
	<p>discussions. But these three new, consolidated panels would need to be more systematically kept abreast of each other. Mr Wilson added that while it could be impractical to bring all the groups together on every occasion there would be occasions when it would be helpful to bring them together.</p> <p>The Group agreed that it would be important that the arrangements should make it possible to hear smaller groups and those whose voices were sometimes crowded out. Patients and parents who had a poor experience or less good outcome were an important group with a lot to teach us.</p>
Action	The new CHD review to be added to the main Board agenda as a standing item.
	<p><b>Programme Board (including proposed terms of reference)</b></p> <p>Mr McCarthy stated that while the Group acted on behalf of the main Board of NHS England in steering and shaping the review, the programme board was responsible for running the programme of work necessary to bring the review to a successful conclusion including the management of risk. It did this work on behalf of this Group and following its direction.</p> <p>It was agreed that Professor Rawlins should be invited to join the programme board.</p> <p>With this amendment the Group were content to convey the terms of reference to the programme board for its consideration and approval.</p>
Action	The chair of the CAP, Professor Sir Michael Rawlins to be invited to join the programme board.
	<p><b>Clinical Advisory Panel (including proposed terms of reference)</b></p> <p>Sir Bruce stated that having reflected on the panel's membership he now considered that an anaesthetist should be added to the group. Even with this addition, he noted that there would be comment about the membership of the CAP. It was not intended that every geography or professional interest group was represented. The review had other mechanisms for that, through the clinical group and the clinical reference group. Members of the CAP had been selected for their personal expertise.</p> <p>With the proposed amendment to membership the Group were content to convey the terms of reference to the CAP for its consideration and approval.</p>
Action	An anaesthetist to be invited to join the Clinical Advisory Panel.
	<p><b>Managing conflicts of interest</b></p> <p>The Chair emphasised the importance of the review's approach to managing conflicts of interest. He welcomed the paper but considered that it should be tightened up even further so that less formal associations were also registered. Everything should be in the open.</p>
Action	The proposed approach to managing conflicts of interest should be further developed to ensure that informal associations were also declared.
	<p><b>Publication scheme for the review</b></p> <p>The publication scheme was welcomed as an important contribution to the review's approach to openness and transparency.</p>

Item	Agenda Item
7	<b>Proposed stakeholder participation and engagement arrangements</b>
	<p>Mr McCarthy explained that this paper complemented item 6 by showing how each stakeholder group would be able to participate in the review's work.</p> <p>Mr Wilson emphasised that it did not present a complete communications and engagement plan; this was being developed.</p> <p>The Chair asked about the plan for working with overview and scrutiny committees (OSCs). Was there an intention to establish a joint national OSC? Mr McCarthy agreed that this would be a very helpful development, since this was a national review of a national service. Nonetheless some local councillors had expressed concerns or questioned the feasibility of such an approach. The Chair agreed to explore the issue with the chair of the Local Government Association, Sir Merrick Cockell.</p>
Action	Sir Malcolm Grant to discuss the potential for joint local government engagement, overview and scrutiny.
8	<b>Developing the proposition</b>
	<p>NHS England had committed to a deliverable proposition by June 2014. The Chair asked whether it would be possible to meet the deadline. Mr Holden replied that the paper defined an implementable solution as a specification for children's and adult congenital heart disease (CHD) services together with a recommended commissioning and change management approach, including an assessment of workforce and training needs. This was achievable for June 2014. But the process was not without risk, and while there were good reasons for seeking to deliver the review at pace, this needed to be balanced against the need to ensure comprehensive engagement and alignment in support of the proposals, which of course was not guaranteed. The Chair stated that it would be important for NHS England to support providers of CHD services to work together in developing a national approach.</p>
9	<b>Highlight report</b>
	<p>The highlight report was noted. The Chair affirmed that the review was a whole organisation priority and the Group agreed the importance of ensuring that the organisation's resources were mobilised to support the review.</p>
10	<b>Any other business</b>
	There was no other business.
Date of next meeting	29 October 2013 – Maple Street, London W1T 5HD



**Action Log: Task and Finish Group**

Action no.	Meeting date	Action description	Responsibility	Progress details	STATUS	Date closed
3	29.07.13	The review to use specialised commissioning approach.	Bruce Keogh / Bill McCarthy	<p><b>A)</b> Role of Clinical Reference Groups defined</p> <p><b>B)</b> Ann Sutton is a member of the Programme Board.</p> <p><b>C)</b> James Palmer is a member of both the Programme Board and the Clinical Advisory Panel.</p> <p><b>D)</b> Programme Board agreed that the review will follow the usual NHS England approach to specialised commissioning and also noted that in some cases the review may have a role in developing or acting as an early adopter for that approach.</p>	CLOSED	
4	29.07.14	Determine characteristics of best possible service.	Bruce Keogh / Bill McCarthy	This is now captured in the objectives of the review (PID section 2.2)	CLOSED	
5	29.07.15	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.	IN PROGRESS	
6	29.07.13	Ensure that there is a clear process for monitoring and raising safety concerns.	Bruce Keogh / Bill McCarthy	<p><b>A)</b> NHS England has worked with providers to develop a 'transition dashboard' and this is now being rolled out across the country to give early warning of any emerging concerns and to allow commissioners and providers to respond promptly whenever concerns arise.</p> <p><b>B)</b> The process for raising safety concerns was highlighted in John' Holden's Blog of 12 August 2013 .....<i>It is important that we have a clear and consistent approach to handling these concerns, so we will always:</i></p> <ul style="list-style-type: none"> <li>• <i>inform the NHS England "domain lead" (Dr Mike Durkin) – a very senior official with lead responsibility in NHS England for patient safety;</i></li> <li>• <i>pass any safety concerns on to NHS England's medical director in the appropriate region (London; North; Midlands &amp; East; and South). The medical director is well placed to ...</i></li> <li>• <i>consider the issue with the Care Quality Commission (CQC), who have legal powers to assure essential levels of safety and quality. CQC hosts the government's new "Chief Inspector of Hospitals" and works with NHS England locally to undertake "quality surveillance".</i></li> </ul>	CLOSED	
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 groups to be established to facilitate dialogue with those potentially affected by change.	IN PROGRESS	
8	29.07.13	Continue engagement and discussion with a view to developing an initial proposition for discussion in the autumn.	Bill McCarthy	<p>Approach to ongoing engagement set out in Communications and Engagement Plan.</p> <p>First round of formal engagement groups scheduled.</p>	IN PROGRESS	

9	30.10.13	The Chair of the Clinical Advisory Panel, Professor Sir Michael Rawlins to be invited to join the Board Task and Finish Group.	Michael Wilson	Invitation sent.	CLOSED	
10	30.10.13	Paper on programme scope to be published on the NHS England website and views invited before the Task and Finish Group makes its decision.	Michael Wilson	Paper published. Fifty responses received and considered by Clinical Advisory Panel in making its recommendations. Paper for consideration by Task and Finish Group on 29 October 2013.	IN PROGRESS	
11	30.10.13	The new congenital heart disease review to be added to the main NHS England Board agenda as a standing item.	Michael Wilson	Secretary to the Board informed.	CLOSED	
12	30.10.13	The Chair of the Clinical Advisory Panel, Professor Sir Michael Rawlins to be invited to join the Programme Board.	Michael Wilson	Invitation sent.	CLOSED	
13	30.10.13	An anaesthetist to be invited to join the Clinical Advisory Panel.	Bruce Keogh	Discussed at Clinical Advisory Panel meeting on 15 Oct 2013. President of the Royal College of Anaesthetists to be invited.	IN PROGRESS	
14	30.10.13	The proposed approach to managing conflicts of interest should be further developed to ensure that informal associations were also declared.	Michael Wilson	Revised paper to be considered by Task and Finish Group 29 October 2013.	IN PROGRESS	
15	30.10.13	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).	IN PROGRESS	



## **Policy on managing potential conflicts of interest**

### **Purpose**

1. The aim of the policy is to ensure the successful management of potential conflicts of interest in relation to the new congenital heart disease review.

### **Background**

2. In line with NHS England's commitment to transparency we believe it is important that any potential conflicts of interest relating to this review are clear and made public from the outset.
3. NHS England already publishes online a Register of Members' Interests in relation to its Board Members which covers all members of the Board Task and Finish Group.
4. Due to the complex governance arrangements of the review, we propose that publication of any potential / perceived conflicts of interest should be applied to:
  - the Task and Finish Group
  - the Clinical Advisory Panel
  - the Programme Board.
  - the Clinician Group
  - the Provider Group
  - the Patient and Public Group
5. The main approach to managing this issue is to ensure that all parties and viewpoints are represented as part of the groups. This recognises that in this context it is quite appropriate for representatives of an organisation, charity or professional group to speak from the perspective of that group. Nonetheless all members will be expected to consider what is in the best interests of patients with congenital heart disease, and their carers, and to put those interests first. The application of the principles described in this paper will be discussed with each of these groups to agree whether any register of interests is appropriate.

### **Definition**

6. Generally a potential conflict of interest can be defined as: "a set of conditions in which professional judgement concerning a primary interest could be unduly influenced by a secondary interest" or a situation in which "one's ability to exercise judgement in one role may be impaired by one's obligation in another"
7. For the specific purposes of this review, we propose the following be used to define a potential / perceived conflict of interest for members of the Clinical Advisory Panel and Programme Board:

- a) A member of your immediate family who is employed either at Board level or as an employee within the congenital heart disease service at one of the affected organisations. (Immediate family would be defined as a spouse, child, sibling, parent, stepchild, stepparent, as well as mother-, father-, son-, daughter-, brother-, or sister-in-law and to any other individuals who live in your household except for tenants and household employees. If a relationship with a distant relative or friend could influence a member's objectivity, then they should apply the policies and avoid the situation); or
  - b) Any position you hold (paid or unpaid) at one of the affected organisations or stakeholder charities. (This would include Trustee and non-executive positions); or
  - c) Any personal affiliation with or close connection to a stakeholder charity or patient group.
  - d) A personal non-pecuniary interest in a topic under consideration which might include, but is not limited to:
    - a clear opinion, reached as the conclusion of a research project, about the clinical and/or cost effectiveness of an intervention under review;
    - a public statement in which an individual covered by this document has expressed a clear opinion about the matter under consideration, which could reasonably be interpreted as prejudicial to an objective interpretation of the evidence;
    - holding office in a professional organisation or advocacy group with a direct interest in the matter under consideration; and
    - other reputational risks in relation to an intervention under review.
8. If members have interests not specified above, but which they believe could be regarded as either influencing their advice or role or be perceived to influence their advice or role, they should declare them.

### **Recording and publication**

9. All members of the groups, listed in paragraph 4 above, will complete a form detailing any potential conflicts of interest in relation to the new congenital heart disease review at the outset. Once completed, all such forms (including nil returns) will be published on the NHS England website so that they are freely accessible.
10. All meetings of these groups will have "declarations of interest" as a standing agenda item so that any new declarations of interest can be noted at the start of the meeting.
11. Any new declaration of interest will be recorded in the minutes of the relevant meeting, and published on the website.

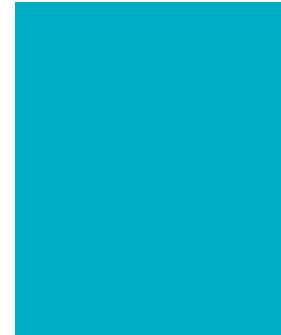
## Handling conflicts of interest

12. Should a member declare a potential conflict of interest, it will be for the Chair of the relevant group to decide how material the conflict is, and what, if any action is required. This will be recorded in the minutes of the meeting.
13. Such conflicts of interest need not lead to exclusion from the process but must be declared, and should be formally recognised by members. The Chair should seek an assurance from the individual that the potential conflict of interest will not influence their advice / contribution to any of the groups listed in paragraph 4 above.

DRAFT

## *New Congenital Heart Disease Review*

# Objectives



**Bill McCarthy**  
**National Director: Policy**



## Programme Initiation Document (PID)

- At its meeting on 21 October 2013 the Programme Board considered the draft PID
- It considered that the objectives expressed in the PID were as important as the scope in defining the review and central to the task of programme planning
- It recommended that the Task and Finish Group should consider and confirm the review's objectives
- The full draft PID is available on the NHS England website, for reference, here:  
<http://www.england.nhs.uk/wp-content/uploads/2013/10/chd-prog-5.pdf>

## Objectives (1)

### **The objectives of the programme are:**

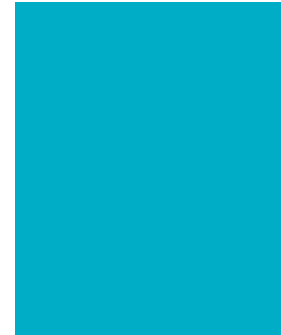
- to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;
- to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;
- to make recommendations about the function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact;
- to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;

## Objectives (2)

- 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
- to improve antenatal and neonatal detection rates.



# Communications and Engagement : Update



**Bill McCarthy**  
**National Director: Policy**



## Communications and Engagement Plan

- At its meeting on 21 October 2013 the Programme Board considered the draft Communications and Engagement Plan
- It approved the plan, but asked for two areas to be made clearer:
  - That in our work to engage with children and young people we treat them in a way that is positive and respectful
  - That the paper sets an expectation of behaviours for those participating in the new review – for NHS England and for stakeholders
- The full draft Communications and Engagement Plan is available on the NHS England website, for reference, here:  
<http://www.england.nhs.uk/wp-content/uploads/2013/10/chd-prog-7.pdf>

## Principles

- Good communication and stakeholder involvement are at the heart of the new review.
- NHS England is committed to openness, transparency and participation.
- We will make every effort to ensure that all voices can be heard.
- The review can only be judged successful when real improvements, in line with the aims stated above, start to be experienced by service users.
- Our aim is that stakeholders from across the spectrum own the review's proposals because they have been able to observe the review at work, influence its thinking and trust its proposals.

## Levels of engagement

- **Participate** - the opportunity to participate in the review's stakeholder groups or targeted engagement activities.
- **Engage** - the opportunity to receive and comment on the review, its findings and recommendations.
- **Inform** - the opportunity to receive summary information about the review, its findings and recommendations.

We will work with stakeholders to ensure that they are able to engage with the review in a way appropriate to them.

## Communications channels

- **Internet** - the NHS England website; John Holden's blog; exploring developing an NHS Choices micro site; social media
- **Mainstream and trade media** - broadcast and print/online. Work with the NHS England media team to develop core materials and proactive media relations
- **Existing NHS communications channels** – eg. NHS News, bulletins, staff briefings, NHS England area teams.
- **Stakeholder owned communications channels** - websites/intranet, established bulletins and newsletters and staff/member events.
- **Other approaches** - roadshows, workshops, briefings and virtual methods.

## Openness and transparency

- John Holden's Blog
- Publication scheme
- Managing interests
- Seeking input as we go
- Engagement groups
- Consultation on specification

## Specialist advice on engagement

- NHS England Specialised Services Patient and Public Engagement Steering Group
- British Heart Foundation
- Healthwatch England
- Local Government Association
- Centre for Public Scrutiny
- National Voices
- Involve



## Summary

- The plan will remain a work in progress as the review unfolds
- We will learn more from our stakeholders about their needs and preferences
- We will inevitably be required to strike a balance between gold standard and cost effective engagement and between pace and inclusivity
- Our experience to date tells us that the review is much better when we listen to and work with our stakeholders
- We will sense check the plan with stakeholders.

## **Scope and Interdependencies**

### **Introduction**

1. The new Congenital Heart Disease (CHD) review has been established to consider the whole lifetime pathway of care for people with congenital heart disease. In order to conduct the review and to ensure that there is a manageable programme of work it is necessary to define its scope in more detail.
2. Patients, clinicians and the public have been asked to advise on what services and conditions should be included in the scope of the new review. Approximately 40 responses were received (these will be made available to the Task and Finish Group in hard copy for reference).
3. NHS England originally proposed three categories (in scope; out of scope; to be determined). It was apparent from the responses received that not enough explanation had been given to respondents which had led to some misunderstanding of the concept of scope. It was also apparent that the reality is more complicated than a simple 'in' or 'out'. There are multiple, complex interdependencies, so this paper recommends a less binary, more nuanced approach that explains how the review relates to a range of other services and conditions, rather than simply declaring them to be either 'in' or 'out' of scope. At the same time, it is important to define the boundaries in such a way that there is a realistic prospect of completing the review and avoids mission creep.
4. A paper was written for the Clinical Advisory Panel summarising stakeholder responses. Members were also provided with the full original responses for reference. The panel met on 15 October 2013 and considered the scope of the review. This paper reflects that group's recommendations.
5. It will also be necessary to consider the relationship of the review to the devolved administrations and the potential impact on services for congenital heart disease offered in those countries and used by their populations. Cross-border flows are significant and need to be taken into account. The NHS in each of the devolved administrations will therefore be asked to agree their relationship to the review and appropriate channels of communication.

### **Summary recommendations**

6. In summary the panel recommends that:
  - A. The heart of the review should be the whole lifetime pathway of care for people with congenital heart disease, and specifically congenital heart disease services.
  - B. There are a number of clinical conditions which while not CHD receive their care wholly or mainly from congenital heart services. The standards for services for these conditions should not be reviewed as part of the review (though the standards being developed may address aspects of the service). However, patients

who fall within this category use congenital heart services and should be able to participate in the review.

- C. There are a number of services beyond congenital heart services that CHD patients may use. Some of these services are reliant on clinical support or backup from CHD specialists. The standards for these services should not be reviewed as part of the review. However, the use of these services by congenital heart disease patients should be considered by the review, including the definition of clinical pathways and referral routes. Any impact of changes recommended by the review on these services should be considered prior to decisions being taken and during implementation. Patients and specialists from these services should be able to participate in the review.

### Detailed recommendations

7. Based on these principles, the Clinical Advisory Panel recommends that:

#### In scope

8. The heart of the review should be the whole lifetime pathway of care for people with congenital heart disease, and specifically congenital heart disease services. This means:
- a) Improving the quality of care of people with suspected or diagnosed congenital heart disease (including those with congenital heart arrhythmias or arrhythmias in the context of congenital heart disease) along the whole patient pathway:
    - Fetal and neonatal diagnosis of CHD
    - Specialist obstetric care (including both care of women whose unborn child has suspected or confirmed CHD and care of pregnant women with CHD )
    - Care for babies, children and young people
    - Transition from children's services to adult services
    - Care for adults
    - End of life care
  - b) Cardiac and respiratory extracorporeal membrane oxygenation (ECMO) for children and young people.
  - c) Care and support for families suffering bereavement and / or poor outcomes from surgery or other intervention for congenital heart disease.
  - d) The review covers all care for congenital heart disease commissioned by the NHS for people living in England.

## Interdependencies

9. There are a number of clinical conditions which while not CHD receive their care wholly or mainly from congenital heart services. The standards for services for these conditions should not be reviewed as part of the review (though the standards being developed may address aspects of the service). However, patients who fall within this category use congenital heart services and should be able to participate in the review. This means:
  - a) Children and young people with acquired heart disease
  - b) Children and young people with inherited heart disease (for which a separate service specification has already been developed).
10. There are a number of services beyond congenital heart services that CHD patients may use. Some of these services are reliant on clinical support or backup from CHD specialists. The standards for these services should not be reviewed as part of the review. However, the use of these services by congenital heart disease patients should be considered by the review, including the definition of clinical pathways and referral routes. Any impact of changes recommended by the review on these services should be considered prior to decisions being taken and during implementation. Patients and specialists from these services should be able to participate in the review. This means:
  - a) Neonatal, paediatric and adult intensive care unit (ICU) services, and transport and retrieval services.
  - b) Other interdependent clinical services (for example other tertiary paediatric services).
  - c) Mechanical circulatory support for adults including cardiac ECMO and VAD.
  - d) Complex tracheal surgery.
  - e) Heart transplant and bridge to transplant services for children and young people.
  - f) Heart transplant for adults.

## Out of scope

11. Adults with inherited heart disease  
It was recommended that this group be excluded from the review because these patients do not receive their care from congenital heart services.
12. Adult respiratory ECMO  
It was recommended that this service should be excluded from the review because it is not dependent on congenital heart services, and operates independently of ACHD services.
13. Local maternity services  
It was recommended that local maternity services should be excluded from the review. Rather, the review should include specialist cardiac obstetric care (see 7a) above).

## *New Congenital Heart Disease Review*



# Standards Update



**Professor Sir Michael Rawlins,  
Chair of the Clinical Advisory  
Panel; and**

**Professor Sir Bruce Keogh,  
National Medical Director.**



## Standards

The new congenital heart disease review is working to create a set of robust clinical standards that will ensure that patients across the country receive the best possible care now and in the future. The standards will cover the entire pathway of care for patients with congenital heart disease and will reduce occasional practice, provide care closer to home and improve patient pathways through the creation of congenital heart networks of care.

## Standards: what has been done?

- **Safe and Sustainable** – standards for children's services, focussed on surgical centres and networking. Consulted on in 2011. Approved by Joint Committee of Primary Care Trusts (JCPCT) in 2012.
- **Adult Congenital Heart Disease (ACHD) advisory group** – standards for adult services. Engagement in 2012 and 2013. Signed off by group in 2013.
- **Clinical Implementation Advisory Group (CIAG) sub-group** – standards for children's services, focussed on cardiology. Group still working; sign off expected 2013.



## Professor Sir Bruce Keogh's letter

- Professor Deirdre Kelly (DK), Dr Tony Salmon (TS) and Professor John Deanfield (JD) to make a joint recommendation on a single combined, **comprehensive** and **consistent** set of standards covering the **whole pathway**.
- The aim of the new review is to ensure that services achieve the **highest possible quality** within the available resources...the standards [must] set out what is needed to achieve this...it is important that your group sets standards that **represent the ideal**.
- If one or more provider is unable to meet some of the standards this is a process that will be managed by commissioners.
- Be **clear about** the nature and limitations of the available **evidence** and about any intention to rely on expert opinion in the absence of evidence.

## Proposed timeline

### **October 2013**

- Paediatric standards group completes its work
- DK agrees plan with group chairs and surgical representative

### **November 2013**

- Revision and reformatting. Full review by chairs.
- Revised standards sent to ACHD Advisory Group and Paediatric sub-group for comments and revision
- Clinical Reference Group (CRG) commences revision of specification
- Prepare for consultation including briefing for stakeholders via engagement groups

### **December 2013**

- CIAG, paediatric standards sub-group and ACHD Advisory Group review and agree standards

### **January 2014**

- Final revision, sign off by Chairs.
- CRG agrees new specifications including final draft standards.

### **February – April 2014**

- Consult on specifications.

### **May – June 2014**

- Analyse consultation responses and respond
- Revise standards and specification in light of consultation responses.

### **July 2014**

- CRG signs off revised specification.

**HIGHLIGHT REPORT to the TASK AND FINISH GROUP**

**SRO:** Bill McCarthy, National Director: Policy  
**Programme Director:** Michael Wilson

**KEY UPDATES SINCE LAST MEETING OF THE TASK AND FINISH GROUP:**

- On 9 October 2013 Professor Sir Bruce Keogh, and Michael Wilson, attended a meeting of the All Party Parliamentary Group on heart disease at the Houses of Parliament to talk about the new congenital heart disease review.
- Published (via the blog) a list of invitees for both the Provider Group (to be chaired by Chris Hopson), the Clinician Group (to be chaired by Professor Deirdre Kelly), Patient and Public Group (to be chaired by Professor Peter Weissberg) so that stakeholders can let us know if we should extend the invitations.
- First meeting of the Clinical Advisory Panel (15 October 2013) – considered the review's scope and interdependencies.
- Michael Wilson attended the Specialised Services Patient and Public Engagement Steering Group (17 October 2013).
- Standards alignment meeting on 21 October 2013
- First meeting of the Programme Board on 21 October 2013.
- Michael Wilson met officers from Healthwatch England on 24 October 2013.
- John Holden attended a meeting of the Joint Health Overview and Scrutiny Committee for Leicester, Leicestershire and Rutland - 25 October 2013.

**KEY RISK**

Description	Current residual risk rating
There is a risk that it may not be possible to deliver an "implementable solution" by June 2014, exacerbating the effects of current uncertainty and delaying the achievement of better outcomes for patients.	<b>Amber / Red</b>

**ISSUES**

Description
Capacity and continuity: In process of rebuilding team as previous staff depart – the review must be adequately resourced and continuity maintained.
Pioneering: the review is setting a precedent for NHS England in terms of what we do and how we do it. It is high risk.
Legacy: the review has inherited a difficult legacy especially in terms of trust and strained relationships which presents a significant challenge.

**NEXT STEPS:**

**COMMS AND ENGAGEMENT:** Further engagement events have been scheduled for November 2013;

- Patient and Public Group – 12 November 2013
- Provider Group – 19 November 2013
- Clinician Group – 22 November 2013

**FUTURE KEY MEETINGS:** Bill McCarthy meeting with Carolyn Downs (CE of the Local Government Association)  
 Programme Board – 13 November 2013  
 Clinical Advisory Panel – December 2013 (date TBA)

**SUPPORT REQUIRED:**

The T&FG is asked to support the review as a whole organisation priority: it impacts on most areas and needs input from many teams to maximise the chance of success.