

**MINUTES**

**Children's Congenital Heart Services Programme Board**

**Thursday 6 December 2012 - 08.00–10.00**

**NCL, Stephenson House, 75 Hampstead Road, London NW1 2PL, Room 4LM1**

<b>Attendees:</b>	<b>Job title and organisation</b>
Caroline Taylor (Chair)	Cluster Chief Executive, NHS North Central London
Ann Jarvis	COO, South of England Specialised Commissioning Group
Anne Keatley-Clarke	Chief Executive, Children's Heart Federation
Catherine O'Connell	Regional Director of Commissioning, NHSCB, Midlands and East
Prof. Deirdre Kelly	Chair of Clinical Implementation Advisory Group
James Ford	Managing Director of Public Sector, Grayling
Jeremy Glyde	Programme Director, <i>Safe and Sustainable</i>
Jo Sheehan	Acting Director of National Specialised Commissioning Team
Michael Wilson	Interim Implementation Programme Director
Sue McLellen	COO, London Specialised Commissioning Group
<b>In attendance</b>	
Angie Cater (Minutes)	Business Support Officer LHP
Debbie Hodges	Interim Implementation Project Officer

<b>Item No</b>	<b>Agenda Item</b>	<b>Action</b>
<b>1</b>	<p><b>INTRODUCTION AND APOLOGIES</b></p> <p>Caroline Taylor opened the meeting and thanked everyone for attending. Introductions were made and apologies noted from Jon Develing, Kate Caston, and Samantha Johnson. Anne Keatley-Clarke was welcomed to her first meeting representing Samantha Johnson.</p> <p>Caroline Taylor set out the context for the Programme Board and its work.</p>	
<b>2</b>	<p><b>MINUTES OF PREVIOUS MEETING</b></p> <p>Minutes of the previous meeting on 7 November 2012 were agreed.</p>	

<p><b>3</b></p>	<p><b>ACTION LOG</b></p> <p><b>Action 2.02: Invite additional representatives to join the Board</b></p> <p>Samantha Johnson, Operations Manager for Children’s Heart Federation (represented at this meeting by Anne Keatley-Clarke) is the first user representative. Anne Keatley-Clarke will nominate a second representative.</p> <p>Michael Wilson is discussing representation from Wales with colleagues in the Welsh specialised services.</p> <p><b>Action 3.04: Circulate copies of joint statement of intent and KPIs to monitor safety</b></p> <p>Sue McLellen circulated hard copy of these documents and gave an explanation of their origins and purpose. It was agreed that these would be circulated electronically to board members.</p> <p><b>Action 6.01: Review objectives of the Communications Plan</b></p> <p>Prof Deirdre Kelly confirmed that she would review the communications and engagement plan once it had been produced.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 Anne Keatley-Clarke to nominate second user representative.</b></li> <li><b>2 Michael Wilson to confirm representative from NHS Wales.</b></li> <li><b>3 Michael Wilson to circulate copies of joint statement of intent and KPIs to monitor safety</b></li> <li><b>4 Prof Deirdre Kelly to review the communications and engagement plan</b></li> </ol>	<p><b>AKC</b></p> <p><b>MW</b></p> <p><b>MW</b></p> <p><b>DK</b></p>
<p><b>4</b></p>	<p><b>TERMS OF REFERENCE (Revised)</b></p> <p>Michael Wilson highlighted changes to the terms of reference since the previous meeting.</p> <p><b>Scope</b></p> <p>Prof Deirdre Kelly suggested adding “To improve the quality of” to the first bullet point ‘Care of children with suspected or diagnosed congenital heart disease...’</p> <p>Prof Deirdre Kelly asked that the wording of the first bullet point be</p>	

	<p>revised (i.e. ‘...through to transition into adult services at the 19<sup>th</sup> birthday’) as age 19 is not a cut off point for transition to adult services which may be delayed for children with learning difficulties.</p> <p><b>Objectives</b></p> <p>The Clinical Implementation Advisory Group (CIAG) had asked that objective 5 be revised and moved to the top of the list so that the delivery of high quality child centred care was the principal objective.</p> <p>Prof Deirdre Kelly reported the concerns of CIAG about the phrasing of objective 3 and their preference that this not be described as relocation of the ECMO service. Jo Sheehan confirmed the need to be consistent with the phrasing of the Secretary of State’s direction. It was agreed that Jo Sheehan and Michael Wilson would consider whether any change from the current wording was possible.</p> <p>Prof Deirdre Kelly also requested the same language be used throughout i.e. Congenital Heart not Cardiac Heart. Sue McLellen added we should be consistent with the consultation document which was subtitled ‘A new vision for children’s congenital heart services in England’.</p> <p>Prof Deirdre Kelly reported a concern that the use of ‘Children’s Congenital Heart’ as a descriptor was felt by some group members to imply that the work did not include pre-natal care or the care of young people through transition. It had been proposed that the descriptor be changed to ‘Congenital Heart’. Following discussion the board agreed that ‘Children’s Congenital Heart’ was the right descriptor, but that a strap line for use on all documentation should be created that made clear that the programme covers care from the prenatal period through to transfer into adult services. Sue McLellen/Michael Wilson/James Ford would develop a proposal on behalf of the group.</p> <p>Caroline Taylor set an expectation that the Terms of Reference would be signed off at the next meeting</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 Michael Wilson to revise the terms of reference in light of the discussion</b></li> <li><b>2 Sue McLellen/Michael Wilson/James Ford to develop proposals for a programme strap-line.</b></li> </ol>	<b>SM/MW/JF</b>
<b>5</b>	<p><b>FIVE BOX REPORT (Status)</b></p> <p>Michael Wilson explained the purpose of the report as a single page summary of the programme at a point in time. Most of the report’s contents would be familiar to the board. The risk section was a summary of the risk register and would show red rated risks, new</p>	

	<p>risks and risks that had changed significantly since the previous meeting.</p> <p>There was discussion about the language used to describe risks in order to give an honest presentation of risks but not lead the programme to become a hostage to headlines. It was noted that while the risk register was still draft, all finalised documents could be requested under the Freedom of Information Act. It was agreed that James Ford would make recommendations on the language used to describe risks.</p> <p>Caroline Taylor confirmed that all final documents could be shared beyond the programme board.</p> <p>Ann Jarvis stated that an urgent 'next step' missing from the report was the need to make recommendations about the application of the standards in the 2013/14 service specification. This would need to be agreed by the end of the day to meet the NHS Commissioning Board (NHSCB) deadline. It was agreed that she would work with Michael Wilson and Jeremy Glyde to agree appropriate wording.</p> <p>Ann Jarvis also highlighted the need to produce a network specification by 21 December as part of the NHSCB approach to commissioning operational delivery networks.</p> <p>Caroline Taylor reported that Ann Sutton would be convening a meeting in January to bring together key people from the NHSCB (national, regional and local) with the programme team to agree how implementation will be led and delivered in each region.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 James Ford to make recommendations on the language used to describe risks</b></li> <li><b>2 Ann Jarvis/Michael Wilson/Jeremy Glyde to agree appropriate wording to describe the application of the CCHS standards in the 2013/14 service specification</b></li> <li><b>3 Ann Jarvis/Michael Wilson/Prof Deirdre Kelly to agree network specification</b></li> <li><b>4 Ann Sutton to convene meeting in January with NHSCB and the programme team re how implementation will be delivered in each region</b></li> </ol>	<p><b>JF</b></p> <p><b>AJ/JG/MW</b></p> <p><b>AJ/MW/ DK</b></p> <p><b>AS</b></p>
<p><b>6</b></p>	<p><b>Project Initiation Document (Revised)</b></p> <p>Michael Wilson highlighted changes to the terms of reference since the previous meeting, which were mostly tightening up but also included amendments made in light of comments received from</p>	

	<p>CIAG.</p> <p><b>1.1 Purpose of this document</b></p> <p>Jeremy Glyde asked that reference was made in the introduction of the PID that the programme's approach assumed that the JCPCT's decision was upheld by the judicial review and the IRP, and that pending those decisions the programme board was continuing to prepare and plan for implementation. It was recognised that this was referred to in section 2.2 but should be clear right at the beginning. Milestones would also need to be set in light of the emerging timetable for the challenges.</p> <p><b>Section 2.6.1 Commissioning</b></p> <p>It was noted that the table was correct for commissioning / decommissioning surgical services but did not show commissioning for specialist cardiology services or local generic services that would form part of the pathway. Michael Wilson to revise.</p> <p><b>2.6.2 Critically interdependent clinical services</b></p> <p><b>ECMO</b></p> <p>The wider impact of transferring ECMO services from Glenfield to Birmingham Children's Hospital on ECMO services nationally had been highlighted at CIAG. It was agreed that further work was necessary to be clear whether this was being managed through the National Specialised Commissioning Team (NSCT) working group or through the Children's Congenital Heart Services (CCHS) programme.</p> <p><b>2.6.7 Services for adults with congenital heart disease.</b></p> <p>Services for teenagers and young people are in scope through transition until they transfer to adult services. It was agreed that the work on services for adults with congenital heart disease should also recognise the needs of this group and the effective management of transition.</p> <p><b>3.2 Milestones</b></p> <p>Michael Wilson reported that the Programme Plan would be developed through a workshop with NHSCB colleagues from regional teams to be held on 17 December.</p> <p><b>4.1. Roles and responsibilities</b></p> <p>Michael Wilson reported that NHSCB regional and local roles and provider medical director roles would be completed following the event being convened by Ann Sutton in January.</p>	<p><b>MW</b></p> <p><b>MW</b></p> <p><b>MW/JS</b></p> <p><b>JS</b></p> <p><b>MW</b></p> <p><b>MW</b></p>
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	<p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 Michael Wilson to revise the PID in the light of the discussion</b></li> <li><b>2 Michael Wilson/Jo Sheehan to ensure that the wider implications of the ECMO changes are being managed.</b></li> <li><b>3 Jo Sheehan to ensure that work on services for adults with congenital heart disease recognises the needs of young people and the effective management of transition.</b></li> <li><b>4 Michael Wilson to develop a programme plan for discussion at the January meeting</b></li> </ol>	
7	<p><b>RISK REGISTER</b></p> <p>The risk register was reviewed.</p> <p>Caroline Taylor asked that all board members review the register to ensure that:</p> <ul style="list-style-type: none"> <li>• the right risks had been captured and have been accurately expressed</li> <li>• the scores are reasonable</li> <li>• appropriate mitigation has been identified</li> </ul> <p>Deadline for any comments was 14 December.</p> <p>It was agreed that it was important to ensure both that the risks are clearly expressed but also that the way in which they are expressed is not unnecessarily alarmist. James Ford agreed to review the wording used in the register and give advice.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 All to review the risk register</b></li> <li><b>2 James Ford to advise on appropriate language.</b></li> </ol>	<p><b>All</b></p> <p><b>JF</b></p>
8	<p><b>COMMUNICATIONS&amp; ENGAGEMENT</b></p> <p><b>8.1 Communications and engagement strategy update</b></p> <p>James Ford reported that a workshop had been organised for 21 December to co-produce the stakeholder analysis and appropriate channels of communication for each. It would also discuss appropriate messaging for this phase of implementation. All board members were invited.</p>	

Prof Deirdre Kelly commented it is not clear that our key messages have been agreed and that it was urgent to do so. We needed to be clear what we wanted to say, to who and when? The messages needed to be tailored to the different stakeholders.

Caroline Taylor agreed that consistent messages would be helpful for those areas where there is clarity, as well what cannot be said because there is not yet clarity.

Caroline Taylor stated that a communications plan would also be needed and that this would be a more dynamic document that would change and develop over time. The communications plan would need to knit together with the programme plan. It would also need to show national, regional and area communications and engagement activities.

Ann Jarvis suggested that it could be helpful to involve the NHSCB medical directorate communications team in the process.

It was agreed that by the time of the next board meeting there needed to be a revised comprehensive communications and engagement strategy as well as a high level communications plan.

JF

## **8.2 Communications protocol**

James Ford introduced the communications protocol which set out proposals for sign off of various different communications activities as well as listing proposed spokespeople, both clinical and non-clinical.

Prof Deirdre Kelly stated that she should be included in the sign-off arrangements described in 2.1 and 2.2

Caroline Taylor suggested the need to make a distinction between CCHS and Safe & Sustainable. It was agreed that two separate communications protocols were needed. It was also agreed that there was a need to establish a separate identity for the implementation work, no longer using the Safe and Sustainable logo, and with a separate distinctive (but linked) web presence. Following discussion it was agreed that there could appropriately be a transitional period so that stakeholders were not confused. This would mean, for example, that the next edition of the newsletter would be co-branded, but subsequently this would not be the case.

“Paediatric Cardiac Surgery Services” was not thought to be a helpful description of the programme and we should move away from this branding so people knew what was being talked about.

Prof Deirdre Kelly asked whether the implementation work should continue to use the Safe & Sustainable website. Caroline Taylor recommended establishing a separate CCHS website, but with links in both directions. It was agreed that plans should be made for this to

<p>become effective from April 1<sup>st</sup> 2013.</p> <p>Caroline Taylor requested that these changes and the plan for transitioning of branding be included in the revised communications and engagement strategy and plan and protocol.</p> <p><b>8.3 Newsletter</b></p> <p>Jeremy Glyde introduced the newsletter flat-plan. The aim was to give a wide-ranging update to all stakeholders of what had happened since the JCPCT decision, regarding both the challenges to the decision and preparation and planning for implementation.</p> <p>It was agreed that, in line with the communications protocol, programme board members would have an opportunity to review and comment on the newsletter before circulation.</p> <p>It was agreed that a full draft would be sent to Caroline Taylor and Jeremy Glyde for sign-off before Christmas, with a target to circulate online and by email in the first week of January.</p> <p>Prof Deirdre Kelly asked for clarity about the target audiences and what messages it needed to communicate to them. Anne Keatley-Clarke responded that it would be good for parents as a transition newsletter. Sue McLellen agreed and said it would also be useful for providers and Health Overview and Scrutiny Committees (HOSCs).</p> <p>All those who attended the national stakeholder workshop and the charities workshop should be included on the circulation list. Sue McLellen highlighted the need for the newsletter to refer to these events and also to respond to the issues that were being raised.</p> <p><b>8.4 Summary of three workshops</b></p> <p>James Ford introduced the paper describing common themes from the three workshops. Caroline Taylor stated that some minor rewording was needed. She would send amendments prior to sign-off and sending out.</p> <p><b>ACTIONS:</b></p> <ol style="list-style-type: none"> <li><b>1 James Ford to produce a comprehensive dedicated implementation communications and engagement strategy, including a revised dedicated implementation communications protocol and high level communications plan for the next programme board.</b></li> <li><b>2 Caroline Taylor to provide comments on the summary of three workshops.</b></li> <li><b>3 Michael Wilson to circulate the summary of three</b></li> </ol>	<p><b>JF</b></p> <p><b>JF</b></p> <p><b>CT</b></p>
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	<p><b>workshops along with the national stakeholder workshop report.</b></p>	
9	<p><b>Safe and Sustainable update</b></p> <p><b>Judicial Review</b> Jeremy Glyde informed the group that the court date is 11/12<sup>th</sup> Feb with judgement expected in mid March or possibly on the day. Witness statements were being prepared and a statement on costs.</p> <p><b>IRP</b> The IRP had commenced its hearings. It was understood that the IRP had requested an additional month so that it would not report to the Secretary of State until the end of March 2013.</p> <p>It was noted that purdah (relating to local government elections in May) was due to start on 21/3/13 and that this could affect the timing of any announcement from the Secretary of State, which might therefore be delayed until after the elections.</p>	
10	<p><b>Clinical Implementation Advisory Group (CIAG) update</b></p> <p>Prof Deirdre Kelly reported that the second meeting had been held and there had been positive discussion</p> <p>Concerns raised by the group had been dealt with earlier in the meeting during the discussion on terms of reference.</p> <p>CIAG had set up one sub-group working on networks. It was in the process of setting up a second sub-group to develop standards for Children's Cardiology Centres and District Children's Cardiology Services.</p> <p>Links had been made with the Paediatric Transport Group and the specialised services Clinical Reference Group.</p> <p>Further work was being done to establish whether an outcomes group was needed. Jeremy Glyde had contacted the National Institute for Cardiovascular Outcomes Research (NICOR) to explore common ground.</p>	
11	<p><b>Updates from Regional Leads</b></p> <p>Catherine O'Connell – reported that key people were not yet in post and therefore progress was limited in Midlands and East.</p> <p>Sue McLellen – London had established a group for specialised commissioning and NHSCB London to work with the three main providers. A joint statement had been developed. Work had also been</p>	

	<p>done on a set of Key Performance Indicators (KPIs) that could be tracked to support assurance during transition. Michael Wilson would circulate these to board members.</p> <p>Caroline Taylor noted that Julie Higgins would be joining the group to represent the north, and asked Michael Wilson to ensure that she was briefed.</p> <p>The importance of clarity about national, regional, area and network roles was raised. Caroline Taylor reported that there would be a meeting with Ann Sutton in January to ensure that there was a clear and shared understanding in each region.</p> <p>James Ford emphasised the importance of clinicians in hospitals inside each network talking together. The board agreed that this was important but noted the difficulty of achieving this in some parts of the country pending resolution of the JR and IRP processes.</p> <p><b>ACTIONS:</b></p> <p><b>1 Michael Wilson to circulate London proposed transition KPIs</b></p> <p><b>2 Michael Wilson to brief Julie Higgins</b></p>	<p><b>MW</b></p> <p><b>MW</b></p>
<p><b>10</b></p>	<p><b>ANY OTHER BUSINESS</b></p> <p>There was no other business.</p>	
<p><b>11</b></p>	<p><b>DATE AND TIME OF NEXT MEETING:</b> 23<sup>rd</sup> January 2013 – 1000-1200 Stephenson House, Room 4LM1.</p>	