

Minutes of the Programme Board held on 13 May 2014

Present:

- Bill McCarthy, National Director: Policy (Chair)
- John Holden, Director of System Policy
- Chris Hopson, Chair of the review's Provider Group
- Professor Deirdre Kelly, Chair of review's Clinician Group
- Mr James Palmer, Clinical Director, Specialised Services
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel
- Giles Wilmore, Director for Patient & Public Voice (by teleconference)
- Michael Wilson, Programme Director

Apologies:

- Professor Sir Bruce Keogh, National Medical Director
- Ann Sutton, Director of NHS Commissioning (Corporate).
- Professor Peter Weissberg, Chair of the review's Patient and Public Group

In attendance:

- Pia Clinton-Tarestad (Head of Specialised Commissioning)
- Jane Docherty, Project Manager
- Lauren Phillips, Programme Development Manager (Secretariat)

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1	Welcome and apologies
	The Chair welcomed everyone to the meeting. Apologies were noted from: Professor Sir Bruce Keogh, Professor Peter Weissberg and Ann Sutton.
2	Minutes of the previous meeting
	The Programme Board approved the minutes of the last meeting (16 April 2014).
3	Declarations of Interest
	There were no specific declarations of interest in relation to today's agenda.
4	Action Log
	The Programme Board considered the action log and discussed the following in more detail: Action 7: legal advice Though the action was closed on the action tracker, following discussion, the

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	<p>Programme Board agreed that it may be helpful to seek advice directly from the Independent Reconfiguration Panel (IRP).</p> <p>Actions 55 – 57: consultation</p> <p>Michael Wilson noted that the issues relating to these actions would be discussed later in the meeting under Item 5.</p>
ACTION	Seek advice from Independent Reconfiguration Panel (IRP).
5	Early detection of congenital heart disease
	<p>Jane Docherty presented the item on “early detection of congenital heart disease”.</p> <p>Jane explained that Objective 6 of the new CHD review is to “improve antenatal and neonatal detection rates of congenital heart disease” and that the review is facilitating multi-agency working to support both detection and reporting.</p> <p>Jane took members through some of the benefits of early detection which included improved family experience and reduction in the number of emergency transfers of undiagnosed babies at birth.</p> <p>At present, Jane explained that there is no national register of anomalies, though Public Health England (PHE) has plans to develop a national register which should be functional by April 2015.</p> <p>Jane explained that the British Isles Network of Congenital Anomaly Register (BINOCAR) reports the proportion of births covered by regional congenital anomaly registers. Coverage in the UK is currently 49%, whereas coverage in Wales for example is 100%.</p> <p>Jane explained that in terms of neonatal detection rates, newborn and infant physical examination (NIPE) picks up approx. 30% of possible CHD cases before discharge.</p> <p>Jane also highlighted to the Programme Board that last week, the National Screening Committee (NSC) announced a one year pilot of pulse oximetry screening in 6 parts of the country, which could demonstrate the potential to increase the neonatal detection of CHD to 70%.</p> <p>Mr James Palmer observed that for other congenital anomalies there were often poor detection rates.</p> <p>Professor Deirdre Kelly added that detection is only the beginning and that the review should also be looking at the associated broader issues such as counselling needs. Michael Wilson explained that such issues were reflected in the standards to be consulted upon.</p> <p>The Chair asked Jane Docherty and Michael Wilson to draft a note on behalf of the Programme Board to send to colleagues at Health Education England (HEE) alerting them to the potential issues in relation to workforce and training</p>

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	<p>in respect of the early diagnosis workstream once they are clear.</p> <p>Jane presented some of the early feedback the review team had received from stakeholder discussions. One of the potential issues highlighted in the early feedback was training. Jane pointed out that some providers were looking to train all their midwives in newborn and infant physical examination (NIPE).</p> <p>Professor Sir Michael Rawlins and Mr James Palmer observed that much of this type of training could be delivered in a Skills Lab or via other innovative means.</p> <p>Jane Docherty informed the Programme Board that approx. 90% of babies with CHD are conceived by women who are not considered “high risk”.</p> <p>Professor Deirdre Kelly observed that there different centres seemed to offer families different “options” following diagnosis and that there was little data about the impact of early diagnosis on the number of terminations.</p> <p>Jane explained to the Programme Board the next steps for the workstream and the current projected timetable of work which was as follows:</p> <ul style="list-style-type: none"> • a plan to be presented to the Fetal Leads Group in mid-June 2014 and then to the Programme Board in July 2014; and • the work to be completed by December 2014.
ACTION	<p>Jane Docherty and Michael Wilson to prepare a note on behalf of the Programme Board to Health Education England (HEE) alerting them to the potential issues in relation to workforce and training in respect of the early diagnosis workstream once they are clear.</p>
6	<p>Children and young people’s engagement events</p>
	<p>Michael Wilson introduced the item on “children and young people’s engagement events” which provided a high-level summary of the nine engagement events held during the easter holidays.</p> <p>Michael explained that though in total approx. 170 children, young people and family members had attended the events; the attendance at each event was very variable. One of the causes of this, the review team believed was due to some providers / units pro-actively advertising their local events.</p> <p>The Programme Board noted the key headlines / themes that had been heard at the events.</p> <p>Michael explained that at the events, parents were sometimes hearing things from their own children that they had not previously heard. He also observed that even very young children become expert quite quickly and also clear about things that they do and don’t want / like.</p> <p>John Holden noted that “transition” had been a recurring theme at the events.</p> <p>Michael explained that the intention was for the review team to create a summary report of “what we heard” from the engagement events which would be published via John Holden’s bi-weekly blog and also provided to those who</p>

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	were writing / finalising the standards.
ACTION	A summary report of the children and young people’s engagement events to be produced and published via John Holden’s bi-weekly blog.
7	Assurance update and preparation for consultation
	<p>John Holden introduced the item “assurance update and preparation for consultation” which describes the review’s work and proposed approach for the key NHS England assurance groups.</p> <p>The Programme Board was asked to:</p> <ul style="list-style-type: none"> • note the risks described; • consider and advise of mitigation; and • endorse the proposed approach. <p>John Holden explained that the two key themes of this item would be stakeholder engagement and governance.</p> <p>Stakeholder engagement</p> <p>John explained that there had been a large amount of work already in terms of “pre-consultation engagement”. He explained that the review was now working with stakeholders to seek their views about how the consultation should be run. John explained that a specific workshop / meeting to look at the consultation with a sub-set of the Patient and Public Group had taken place on 12 May 2014. One of the points raised at the workshop was not to assume that everything can be done digitally, though one of the other solutions suggested were videos with commentary rather than printing materials in different languages.</p> <p>John explained that slide 13 onwards describes the review’s proposed approach to the consultation and engagement. Some of the key themes are possible ways of reaching the rights audience, how to support the local charities and patient support groups; the nature of the consultation document itself along with the other supporting materials and media; importance of reaching hard to reach groups and acknowledging that a segmented approach is required as one size does not fit all.</p> <p>Professor Sir Michael Rawlins commented that in respect of analysis of responses, one of the learnings from the National Institute for Health and Care Excellence (NICE) was that it is not just a matter of noting comments received. It is also very important to respond to those comments as stakeholders really appreciate knowing that their comments have been considered. Professor Deirdre Kelly agreed that while this was very important it might not be possible to respond to every comment individually.</p> <p>John Holden confirmed that the review team was intending to describe how comments and responses received had been taken into account in its own its own response. John went on to explain that as the number of responses that would be received was unknown, though the Safe and Sustainable process</p>

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	<p>had received 75,000 responses, some external support may be required. As such some initial conversations were taking place with organisations such as IPSOS, Nuffield and the Kings Fund to find out how much this sort of support would cost, whilst acknowledging that there was potentially different levels of external support from doing all of it, to quality assuring the work of the review team.</p> <p>Chris Hopson added that he was aware of some specialist / boutique agencies that did this type of work and that he would pass the details to John Holden outside of the meeting.</p> <p>The Chair suggested that the review team scope the whole spectrum of potential external support required for analysis of the consultation responses.</p> <p>Mr James Palmer noted that there would be a public consultation on approximately 40 other specialised service specifications this year and therefore it would be important not only to develop a good consultation process, but also one that was re-producible.</p> <p>Giles Wilmore supported the possible option of outsourcing the analysis of responses, but advised that it would be better to draft the response internally as this way the review could be clear and transparent and any perceived conflicts.</p> <p>The Chair suggested that there may be some procurement frameworks in place for this type of work and Pia Clinton-Tarestad suggested that a Commissioning Support Unit (CSU) may be able to provider this support.</p> <p>The Programme Board affirmed the importance of listening to and responding to what was said in consultation, including amending the standards and associated specification as necessary.</p> <p>The Chair observed that getting the language right in the consultation would be very important along with being very clear and honest about where evidence is qualitative, rather than quantitative.</p> <p>The Programme Board noted that the estimated timescale for the start of consultation was currently the end of July 2014.</p> <p>Governance</p> <p>John Holden noted that the service specification for congenital heart services is one of many specialised service specifications and therefore needed to be consistent with the NHS England way of doing things.</p> <p>John explained that though the review team had now mapped out the route it would need to follow, the aim of the discussion today would be regarding the mitigation of any risks and hurdles identified.</p> <p>John reminded members that at the last meeting of the Programme Board (April 2014) the review team had described the proposed approach for both the Women and Children’s Programme of Care Board and the Clinical Priorities Advisory Group (CPAG). Both of these groups would need to give</p>

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	<p>approval before the review could formally go out to consultation.</p> <p>John explained that since this meeting, the review team had attended both the PoC Board (29 April 2014) and the CPAG meeting (30 April 2014) to seek each groups' feedback on what they would need to see in order to approve the consultation.</p> <p>John reported that both groups were broadly supportive of the review's intended approach to assurance and governance, stakeholder testing and having due regard to the aims of the Equality Act 2010. However, both groups wanted to see a financial impact assessment that would go beyond the scope of the review (as detailed in slide 10). The reviews' approach has always been to consult on a set of standards that describe what a very good service looks like, whilst being mindful that this was not the same as asking for a blank cheque and acknowledging the significant financial pressures facing the specialised commissioning functions. John explained that slide 11 set out the review's proposed approach to dealing with this issue.</p> <p>Michael Wilson explained to the Programme Board that a line-by-line analysis of each standard was underway. This analysis would include a comparison of each of the proposed standards against the standards that are currently in the existing specification (even they are not necessarily being met) Pia Clinton-Tarestad supported this approach. Michael Wilson advised the Programme Board that when the review team is in a position to present this analysis, along with the intended consultation questions, it would be possible to have a more granular discussion. This may be possible for the June 2014 meeting of the Programme Board. Similarly the Chair suggested that at a future meeting of the Programme Board the different cost drivers and potential savings should be discussed.</p> <p>The Programme Board suggested that for the next round of engagement and advisory groups meeting, stakeholders should be asked which standards they believe to be "core" and which "developmental". Michael Wilson explained that this was the role of the Congenital Hearts Service Clinical Reference Group.</p>
ACTION	The review team to scope the whole spectrum of potential external support required for analysis of the consultation responses.
ACTION	At a future meeting, the Programme Board should consider the drivers of costs in the new standards and the potential savings.
8	Risk and issue register
	<p>The Chair introduced the item on "risk and issue register."</p> <p>The Programme Board noted the risks and issues though specific comments were made in relation to the following:</p> <p>Risk 8 - The Chair suggested that the mitigating action "work closely with clinical commissioning groups to ensure that changes could be made across the pathway" should be made more explicit. For example, the Commissioning</p>

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	<p>Assembly create a sub-group to look at this work. The review team to discuss options for working with clinical commissioning groups (CCGs) on the commissioning of Tier 3 of the standards with colleagues in the Commissioning Development Team.</p> <p>Risks 9, 10 and 11 – Michael Wilson noted that these risks had been discussed earlier in the meeting.</p>
ACTION	<p>Discuss options for working with clinical commissioning groups (CCGs) on the commissioning of Tier 3 of the standards with colleagues in the Commissioning Development Team.</p>
9	<p>Highlight report</p>
	<p>The Chair noted that a large amount of activity, specifically engagement activity that had taken place since the last meeting of the Programme Board. The Programme Board noted the highlight report.</p>
10	<p>Any Other Business</p>
	<p>Trust visits</p> <p>Professor Deirdre Kelly provided a verbal updated to the Programme Board on progress of the Trust visits to Specialist CHD Surgical Units. Since the last Programme Board meeting, Professor Kelly and members of the review team have visited Southampton (30 April 2014), Brompton (2 May 2014), Guy’s and St Thomas’ (2 May 2014) Newcastle (7 May 2014) and Leeds (9 May 2014).</p> <p>Professor Kelly made the following points:</p> <ul style="list-style-type: none"> • conducting the Trust visits had been a privilege; • no two centre works in exactly the same way; • team working is absolutely key to delivering an effective service; • no centre will be able to meet all of the standards immediately; <p>Professor Kelly explained to the Programme Board that once all Trust visits were complete, a paper would be produced. The paper, amongst other things would look at themes of good practice and would be fed into the process.. The paper would add strategic value to the review and maybe helpful for other niches services.</p> <p>Professor Kelly noted that attendees at the Trust visits had appreciated the honesty of the review team when they didn’t know the answer.</p> <p>Jane Docherty noted that the review team had met approximately 20 people at each of the patient and family sessions as part of the Trust Visits. Jane noted that the patient and family stories had been fascinating with some very important themes emerging for example around transition and communication.</p> <p>The Chair noted that the engagement to date had been incredibly powerful.</p>

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	<p>Programme Board membership</p> <p>John Holden noted that the next meeting of the Programme Board (10 June 2014) would be Bill McCarthy’s last meeting as he was to be taking up his new role from July 2014.</p> <p>John Holden also suggested that due to previous problems relating to quoracy of the Programme Board (March 2014 meeting), the Programme Board may want to consider extending its membership.</p> <p>Bill McCarthy confirmed that the new NHS England Chief Executive (Simon Stevens) had received a both a briefing paper and verbal update on the work of the new CHD review.</p>
ACTION	Proposals to be made regarding the membership of the Programme Board from July 2014.
11	Next meeting
Date of next meeting	Tuesday 10 June 2014, 2pm – 4pm, Skipton House, London.

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