

Report of the Head of Scrutiny and Member Development

Report to the Scrutiny Board (Health and Wellbeing and Adult Social Care)

Date: 24 April 2013

Subject: Review of Adults with Congenital Heart Disease – engagement on revised proposals

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

1.0 Purpose of this report

1.1 The purpose of this report is to seek the views of the Scrutiny Board in relation to revised proposals, in terms of the proposed model of care and draft designation standards, associated with the national review of services for Adults with Congenital Heart Disease (ACHD).

2.0 Background information

2.1 Under the new NHS arrangements that came into force on 1 April 2013, NHS England is now responsible for taking forward the review services for Adults with Congenital Heart Disease (ACHD). This review is separate to the Safe and Sustainable review of children’s congenital cardiac services – although there are connections between both patient groups and the staff that provide services. A previous 10-week period of public engagement was held from May to July 2012, which detailed a proposed model of care and draft designation standards. This was previously considered by the Scrutiny Board at its meeting on 27 June 2012.

2.2 At the meeting in February 2013, members of the Scrutiny Board were provided with a further stakeholder newsletter published earlier that month. Following that meeting, further contact was made with the review team to clarify a number of matters. Details of the questions posed were presented to the Scrutiny Board in March 2012 and assurance provided that any substantive responses would be provided. Details of the questions posed and the associated responses are detailed in the table below:

Q	Under the new working arrangements, which part of the NHS will be responsible for taking forward the review? Notwithstanding overall responsibility for the review, will aspects of the review be discharged to other bodies? If so, which ones and how will these be established?
A	<i>The NHS Commissioning Board (NHS CB) will assume responsibility for the management of the review from 1 April 2013. It is not envisaged that any aspects of the review will be discharged to other bodies, as legal powers for consultation and decision making will rest solely with NHS CB.</i>
Q	What will be the overall governance and decision-making arrangements for the review?
A	<i>Overall governance and decision making arrangements will be confirmed by NHS CB as soon as possible after the formal establishment of the NHS CB on 1 April.</i>
Q	Please confirm the revised review timetable.
A	<i>The draft review timeline has slipped by around 4 months as the ACHD Advisory Group continues to develop the new quality standards taking into account the views of stakeholders submitted during last year's engagement exercise. A revised draft timeline will be published in May 2013.</i>
Q	Please confirm when further stakeholder newsletters are planned.
A	<i>Subject to endorsement by the NHS CB, the next newsletter is planned to be published in April or May 2013.</i>

2.3 It should be noted that the Scrutiny Board's involvement to date represents pre-engagement activity – i.e. prior to formal public consultation on any proposals. As such, and as previously reported, it should also be noted that the Scrutiny Board (Health and Wellbeing and Adult Social Care) is likely to be asked to consider the merits of establishing a further Joint Health Overview and Scrutiny Committee to consider and respond to specific proposals around the ACHD review.

2.4 The timing of this may be affected by a number of factors, including the overall progress of the review and any decision from the Secretary of State for Health in relation to the Review of Children's Congenital Cardiac Services.

3.0 Main issues

3.1 On 11 April 2013, NHS England distributed details of some further engagement activity on behalf of the Chair of the ACHD Advisory Group – which has been working to revise and improve the proposed model of care and draft designation standards taking into account the views received during the period of engagement.

3.2 Details of the revised model of care and draft designation standards are provided at Appendix 1. Interested parties and stakeholders are invited to provide any comments by 10 May 2013.

Review of Children's Congenital Cardiac Services

3.3 Members will be aware of the review of children's congenital cardiac services in England and the recent High Court ruling that found in favour of Save Our Surgery

(SOS) Ltd. in its action brought against the Joint Committee of Primary Care Trusts (JCPCT). The outcome of the High Court ruling is still subject to further legal proceedings, alongside the pending report of the Independent Reconfiguration Panel to the Secretary of State for health.

- 3.4 In relation to services for adults with congenital heart disease, Members of the Scrutiny Board have previously been made aware of the concerns raised by the Joint Health Overview and Scrutiny Committee (JHOSC) for Yorkshire and the Humber. Relevant extracts from the JHOSC's October 2011 report are repeated below:

Adults with congenital cardiac disease

90. *We are aware that the minimum number of surgical procedures, within designated centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. We note the rationale behind the minimum numbers, but remain to be convinced by the clinical evidence used to support the number of procedures presented in the proposals.*
91. *We understand that the NHS is reviewing the provision of congenital cardiac services via two separate but related reviews and that the process for the designation of adult congenital services will proceed in 2011. This will include reference to the separate standards that have been developed by a separate expert group which were published in 2009. In preparing this report, it should be noted that we have not sought to consider these service standards.*
92. *As previously stated, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. We also understand that elsewhere in the country, other surgeons also treat both children and adult congenital cardiac patients.*
93. *We received evidence that Adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. This is clearly not safe or sustainable.*
94. *We understand that when reviewing any service, it is necessary to define the scope of the review. We also understand that this can be a complex exercise in itself. Nonetheless, we believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice.*
95. *We firmly believe that on a similar basis to the sustainability issues put forward in the children's congenital cardiac services consultation*

document, and by considering adult congenital services separately, the outcome from the children's congenital cardiac services review will almost certainly pre-determine the outcome of the adult's services review.

96. *Adult congenital heart patients at the Leeds Centre have also made their views clear that they feel disenfranchised by the fact that their service is not being consulted upon jointly with the children's service in this review.*
97. *Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country. We learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Enough to justify retaining another two centres if the suggested minimum number of 400 surgical procedures is applied.*
98. *As previously stated, we understand that with three surgeons in post, 392 surgical procedures (adults and children combined) were undertaken last year at the current surgical centre in Leeds.*
99. *Although we have not been provided with any detailed projections, we are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.*
100. *As such, simply by continuing to treat patient numbers arising in Yorkshire and the Humber, we would question whether in reality there are indeed any sustainability issues around the surgical centre in Leeds. Similar considerations may also be true for other areas.*
101. *We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We understand that concerns have been raised both in terms of absolute patient numbers and also around pre-determination. Such concerns appear to remain unaddressed.*

Recommendation 5:

Adult cardiac services and the overall number of congenital cardiac surgical procedures carried out should be considered within the scope of this review and used to help determine the future configuration of surgical centres. As a minimum there should be a moratorium on any decision to designate children's cardiac surgical centres until the review of the

adult congenital cardiac services is completed and the two can be considered together.

3.5 Members of the Scrutiny Board may wish to take account of these comments in drafting any response as part of the current engagement process.

4.0 Recommendations

4.1 Members are asked to identify any comments to inform its response to the current engagement activity (if appropriate) and determine any other appropriate scrutiny activity at this time.

5.0 Background documents¹

- None

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works..