

New Congenital Heart Disease Review

Minutes of the Programme Board held on 10 June 2014

Present:

- Bill McCarthy, National Director: Policy by V/C
- John Holden, Director of System Policy (Chair)
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel
- Giles Wilmore, Director for Patient & Public Voice
- Michael Wilson, Programme Director

Apologies:

- Chris Hopson, Chair of the review's Provider Group
- Professor Deirdre Kelly, Chair of the review's Clinician Group
- Professor Sir Bruce Keogh, National Medical Director
- Professor Peter Weissberg, Chair of the review's Patient and Public Group
- Ann Sutton, Director of NHS Commissioning (Corporate)
- Mr James Palmer, Clinical Director, Specialised Services

In attendance:

- Caroline Gillespie, Project Manager (Secretariat)

Item	Agenda item
1	Welcome and apologies
	<p>The Chair welcomed everyone to the meeting. Apologies were noted from: Chris Hopson, Professor Deirdre Kelly, Professor Sir Bruce Keogh and Professor Peter Weissberg.</p> <p>It was noted that the meeting was not quorate. Those present agreed to continue with the meeting; any decisions would be reviewed by absent members and agreed post-meeting by correspondence. They would be ratified at the next quorate meeting.</p>
2	Minutes of the previous meeting
	The Programme Board approved the minutes of the last meeting (13 May 2014).
3	Declarations of Interest
	<p>There were no specific declarations of interest in relation to today's agenda.</p> <p>The Chair requested that the declarations of interest for the current Programme Board members be made available on the NHS England website in advance of the next meeting.</p>
ACTION	Declarations of interest forms to be made available on the NHS England website in advance of the July 2014 Programme Board meeting.

Item	Agenda item
4	Action Log
	<p>The Programme Board considered the action log and discussed the following in more detail:</p> <p>Action 65: Colleagues from finance are now working with the programme team on the assurance of the Financial Impact Assessment and are currently looking at ways to source some further support to deliver this assessment.</p> <p>Action 66: An additional resource has been sourced from a Commissioning Support Unit (CSU) to lead engagement with NHS England Area and Regional teams and Clinical Commissioning Groups (CCGs).</p>
5	Timeline update
	<p>Michael Wilson introduced this item. The Programme Board were reminded of the March 2014 paper outlining possible timeline scenarios, and were provided with a brief narrative overview of the slides tabled for this item. This included confirmation that all the expected activities that need to take place, including the assurance process which will provide approval to launch consultation, have been identified and planned in detail.</p> <p>Michael Wilson reported that the key message within the slides was that whilst it is currently expected that the consultation will launch in September, this is still an optimistic target. The programme team are confident that the work can be delivered, however there are still some significant risks in terms of the governance process. Therefore a September launch cannot be guaranteed.</p> <p>In order to meet a consultation launch date of September the Programme of Care (POC) board would need to meet as expected in August, the POC and Clinical Priorities Advisory Group (CPAG) would need to accept papers in parallel (as the meetings are so close together) and the Directly Commissioned Services Committee (DCSC) of the NHS England board would need to review by correspondence. It was noted that board sub-committees approving by correspondence is not the organisation's preferred approach and a new exception process has been put in place.</p> <p>Michael Wilson advised that in order to launch in September the consultation products would need to be approved at the first time of asking.</p> <p>Bill McCarthy advised that this needs to be a shared priority across the organisation to ensure it succeeds and to provide the level of assurance required. All areas of NHS England must collectively support the programme to launch consultation in September as:</p> <ul style="list-style-type: none"> ○ there are significant resilience risks associated with the time it takes to conduct the review; and ○ if consultation is launched any later than September it will include the Christmas period which will require an extension, resulting in no possible way to respond by the end of the financial year. <p>The Programme Board agreed that the current plan looked suitable and that</p>

Item	Agenda item
	<p>consultation launch should not be any later than September.</p> <p>Bill McCarthy advised that this should be raised at the Task and Finish Group (T&FG) on 23 June 2014 and the Chair may wish to issue a request to the decision making groups to advise them that support should be provided to ensure this timescale is met.</p>
ACTION	<p>John Holden was asked to contact the Chair of the Task and Finish Group (T&FG) to advise of the risk associated with the timeline and to recommend that this issue is discussed at the 23 June 2014 meeting.</p>
6	<p>Engagement and communications plan: consultation and beyond</p>
	<p>Michael Wilson introduced this item.</p> <p>Michael advised that the details of the papers had been brought to the Programme Board for discussion in order that they understood what the new CHD review team would be delivering for the consultation and could contribute to and approve the plans.</p> <p>Specific discussions were held around Annexes A and B:</p> <ul style="list-style-type: none"> ○ Engagement during consultation ○ Consultation documents <p>Annex A identified an intention to hold four regional events plus targeted initiatives (not necessarily events) for adults; for black Asian and minority ethnic groups; patients with learning disabilities; and bereaved parents. It is expected that an active role will be played by our partners (charities, patient support groups, professional colleges, providers, regional teams and area teams). Work is ongoing with the engagement and advisory groups to shape this work and it is expected to include awareness raising and facilitating conversations.</p> <p>As the nature of the information that will be consulted on is complex and detailed, the feedback the review has received is that “town hall” style events may not be the best approach. The Patient and Public Group have advised that a dialogue, with an opportunity for questions and answers, would be required. An opportunity must also be provided for local government and Healthwatch to play a role.</p> <p>Giles Wilmore advised that it may be possible to work with charities for the specific targeted engagement and to attend events already scheduled rather than develop specific additional sessions, and that the regional sessions must be an open invitation. These sessions must be participative and facilitative. People will need to give their views as groups or communities and also must have an opportunity to communicate and share views with others.</p> <p>Giles advised the team that four regional events would take significant work to both plan and facilitate and that the effort required should not be underestimated. It may also be possible to join up the plans for social media with the events possibly live streaming, providing a hash tag and tweeting out</p>

Item	Agenda item
	<p>key messages on the day.</p> <p>The Programme Board agreed that these events should ideally be held in cities that do not contain a CHD surgical centre, to mitigate any perception of bias.</p> <p>Discussion took place around potential provider input and the programme board asked the review team to consider the possibility of groups of clinical leaders working together across a region to present the problem as one section of the regional events.</p> <p>A brief overview of Annex B was provided outlining the intention to create a brief and easy to read consultation document, which might nonetheless be 30-40 pages, complemented by a detailed reference document containing all the standards and other supporting materials. In addition a simple audio/visual version will be created.</p> <p>Giles Wilmore advised it would be possible to do a short film and suggested the team look at that produced for the 6C's. He also strongly advised that a true 'easy read' version would not be 30-40 pages; it would be much shorter and contain symbols and pictures. The Patient Voice team could help advise on the production of this.</p> <p>Professor Sir Michael Rawlins advised that it would be necessary to flag up the areas within the standards that advice is required on and Michael Wilson confirmed that there was an intention to 'spotlight' certain issues within the consultation document.</p> <p>Bill McCarthy reminded the review team to ensure that the process was checked through by the legal team.</p>
ACTION	Michael Wilson to contact the legal team to arrange for a lawyer to check the process.
7	Activity analysis update
	<p>John Holden introduced this item and gave a brief overview of the paper outlining both the qualitative and quantitative information being used to forecast the activity.</p> <p>A combination of factors are driving activity increases and this means it will not be easy to forecast. The review will, as a minimum, present two scenarios, population growth only and population growth plus other factors.</p> <p>The T&FG have advised that it may be necessary to illustrate the effective of different sensitivities, so the review is looking at what else is possible, however the level of data available may mean this is not possible. As a minimum two scenarios will be presented.</p> <p>The programme board were advised that there is no comprehensive reliable data available about the number of people living with CHD, only the number of procedures carried out.</p> <p>Discussion was held on the consequences of over or under estimating the</p>

Item	Agenda item
	<p>volume of future activity, and the programme board noted that there is a risk that the analysis will be revisited post-consultation.</p> <p>The Programme Board agreed that tracking of the volumes carefully in future would need to happen regularly, particularly as this is no longer solely a children’s service and much growth may come from adult procedures in future.</p> <p>Bill McCarthy advised the review team to map out the process it is going through and which deliverables are part of the consultation and which are not. The analysis of the data is taking place as NHS England’s role as a commissioner rather than something that will be consulted upon.</p> <p>John Holden explained to the board that the quantitative data available is coming from two sources hospital episode statistics (HES) data and data from NICOR (National Institute for Cardiovascular Outcomes Research) and the two are being compared to look for material differences in order to validate the data that is being used.</p> <p>The Programme Board were advised that getting access to the data has proven challenging and the adult data will be partial. By the end of July 2014 the review will have a current baseline and a ten to fifteen year paediatric and adult forecast for activity.</p> <p>Giles Wilmore confirmed that whilst it would not be appropriate for a consultation on standards to focus on the activity data, this data nonetheless needs to be publicly available, and there should be a place for an open debate about the forecasts and their interpretation.</p>
<p>8</p>	<p>Transition dashboard</p>
	<p>Michael Wilson introduced this item on behalf of Julia Grace, the accountable commissioner.</p> <p>Michael advised the board that this update was in response to the risk to safety associated with no change happening whilst the services are under review.</p> <p>The dashboards provide early warning measures to NHS England commissioners in Area Teams. Their purpose is to facilitate a conversation between the unit and the commissioner which will lead to an improvement plan where necessary.</p> <p>The Programme Board were advised that the dashboard is in place in all units and a monthly “sitrep” telephone call happens across commissioners in all areas to enable identification of themes.</p> <p>Bill McCarthy advised that this information should be routinely shared with the Care Quality Commission (CQC) and asked the review team to advise the accountable commissioner of this view and ensure that the sharing of this information was investigated.</p> <p>Giles Wilmore advised that an appropriate narrative should be developed around the data, prior to sharing.</p> <p>Discussion then followed around the ownership of the data and sharing it</p>

Item	Agenda item
	<p>publicly. This resulted in a steer from Bill McCarthy that the only circumstance in which the data should not be shared would be a strong argument based on patient interest.</p> <p>John Holden confirmed that Objective 5 of the review would resolve the issue of data availability in the long term.</p> <p>The Programme Board agreed that a judgement needs to be made by the NHS England board, via the review T&FG, about how and when the transition dashboard data should be made publicly available.</p>
ACTION	Michael Wilson to discuss the routine sharing of dashboard data with the CQC and more widely, with the accountable commissioner.
ACTION	Public sharing of the transition dashboard data to be considered by the Task and Finish Group, in order that a judgement can be made by the NHS England Board.
9	Programme Board membership
	<p>John Holden introduced this item which was in response to the action from the previous meeting to build in resilience and some changes due to members leaving NHS England.</p> <p>John Holden advised that in the paperwork provided for this meeting, the omission of the Director of NHS Commissioning from future membership was an error. However this job role/title may change due to internal NHS England discussions about management of specialised services.</p> <p>John outlined the recommendation to both expand the membership to include commissioners and a finance representative, and to allow named deputies to be included in the quoracy.</p> <p>The Programme Board were asked if the membership had been adjusted appropriately and whether these changes would make it more resilient.</p> <p>All board members in attendance agreed that the inclusion of named deputies for quoracy was appropriate as they are acting with the authority of the member who has nominated them.</p> <p>It was recommended that both a regional and area team commissioner should be asked to join the board plus CCG leaders who will need to be close to some of the commissioning decisions.</p> <p>Bill McCarthy recommended that the review team seek advice from Rosamond Roughton about the most suitable body to approach for nominations.</p>
ACTION	Contact Rosamond Roughton to advise on Area Team, Regional Team and CCG representatives to join the programme board.

Item	Agenda item
10	Progress report to the NHS England Board
	<p>John Holden outlined the intention of the review team to issue a paper to the Task and Finish group on 23 June, which will in turn report to the NHS England board on 3 July reporting back on the board’s ambition set out on 12 June 2013 to deliver an “implementable solution” within twelve months.</p> <p>The review team will provide both the NHS England board and the public with an update on progress to date. This will advise where the review is in the lifecycle of the work. It will describe that this is a task and finish project which should in the normal course of events be “mainstreamed” – i.e. handed on to NHs England’s direct commissioners by the end of the financial year.</p> <p>John proposed that the paper will report the challenge set by the board and the progress made against each of the 6 objectives and the overall timeline.</p> <p>The Programme Board members were asked for a steer on both the content and the approach being taken to this report.</p> <p>Professor Sir Michael Rawlins advised that an appendix of all the events, meetings and trust visits that have taken place should be included. Advice was also provided that the report should focus on the need for the review to start with the rebuilding of trust, and that this has been successful in large part because it was not rushed, even though this makes it harder to meet the ambitious timeline set.</p> <p>Bill McCarthy advised that the report should be framed in terms of decisions made within the first twelve months, and the very different approach to the previous review particularly highlighting:</p> <ul style="list-style-type: none"> ○ a different and more extensive approach to engagement; ○ an increased scope, covering the full lifetime pathway from screening through to adults and palliative care; and ○ additional standards such as bereavement and care. <p>The review team were also advised to ensure the approach which has been to capture information and make decisions throughout the process, is clearly represented.</p> <p>John Holden advised that if it timescales allowed a draft would be shared with programme board members before submission to the T&FG.</p>
11	Risk and issue registers
	<p>The Programme Board noted the risk and issue registers. Their attention was drawn to the mitigation action against risk 1 (delivered by item 8 at this meeting) and to the issue raised from risk 10, referring to the lack of resource to deliver the required Financial Impact Assessment.</p>

Item	Agenda item
12	Highlight report
	<p>John Holden introduced this item and drew the Programme Board's attention to the visits that Professor Deidre Kelly and members of the programme team have been making to the trusts delivering CHD services. The initial planned visits are now completed, however a number of additional visits are planned to trusts delivering second tier adult services. Following an approach from a trust for the team to visit, a commitment has been made by the team to visit up to three trusts delivering this type of service.</p> <p>In addition the patients and families in three areas will be met with again. Families of Ocean ward at Southampton were visited by Michael Wilson and Claire McDonald on 31 May 2014, as they have so far been unable to contribute to the Patient and Public Group due to logistical challenges. A similar arrangement is being considered for Newcastle patients and families.</p> <p>An additional session will be arranged in Bristol to meet families, who were not in attendance when the review team visited the unit. It is important for the review to hear from these families.</p> <p>John Holden expressed his concern that any or all of these sessions could be misconstrued as preferential treatment. Giles Wilmore advised the review team that they are taking the right approach. It is critical that all voices are heard and the approach taken must be flexed to allow that to happen and to meet on the terms of stakeholders. There are justifiable reasons to carry out these additional sessions and whilst this may leave the team open to challenge about consistency or even-handedness, it is nonetheless the right thing to do.</p> <p>Bill McCarthy raised a risk around workforce issues associated with the review. He asked the team to confirm the plans that are in place to engage with Health Education England (HEE) and the Royal Colleges. John Holden confirmed that work is ongoing and meetings are planned.</p> <p>Bill McCarthy asked about progress on the equalities impact assessment and John Holden confirmed that the review team are working with the equalities team to ensure the approach meets their requirements.</p> <p>The Programme Board noted the highlight report.</p>
13	Any other business
	No other business raised.
14	Next meeting
Date of next meeting	Thursday 10 July 2014, 10pm – 12pm, Skipton House, London <i>[subsequently rescheduled]</i>