

Paper NHSE131108

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; and
- approve the task and finish group terms of reference (Annex C).

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

Background

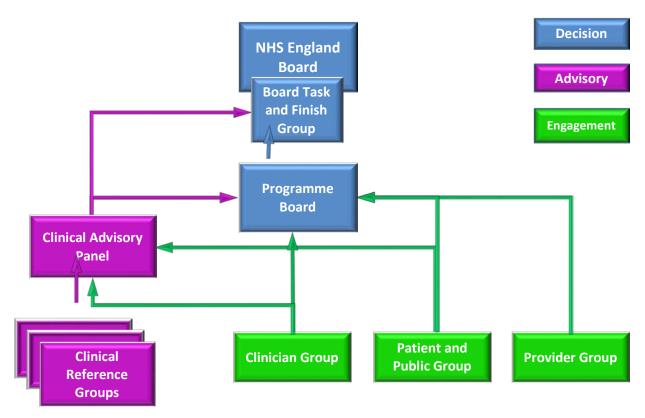
- 1. At its meeting on 18 July 2013, the NHS England Board received a paper regarding the new congenital heart disease review. The paper described the challenge facing NHS England in improving these services, and outlined early thinking on the way forward.
- 2. The purpose of this paper is to provide an update to the NHS England Board on the progress of the review.

Board task and finish Group

- 3. 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.
- 2. Since the NHS England Board meeting on 18 July 2013, the Board task and finish group (the "Group") has met on two occasions, 29 July 2013 and 30 September 2013, with a further meeting scheduled for 29 October 2013.
- 3. At its meeting on 29 July 2013, the Group discussed the progress of the review to date, including the 18 July 2013 Board paper, the outline timetable for the review and the discussion at the Board meeting itself.
- 4. At its meeting on 30 September 2013, the Group discussed the review's proposed governance, decision making, stakeholder participation and engagement arrangements, the scope and interdependencies and also considered how the proposition would be developed.
- 5. The notes / minutes of both the meeting on 29 July 2013 and 30 September 2013 meetings have been published on the NHS England website in line with the review's commitment to transparency and are attached as Annex A and Annex B.
- 6. At the time of writing, the meeting on 29 October 2013 has not yet taken place, however Professor Sir Malcolm Grant will provide a verbal update to the Board during the Board meeting.

Governance

7. The governance, decision making and stakeholder participation and engagement arrangements for the review are depicted in the diagram below:



- 8. During the discussion on 30 September 2013, the Group considered its own draft terms of reference along with those of the programme board and clinical advisory panel. It was during this discussion that it was agreed that Professor Sir Michael Rawlins (Chair of the clinical advisory panel) should be invited to join the Group to ensure the views of the clinical advisory panel were represented fully. Professor Rawlins has since accepted this invitation and will attend future meetings of the Group. The Board are now asked to consider and approve the Group terms of reference (attached at Annex C).
- 9. Both the review's programme board and clinical advisory panel met for the first time during October 2013. Both the agendas and papers for these meetings were published on the NHS England website.
- 10. The review's three engagement groups (patient, public, clinician and provider) are due to hold their first meetings during November 2013.

Managing conflicts of interest

11. In line with NHS England's commitment to transparency the Group believe it is important that any potential conflict of interests relating to this review are clear and made public from the outset. Though NHS England already publishes online a Register of Members' interests in relation to its Board Members, the

Group believe 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; and
- the patient and public group.
- 12. We have sought to ensure that a wide cross section of parties and viewpoints is represented in the governance arrangements. 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 all patients with congenital heart disease, and to put those interests first. A policy has been developed defining a "potential conflict of interest" for these purposes and also in the event that a conflict arises, the necessary action to be taken. The application of the principles described in the policy will be discussed with each of these groups to agree whether any register of interests is appropriate.

Scope and Interdependencies

13. At its meeting on 30 September 2013, the Group considered a paper regarding the scope and interdependencies of the review which also outlined the process in place to resolve the remaining questions. This paper was published online and comments were invited from stakeholders, approximately 40 comments were received. These comments were collated and passed to the Clinical Advisory Panel for their consideration in providing advice to the Group who will make the final decision on scope of the review at the meeting on 29 October 2013.

Recommendations

- 14. The Board is asked to:
 - note the progress of the new congenital heart disease review to date; and
 - approve the task and finish group terms of reference (Annex C).

Bill McCarthy National Director: Policy October 2013

New Congenital Heart Disease Review

Note of meeting of Board CHD sub group - 29 July 2013

The group discussed progress to date including the recent Board paper and outline timetable, and the discussion on 18 July.

In discussion the following points were made:

- in response to the Secretary of State's request for an update by the end of July, the Chair would write to Mr Hunt, with a short explanatory letter, enclosing the Board paper
- an initial series of meetings with stakeholders was underway, including a meeting with local charities and patient groups, scheduled for 7 August
- NHS England would need to be able to reconcile the work of the new CHD review with the "Call to Action" and explain clearly how the two were related
- the process for the new CHD review would establish a precedent for similar exercises in future dealing with other specialties and should, as far as possible, use the specialised commissioning approach (clinical reference groups to advise on standards, development of networks etc).
- we must avoid well-intentioned but misguided pragmatism, ie the path of least resistance, or simply developing a solution to accommodate every existing provider. NHS England must determine the characteristics of the best possible service and commission with that in mind
- the number of units, and the link between volume of activity and patient outcomes, were recurrent themes in early discussions. IRP had criticised the way in which evidence regarding volume and outcomes had been presented in the previous review. So – if the new review relied on numbers of cases per surgeon/centre, it would need to differentiate clearly between evidence and judgement
- irrespective of any evidenced link between volume and outcome, there were intuitive grounds for having four surgeons in each unit, to ensure sustainability and to "future proof" the service. These included mutual support, better oncall arrangements, opportunities for training etc. Having enough surgeons meant removing some of the stress of what was intrinsically a very stressful job
- similarly, the intuitive arguments for larger units, with greater concentration of expertise, were that public expectations were rising, pressures on surgical teams was greater, babies were operated on earlier and operations were increasingly complex. These were potential reasons for performing some of the most difficult and complex operations in a very limited number of centres

- it will be important to think radically about what is best for patients in the long term, which requires a focus on principles and standards, and how best to future-proof the service – for example anticipating changes in technology and clinical practice. This requires a broader approach than simply reviewing the merits of the current providers – how, for example, to best align leading edge research and current practice?
- given the need to consider adults' services alongside children's, the questions about the precise meaning of "co-location", and the need to consider the latest data and best projections, NHS England was not required to work towards a set number of units (eg reducing from 10 to 7). It may be that the conclusion of the review will be to prescribe a number of units, which could be the same or fewer, but this was not the starting point of the review
- some stakeholders had raised safety concerns and there were undoubtedly risks during transition – this was being discussed with NHS England's patient safety domain lead and we would agree a consistent process to be followed. CQC had legal responsibility for essential levels of safety & quality, and NHS England could address issues locally through its regional medical directors working with CQC (eg in Quality Surveillance Groups), with potential escalation to the Chief Inspector of Hospitals
- as the sole national commissioner NHS England wanted a single national service to a single set of national standards, consistently applied. This may require some sharing of accountability, potentially though the way that contracts are let and managed (it was a matter of concern that relationships between centres appeared to have broken down).
- whatever the outcome of this review it was clear that there were practical issues to overcome, for example in the relationships between centres to help ensure an appropriate degree of co-operation and collaboration. NHS England would also need to 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
- summing up, the Chair reiterated the importance of openness, transparency, clinical leadership and service user engagement in the way NHS England conducted its business. The success of this new review would depend in part on early clarity about the fixed points around which the service must be built, the use of formal standards and networks, and consideration of the sustainability and "future proofing" of the service, including links to research. This in turn would require careful thought as to how to rebuild damaged relationships and the potential for some sharing of accountability in a national service of the future.
- NHS England would continue engagement and discussion with a view to developing an initial proposition for discussion in the autumn.

New Congenital Heart Disease Review

Annex B

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		
1	Welcome and Apologies		
	The Chair welcomed everyone to the meeting. Apologies were noted. 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.		
2	Note of the last meeting		
	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.		
	The notes of the meeting on 29 July 2013 were accepted as an accurate record.		
3	Action log		
	The Chair noted that all items on the Action Log were either completed or in progress.		
	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		

Item	Agenda Item	
	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.	
4	Terms of reference	
	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.	
	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.	
	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.	
	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.	
	With this amendment the terms of reference were agreed.	
Action	The chair of the CAP, Professor Sir Michael Rawlins to be invited to join the Group.	
5	Scope and interdependencies	
	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	

Item	Agenda Item		
	decision. Advice would be sought from the CAP and a final decision would be made at the next Group meeting.		
	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 hand, but it would be important for the review to recognise the interdependency and be clear how the connections would be managed.		
	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.		
	The Group considered that criteria needed to be developed to shape decisions about what was in and why.		
	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.		
	The review needed to ensure an appropriate balance between clinical expertise and public opinion. It was important that the CAP was clinically led.		
	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.		
Action	CAP advice on programme scope to be published on the NHS England website and views invited before Group makes its decision.		
6	Proposed governance and decision making		
	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.		
	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.		
	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.		
	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		

Item	Agenda Item		
	of the group. Questions were raised:		
	(1) whether the provider group should feed into the clinical advisory pan as well as the programme board. This was not considered essentia 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.		
	(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 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.		
	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.		
Action	The new CHD review to be added to the main Board agenda as a standing item.		
	Programme Board (including proposed terms of reference)		
	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.		
	It was agreed that Professor Rawlins should be invited to join the programme board.		
	With this amendment the Group were content to convey the terms of reference to the programme board for its consideration and approval.		
Action	The chair of the CAP, Professor Sir Michael Rawlins to be invited to join the programme board.		
	Clinical Advisory Panel (including proposed terms of reference)		
	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. With the proposed amendment to membership the Group were content to convey the terms of reference to the CAP for its consideration and approval.		

Item	Agenda Item			
Action	An anaesthetist to be invited to join the Clinical Advisory Panel.			
	Managing conflicts of interest			
	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.			
Action	The proposed approach to managing conflicts of interest should be further developed to ensure that informal associations were also declared.			
	Publication scheme for the review			
	The publication scheme was welcomed as an important contribution to the review's approach to openness and transparency.			
7	Proposed stakeholder participation and engagement arrangements			
	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.			
	Mr Wilson emphasised that it did not present a complete communications and engagement plan; this was being developed.			
	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.			
Action	Sir Malcolm Grant to discuss the potential for joint local government engagement, overview and scrutiny.			
8	Developing the proposition			
	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.			
9	Highlight report			
	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.			

ltem	Agenda Item
10	Any other business
	There was no other business.
Date of next meeting	29 October 2013 – Maple Street, London W1T 5HD



New Congenital Heart Disease Review Board Task and Finish Group:

DRAFT Terms of Reference









New Congenital Heart Disease Review Board Task and Finish Group

DRAFT Terms of Reference

Issue Date: 24 October 2013

Prepared by: Michael Wilson, Programme Director

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Information Reader Box			
Directorate			
Medical	Operations		
Nursing	Commissioning Development		
Patients & Information	Policy		
Finance	Human Resources		
Document Purpose To described the terms of reference of the New Congenital Heat Disease Review: Board Task and Finish Group			
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Author	NHS England, Policy Directorate		
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Purpose

The purpose of this document is to define the Terms of Reference for the 'Board Task and Finish Group (New Congenital Heart Disease Review)'.

1. Background

- 1.1 Following the outcome of judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the Safe and Sustainable review of children's congenital heart services, in summer 2013, NHS England established a new review to consider the whole lifetime pathway of care for people with congenital heart disease.
- 1.2 The aim of the review is to ensure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality within the available resources:
 - To secure the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
 - To tackle variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care.
 - To ensure great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.
- 1.3 The Task and Finish Group (referred to as "the Group" from here on in) has been established by the NHS England Board (referred to as "the Board" from here on in) to provide oversight to, and assure the development of the new review of congenital heart disease services.
- 1.4 The Board has authorised the Group to provide strategic direction on behalf of the Board on all matters relevant to the new Congenital Heart Disease review.
- 1.5 The Group does not have permanency, and will exist until such time as the review has concluded and an implementable solution has been agreed. The high level programme plan and ambition of the organisation suggests that this will be June 2014.

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2. Role and Responsibilities

- 2.1 The role of the Task and Finish Group is to:
 - provide strategic direction to the new congenital heart disease review on behalf of the Board;
 - provide assurance to the Board that the work of the review is aligned with the aims stated above 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 Programme Board in order for the Group to fulfil its function.
- 2.2 The Task and Finish Group will be responsible for the following:
 - making arrangements for the proper governance of the review and its programme of work;
 - appointing a senior responsible owner for the programme;
 - taking decisions on the direction and running of the review;
 - ensuring that arrangements are in place to provide the group with clinical advice and the review with clinical leadership;
 - assuring the board that appropriate arrangements have been made for the engagement of stakeholders in the review;
 - resolving any issues and risks escalated by the Programme Board;
 - ensuring that the review is properly resourced including ensuring that the review is a priority for the whole organisation and that the resources of the whole organisation are appropriately mobilised to support the work;
 - making recommendations to the board on the actions to be taken as a result of the review, in particular decisions affecting the commissioning and delivery of congenital heart disease services; and
 - at the end of Phase 3 (*preparation for implementation*), providing a recommendation to the Board in respect of ongoing governance arrangements in light of any decisions made and plans for implementation.

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3. Membership

3.1 Core Membership

The core membership of the Task and Finish Group is as follows:

- Professor Sir Malcolm Grant, NHS England Chair (Chair);
- Ed Smith, NHS England Non-Executive Director ;
- Margaret Casley-Hayford, NHS England Non-Executive Director;
- Professor Sir Bruce Keogh, National Medical Director;
- Bill McCarthy, National Director: Policy and Chair of the Programme Board; and
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel.

3.2 Additional attendees

The additional attendance at the meetings is as follows:

- John Holden, Director of System Policy; and
- Secretariat.
- 3.3 On occasions when the Chair is unable to attend the meeting it will be chaired by a non-executive director.
- 3.4 The meeting will be quorate if three members are present, one of which must be a non-executive director and one, a national director
- 3.5 Where members are unable to attend a meeting, deputies will not normally be appropriate. Where a member considers that a deputy may be appropriate this should be agreed with the Chair in advance. Such deputies in attendance will not count toward the meeting being quorate.

4. Frequency

4.1 The Task and Finish Group will meet at the end of each phase of the programme and on such occasions as the Chair shall deem necessary.

5. Secretariat

5.1 The Task and Finish Group Secretariat function will be provided by the new congenital heart disease review Programme Director.

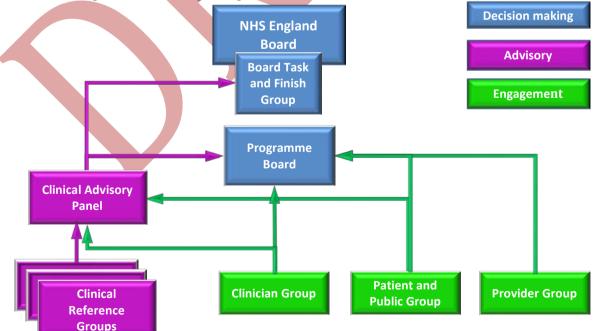
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6. Agenda and papers

- 6.1 The agenda and all papers will be normally be distributed via email to members and those in attendance in advance of the meeting by the new congenital heart disease review team. The agenda and papers will be published on the NHS England website in advance of the meeting.
- 6.2 The actions to be taken will be recorded in the Task and Finish Group's minutes which will be circulated to all members of the Group.
- 6.3 The Chair is responsible for ensuring that the minutes of meetings, produced by the Secretariat, and any reports to NHS England accurately record the decisions taken and, where appropriate, that the views of the individual group members have been taken into account. Once agreed by the Chair the minutes will be published on the NHS England website as outlined in the procedural rules document.
- 6.4 Minutes will be formally approved at the subsequent meeting (or by email where this would be more than one month later). Approved minutes will be published on the NHS England website.

7. Reporting line(s)

- 7.1 A report from the SRO on the work of the review will be provided at each board meeting.
- 7.2 The Group will make recommendations to the Board of any decisions requiring full Board approval and at the end of phase 3.
- 7.3 A diagram illustrating the governance structure is shown below:



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8. Declaration of interests

8.1 Members must comply with the "*Policy for managing potential conflicts of interest*¹" which details the approach and broad principles for the management of potential and perceived conflicts of interest, specifically in relation to the new congenital heart disease review.

9. Public services values for members

9.1 Members must comply with the NHS England Standards of Business Conduct Policy at all times. Available here: <u>http://www.england.nhs.uk/wp-</u> <u>content/uploads/2012/11/stand-bus-cond.pdf</u>

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¹ This document is currently unavailable as the policy for managing potential conflicts of interest is due to be approved by the Task and Finish Group at its meeting on 29 October 2013.

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