

**Minutes of the Programme Board held on 13 November 2013**

**Present:**

- Bill McCarthy, National Director: Policy (Present from section four onwards)
- John Holden, Director of System Policy (Chair)
- Professor Sir Bruce Keogh, National Medical Director
- Mr James Palmer, Clinical Director, Specialised Services
- Giles Wilmore, Director for Patient & Public Voice
- Michael Wilson, Programme Director
- Pia Clinton-Tarestad, Head of Commissioning Policy and Resources (Deputy for Ann Sutton)

**Apologies:**

- Professor Deirdre Kelly, Chair of review’s Clinician Group
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel
- Chris Hopson, Chair of the review’s Provider Group
- Ann Sutton, Director of NHS Commissioning (Corporate).
- Professor Peter Weissberg, Chair of the review’s Patient and Public Group

**In attendance:**

- Jane Docherty, Project Manager (Secretariat)
- Jo Glenwright, Senior Manager (Analytical Function)
- Mark Cohen , Deputy Head of Office , Medical Directorate

Item	Agenda Item
1	<b>Welcome and Apologies</b>
	The Chair welcomed everyone to the meeting. Apologies were noted from Professor Sir Michael Rawlins, Professor Deirdre Kelly, Chris Hopson, Professor Peter Weissberg and Ann Sutton.
2	<b>Minutes of the previous meeting</b>
	Minutes agreed. It was noted that the managing conflicts of interest policy was submitted to the 29 October 2013 Task and finish group (T&FG) for approval and an amendment was agreed. The revised draft policy will be submitted to the T&FG on 26 November 2013 for approval. <i>[FILE NOTE: 26 NOVEMBER T&amp;FG WAS CANCELLED]</i>
<b>Action</b>	Amends to the conflicts of interest policy to be made for presentation at the next task and finish group.

## New Congenital Heart Disease Review

Item	Agenda Item
3	<b>Action Log</b>
	<p>A discussion took place regarding the appointment of patient and public representatives to the congenital heart clinical reference group (CRG). Examination of the audit trail showed that the correct recruitment process was followed. On this evidence there was no reason to unwind the appointments which had been made in good faith. However, for this CRG and others with similar potential reconfiguration implications, there would be heightened patient and public interest. It was therefore agreed that it would be helpful to increase the number of patient and public posts in these CRGs (ie in addition to the posts already recruited). The process to recruit four additional members would be subject to the usual requirements of transparency and contestability.</p>
<b>Action</b>	Four additional patient and public posts will be made available on the congenital heart CRG and on other CRGs with similar, potential reconfiguration implications.
<b>Action</b>	Action point 7: JH has asked for a future programme board meeting to receive advice on how the need for legal advice on process, engagement and scope would be taken forward.
4	<b>Objectives of the review</b>
	<p>The Programme Board noted the objectives for the new Congenital Heart Disease review, which they had discussed previously, and which were approved by the 29 October 2013 T&amp;FG. The approved version of the objectives was presented to the patient and public group on 12 November 2013 for information.</p>
5	<b>Standards – update and timeline</b>
	<p>Discussion took place about the process to develop an aligned set of standards for congenital heart disease. It was noted that there are currently three sets of standards to be aligned:</p> <ul style="list-style-type: none"> <li>• <b>Safe and sustainable</b></li> <li>• <b>Adult</b></li> <li>• <b>Paediatric standards from the new review</b></li> </ul> <p>It is expected that draft aligned standards will be discussed by the Standards Sub Group of the Clinical Implementation Advisory Group (CIAG) on 9 December 2013 and by CIAG on 11 December 2013. The intention is that the draft standards will then be submitted to the congenital heart CRG for ratification. It is envisaged that these standards will then form the core of the revised service specification for congenital heart disease which will be subject to public consultation, ideally from February 2014. This specification will form part of a consultation exercise with several other service specifications – the intention is to have a rolling programme with a new consultation launched every few months - but if the congenital heart specification is not ready it will not be held up for several months simply to wait for the next cycle.</p>
<b>Action</b>	JP to discuss timing and approach with CRG clinicians.

## New Congenital Heart Disease Review

Item	Agenda Item
6	<b>Analysis of demand for specialist inpatient congenital heart disease – proposed approach</b>
	<p>JG explained that Objective 2 of the review requires analysis of the demand for congenital heart disease; the plan is to look ahead to 2025, working from a baseline of either 2011/12 or 2012/13. JG is working with Rodney Franklin from NICOR, who is an expert in this area of care and the clinical coding and data, to understand and come up with a defined list of procedures that determine the scope of the activity analysis. This detailed definition is required in order to be able to utilise all data from SCTS, NICOR and hospital episode statistics (HES).</p> <p>The Programme Board discussed the importance of ensuring that analytical work is (and is seen to be) consistent with the scope of the review as agreed by the Task and Finish Group on 29 October 2013. This will need to be at a fairly granular level ie HRGs, OPCS and ICD codes etc.</p> <p>The data will be used to forecast activity and therefore capacity requirements taking into account population growth change in the birth rate, technical advances and changes to clinical practice to come up with a model to describe the future.</p> <p>It had been proposed that patent foramen ovale (PFO) should be excluded from the data analysis since this procedure was undertaken in numerous settings and not always by congenital surgeons – arguably it was not part of the congenital workload. The Programme Board however asked that it should be included in the data analysis to inform the discussion about service capacity requirements and to help understand any risk of occasional practice.</p> <p>Various challenges in data collection were discussed, eg the variable quality of coding, and the fact that some procedures take place in neonatal ICU, and data are not captured.</p>
<b>Action</b>	JG to include PFO in data collection; to demonstrate alignment of data collection with scope of review; and provide a regular update on analytical work as necessary.
7	<b>DRAFT Risk Register</b>
	<p>JH reminded the Programme Board they had previously noted NHS England’s risk management process, and he presented the draft new congenital heart disease review risk register. In discussion it was agreed that</p> <ul style="list-style-type: none"> <li>• Any concerns about patient safety/clinical practice would be referred to chief inspector of hospitals (CQC).</li> <li>• Capacity of the review team to complete the programme is a risk. Identified need for full time resource on engagement as well as more junior resource to support the work.</li> </ul>
<b>Action</b>	Resource for the programme to be identified quickly
8	<b>Highlight report</b>
	The Programme Board noted the highlight report and discussed risk scores post-mitigation
<b>Action</b>	Risks rated red should be re-scored after mitigating actions.

## New Congenital Heart Disease Review

Item	Agenda Item
9	<b>Any other business</b>
	<p>JH provided an update on the patient and public event on 12 November 2013 and reported strong interest from attendees in the last two objectives (availability of performance data and antenatal testing). JH explained that he has asked the National Clinical Director for Children &amp; Young people, Jackie Cornish, to help initiate the project to improve ante natal testing. There are a number of inter-related issues which mean that detection rates are currently low and there is not always consistent follow up when anomalies are identified.</p> <p>In addition JH reported that there is work underway to increase the use of pulse oximetry for newborns which can help detect heart problems which would otherwise have been missed. There is national screening consultation at present to introduce pulse oximetry at birth. JH was advised by the Board to discuss with Jackie Cornish and/or Catherine Calderwood (NCD for women and maternity).</p>
<b>Action</b>	JH to discuss pulse oximetry with Jackie Cornish and Catherine Calderwood
Date of next meeting	16 December 2013 – 4-8 Maple Street, London W1T 5HD