

**Minutes of the Programme Board, held on 30 June 2015
Skipton House, London**

Members in attendance:

- John Holden, Director of Policy, Partnerships & Innovation, NHS England (Vice Chair) (JH)
- Ben Day, Senior Finance Manager, Strategic Commissioning (BD) deputising for Sam Higginson
- Chris Hopson, Chair of the review's Provider Group (CH)
- Professor Deirdre Kelly, Chair of the review's Clinicians Group (DK)
- Ian Langfield, Assistant Director of Planning & Performance (IL) for Daniel Phillips, Director of Planning, Welsh Health Specialised Services Committee (DP)
- Mr James Palmer, Clinical Director for Specialised Services, NHS England, (JP)
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel (MR)
- Dr Alison Rylands; Regional Clinical Director (North) Specialised Commissioning (AR)
- Michael Wilson, Programme Director, NHS England (MW)

Apologies:

- Ian Dodge, National Director: Commissioning Strategy (Chair) (ID)
- Bill Gillespie, Director of Specialised Commissioning, NHS England, South (BG)
- Sam Higginson, Director of Strategic Finance, NHS England (BH)
- Will Huxter, Director of Specialised Commissioning, NHS England, London (WH)
- Professor Sir Bruce Keogh, National Medical Director, NHS England (BK)
- Professor Peter Weissberg, Chair of the reviews Patient and Public Group, (PW)
- Giles Wilmore, Director for Patient & Public Voice & Information, NHS England (GW).
- Dr Cathy Winfield, CCG representative, NHS Wokingham CCG (CW);

In attendance:

- Nicola Humberstone, Programme Manager
- Ben Parker, Programme Development Manager
- Jennie Smith, Programme Coordinator (Secretariat)

Item	Agenda Item
1	Welcome and apologies
	John Holden opened the meeting by welcoming attendees, introductions were made and apologies were noted. It was noted that Michael Wilson would join the meeting after 10:30.
2	Minutes of the previous meeting
	Professor Deirdre Kelly proposed minor re-drafting of certain parts of the previous minutes relating to ASD closures and colocation. Page 3 – paragraph 1

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	<p>Line 4 – remove ‘extensively’</p> <p>Line 6 - ‘providing’ change to ‘as long as’</p> <p>Line 7 – ‘work’ changed to ‘all work’</p> <p>Paragraph 3</p> <p>Line 3 – ‘not put off work to achieve this standard to an indefinite future date’ change to ‘work towards achieving this standard to a definite future date’</p> <p>Line 7 – ‘ it would be unlikely that the commissioners would decommission the service. A realistic plan effectively delivered was key’ change to ‘it would be unlikely that the commissioners would decommission the service if there was a realistic plan in place’</p> <p>Mr Holden advised that these changes would be picked up outside of the meeting.</p> <p>The Board agreed.</p>
3	<p>Declarations of Interest (verbal)</p>
	<p>Mr Holden then asked the Board members to advise of any declarations of interest, related to the day’s agenda.</p> <p>None were noted.</p>
4	<p>Action log</p>
	<p>Mr Holden then asked Nicola Humberstone to discuss the action log.</p> <p>Action 85 – The Provider Leaders’ Sub-Group had been established under the lead of NHS Providers. Commissioners were supporting this work. Their next meeting was planned for the 13 July 2015. A CHD Commissioning Group had also been established to review the commissioning options both regionally and nationally; this group was set to meet again on the 8 July 2015. This action was closed.</p> <p>Action 87 – It was agreed that this action would be covered under objective 6 as part of the agenda; this would outline NHS England’s involvement.</p> <p>Action 88 (encompassing 50, 51, 62 and 86) – Letters to societies had been written and responses received from some; the programme was continuing the work on workforce requirements with the society representatives and provider stakeholders.</p> <p>Action 96 – Review and analysis of surgical data continued with consultant support. Further analysis was due on 30 June 2015.</p> <p>Action 97 – The CHD Implementation Group had now changed its name to CHD Commissioning Group. A further group would be developed to support the implementation of the standards and service specifications after the completion of commissioning. This action was closed.</p>
ACTION	<p>Programme team to close actions 85 and 97.</p>
5	<p>Objective 5 – Better Information</p>

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	<p>Mr Holden then invited Ben Parker to speak to his slides re: objective 5 on better information and improving data for congenital heart disease services.</p> <p>‘Better information – rationale’ - It was noted that the available information was limited, not timely or available to all stakeholders. The data was limited to mortality data at present and needed to be expanded to support improvement of services and to improve patient experience.</p> <p>‘Better information – deliverables’ – An interim report had been provided on objective 5 in March 2015. The new report built on this.</p> <p>It was noted that the latest data available on mortality had been published on the 3 June 2015 using data from April 2013 and so was approximately 24 months old. This was considered unsatisfactory if any action was required.</p> <p>Professor Sir Mike Rawlins asked what was the blockage to current data? Mr Parker reported that that this was partly due to the data validation requirements. It was agreed that rolling quarterly reports would be more appropriate.</p> <p>Only limited analysis of adult data was available with no whole centre comparisons. Further analysis was to be developed, including eventually a risk model.</p> <p>A discussion followed on the current practice for data delivery to stakeholders. It was noted that societies were informed of any centres or clinical practice that was classed as an outlier. Dr Alison Rylands asked if in future commissioners would hear the outcomes at the same time as societies. Mr Parker confirmed this would be the case. Mr Holden commented that it would also be sensible to alert appropriate stakeholders of publications from the National Institute for Cardiovascular Outcomes Research (NICOR), so that individuals, teams and organisations were aware of any new findings.</p> <p>Mr Parker went on to discuss progress on the information components of the review’s work on Objective 6. The importance of accurate information on antenatal diagnosis rates was highlighted. To prevent duplication of data, a data sharing agreement was to be set up between NICOR and the National Congenital Anomalies and Rare Diseases Registration Services (NCARDRS). A pilot for monitoring what proportion of women receive a complete antenatal screen was underway. This would improve understanding of any gaps in service delivery.</p> <p>Mr Parker described how information on quality of care would be improved by the expansion of the quality dashboard This would also help with monitoring the introduction of the standards. The Congenital Heart Services Clinical Reference Group (CHSCRG) would be setting up a subgroup to focus on new information requirements.</p> <p>Where procedure volumes were low so that statistically meaningful outcomes data were not available centre activity levels would be published by NICOR, so that all centres undertaking procedures could be identified to inform patient choice.</p> <p>A process was to be established for reporting via the quality dashboard, for adults and paediatric reporting measures of patient experience (PREMS). Patient groups and the CHS CRG strongly support this development. The review would fund the initial development of the questionnaires. However the longer-term hosting and reporting of the surveys to be met by providers. Maintenance costs were to be discussed with providers through the CRG. Mr Hopson advised that providers would need to agree to any figure proposed. Mr Bartlett-Syree noted further discussions would be had on Patient Reported Outcome Measures (PROMs) and PREMs in the wider context of</p>

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	<p>specialised services.</p> <p>Mr Parker reported that he had discussed his recommendations with NICOR, which runs the National Congenital Heart Disease Audit and HQIP which commissions the audit on behalf of NHS England. They supported the recommendations, but further discussion was needed on publishing adult outcome data before a risk adjustment tool was available. A discussion followed on how risk adjustment of the adult data would be different to the risk adjustment designed for paediatrics.</p> <p>Mr Parker then went on to discuss the timeline for the recommendations, the full report identifying each individual timeline and the presentation slide demonstrating the overarching timeframe.</p> <p>It was noted that providers, clinician and patient/public groups had requested that the information already collected should be used more effectively. The information subgroup to the CRG would develop the quality dashboard using existing data wherever possible.</p> <p>The transition and quality dashboards were currently running in parallel, but once satisfied that the quality dashboard offered sufficient information, the transition dashboard would be stopped, reducing the burden of data collection and submission on providers</p> <p>It was noted that the CRG would in future have oversight of the dashboard, with a range of projects potentially leading to new metrics. .</p> <p>James Palmer noted that eighteen months previously collaboration with centres in the United States on the dashboard had been discussed. This could be revisited and would provide an international perspective for comparison.</p> <p>Mr Parker advised that there was a need to publish more data so providers, commissioners and patients could use the information. Only a limited amount of information was currently in the public domain.</p> <p>Mr Holden noted that a flow diagram could be helpful to show how information flowed and which organisations formed part of the delivery of the data e.g., societies, NICOR, NHS England etc.</p>
ACTION	
6	Objective 6 – Early Diagnosis
	<p>Mr Parker described the progress on objective 6, which was currently being led by Julia Grace (CRG Accountable Commissioner), who was unable to be present at the meeting, but had drafted the paper presented to the Board. A previous report described the findings and recommendations of this work, and this update concentrated on implementation.</p> <p>Professor Rawlins advised that early detection was good because better outcomes were achieved and this should be emphasised more.</p> <p>Mr Parker went on to describe the work that has been going on around early detection.</p> <ul style="list-style-type: none"> - A project group of the relevant stakeholders had been established to review antenatal detection rates for CHD, review the pathway and the partners involved, presenting a joint project plan, that would be monitored by the CRG.

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	<p>‘What were the challenges’</p> <p>The complexity of commissioning and the assurance process was discussed, given all the stakeholders involved in commissioning and providing the service; the various datasets available, with no conclusive dataset that provided a full and accurate set of data for the whole pathway, to support appropriate commissioning, this posed a challenge.</p> <p>Mr Parker explained that the sonographer workforce was not currently regulated; feedback on work undertaken was not consistent to develop the individuals, teams and the services.</p> <p>‘Where are we against targets?’</p> <p>Mr Parker noted that the Fetal Anomaly Screening Programme had a set a target for detection of anomalies of 50% and the latest data showed a rate of 45% in some areas. In other areas the rate was much lower.</p> <p>Mr Parker reported that improved data would come from the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). The timescales were discussed and it was noted that it would be important to see how the information would help with understanding detection rates.</p> <p>Mr Parker stated that a Health Education England working group had been established and a survey sent to all centres to gain a better understanding of the sonography workforce issues.</p> <p>The Fetal Anomaly Screening Programme was providing training to support sonographers in obtaining the five cardiac views. This was supplemented by unregulated training from charities.</p> <p>A pilot of pulse oximetry would help answers questions about wider roll-out of this test in March 2016.</p> <p>A working group had been formed, chaired by Julia Grace, to co-ordinate work by all these different organisations that related to early diagnosis.</p> <p>Professor Kelly asked the Board to note the variation in the counselling received across centres, to support families when CHD was detected. There was often not a referral to a better qualified centre to support patient’s decision-making. Mr Parker noted that the information available on the number of terminations needed improvement.</p> <p>Professor Rawlins asked how effective commissioning of the proposals would be taken forward with Clinical Commissioning Groups?</p> <p>Mr Wilson noted that scans were commissioned as part of general maternity commissioning. Improvements would require effective collaboration between NHS England, CCGs and others. Dr Rylands advised that the Directors of Specialised Commissioning could support the raising of awareness around CHD.</p> <p>Mr Holden and Ian Langfield explained that Tiny Tickers had undertaken a significant amount of improvement work in South Wales to support early diagnosis.</p>

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ACTION	
7	Commissioning Strategy Approach
	<p>Mr Bartlett-Syree introduced the item, explaining that the NHS England’s commissioning approach would need to be tailored for the requirements of the service. The current work was the pre-commissioning phase. It was envisaged that commissioning against the standards would be from April 2016. After the NHS England Board decision, collaborative working would need to become more formal to allow assessment of the emerging service delivery models to inform judgements about the appropriate contracting approaches. The work on service delivery model options would be pursued exhaustively before considering a full procurement route for the CHD service, as this seemed likely to enable the best outcome.</p> <p>Commissioning of level 3 centres would require further consideration at this point to support the collaborative commissioning with CCGs.</p> <p>Professor Kelly asked about the level of support for this approach. Mr Hopson asked if NHS England in particular supported this proposal. Mr Bartlett-Syree advised that the approach had been set out as part of the Specialised Commissioning assurance process and it was agreed that every effort should be made to find collaborative solutions that allowed providers to meet the standards.</p> <p>‘Provider Leaders’ Subgroup’</p> <p>Mr Hopson then reported on the work of the Provider Leaders’ Subgroup; they had met three times and were on a journey of discovery that had some difficult challenges and issues. The outcome of this work was unknown, as there was no magic answer to delivering the standards. The subgroup had acknowledged that they had to work through the process; this meant living with a high level of ambiguity which brought with it a higher level of risk. Mr Hopson commented on the developing interactions between stakeholders and the time spent trying to work out knotty issues and practicalities. Professor Kelly commented that the subgroup was beginning to work collaboratively and there was no longer an expectation that NHS England would sort everything out.</p> <p>Mr Palmer advised that some more formality/clarity would need to be put around the process. Mr Bartlett-Syree advised that there would be increased formality to the process as it progressed towards the receipt of submissions from providers during September/October. These would need to have clear implementation plans. However it was noted that even with increasing formality there was a need to keep people informed to ensure continued buy-in.</p> <p>Mr Palmer commented on the exceptional piece of work that had been undertaken to get the programme this far. There now needed to be clarity on the next phases to ensure providers could continue to deliver their part. Mr Palmer asked that the role of quality surveillance in supporting peer review be considered. Mr Bartlett-Syree agreed that he would discuss this further outside the meeting.</p> <p>Mr Hopson commented that to meet all the standards would be difficult, but with multicentre networking there may be some different solutions. Even so geography and activity were difficult factors.</p>

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	<p>It was agreed by the group that documenting the process in advance was difficult because there was a sense that this was a new way of working. However following the board decision it would start to be possible to be clearer.</p> <p>The good work of the subgroup was noted and the Board asked for it to continue.</p>
8	Proposed Board Paper
	<p>Mr Wilson outlined the proposed structure of the board paper and asked for comments. It was noted that each section had the proposed allocated number of pages per section. Professor Kelly suggested that section 5 and 6 should be swapped around; there needed to be clear differentiation between 'paediatric', 'Grown-up congenital heart disease' and 'adult congenital heart disease'. The distinction needed to be clear for those that grow up with a condition and those diagnosed as adults.</p> <p>Professor Rawlins advised that the paper needed to draw out any issues i.e., those areas that providers were finding difficult e.g., co-location.</p> <p>Mr Bartlett-Syree advised that this could be considered under deliverability and risk in section 6. J. It was also noted that referral pathways needed to be considered further. Professor Kelly added that the aim was to improve quality of care.</p> <p>Mr Wilson advised that all six objectives were covered within the paper; Mr Hopson advised that they needed to be clearly signposted.</p> <p>Mr Holden summarised that the report needed to encapsulate what had been done and how we got here; an outline plan for the next stages and the amount of work left to do.</p> <p>Mr Langfield left the meeting.</p> <p>Mr Hopson advised that a paper on the provider work would be written to issue as part of a blog, with provider sign-off. This would inform the board paper</p>
ACTION	
9	Highlight Report & Risk Register
	<p>Ms Humberstone summarised the highlight report.</p> <p>The Board was asked to note the key meetings, prior to the NHS England Board, on 23 July 2015: a key stakeholder meeting was being held on the 13 July 2015, to communicate the programme's progress to stakeholders and ask them for advice to support and help inform the board paper further.</p> <p>The Provider Subgroup meetings would continue as described by Mr Hopson – the next meeting also to be held on 13 July 2015.</p> <p>The risk register was reviewed.</p> <p>The Board accepted the updates.</p>
10	Any other business
	<p>Professor Rawlins asked how, if there were any queries on the standards in the future, these would be managed? Professor Kelly advised that these would be picked up within the CRG.</p>

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Item	Agenda Item
Date of next meeting	Members were advised that another meeting would be set up following the NHS England Board decision. Notification of the date would be sent to members of the group.