

**MINUTES**  
**Children's Congenital Heart Services Programme Board**  
**Wednesday 23 January 2013 – 10:00-12:00**  
**NCL, Stephenson House, 75 Hampstead Road, London NW1 2PL, 4LM1**

Present:	Job title and organisation
Caroline Taylor (Chair)	Cluster Chief Executive, NHS North Central London
Ann Jarvis	Chief Operating Officer, South of England SCG
Catherine O'Connell	Regional Director of Commissioning, NHSCB, Midlands and East
Prof. Deirdre Kelly	Professor of Paediatric Hepatology, The Liver Unit, Birmingham Children's Hospital
Hannah Wynne	Senior Consultant, Grayling
Julie Higgins	Regional Director of Commissioning, NHSCB, North
Michael Wilson	Interim Implementation Programme Director
Sue McLellen	Head of Specialised Commissioning, NHSCB London

In attendance:	Job title and organisation
Ali Lawrence (Minutes)	PA to Michael Wilson, LHP
Debbie Hodges	Interim Project Officer
Jo Pope	Commissioning Manager/Senior Project Manager, London SCG

Apologies:	Job title and organisation
James Ford	Managing Director of Public Sector, Grayling
Jeremy Glyde	Programme Director, Safe and Sustainable, NHSCB
Jo Sheehan	Acting Director of National Specialised Commissioning Team
Kate Caston	Head of Specialised Commissioning (Corporate), NHSCB
Sam Johnson	Operations Manager for Children's Heart Federation

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1	<p><b>INTRODUCTION AND APOLOGIES</b></p> <p>Caroline Taylor opened the meeting and thanked everyone for attending. Introductions were made and apologies noted. Hannah Wynne was welcomed to the meeting representing James Ford. Jo Pope was welcomed to the meeting as part of her induction as the programme lead for London.</p>	

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2	<p><b>DRAFT MINUTES OF THE PREVIOUS MEETING</b></p> <p>The draft minutes of the previous meeting were reviewed. Clarification was sought by Deirdre Kelly and confirmed by Michael Wilson that the wording regarding age ('19<sup>th</sup> birthday') in the Terms of Reference had been revised. The draft minutes were therefore agreed as an accurate record of the meeting.</p>	
3	<p><b>MATTERS ARISING AND ACTION</b></p> <p>The Action Log was reviewed.</p> <p><b>Action 2.02 (3.1 &amp; 3.2): Invite additional representatives to join the Board</b>                      Michael Wilson confirmed that Anne Keatley-Clark had identified a second user representative. Daniel Phillips would be the representative for the NHS in Wales.</p> <p><b>Action 4.02: Produce a workstreams matrix and programme plan with Regional Leads and clinical leaders</b>                      This appears as an item on the agenda.</p> <p><b>Action 6.01 (3.4): Review objectives of the Communications and Engagement Plan</b>                      This appears as an item on the agenda.</p> <p><b>Action 4.1: Terms of Reference to be revised in light of comments made</b>                      A revised version had been circulated for discussion at the meeting.</p> <p><b>Action 6.1: PID to be revised in light of comments made</b>                      A revised version had been circulated for discussion at the meeting.</p> <p><b>Action 6.2: To ensure the wider implications of the ECMO changes are being managed</b>                      This appears as an item on the agenda.</p> <p><b>Action 6.3: To ensure work on services for adults with congenital heart disease recognises the needs of young people and the effective management of transition</b>                      This appears as an item on the agenda.</p>	

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	<p><b>Action 6.4: To develop a Programme Plan</b> This appears as an item on the agenda.</p> <p><b>Action 7.1: Risk Register to be reviewed and comments sent to Michael Wilson</b> No comments had been received. A meeting between Caroline Taylor, Michael Wilson and Debbie Hodges was in the process of being set up to discuss the Risk Register.</p> <p><b>Action 11.2: Julie Higgins to be briefed prior to her joining the Programme Board</b> It was reported that unfortunately the briefing had had to be scheduled for immediately after the meeting</p>	
4	<p><b>PLANNING FOR IMPLEMENTATION</b></p> <p><b>4.1 Programme Initiation Document (PID) (revised)</b></p> <p>Michael Wilson presented the revised PID. Key changes were the harmonisation of the PID and the programme's various Terms of Reference. The PID had also been revised to take account of the new programme plan (see item 4.2).</p> <p>Caroline Taylor proposed that the PID be adopted, recognising that it may need to be amended as the programme develops. This was agreed.</p> <p><b>4.2 Programme plan</b></p> <p>Michael Wilson introduced the programme plan, comprising a covering paper and a series of excel spreadsheets, each sheet relating to one of the programme objectives outlined in the PID.</p> <p>Michael Wilson explained that the covering paper set out the context for the programme plan, while the excel spreadsheets show the actions relating to each objective and the timescales for the work. This allowed the board to consider whether the planned actions were those necessary and sufficient to deliver each objective. In preparing the plan reference had been made to the earlier plan written in the summer of 2012. Implementation issues identified in the Decision Making Business Case were also incorporated. Finally a workshop with specialised commissioning leads had contributed to the</p>	

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	<p>formation of the plan. This meant that the plan should be a reasonable first draft, but he expected that it would be significantly refined and improved following discussions with stakeholders.</p> <p>It was agreed that a CIAG (Clinical Implementation Advisory Group) version of the plan would need to be produced showing its work programme.</p> <p>Responding to a question about capital funding Ann Jarvis noted that the business case had stated that providers were expected to meet such costs from their capital programmes. Catherine O'Connell said that these assumptions need to be tested locally and would need to be made explicit.</p> <p>Sue McLellen advised that the table in section 3.3 was historical data and not current activity with some centres already having increased their activity. Michael Wilson acknowledged that this was the case, but that its purpose was to illustrate the point that there would be a greater scale of activity and capital change at some units than others. Sue McLellen stated that she would confirm when the next CCAD (Central Cardiac Audit Database) data will be available. It was agreed that once this data was available the table would be reviewed.</p> <p>Deirdre Kelly asked about the baseline quality and safety review in April as she had not previously been aware of this. Michael Wilson advised that this had not yet been discussed, but it had been included in the plan as part of the work to ensure the system is safe and remains so through transition. Deirdre Kelly stated that CIAG should contribute to or lead this process.</p> <p>Deirdre Kelly noted that capital development costs did not include costs for cardiac extracorporeal membrane oxygenation (ECMO). The board asked for clarification as to whether cardiac ECMO was in scope for the programme (because part of the service offered by all specialist surgical centres) and if so whether provision had been made for any increased costs. Deirdre Kelly agreed to seek advice from David Baron at the CCHS CIAG Executive Group later that day. Catherine O'Connell stated that it would also be helpful to seek advice from Jo Sheehan.</p> <p>Caroline Taylor asked that the PID be amended once the position was clear.</p>	<p><b>MW</b></p> <p><b>SM</b></p> <p><b>DK, MW</b></p> <p><b>MW</b></p>

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	<p>Ann Jarvis suggested an extra line in the programme plan to check implications for cardiac ECMO.</p> <p>Caroline Taylor summarised the next steps for sharing and developing the programme plan:</p> <ul style="list-style-type: none"> <li>• Regional leads to test the plan with commissioning colleagues</li> <li>• Test the plan with providers                             <ul style="list-style-type: none"> <li>○ The national programme team to circulate to all participants in the October workshop with a covering letter stating 'This is being tested with organisations but if as an individual you would like to comment .....'. Comments would be returned directly to the programme team.</li> <li>○ Regional leads to test with the 10 surgical centres plus Oxford, Cardiff and Manchester. It was agreed that the programme director would draft the letter from regional leads to provider chief executives to ensure consistency. Regional leads would forward comments to the programme team.</li> <li>○ Deirdre Kelly to test with CIAG and forward comments to the programme team.</li> </ul> </li> </ul> <p>In each case colleagues would be asked to validate, test and suggest improvements to the plan. They would also be asked about their state of preparedness to implement those aspects of the plan that they would be responsible for and what support they would need. Comments should be returned within one month of the date of the documents being sent.</p> <p>Sue McLellen noted that in testing the paper it would then become public. It was agreed that this was appropriate. Caroline Taylor asked that the status of the plan should be made more explicit in the covering paper and that where decisions were still to be made this should also be stated. The paper should be watermarked 'Draft' and appropriate caveats such as 'pending', 'subject to' should be added where necessary for the purpose of clarification.</p> <p>It was agreed that a workshop would be convened with nominated leads to consider all comments received and revise the plan and that the output from this group should be presented to the March Programme Board</p> <p>It was agreed that District General Hospitals would not be included in</p>	<p><b>MW</b></p> <p><b>RLs</b></p> <p><b>MW</b></p> <p><b>RLs</b></p> <p><b>DK</b></p> <p><b>MW</b></p> <p><b>MW</b></p>

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	<p>this exercise but would be included as the process evolved.</p> <p>Deirdre Kelly stated that it would be important to stress that at this stage what is trying to be done is get the Programme Plan agreed. She also stated that the feedback process should be clearly explained in the covering letter.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1. Michael Wilson to produce separate workplan for CIAG</b></li> <li><b>2. Sue McLellen to clarify when the next CCAD data will be available</b></li> <li><b>3. Deirdre Kelly to seek advice from David Barron on cardiac ECMO</b></li> <li><b>4. Michael Wilson to seek advice from Jo Sheehan on cardiac ECMO</b></li> <li><b>5. Michael Wilson to amend the PID to clarify the position on cardiac ECMO</b></li> <li><b>6. Extra line to be added to the programme plan to check implications for cardiac ECMO</b></li> <li><b>7. Regional leads to test the plan with commissioning colleagues</b></li> <li><b>8. Michael Wilson to circulate covering letter and programme plan to everyone who attended the October workshop</b></li> <li><b>9. Michael Wilson to draft covering letter to be sent out with Programme Plan</b></li> <li><b>10. Regional Leads to send covering letter and Programme Plan to CEOs and Medical Directors in all provider organisations</b></li> <li><b>11. Deirdre Kelly to test programme plan with CIAG</b></li> <li><b>12. Michael Wilson to amend the plan to ensure it is clear</b></li> </ol>	

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	<p style="text-align: center;"><b>document is in draft, including adding watermark</b></p> <p style="text-align: center;"><b>13. Michael Wilson to set up workshop to collate comments received</b></p>	
<p><b>5</b></p>	<p><b>IMPLEMENTATION UPDATES</b></p> <p>The regional leads presented their updates. There was further discussion of the 'Quality Assurance Metrics...' developed in London. Caroline Taylor described the experience from work on Barnet, Enfield and Haringey and in South London which had highlighted the importance of staffing including vacancies and use of locums, CQC visit reports and monitoring of serious incidents. She asked that this be incorporated into the proposed approach. The work being undertaken by the Clinical Reference Group to develop dashboards was also highlighted. Sue McLellen agreed to further develop the proposed metrics taking these into account.</p> <p><b>ACTIONS:</b></p> <p style="text-align: center;"><b>1. Sue McLellen to further develop the proposed metrics</b></p>	<p style="text-align: center;"><b>SM</b></p>
<p><b>6 / 7</b></p>	<p><b>PIC and PAEDIATRIC TRANSFER UPDATE</b></p> <p>Ann Jarvis gave a verbal update, describing the work that is underway nationally.</p> <ul style="list-style-type: none"> <li>• The National Specialised Commissioning Team has commissioned PICANET to review historic activity data and capacity and forecast the impact of the changes. This would inform future capacity planning.</li> <li>• A sub-group set up by the NCG was looking at PIC retrieval services and their compliance with the PIC standards.</li> <li>• The service specifications for both PIC and retrieval have been published for consultation. Once implemented these will lead to consistent high quality services being commissioned across the country.</li> <li>• A review of systems to prospectively monitor and anticipate pressure on PIC (and other services) to strengthen and harmonise those systems across the country.</li> <li>• Work as part of managing winter pressures to ensure that there was enough capacity in the system in real time.</li> </ul>	

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8	<p><b>ECMO UPDATE</b></p> <p>Jo Sheehan's report was noted. Deirdre Kelly stated that it would be helpful to receive the output from the workshops described in the report.</p> <p><b>ACTION:</b></p> <p><b>1. Jo Sheehan to be asked to provide feedback on the ECMO events</b></p>	<p><b>JS</b></p>
9	<p><b>ADULTS WITH CONGENITAL HEART DISEASE UPDATE</b></p> <p>Jo Sheehan's report was noted. Sue McLellen reported that work was being done on databases to consistent data was available from all providers. Deirdre Kelly reported that she had written to NICOR (the National Institute for Cardiovascular Outcomes Research) about this, but had received no response. Sue McLellen asked to be copied into the letter.</p> <p><b>ACTION:</b></p> <p><b>1. Deirdre Kelly to copy the letter she sent to NICOR to Sue McLellen</b></p>	<p><b>DK</b></p>
10	<p><b>UPDATE FROM CIAG (AND SUB-GROUPS)</b></p> <p>Deirdre Kelly advised the meeting that the Clinical Implementation Advisory Group had not met since the last Programme Board. The Networks Sub-group had been set up, chaired by Ann Jarvis. It had been very effective and a pathway had been agreed.</p> <p>The Standards Sub-group, to look at standards for Children's Cardiology Centres and District Children's Cardiology Services, had been set up with Dr Tony Salmon as chair. The first meeting was due to take place next Monday, 28<sup>th</sup> January.</p> <p>The Specialist Surgical Centres Sub-group would be discussed with David Barron, the proposed chair.</p> <p>The Clinical Outcomes Sub-group had not yet been established.</p>	



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	<p>The Executive Group was due to hold its first meeting later that afternoon. It included the chairs of all the above sub-groups plus representation from the PIC / Paediatric Transport Group and the Clinical Reference Group. The purpose of this group would be to make sure that the programme plan is delivered through the sub-groups. Other aspects to be addressed are the evaluation of the whole process.</p> <p>Deirdre Kelly informed the group that backfill had been offered to people attending these meetings but that funding for this had not been agreed. This would need to be resolved.</p> <p>Ann Jarvis reported that the Operational Delivery Network (ODN) specification had been completed and had been circulated to Heads of Commissioning for local implementation. CQUIN (Commissioning for Quality &amp; Innovation) funding would be available to organisations hosting the networks. Deirdre Kelly said that she thought some people may not be aware that there was funding available and that it was important that this message was sent out correctly. Ann Jarvis stated that while money had been identified, the amount available for each network would vary, and would be negotiated according to local priorities.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>Deirdre Kelly and Michael Wilson to agree the process for approving clinician claims for back-fill.</b></li> </ol>	<p><b>DK/MW</b></p>
<p><b>11</b></p>	<p><b>COMMS &amp; ENGAGEMENT</b></p> <p><b>11.1 Comms &amp; Engagement strategy and plan</b></p> <p>Hannah Wynne presented the strategy and plan. It had been developed following a workshop held in December. She explained that this was a high level plan and that a separate document would have dates and activities in more detail. The focus of this plan was implementation and did not cover communications activities related to the IRP (Independent Reconfiguration Panel) and JR (Judicial Review).</p> <p>Ann Jarvis noted that the programme was accountable to the NHSCB which would have its own approach to communications. She felt that the NHSCB should be consulted on this document and their approval</p>	

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	<p>sought. Caroline Taylor agreed to discuss this with Ann Sutton.</p> <p>The document posed a number of questions which were considered by the board:</p> <p><b>Does the draft strategy reflect the Programme Board's business objectives and those of the Clinical Advisory Group?</b> It was agreed that it did, however Deirdre Kelly stated that she felt the purpose of this document was to separate the implementation programme from Safe and Sustainable and she was not clear this document achieved this. Catherine O'Connell suggested that something about pathways should be added.</p> <p><b>Does the strategy address all the key milestones and risks associated with implementation?</b></p> <p><b>Is the strategy sufficiently patient focused?</b> Julie Higgins suggested asking parents about their journey and their understanding of the improvements. Catherine O'Connell suggested that input from parent groups should be sought. Caroline Taylor stated that we need to articulate the patient experience and the impact the changes will make for patients and their families.</p> <p><b>What comments do you have on the key messages?</b> Deirdre Kelly felt that the messages were not strong enough, that they were not 'warm'. She stated that she would like to spend some further time on the document as well as sharing it with the CIAG Executive Group.</p> <p><b>Do you have a preferred strapline or want to suggest a different one?</b> Sue McLellen proposed a hybrid strap-line: "<i>Working together to improve children's congenital heart services</i>". This was agreed.</p> <p><b>Have all the key audience groups been identified?</b> Sue McLellen suggested that the Nursing Times should be added to the Trade Media section.</p> <p><b>Does the proposed activity look reasonable and proportionate with the rest of the Programme?</b> Caroline Taylor that the focus of the plan was on communications and a greater focus on encouraging engagement was needed. Michael Wilson stated that the document was helpful in identifying</p>	<p><b>CT</b></p>



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	<p style="text-align: center;"><b>strategy with CIAG Executive Group</b></p> <p><b>3. All to send comments on the newsletter to Michael Wilson</b></p> <p><b>4. Michael Wilson, James Ford and Hannah Wynne to review the communication and engagement strategy and newsletter in light of comments</b></p>	
12	<p><b>SAFE AND SUSTAINABLE UPDATE</b></p> <p>Jeremy Glyde was not present but Michael Wilson reported that the latest update he had received suggested there was nothing materially different to report. The original IRP timetable had been extended. Sue McLellen asked if this was widely known and it was agreed to seek advice from Jeremy Glyde regarding this.</p> <p><b>ACTIONS:</b></p> <p><b>1. Michael Wilson to confirm with Jeremy Glyde whether the IRP extension has been made known publicly.</b></p>	MW
13	<p><b>TERMS OF REFERENCE (REVISED)</b></p> <p>The Terms of Reference were agreed.</p>	
14	<p><b>STATUS (FIVE BOX) REPORT</b></p> <p>The report was noted.</p>	
15	<p><b>RISK REGISTER</b></p> <p>Caroline Taylor noted that more work needed to be done on the mitigation of risks identified. Catherine O'Connell said that it was planned that the risk register would be worked through regionally. Caroline Taylor asked that all members of the group review the risk register and send comments to Michael Wilson with a view to signing off the opening risk register at the February programme board. Grayling were asked again to look at the wording of the risks and give advice.</p> <p><b>ACTION:</b></p> <p><b>1. Comments on the risk register to be sent to Michael Wilson</b></p>	All JF

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	<b>2. James Ford to review the wording in the risk register and give advice</b>	
16	<b>Any other business</b>  There was no AOB.	
17	Next meeting: Tuesday 26 February 2013 – 10:00-12:00 – Stephenson House, Room 4LM1	

cc. Ann Sutton, Director of Commissioning (Corporate), NHSCB