

**Clinical Advisory Panel, 15 October 2013  
Minutes**

**Present:**

- Professor Sir Michael Rawlins, President, Royal Society of Medicine (Chair)
- Dr Hilary Cass, Royal College of Paediatrics and Child Health
- Dr Jacqueline Cornish, National Clinical Director for Children and Young People, NHS England
- Professor John Deanfield, Chair of Adult with Congenital Heart Disease Advisory Group
- Professor Huon Gray, National Clinical Director for Cardiac Care, NHS England
- Professor Deirdre Kelly, Chair of the review's Clinician Group
- Mr James Palmer, National Clinical Director for Specialised Services, NHS England
- Mr James Roxburgh, Society for Cardiothoracic Surgery
- Dr Tony Salmon, Chair of the review's Standards Sub Group
- Fiona Smith, Royal College of Nursing
- Professor Peter Weissberg, Chair of the review's Patient and Public Group.

**Apologies:**

- Professor Pedro del Nido, International Adviser
- Dr Andy Mitchell, Regional Medical Director (London), NHS England
- Professor Terence Stephenson, Academy of Medical Royal Colleges
- Professor Norman Williams, Royal College of Surgeons

**In attendance:**

- Joanna Glenwright, Senior Manager (Analytical Function), NHS England
- Professor Sir Bruce Keogh, National Medical Director, NHS England
- Michael Wilson, Programme Director, NHS England

Item	Agenda Item
1.	<p><b>Welcome and apologies</b> The Chair welcomed members to the first meeting of the Panel. Members introduced themselves.</p>
2.	<p><b>Introductory remarks</b> Professor Keogh opened the meeting with some introductory remarks on the new review. He explained that the case for change for the new review needed to be considered in current context, which was different from the context of earlier reviews. The case for change was now about the ambition to be the best; improving quality and future proofing services. He explained that there was limited time to make a difference because people were despondent that having invested effort in the previous work it had gone nowhere. However in his view this had not all been wasted – there was much that could be retained, for example the standards.</p> <p>The context was different now. NHS England was a single national commissioner and could have a single view, a single commissioning decision. In addition everything was now being done in public: transparency was key.</p>

## New Congenital Heart Disease Review

Item	Agenda Item
	<p>Sir Bruce emphasised the need for openness and transparency, and for all those participating in the review (professionals, patients, the public and politicians) to be respectful of those who may hold very different views.</p>
<p><b>3.</b></p>	<p><b>Proposed governance and decision making arrangements</b></p> <p>Mr Wilson explained the governance diagram in the paper.</p> <p>Any decisions affecting the commissioning and delivery of congenital heart disease services as a result of the review would be taken by the full NHS England board. The Board Task and Finish Group would oversee the review, to provide assurance to the board and to provide strategic direction to the programme on behalf of the board. It would take decisions on the direction and running of the review. The programme board was responsible for ensuring that the programme delivered its objectives. It would manage all aspects of the review's work and take day to day decisions on the running of the review.</p> <p>The role of the clinical advisory panel was to provide clinical leadership, and to provide clinical advice, considering the work in a broad strategic clinical context, using their experience from across a wide range of specialties. Clinical reference groups (specialised commissioning) had a particular role with standards and specifications.</p> <p>Three other groups formed the building blocks for stakeholder engagement; the clinician group, the patient and public group and the provider group. Each group fed into the programme through its chair.</p>
<p><b>4.</b></p>	<p><b>Proposed approach for managing conflicts of interest</b></p> <p>The Chair stated this was important and members should over declare rather than under declare.</p> <p>Professor Kelly asked if there was a process in place for managing any unreasonable comment or individual lobbying based on members declared potential conflicts of interest. It was agreed that NHS England's usual moderation policies would apply.</p> <p>Professor Gray raised the issue of asking other groups to declare potential conflicts of interest e.g. members of patient and public group, clinician group. The Chair asked Mr Wilson to ask the Task and Finish Group to consider applying the policy to the three engagement groups.</p>
<p><b>5.</b></p>	<p><b>Supplementary publication scheme</b></p> <p>Mr Wilson explained that all documents relating to the review will be published via NHS England website as a means of promoting transparency. The Chair noted that the Panel's terms of reference anticipated that on occasion the panel would need to meet virtually or exchange email correspondence. He advised members to copy in Mr Wilson whenever they emailed each other about the review.</p>

Item	Agenda Item
6.	<p data-bbox="260 275 1286 313"><b>Clinical Advisory Panel – Terms of Reference Confirm Membership</b></p> <p data-bbox="260 349 1002 387">Mr Wilson referred members to the paper for item 6.</p> <p data-bbox="260 423 1366 499">The Chair stated that the section on metrics need more work: there was more than 30 day mortality which would be relevant.</p> <p data-bbox="260 535 1353 611">Professor Kelly stated that the Panel would need to think about evaluation of whether the review had made a difference.</p> <p data-bbox="260 647 1430 1193">The Chair highlighted the importance of workforce and training issues. He asked Mr Roxburgh whether the colleges were interested in the review. Mr Roxburgh was not sure how aware they had been of the review. Dr Salmon reminded the Panel that the workforce and training issues applied to many clinical staff as well as surgical. The training of paediatricians with expertise in cardiology was a particular concern. Dr Cornish stated that workforce and training issues were fundamental to future proofing services, e.g. detection, nursing and staffing on wards. Professor Gray noted that the workforce and training issues in the terms of reference were also in the terms of reference of the provider group. He was concerned that this might mean two sets of advice for the Programme Board. Professor Keogh said that it would be good to get some workforce experts to consider the advice of the groups before it went to the Programme Board. Professor Kelly suggested this panel (CAP) would have a more national view while the Provider Group would have a more local view which could ensure work was not duplicated.</p> <p data-bbox="260 1229 1414 1344">Professor Deanfield stated that it always needed to be clear that the review was not just looking at paediatrics, as adult congenital heart disease was increasingly common with improved survival rates.</p> <p data-bbox="260 1379 1414 1494">The issue of research was raised and it was agreed that the Panel should advise on priorities for research. Professor Weissberg noted that BHF was a major funder of research.</p> <p data-bbox="260 1529 1430 1747">Mr Palmer asked that section 2.2 should be strengthened to ensure that commissioning products from the CRG were brought to the Panel for consideration while the review was underway. He suggested that the CAP review should fit between the National Programme of Care Board and the Clinical Priorities Advisory Group. Final sign-off of specifications and other commissioning products was by the Directly Commissioned Services Committee.</p> <p data-bbox="260 1783 1414 1933">The Chair asked the Panel to consider whether its membership was appropriate. Sir Bruce recommended that an anaesthetist should be added and asked for the panel's advice as there was such a range of groups that could be asked. The Chair advised asking the president of the Royal College of Anaesthetists.</p> <p data-bbox="260 1968 1414 2033">Mr Roxburgh raised a concern about his membership. He noted that he was an adult cardiothoracic surgeon not a congenital heart surgeon. SCTS were content</p>

Item	Agenda Item
	<p>with his membership of the panel but considered that there should also be a congenital surgeon on the panel. Professor Deanfield considered that it was useful to have some who could step back and take a more independent view. He found this to be the case in the ACHD advisory group of which Mr Roxburgh had been a member. Professor Kelly agreed but considered that the panel did need a congenital surgeon as a member. Not to do so was an obvious weakness. Some standards needed to be accepted by surgeons and it was important that they were represented in the process. Dr Salmon raised a concern as to whether he was a member because he was president of BCCA or chair of the standards sub-group. His presidency ended in the next month. BCCA would be concerned if not formally represented by their current president. The Chair confirmed that Dr Salmon had been asked to be a member because of his role with the standards sub-group.</p> <p>Sir Bruce stated that it was essential that members of the group must have the support of their college or professional society. Mr Roxburgh and Dr Salmon should seek a mandate from their societies or alternative nominations. Mr Roxburgh was asked to discuss the position with SCTS and request a congenital surgeon be nominated to join. The Panel also saw value in Mr Roxburgh's continued membership if supported by his society. BCCA should be asked whether they were happy for Dr Salmon to act as their representative. In the event that they were not they would be asked to nominate a member in addition to Dr Salmon.</p> <p>The group considered the appropriate frequency for meetings and agreed that every 2 months was right but that the Chair would convene additional meetings if he felt that they were necessary.</p>
7.	<p><b>Proposed stakeholder participation and engagement arrangements</b></p> <p>Mr Wilson referred members to the paper for item 7 and explained that this presented similar material to the paper for item 3 but from the perspective of each stakeholder group.</p> <p>Mr Palmer drew attention to the role of Specialised Services Patient and Public Engagement Steering Group which would have a mandate to draw attention to any shortcomings in patient and public engagement for this and any other part of NHS England's specialised commissioning processes. It should have a 'dotted line' relationship to the programme board. Mr Wilson confirmed that he had attended the steering group twice to discuss the review's arrangements and had welcomed its advice.</p>
8.	<p><b>Standards and specifications</b></p> <p>Professor Kelly stated that standards were at the heart of the review and that getting them right would provide a real opportunity to improve the quality of care. She explained the history of standards development to date and the process now underway to bring the various sets of standards together. She emphasised that</p>

## New Congenital Heart Disease Review

Item	Agenda Item
	<p>the focus for the standards is the needs of patients and families.</p> <p>Professor Kelly noted that while Sir Bruce had asked for clarity about the evidence supporting the standards there was often only limited scientific data. Standards will need to rely on expert opinions about clinical best practice. The Chair stated that clinical opinion was a form of evidence. Professor Kelly noted that some of the standards remain contentious.</p> <p>The Chair suggested that consultation responses should be handled through a process similar to that used by NICE where each comment received its own response. That way, even if it the comment is not accepted people knew it had been considered. Based on his experience he suggested there could be 2000-3000 comments which would take a couple of months to respond to all and hence would not be ready for June 2014 deadline. Mr Palmer stated that in the previous consultation on specifications, NHS England had published all consultation comments and responses. His advice was to follow the same process as all the other CRG consultations. Responses to the comments should be a joint effort between the CRG and the standards groups. Dr Cornish stated that there had been 650 comments relating to specifications from the women's and children's programme of care in that process. Mr Wilson stated that an issue with the previous review was that people did not feel listened to and this approach demonstrated that all contributions had been considered.</p> <p>Mr Wilson agreed with Professor Kelly that some standards would be contentious. It would be important to understand the level of professional support for the standards before embarking on consultation. Dr Cornish stated that unanimous clinician support would be a real strength. The Chair stated that where there was not unanimous support, the panel would have to come to a decision on what to advise NHS England. Professor Deanfield stated that there may be consensus and unanimous support until it comes to implementation and when particular clinicians or centres were affected by the standards being set. Professor Kelly stated that this could be explored with the clinician group. It would be good to get a majority in support.</p> <p>Professor Weissberg stated that it was important to be clear what the problems were with the service. Sir Bruce agreed that the case for change needed to be reassessed, defined and articulated. But this was a different sort of process focussed on excellence and the case for change would be developed by all the stakeholders working together on the review. Professor Gray asked Sir Bruce what he wanted the output of the panel to be and what the panel were being asked to do. The Chair said that the Panel's role was to consider the evidence and see where it led. Professor Kelly stated the aim of the review was not to reduce the number of centres; it was to provide the best service. The Chair stated that it was important form followed function. Sir Bruce noted that it would be important to consider what constituted success. This was unlikely to be about mortality and more likely to be about better quality and future health outcomes. The profession needed to be given a chance to lead.</p>



Item	Agenda Item
	<p>Dr Salmon noted that the Safe and Sustainable process had resulted in a binary decision – in or out. It was important to be clear how decisions from this review would be implemented. There was a lack of trust in the transition process and that disinvestment in one centre would be offset by investment in another. Mr Wilson noted that the specialised commissioning process allowed standards to be implemented over a period of time. Professor Gray asked if the panel were to be involved in thinking about how any recommendations would be implemented. Ms Smith supported Professor Kelly’s assertion that the review needed to focus on patients not surgeons or units. That was a major difference from the previous review. Mr Wilson stated that the new review had been asked to bring forward an implementable plan by June 2014. This was being taken to mean a set of standards, an understanding of what future capacity the service needed, proposals for the future form and function of the system and proposals for the process of commissioning and change to be adopted. It was not to say “this centre or that centre”.</p>
<p><b>9.</b></p>	<p><b>Scope and interdependencies</b></p> <p>Mr Wilson referred members to the paper for item 9. Stakeholders had been asked for their views on what should be “in scope” for the review. Panel members had been provided with these responses. The responses had shown him that this was not the straight forward question he had initially thought it was. He was now clear the question was much more ‘in what way should the review relate to these services and patients’ rather than it being a binary question of in scope or out of scope.</p> <p>Four categories were being proposed:</p> <ul style="list-style-type: none"> <li>• The congenital heart disease service</li> <li>• Patients with conditions that are not congenital heart disease, but who receive their care wholly or mainly from congenital heart services</li> <li>• Services that are not congenital heart disease services but which congenital heart disease patients may use as part of the congenital heart disease pathway.</li> <li>• Services that are not part of the congenital heart disease pathway, but that are reliant on clinical support or backup from CHD specialists.</li> </ul> <p>The panel reviewed the proposed categorisation of services. Dr Cass stated that the categories perhaps were not quite worded right, almost too specific. The panel suggested a revised approach. Professor Weissberg stated that the bulk of paediatric cardiac services were congenital but not all. It would be useful to make distinction between cardiac surgery and all cardiac services and acquired vs. congenital. Professor Deanfield suggested that there were three principal categories; congenital heart disease services from cradle to grave; all cardiac disease in children (and some acquired heart disease in adults); and interdependencies.</p>

## New Congenital Heart Disease Review

Item	Agenda Item
	<p>The panel then reviewed each of the services and patient groups identified in the paper and made recommendations about their relationship to the review. Mr Wilson was asked to write up the group's recommendations in the form of a paper for the Task and Finish Group which would make the final decision on scope. Mr Wilson agreed and stated that he would send this paper to Panel members in advance of the Task and Finish Group's meeting.</p> <p>The Chair asked if services in Scotland were in scope. Sir Bruce stated that flows between northern England and Scotland were important. The relationship of the devolved administrations to the review was however a matter for them and they would be approached. Mr Wilson noted that some patients view it as one NHS and consider that the same standards should prevail across the whole United Kingdom.</p>
<b>10.</b>	<b>Any other business</b>  Professor Gray asked whether the review had appropriate legal and other advice to ensure that its processes were sound and did not leave the review's decisions open to judicial or other challenge. The Chair asked that the Programme Board consider this matter, considering not just the legal perspective but also engagement and equalities duties.
<b>11.</b>	<b>Future meetings</b> Dates for future meeting would be circulated as soon as they were agreed.