Item 2

New Congenital Heart Disease Review

Minutes of the Programme Board held on 23 September 2014

Present:

- John Holden, Director of System Policy (Vice Chair);
- Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw);
- Will Huxter, Regional Team representative, Head of Specialised Commissioning (London) *(10am – 11am only)*;
- Professor Deirdre Kelly, Chair of the review's Clinician Group;
- Daniel Phillips, Director of Planning, Welsh Health Specialist Services Committee;
- Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South) *(10am – 11am only)*;
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel;
- Giles Wilmore, Director for Patient & Public Voice;
- Michael Wilson, Programme Director; and
- Dr Cathy Winfield, NHS Wokingham Clinical Commissioning Group.

Apologies:

- Ian Dodge, National Director: Commissioning Strategy (Chair);
- Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning);
- Sam Higginson, Director of Strategic Finance;
- Chris Hopson, Chair of the review's Provider Group;
- Professor Sir Bruce Keogh, National Medical Director;
- Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce;
- Mr James Palmer, Clinical Director, Specialised Services; and
- Professor Peter Weissberg, Chair of the review's Patient and Public Group.

In attendance:

- Jem Rashbass, National Director of Disease Registration, Public Health England *(from 11am onwards)*;
- Siobhán Clibbens, Programme Coordinator (Secretariat);
- Jane Docherty, Project Manager;
- Alison Hughes, Programme Lead for Commissioning and Change; and
- Lauren Phillips, Programme Development Manager.

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1	**Welcome and apologies**
	John Holden welcomed everyone to the meeting. Apologies were noted from: Ian Dodge, Wayne Bartlett-Syree, Sam Higginson, Chris Hopson, Professor Sir Bruce Keogh, Michael Macdonnell, James Palmer and Professor Peter Weissberg.

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	John Holden informed the Programme Board that as this was a shorter meeting than usual and the second meeting in September 2014, standing items (such as agreement of meeting notes and an actions update) would be carried over to the meeting on 23 October 2014.
2	**Declarations of Interest**
	There were no specific declarations of interest in relation to today's agenda.
3	**Consultation update (verbal)**
	Michael Wilson provided a verbal update on the consultation into the proposed congenital heart disease standards and service specifications. The 12 week public consultation was launched as anticipated on Monday 15 September 2014. The launch was largely uneventful. Mr Wilson thanked the review team for the enormous amount of work involved in order to accomplish this. He also offered his thanks to the internal web team for their support in assembling the online consultation hub. The Guardian newspaper covered the launch with an article which was largely positive and set the tone for coverage in other outlets. There has also been some regional media interest. Other coverage included Moscow (unexpected)! After this initial flurry, media interest is currently quiet. As of 22 September 2014, the consultation had received 16 responses via the Consultation Hub (CitizenSpace). The review team expects most responses to come in in the last week or two. Mr Wilson along with other members of the review team had a meeting last week with Dialogue by Design (DbD) to discuss the level of analysis and reports we can expect from them during the consultation period. Copies of the standards and specification and consultation document were available for Programme Board members to examine. Mr Wilson also noted that a narrated slidepack accompanying the consultation documentation was available on NHS England's YouTube channel. In addition to the work around the consultation documents, the consultation hub publicised the dates for the 'roadshow events'. Web software allows interested parties to book attendance at an event. Mr Wilson noted that direct access to the software ensured that interest in the events could be noted and reacted to: so far there was quite an asymmetric pattern of registration (50 people registered in Yorkshire, single digit numbers elsewhere) – this would enable extra publicity to be arranged for the areas of the country with less uptake if required. Daniel Phillips noted that colleagues had been liaising offstage about the consultation in Wales, and were picking up the translation work concerning the consultation materials with the review team. John Holden congratulated the review team on a remarkable effort – the team had successfully "rolled the pitch" and stakeholders were expecting the

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	launch and were familiar with the material. The Programme Board noted the update from Michael Wilson.
4	**Commissioning and change**
	John Holden introduced this item, noting that the focus of the review team would be shifting from the task of developing the standards to how we commission excellent services. The Programme Board noted that John Holden, Alison Hughes and Chris Hopson (not present) had spoken in advance of this meeting about the paper, in particular about the role of providers in the development of the commissioning process. Mr Hopson had raised a concern that provider involvement in that next phase was not clearly identified in the discussion paper. Mrs Hughes emphasised that involvement and engagement has been core to the programme to date and that this approach would continue through the next phase. The Programme Board had been reshaped to include representation from clinical commissioning groups and NHS England area teams. She acknowledged that there are understandable concerns about getting the process right. Mrs Hughes stated that there is a need to have a national process with national oversight that is consistent with the approach that is taken with all new standards and specifications. There are different challenges in meeting the standards in different parts of the country and some issues sit across a number of area teams, hence the important of national support. The Programme Board noted that lessons should be learnt from previous commissioning work such as children's epilepsy surgery. Mrs Hughes explained that a concern raised by Area Teams was that CHD represents a very small percentage of spend in specialised commissioning and what resource would be available to support implementation in view of the other very significant challenges that the teams are facing. This issue will need to be considered as part of the development of the handover plan. Another key issue is how oversight and the quality of the service is managed. There are a number of existing arrangements to assess and improve provider quality, for example: the Care Quality Commission inspection, contract management, or, in some specific services, peer review. The definition of this ongoing oversight to ensure quality will be an important part of the commissioning process. The Programme Board noted the importance of the appropriate handover of this work to the commissioning teams. Members noted that handover can be high risk as it can be the point in the process where organisational memory is lost and things fall through gaps. NHS England's Organisational Alignment and Capability Programme (OACP) would also have an impact this handover as there are significant changes to how area teams will work. The proposed arrangements will be subject to consultation from 1 October 2014. Mrs Hughes explained that Level 3 standards cannot be commissioned by NHS England nationally but that the review team will work with CCGs on those. Dr Cathy Winfield is part of a group who will look at what CCGs

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	already have in place, e.g. palliative care arrangements.
	Mrs Hughes explained the intention to bring a draft business case to the Programme Board for consideration, and then onto the Board Task and Finish Group for sign off in Quarter 1 of 2015/16. The Programme Board agreed that the business case would need to be explicit, describing the benefits that the service will deliver; how will we know we have made a difference in, for example, two years' time; the commissioning process; commissioning intentions and the timeline of how to make that happen.
	Mrs Hughes drew the members attention to page 3 of the paper "Indicative milestones and timeline".
	John Holden noted that it would be important to achieve the right balance between a collaborative engaged approach and ensuring that the commissioning process is robust enough to ensure that the standards are met.
	The Programme Board discussed potential commissioning models and the associated benefits and difficulties of each. Members agreed that it was important for the process to enable providers to be innovative.
	Ms Prosser stated that as a commissioner, she welcomed the paper. It recognised that commissioning process would need to be nationally led but informed by local knowledge and expertise. Ms Prosser suggested that the review should be supporting commissioning with toolkits and noted that the OACP will mean teams working on a more regional basis.
	Eleri de Gilbert also welcomed the paper and stressed that the timing of the handover to commissioners would be crucial in light of NHS England's OACP.
	Michael Wilson highlighted the need to consider what programme resource/ structure would need to look like for 15/16. Some of the resource would be for handover and some, to do with the commissioning itself. Mr Wilson suggested that NHS England would need to make some dedicated provision for the programme structure into 15/16.
	Mr Wilson also reminded the Programme Board that the review should not underestimate how the process of commissioning can influence the outcome. Therefore, for example, if the intention is for providers to work together to ensure that they collectively meet the standards, the commissioning process could encourage providers to make collaborative bids. Providers themselves will be part of the discussion and design process.
	Giles Wilmore advised that the review should provide an agnostic process as local services are commissioned very differently and would require local consultation. He explained the importance of giving strong enough signals to set expectation levels.
	Will Huxter advised that the review would need to make sure it aligned a consistent national process with local engagement with providers, this includes making it clear who is making the decisions in the commissioning

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	process. Linda Prosser asked if the service is affordable as this will affect whether providers are ready to invest in changes and to bid for services. Mr Holden agreed that this was a legitimate question and that testing would need to continue around the financial analysis and local reconfiguration requirements. Dr Cathy Winfield added that the review would need to understand population in terms of specialised commissioning budgets versus clinical commissioning group (CCG) budgets in some level of granularity. Daniel Phillips explained that the experience in Wales says that if you are commissioning across the network you will get better join-up. Mrs Hughes advised that there were potentially three or four options of how the service might be commissioned and that work would be carried out to understand the implications of each, what the delivery of each would look like and, if any would lead to significant reconfiguration. Engagement of key stakeholders in testing out these approaches, and potentially suggesting new ones, will be a critical part of the work. The Programme Board supported the approach outlined. Giles Wilmore reiterated the importance of transparency and positioning, specifically that all affected providers and all commissioners are invited to participate.
ACTION	Different commissioning options will be worked up and tested with providers, clinicians and other stakeholders.
5	**Update on neonatal and antenatal detection of CHD**
	Jane Docherty presented the item “update on neonatal and antenatal detection of CHD” which detailed progress made on objective 6 of the review since the Programme Board had last been updated at its meeting on 13 May 2014. Mrs Docherty explained that the current rate of detection according to the National Institute for Cardiovascular Outcomes Research (NICOR) shows that in England 35% of anomalies that could be detected before birth were detected, but that the current target required by the Fetal Anomaly Screening Programme (FASP) was 50%. Mrs Docherty explained that the three issues which have come up repeatedly in discussions, and are the target of the project group presently, are: • development of a single national anomaly register (which would be covered in more detail in Item 6); • commissioning to improve detection; and • sonographer workforce and training.

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	Single National Anomaly Register Mrs Docherty explained that in England at present, only some areas are covered by congenital anomaly registries and that each register works as a separate entity, collecting and submitting data to the European register of congenital anomalies (EUROCAT). Mrs Docherty explained that Public Health England (PHE) are progressing work to create a single register for congenital anomalies and rare diseases which involves establishing a single database and setting up congenital anomaly registers in the five areas not covered currently. Further detail is discussed in Item 6. **Commissioning to improve detection** The Programme Board noted that the Fetal Anomaly Screening Programme (FASP), part of the National Screening Committee (NSC), creates the standards and the service specification for all antenatal screening and that the service is commissioned by the NHS England Area Public Health commissioners. Mrs Docherty explained that professional surveillance is with Public Health England (PHE). PHE staff embedded in NHS England carry out assurance visits and that the Project Group would be engaging with the quality assurance leads going forward. **Sonographers** Mrs Docherty explained that sonographers are trained initially as radiographers and that for a radiographer to become a sonographer, they will then need to complete further training on the job with formal education. It has been reported that there is little incentive to train as a sonographer after graduating as a radiographer due to restrictions of the agenda for change (AFC) pay scheme. Mrs Docherty explained the some other issues relating to the sonography workforce are: • the sonography workforce in some areas are moving close to retirement age; • a high incidence of repetitive strain injury further reducing availability of sonographers; • fear of litigation in the event of missing the views; and • increased scrutiny on the discipline, more so than for other disciplines within radiography. Mrs Docherty noted that sonographers have so far not been well represented in the project group and that more factors may be discovered when they are engaged. The Programme Board noted that there is a possibility that the changes NHS Fetal Anomaly Screening Programme (FASP) want to make would require strengthening of the proposed standards and it is anticipated that the review may get responses to that effect as part of the consultation.

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	Professor Deirdre Kelly noted that whilst carrying out the Trust Visits earlier in the year, there had been anecdotal reports of a correlation between the experience of obstetric sonographers and detection rates. Mrs Docherty explained that FASP are currently using the training package developed in South Wales in the new training; Tiny Tickers (a national charity whose focus is to improve the early detection and care of babies with serious heart conditions) are closely involved in supporting that. Alison Hughes explained that in the past there had been a similar issue relating to midwifery which had led to a direct entry programme. John Holden advised the some of these issues require discussion with Health Education England (HEE) and others with the NHS England Nursing Directorate. **Recommendations** Mr Holden commented that the root cause analysis was very helpful, but advised that by the end of March 2015, the Programme Board would need to be confident that the proposals / recommendations were credible. Michael Wilson commented that there was a need to understand what the distinct NHS England contribution is in relation to this work, i.e. what can NHS England add to the work that is already going on. Mr Wilson added that at present, the answer to that question was unknown and that it may be that all the work required sits with other organisations, in which case the review may just need to provide assurance that the necessary steps are already in place. The Programme Board noted that it would receive a report in December 2014, from the project groups, detailing recommendations to improve detection rates of congenital heart disease.
ACTION	Issues relating to sonographers to be discussed with Health Education England and the NHS England Nursing Directorate.
ACTION	Recommendations to improve early detection rates of congenital heart disease to be received by the Programme Board in December 2014.
6	**Update from Public Health England on the National Anomaly Register**
	John Holden welcomed Jem Rashbass, National Director for Disease Registration at Public Health England to the meeting. Mr Rashbass explained that he worked for Professor John Newton, Chief Knowledge Officer at Public Health England. Mr Rashbass explained that work was progressing to create a single register for congenital anomalies and rare diseases which involves establishing a single database and setting up congenital anomaly registers in the five areas not covered currently. Mr Rashbass added that once all congenital anomalies

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	from birth were being tracked, the register would be extended to also include those which are discovered later in life. Mr Rashbass explained that much of the thinking for the design of the National Rare Disease Registration Service is based on PHE's experience of creating and managing the National Cancer Registration Service (NCRS) The NCRS is measuring cancer activity across the whole of the NHS in near real-time and has built a range of systems and processes that pull data across different systems and normalise the data at the centre. Mr Rashbass explained that funding was now in place to expand registration activity to cover the whole country and that PHE's aim is to ensure the infrastructure is in place for national coverage by the end of 2015. He explained the PHE are working with partners such as the Department of Health; UK genetics labs; molecular genetics labs; and cytogenetics labs, to identify where to pull the data from. Mr Rashbass explained that in some cases, termination reasons can be recorded as 'medical reasons' rather than 'congenital abnormality' if, e.g. patient is diagnosed at one centre and termination occurs elsewhere. Daniel Phillips asked if it would be possible to look at the data by births rather than terminations, e.g. is rate of live births different in areas with higher detection rates. Mr Rashbass explained that the most important thing to get right first was the data itself. Once this was in place, the focus could then move to the questions that the register was trying to answer. Michael Wilson asked about how a foetus could be followed through the system without an NHS number. Mr Rashbass explained that the as many reporting centres don't use NHS numbers; the bigger issue was in fact that a foetus does not have a name. Mr Rashbass referred to Section 251[i] of the NHS Act 2006 and explained the ethics issues around holding parental data and prescription (maternal/paternal data) data with the foetus / child. The Programme Board thanked Jem Rashbass for attending the meeting and updating them on the work of Public Health England in relation to the national anomalies register.
7	**Any other business**
	No other business raised.
8	**Next meeting**
Date of next meeting	Thursday 23 October 2014, 10am – 12pm, 6B2, Skipton House, London

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[i] Section 251 of the NHS Act 2006 enables the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information for medical purposes, where it is not possible to use anonymised information and where seeking consent is not practical, having regard to the cost and technology available.