Minutes of the Programme Board held on 8 September 2014

Present:
- John Holden, Director of System Policy (Vice Chair);
- Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning);
- Chris Hopson, Chair of the review’s Provider Group;
- Will Huxter, Regional Team representative, Head of Specialised Commissioning (London);
- Mr James Palmer, National Clinical Director, Specialised Services *(via teleconference)*;
- Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South);
- Professor Sir Michael Rawlins, Chair of Clinical Advisory Panel;
- Professor Peter Weissberg, Chair of the review’s Patient and Public Group;
- Giles Wilmore, Director for Patient & Public Voice & Information; and
- Michael Wilson, Programme Director.

Apologies:
- Ian Dodge, National Director: Commissioning Strategy (Chair);
- Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw);
- Sam Higginson, Director of Strategic Finance;
- Professor Deirdre Kelly, Chair of review’s Clinicians’ Group;
- Professor Sir Bruce Keogh, National Medical Director;
- Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce;
- Daniel Phillips, Director of Planning, Welsh Health Specialised Services Committee; and
- Dr Cathy Winfield, NHS Wokingham, Clinical Commissioning Group.

In attendance:
- Caroline Gillespie, Project Manager; and
- Lauren Phillips, Programme Development Manager (Secretariat).

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<td>Welcome and Apologies</td>
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<td>The Chair welcomed everyone to the meeting and noted apologies from Ian Dodge, Eleri de Gilbert, Professor Deirdre Kelly, Professor Sir Bruce Keogh, Michael Macdonnell, Daniel Phillips, and Dr Cathy Winfield.</td>
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<td>2</td>
<td>Note of the last meeting</td>
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<td>The minutes of the last meeting of the Programme Board were agreed.</td>
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<td>Declarations of Interest</td>
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<td>No specific interests in relation to today’s agenda were declared.</td>
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## New Congenital Heart Disease Review

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### Action 51: (workforce issues for discussion with Health Education England)

Linda Prosser raised the issue of current capacity constraints within paediatric pathology. Ms Prosser suggested that this was picked up with Health Education England (HEE) under the heading of future workforce, but suggested that there were other professions also affected, but not listed in the action. Professor Rawlins suggested that this issue could be discussed at a future meeting of the review’s Clinical Advisory Panel (CAP).

Professor Sir Michael Rawlins explained that he had a meeting scheduled with the President of the Pathology College this week and could raise the issue at that meeting.

Professor Peter Weissberg commented that at present, pathologists are in very short supply (not just paediatric).

Ms Prosser also suggested that following the Bristol review, there may well be some work to do on the end of life part of the pathway.

Linda Prosser and Michael Wilson to discuss further outside of the meeting.

### Action 71: (sharing of dashboard data)

Michael Wilson explained that this area would form part of the work on objective 5 of the review: **provision of information about services to inform commissioners and to support patient choice**.

Mr Wilson explained that in the interim, assurance was provided by the Transition Dashboard which tests the current health of the system by collecting specific information on defined operational delivery aspects of the Children’s Congenital Heart Services in England. Mr Wilson explained that since May 2014, a monthly SitRep call has taken place and will continue to take place between the relevant Area Team commissioners for each unit and chaired by the Accountable Commissioner.

### Action 82: (links to Strategy work)

Chris Hopson asked if there was a sense that the change of direction in relation to specialised commissioning would impact the work of the new CHD review. Wayne Bartlett-Syree explained that any impact would be limited.

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<th>ACTION</th>
<th>Linda Prosser and Michael Wilson to discuss issues relating to pathology.</th>
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<td>Update from the Board Task and Finish Group</td>
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John Holden provided a verbal update from the last meeting of the Board Task and Finish Group held on 1 September 2014.

Mr Holden explained that the focus of the meeting had been on the work required by the team to get to consultation, the timeline, the launch criteria, and engagement. At this meeting, the Board Task and Finish Group delegated authority to the Programme Board to give the necessary approval to launch the consultation.

Mr Holden explained that since the meeting of the Board Task and Finish Group, Margaret Casely-Hayford had provided support and advice to the review team in
### New Congenital Heart Disease Review

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<td>relation to the consultation questions, the respondent criteria and engagement with Black, Asian and Minority Ethnic (BAME) communities.</td>
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<td>Consultation Launch</td>
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John Holden introduced the item on “Consultation Launch”. The paper asked the Programme Board to review the criteria and evidence provided (both in the paper and via verbal update during the meeting) in order to approve the launch of public consultation.

The Programme Board noted the criteria which had been "completed/met" at the time of writing the paper. In respect of the other criteria, and in addition to the content of the paper, the Programme Board noted the following:

**Commissioning Governance (COMPLETED)**

At its meeting on the 2 September 2014, the Clinical Priorities Advisory Group (CPAG) approved the draft service specifications for consultation and recommended this to the Directly Commissioned Services Committee (DCSC).

The DCSC had given approval for consultation of the draft service specifications, by Chair’s action on 4 September 2014.

**Assurance (COMPLETED)**

The main consultation document has successfully been through the NHS England Gateway process and had been cleared for publication. The Easy Read version of the consultation document was Gateway “exempt” and instead had been tested with stakeholders working with children, young people and those with learning disabilities and proof read by the review team.

Mr Wilson explained that a query from the NHS England Service Reconfiguration Oversight Group (SROG) had been raised on 4 September 2014 regarding the consultation and whether it should also be involved in the governance to give approval for consultation. Mr Wilson explained that following subsequent telephone and email conversation, SROG were satisfied that as the consultation was on standards of care rather than service reconfiguration they did not need to give approval for the consultation.

Mr Wilson went on to explain that during this conversation, the review was asked by Sarah Pinto-Duschinsky on behalf of the NHS England Service Reconfiguration Oversight Group to consider whether the four tests introduced by the government in 2010 (and sometimes referred to as the “Lansley Tests”) and intended to apply in all cases of major NHS service change were applicable to the new CHD review work. The four tests are: clar **ity about the clinical evidence base underpinning the proposals; support of the GP commissioners involved; must genuinely promote choice for their patients; and the process must have genuinely engaged the public, patients and local authorities.**

Whilst the Programme Board had not previously formally considered this question, because the review team’s opinion was that the tests were not triggered, it had obtained legal advice from Capsticks Solicitors LLP (commissioned by NHS England Head of Legal, Katherine Ibbotson) to clarify the position. The conclusion was that the
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 | four tests do not apply because there are no proposals to reconfigure a service.

**Briefings and Communications Planning (IN PROGRESS)**

Initial pre-launch communications were prepared and ready for distribution on Tuesday 9 September 2014, following approval to launch by the Programme Board.

All remaining briefing packs were currently in the process of sign-off and would be distributed as per plan from Thursday 11 September 2014.

A specific briefing pack for partners intending/wanting to hold their own consultation events had been created.

The communications launch plan was tabled during the meeting but would not be published on the NHS England webpages until after launch due to the sensitivity of media planning.

John Holden expressed his gratitude towards the NHS England Communications Team for their support and work, particularly over the last few months. Giles Wilmore agreed to pass this on to the relevant managers within the Patients and Information Directorate.

**Stakeholder Involvement (IN PROGRESS)**

Clear arrangements with the devolved administrations in relation to their role in consultation had been agreed and were in place as follows:

- Scotland – government department satisfied with plans. NHS England to provide materials which will be disseminated by NHS Scotland.
- Wales – government department satisfied with plans. NHS England to provide materials which will be disseminated by NHS in Wales. NHS England and NHS in Wales will promote the event in Cardiff.
- Northern Ireland – arrangement made to distribute to 10 contacts to avoid confusion with their own consultation on the centre in Belfast.
- Republic of Ireland – arrangement made to 4 clinicians and heads of service in Dublin. Waiting for final confirmation that this is satisfactory from their DH contact.

The following support materials had been developed to enable partners to run events during consultation:

- ‘How to’ support guide prepared;
- Q and As prepared; and
- Audio-visual version (YouTube).

Consultation Document had been written in a style that is accessible as possible – bearing in mind the issues are complex/technical.

Easy Read version of the consultation document aimed at people with learning disabilities, children, people who have difficulties reading, and those with English as a second language. Final changes/tweaks to the Easy Read version had been issued back to agency (in progress).

Copies of the full consultation document and easy read consultation document would
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<td>be posted out by second class post to stakeholders on Friday 12 September 2014, to ensure that they would be received on launch day (15 September 2014). The audio-visual version of the consultation document (YouTube) is considerably shorter than reading the whole consultation document and is more visual. The narration helps people with poor sight and those who have reading difficulties. Michael Wilson explained that though the individual elements of content for the audio-visual version of the consultation was complete (slides and audio), the work to make it ready to be uploaded was taking longer than expected (only one of four completed so far). The expected date for completion of the remaining three was close of business on Tuesday 9 September 2014. Mr Wilson explained that these products were not required to gain approval via the NHS England “Gateway Process” and so once they were signed off by the review team, they could be uploaded to the NHS England YouTube Channel. Mr Wilson explained that the one audio-visual section that was complete was not as crisp as the review team had anticipated. Giles Wilmore commented that there had been similar issues with an audio-visual version of a different consultation recently and that the problems were related to the NHS England website capability.</td>
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**Accessibility (IN PROGRESS)**

An easy-read version of the consultation document had been created; appropriately assured; final changes were being made by the design agency. The equalities impact assessment would be published as part of the “reference pack”.

**Consultation Mechanisms (IN PROGRESS)**

Response mechanisms for the consultation had been defined; met NHS England standard requirements and the relevant contact details had been input into the consultation materials. A provider has been selected to analyse the responses to consultation following a robust procurement exercise. The cooling-off period had closed on 5 September 2014 at midnight with no challenges. The contracts would therefore be signed by close of play on the day of the programme board meeting (8 September 2014).

The Consultation Hub (CitizenSpace) had been developed in line with the NHS England standard, and all documents and links for inclusion were ready to be made live. The test site had been fully tested (100% success rate) and a few minor changes to the questions had been made. These changes were in the process of being re-tested and would be completed for sign-off by the review team later that day (8 September 2014). All data flowed accurately to the database and would be made accessible to supplier of the response analysis after contract signing.

Mr Wilson noted that questions regarding the respondents themselves had been included. Mr Wilmore advised that this should correlate to the equalities impact assessment and Mr Wilson confirmed that it did.

**Timeline**

**Responding to consultation:** Commissioning of supplier organisation and finalising response mechanisms now completed.
**Specialised commissioning governance:** Approvals from both the CPAG and DCSC had now been provided.

**Consultation materials:** Content and design finalised and signed off. Final changes with the agency pre-printing.

**Engagement:** plans for engagement during consultation on track and well advanced; see paper of item 7 for further details.

The Programme Board noted that there were no ‘consultation critical’ items outstanding, and subject to two conditions the Programme Board gave its approval for the launch of consultation on Monday 15 September 2014. The conditions were:

- Uploading of all documents on to the consultation hub (with the digital media team); and
- Availability of print copies of the consultation document and Easy Read version (with Williams Lea).

### 7 Engagement update

Michael Wilson introduced the paper which outlined the planned engagement activities the review team intended to hold or attend during the consultation period. It provided further detail and progress since the paper reviewed and commented on by the Programme Board at their meeting of 28 July 2014.

**Consultation events**

The Programme Board noted that the review team would be hosting a number of “exhibition style” consultation events across the country in 12 cities (including Cardiff) which would be suitable for all audiences: patients, parents, children and adults, local representatives, local clinicians etc. The events would include panel displays, audio-visual materials, and team members to talk to. Consultation response forms would be provided on request but the principal purpose of the events was to inform and encourage attendees to be able to complete a consultation response at a later time. All the events would be ‘drop-in’ events held across the afternoon and evening to encourage as wide an audience as possible, between weeks 4 and 9 of the consultation, avoiding the half-term week in October 2014. Mr Wilson confirmed that the venues for such events would have Wi-Fi and be Disability Discrimination Act (DDA) compliant.

Linda Prosser commented that it would be very beneficial for both providers and commissioners to also “drop in” at such events. Mr Wilson confirmed that relevant information would be included in the Area Team Bulletin.

Mr Wilson reported that there had been an enquiry from a local newspaper asking “why it was decided to have the engagement events as a “drop in” rather than public meeting style event” and then going on to say “There is some criticism here – how will the review team gather views from this type of event and how will the public know it a fair reflection of views given”. Michael explained that the events were not designed to gather views but rather to help people to make an informed response to the consultation. Giles Wilmore commented that they were about raising awareness. The Programme Board affirmed this approach.
## Seldom heard groups

The Programme Board noted that through pre-consultation engagement and the equalities analysis four groups of service users had been identified that it would be important to hear from in consultation, either because they were heard from less often than others, or because there was a link with CHD. Those groups were bereaved families, adults with CHD, people with learning disabilities and people from Black, Asian and Minority Ethnic (BAME) communities. Members noted the work to date and the work continuing to establish methods of enabling those groups to contribute and respond to the consultation.

Professor Peter Weissberg noted that there was not only an increased incidence of CHD in people with Down’s syndrome, but also secondary heart disease as a result of other illnesses of which people with Down’s syndrome are at increased risk, such as leukemia.

Mr Holden added that Margaret Casely-Hayford (member of the Board Task and Finish Group) had provided some advice and suggestions regarding engagement with Black, Asian and Minority Ethnic (BAME) communities.

Giles Wilmore advised that the Health and Care Strategic Partner Programme (consisting of Voluntary and Community Sector (VCS) organisations) would be a good route to engaging with seldom heard groups. Mr Wilson confirmed that under the proposed plan the Strategic Partners would all receive notification of the launch of consultation.

## Local government and Healthwatch

Mr Wilson explained that an event was planned for the 9 October 2014 in Birmingham, similar to the meeting held for the local government and Healthwatch earlier in the review.

Giles Wilmore suggested that circulation of the event to Healthwatch colleagues could be done using the monthly, NHS England Healthwatch and Health and Wellbeing Boards bulletin.

Linda Prosser advised that every Health and Wellbeing Board has an NHS England member. Mr Wilson confirmed that Area Teams would be asked to brief HWBs and OSCs. The Programme Board noted that in addition the review team plan to attend Overview and Scrutiny Committees (OSCs), Health OSCs and Joint OSCs as requested and are proactively approaching likely OSCs who will request meetings to diarise them as early as possible.

Mr Wilson explained that a proposal for a drop-in session for MPs and Peers was being considered by the office of the NHS England Chief Executive.

The Programme Board agreed the plan of proposed events during the consultation period.

## Risk register

The Programme Board noted the risk and issue registers.

Michael Wilson advised the Programme Board of the following future publications, which may have an impact on the new CHD review.
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<td>1.</td>
<td>Following the suspension of children’s heart surgery at Leeds Teaching Hospitals Trust a number of investigations were launched. The third report which was being produced by an independent investigation agency “Verita” was due for publication. Mr Wilson reported that he had been informed of a fourth “overarching” report also due for publication which would draw the three reports together and would include a list of recommendations.</td>
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<td>2.</td>
<td>The 2010/13 data release from the National Congenital Heart Disease Audit (NCHDA) at National Institute for Cardiovascular Outcomes Research (NICOR) was due for publication during September 2014. Mr Wilson confirmed that Dr Mike Bewick, Deputy Medical Director at NHS England would be the spokesperson for NHS England for both. Professor Sir Michael Rawlins commented that though it would have been very useful to have both sets of information available much earlier in the review to inform the standards, any learning from the reports/data could still be reflected in NHS England’s response to the consultation responses.</td>
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**ACTION**

The Programme Board to consider the third and fourth report on children’s heart surgery at Leeds Teaching Hospitals NHS Trust once published.

8 Highlight report

The Programme Board noted the highlight report.

Professor Sir Michael Rawlins thanked both Professor Deirdre Kelly and Michael Wilson for carrying out the visits to units. Mr Wilson explained that now the three additional visits to (a representative sample of adult centres) had been completed, the report on the programme of visits could be completed and published.

Mr Wilson also confirmed that the summary write-up of the children and young people’s engagement events would also be published in the near future.

9 Any other business

A revised Terms of Reference document for the Programme Board was tabled at the meeting. The revisions were to both the membership and quoracy of the Group:

- Mr Daniel Phillips, Director of Planning, Welsh Health Specialised Services Committee as a new member; and
- Quoracy of 10 members.

The Programme Board agreed the revised Terms of Reference. There was no further business.

**Date of next meeting**

Members noted that the date for the next meeting of the Programme Board was scheduled to take place on Tuesday 23 September 2014.