

BOARD PAPER - NHS ENGLAND

Title: Update from the Board task and finish group on the new congenital heart disease review.

Clearance: Bill McCarthy, National Director: Policy

Purpose of paper:

- To update the Board on progress of the new congenital heart disease review.

Key issues and recommendations:

This paper contains an update on the progress of the new congenital heart disease review and key points, which the task and finish group wish to draw to the Board's attention.

Actions required by Board Members:

The Board is asked to:

- note the progress of the new congenital heart disease review to date.

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 review since the last update to the Board on 8 November 2013.

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 8 November 2013, the Board Task and Finish Group (the "Group") has met on 29 October 2013 and 7 January 2014.
4. At its meeting on 29 October 2013, the Group agreed the objectives of the review, discussed the approach to communications and engagement, agreed the scope and interdependencies of the review and received an update on the standards work. The minutes of this meeting have been published on the NHS England website in line with the review's commitment to transparency and are attached as Annex A.
5. At its meeting on 7 January 2014, the Group heard updates from the review's programme board and Clinical Advisory Panel, agreed the policy for managing conflicts of interest and reviewed the work to date in the form of a programme stocktake. At the time of writing, the minutes of the meeting on 7 January 2014 are not available, however a verbal update will be provided to the Board during the meeting.

Objectives of the review

6. The objectives of the review were considered, confirmed and approved by Group at its meeting on 29 October 2013 as follows:
 - 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;
- 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.

Scope and Interdependencies

7. At its meeting on 29 October 2013, the Group considered a recommendation from the Clinical Advisory Panel regarding the scope and interdependencies of the review. Whilst considering the recommendation, the Group recognised the difficult balance to be struck between the scope being broad enough to take account of important dependencies, but not so wide that the project had no realistic prospect of completion.
8. The Group agreed the Clinical Advisory Panel's recommendation on scope though two further clarifications were proposed responding to stakeholder comments received relating to extra corporeal life support (ECLS) and pulmonary hypertension services.

Communication and Engagement

9. The Group noted that the review's three advisory / engagement groups (patient and public, clinician and provider) held meetings during November 2013, with the next round of meetings scheduled for late January / early February 2014.
10. The Group noted that a meeting is scheduled for all local authorities and local healthwatch organisations that currently host congenital heart services for children and adults within their boundaries, on 8 January 2014.

Standards and service specifications

11. At its meeting on 7 January 2014, the Group considered the projected timeline for the work relating to the standards and service specification (objective 1) as follows:

January 2014: paediatric standards group signs off work

February 2014: Clinical Advisory Panel (CAP) to agree aligned standards for consultation

From March 2014: work with Clinical Reference Group (CRG) for Congenital Heart Services to develop and run consultation on proposed specifications (child and adult)

- CRG sense checks standards with registered stakeholders
- undertake impact assessments (finance/workforce)
- seek Clinical Priorities Advisory Group (CPAG) recommendation / Directly Commissioned Services Committee (DCSC) approval for consultation

Late spring 2014: 12 week public consultation

Early autumn 2014: analyse and consider consultation responses

Late 2014: CRG to revise and agree specification then make recommendations on the final specification

2015: commission against the new specifications

12. The group noted that this was the timeline for agreeing new standards and putting them into practice through commissioning. Work on the other five objectives would be undertaken as far as possible in parallel but the work on objective 3 (the form and function of the service) and objective 4 (the commissioning and change process) could not be brought to a conclusion until after the new standards were finally agreed and adopted as they were, in part, dependent on the standards.

Recommendations

13. The Board is asked to note the progress of the new congenital heart disease review to date.

Bill McCarthy
National Director: Policy
January 2014

Minutes of the Board Task and Finish Group held on 29 October 2013

Present:

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

Apologies:

- Ms Margaret Casely-Hayford, Non-Executive Director
- Mr Ed Smith, Non-Executive Director
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel

In attendance:

- Mr Michael Wilson, Programme Director
- Lauren Phillips, (Secretariat)

Item	Agenda Item
1	Welcome and Apologies
	The Chair welcomed everyone to the meeting and the apologies were noted.
2	Note of the last meeting
	<p>The notes of the meeting on 30 September 2013 were accepted as an accurate record.</p> <p>The Group noted that the full NHS England Board would be considering, with a view to approving, the Task and Finish Group's Terms of Reference at its meeting on 8 November 2013.</p>
3	Action log
	The Chair noted that all items on the action log were either completed or in progress.
4	DRAFT Policy for managing conflicts of interest
	<p>Professor Sir Bruce Keogh introduced the paper detailing the proposed approach for managing conflicts of interest during the review.</p> <p>The Group noted that this was a programme specific approach and one which recognised concerns about perceived bias and undeclared interests highlighted in the Independent Review Panel (IRP) report on the Safe and Sustainable process.</p> <p>It was noted that since this issue was initially considered by the Board Task and Finish Group at its meeting on 30 September 2013, it had subsequently been discussed at both the first meetings of the Clinical Advisory Panel and Programme Board and amended following their comments, including the suggestion to also make this applicable to the engagement groups (not just the decision making and advisory groups).</p>

Item	Agenda Item
	<p>Michael Wilson reminded the group that the intention of this policy / approach was to balance the real / perceived conflicts of interest, rather than remove them.</p> <p>The Task and Finish Group considered the policy and the agreed amendments relating to:</p> <ul style="list-style-type: none"> • making explicit that the policy includes “actual” as well as potential and perceived conflicts of interest; • pecuniary interest; • declaring the city / area in which a group member lives; • declaring an actual / perceived interest in relation to a specific item during a meeting • possible remedies for an individual with an actual / perceived conflict of interest in a particular agenda item; and • a situation where several / all members of a particular group have an “interest”. <p>The Task and Finish Group emphasised that the form to be produced for members of the specified groups to complete must be comprehensive and be accompanied with clear and explicit guidance to aid completion and ensure a consistent approach (paragraph 9).</p>
ACTION	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.
ACTION	Guidance to be produced to support group members in completing their declarations.
5	Update from the Programme Board
	<p>Bill McCarthy (Chair of the Programme Board) provided a verbal update on the first meeting of the Programme Board (21 October 2013).</p> <p>The Group noted that as it was the first meeting of the Programme Board, it had largely been a process meeting where members had considered and discussed the terms of reference, the draft Programme Initiation Document (PID), the proposed approach for managing conflicts of interest, the draft communications and engagement plan, the supplementary publication and the proposed approach to risk management etc</p> <p>The Group noted that members of the Programme Board were very supportive of the work of the review and that they expressed concern about the scale of the challenge and noted the tension between the need for pace and inclusivity. The Programme Board would further consider these challenges at a future meeting.</p>
6	Objectives of the review
	<p>Bill McCarthy introduced the item on the objectives of the review.</p> <p>At its meeting on 21 October 2013, the Programme Board discussed the objectives of the review as part of the discussion of the draft Programme Initiation Document (PID). Programme Board members felt that the objectives were as important as the scope in defining the review and also central to the task of programme planning. As such the</p>

Item	Agenda Item
	<p>Programme Board recommended that the Board Task and Finish Group should consider and confirm these objectives at their next meeting.</p> <p>The objectives of the review were considered, confirmed and approved by the Board Task and Finish Group as follows:</p> <ul style="list-style-type: none"> ▪ 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; ▪ 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.
ACTION	The Programme Initiation Document (PID) to be updated with the agreed objectives
7	Communications and Engagement update
	<p>Bill McCarthy introduced the item on the communications and engagement update.</p> <p>At its first meeting on 21 October 2013, the Programme Board had considered a full draft communications and engagement plan, which it approved, but asked for two sections be made more explicit:</p> <ul style="list-style-type: none"> • that in our work to engage children and young people, we treat them in a way that is positive and respectful; and • that the paper / plan sets an expectation of behaviours for those participating in the new review – for both NHS England and stakeholders. <p>The Group noted that a second round of engagement events with patients and public, providers and clinicians were scheduled for November 2013 and that that a separate event was being designed / planned for those local government authorities which currently “host” a specialist centre to attend for December 2013 / early January 2014 – to which the relevant local healthwatch organisations would also be invited.</p> <p>Bill McCarthy reported that he and Michael Wilson had met that morning with colleagues from the Local Government Association (LGA) to discuss local government engagement.</p> <p>The Task and Finish Group noted the communications and engagement update.</p>
ACTION	Ensure that the Local Government Association (Sir Merrick Cockell, Chair and Carolyn Downs, Chief Executive) are regularly briefed on the review.

Item	Agenda Item
8	Update from the Clinical Advisory Panel
	<p>Professor Sir Bruce Keogh provided a verbal update on the first meeting of the Clinical Advisory Panel (15 October 2013), chaired by Professor Sir Michael Rawlins.</p> <p>This had been the first meeting of the Clinical Advisory Panel there was discussion on terms of reference, approach to managing conflicts of interest, proposed governance etc.</p> <p>Additionally the Panel had discussed standards and specifications and also the scope and interdependencies of the review which would be explained further in the next agenda item.</p>
9	Scope and Interdependencies
	<p>Professor Sir Bruce Keogh introduced the paper on scope and interdependencies.</p> <p>Patients, clinicians and the public were invited to advise on what services and conditions should be included in the scope of the new review and approximately 40 responses were received.</p> <p>A paper was prepared for the Clinical Advisory Panel summarising the stakeholder responses and 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 based on this material.</p> <p>As a result the Clinical Advisory Panel made a recommendation to the Task and Finish Group in the form of the paper being presented today.</p> <p>Whilst considering the recommendation, the Task and Finish Group recognised the difficult balance to be struck – scope had to be broad enough to take account of important dependencies, but not so wide that the project had no realistic prospect of completion.</p> <p>Two further clarifications were proposed responding to stakeholder comments received relating to Extra corporeal life support (ECLS) and pulmonary hypertension services.</p> <p>The Task and Finish Group agreed the Clinical Advisory Panel's recommendation on scope as presented in the paper with the proposed clarifications as discussed.</p>
ACTION	The Programme Initiation Document (PID) to be updated with the agreed scope.
10	Standards update
	<p>Professor Sir Bruce Keogh introduced the item on standards update.</p> <p>The Task and Finish Group discussed and noted the standards based approach being taken by the review and considered a timeline (up to summer 2014) for the production and agreement of standards.</p> <p>The Chair emphasised the importance of proceeding with pace in order to mitigate risks to the current delivery of services, but always to do so with full public and clinical engagement.</p>

Item	Agenda Item
11	Highlight report
	<p>Bill McCarthy presented the highlight report to the Group which summarised progress since the last meeting of the Task and Finish Group on 30 September 2013.</p> <p>The report detailed key updates, strategic risks, issues, next steps and support required.</p> <p>The Chair re-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>
12	Any other business
	There was no other business.
Date of next meeting	26 November 2013 <i>[DN: this meeting was subsequently cancelled]</i>