



## JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE & THE HUMBER)

Meeting to be held in the Civic Hall, Leeds on  
 Friday, 16th November, 2012 at 10.30 am

### MEMBERSHIP

S Ali	-	Rotherham Metropolitan Borough Council
J Bromby	-	North East Lincolnshire Council
D Brown	-	Hull City Council
J Clark	-	North Yorkshire County Council
P Elliott	-	North Lincolnshire Council
C Funnell	-	City of York Council
M Gibbons	-	Bradford Metropolitan Council
R Goldthorpe	-	Calderdale Council
B Hall	-	East Riding of Yorkshire Council
J Illingworth (Chair)	-	Leeds City Council
T Revill	-	Doncaster Metropolitan District Council
B Rhodes	-	Wakefield Council
M Rooney	-	Sheffield City Council
L Smaje	-	Kirklees County Council
J Worton	-	Barnsley Council

*Please note: Certain or all items on this agenda may be recorded.*

**Agenda compiled by:**  
**Stuart Robinson**  
**Governance Services**  
**Civic Hall**  
**LEEDS LS1 1UR**  
**Tel: 24 74360**

**Principal Scrutiny Advisor:**  
**Steven Courtney**  
**Tel: 24 74707**

# A G E N D A

Item No	Ward/Equal Opportunities	Item Not Open		Page No
8			<b>REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: REFERRAL TO THE SECRETARY OF STATE FOR HEALTH - DRAFT REPORT</b>  (Appendices attached)	1 - 130

## Report of the Head of Scrutiny and Member Development

### Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

**Date: 16 November 2012**

**Subject: Review of Children's Congenital Heart Services in England: Referral to the Secretary of State for Health – draft report**

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 checked="" type="checkbox"/> Yes	<input 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

### Summary of main issues

- Proposals around the future of Children's Congenital Heart Services in England were launched for public consultation on 1 March 2011, running until 1 July 2011.
- At its meeting on 4 October 2011, the Joint HOSC agreed its consultation response and outline report. The Joint HOSC submitted its formal response to the consultation on 5 October 2011 and subsequently issued a formal report to the Joint Committee of Primary Care Trusts (JCPCT) – as the appropriate decision-making body – on 10 October 2011.
- At its meeting on 4 July 2012, the JCPCT agreed consultation Option B for implementation and the designation of congenital heart networks led by the following surgical centres:
  - Newcastle upon Tyne Hospitals NHS Foundation Trust
  - Alder Hey Children's Hospital NHS Foundation Trust
  - Birmingham Children's Hospital NHS Foundation Trust
  - University Hospitals of Bristol NHS Foundation Trust
  - Southampton University Hospitals NHS Foundation Trust
  - Great Ormond Street Hospital for Children NHS Foundation Trust
  - Guy's and St. Thomas' NHS Foundation Trust
- A formal response to the Joint HOSC's report was received on 18 July 2012 and considered at the Joint HOSC's previous meeting on 24 July 2012.

5. At the same meeting (24 July 2012) the Joint HOSC considered the JCPCT's decision and the associated Decision-Making Business Case. The Joint HOSC also heard from a range of interested parties / stakeholders, including:
  - The JCPCT and supporting secretariat;
  - Parent representatives;
  - The Children's Heart Surgery Fund;
  - Leeds Teaching Hospitals NHS Trust
  - Executive Member for Health and Wellbeing (Leeds City Council)
  - Stuart Andrew (MP)
6. At that meeting, the Joint HOSC made the following resolutions:
  - (a) *That the 4 July 2012 decision of the Joint Committee of Primary Care Trusts, regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres, and associated network configuration, be referred to the Secretary of State for Health for consideration, on the basis of the decision not being in the interest of the local NHS.*
  - (b) *That, reflecting the evidence considered and the issues raised by members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), a draft report be prepared to support the referral to the Secretary of State for Health*
7. The purpose of this report is to present the draft report to support the referral to the Secretary of State for Health detailed above.

## **Recommendations**

8. That the Joint HOSC:
  - a. Considers the details presented in draft report and identifies any necessary amendments; and,
  - b. Subject to any amendments, agree the report for submission to the Secretary of State for Health.

## **1.0 Purpose of this report**

- 1.1 The purpose of this report is to present the draft report to support the referral to the Secretary of State for Health of the decision of the Joint Committee of Primary Care Trusts (JCPCT) decision in relation to the review of Children's Congenital Heart Services in England and the reconfiguration of designated surgical centres.

## **2.0 Background information**

- 2.1 Proposals around the future of Children's Congenital Heart Services in England were launched for public consultation on 1 March 2011, running until 1 July 2011
- 2.2 At its meeting on 4 October 2011, the Joint HOSC agreed its consultation response and outline report. The Joint HOSC submitted its formal response to the consultation on 5 October 2011 and subsequently issued a formal report to the Joint Committee of Primary Care Trusts (JCPCT) – as the appropriate decision-making body – on 10 October 2011.
- 2.3 A formal response to the Joint HOSC's report was received on 18 July 2012 and considered at the Joint HOSC's previous meeting on 24 July 2012.
- 2.4 The Joint HOSCs report highlighted a number of areas that it believed required further and more detailed consideration, while the overall view of the Joint HOSC was that any future service model that did not include a designated children's cardiac surgical centre at Leeds would have a disproportionately negative impact on the children and families across Yorkshire and the Humber. This view, as detailed in the full report, was specifically based on the evidence considered in relation to:
- Co-location of services;
  - Caseloads;
  - Population density;
  - Vulnerable groups;
  - Travel and access to services;
  - Costs to the NHS
  - The impact on children, families and friends;
  - Established congenital cardiac networks;
  - Adults with congenital cardiac disease;
  - Views of the people across Yorkshire and the Humber
- 2.5 In October 2011, the Joint HOSC referred this matter to the Secretary of State for Health on the basis of inadequate consultation. The outcome of this referral was that, while the consultation arrangements overall were deemed satisfactory, there was agreement that some of the information requested by the Joint HOSC (namely the PwC report that tested the assumed patient travel flows and clinical networks under each of the four options presented for public consultation) should have been made available ahead of the consultation deadline.
- 2.6 Additional comments on the findings of the PwC report that tested the assumed patient travel flows and clinical networks under each of the four options presented for public consultation were issued to the JCPCT at the end of April 2012.

2.7 At its meeting on 4 July 2012, the JCPCT agreed consultation Option B for implementation and the designation of congenital heart networks led by the following surgical centres:

- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St. Thomas' NHS Foundation Trust

### **3.0 Main issues**

3.1 At its meeting on 24 July 2012, the Joint HOSC considered the JCPCT's decision and the associated Decision-Making Business Case. The Joint HOSC also heard from a range of interested parties / stakeholders, including:

- The JCPCT and supporting secretariat;
- Parent representatives;
- The Children's Heart Surgery Fund;
- Leeds Teaching Hospitals NHS Trust
- Executive Member for Health and Wellbeing (Leeds City Council)
- Stuart Andrew (MP)

3.2 At that meeting, the Joint HOSC made the following resolutions:

- (a) *That the 4 July 2012 decision of the Joint Committee of Primary Care Trusts, regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres, and associated network configuration, be referred to the Secretary of State for Health for consideration, on the basis of the decision not being in the interest of the local NHS.*
- (b) *That, reflecting the evidence considered and the issues raised by members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), a draft report be prepared to support the referral to the Secretary of State for Health*

3.3 The purpose of this report is to present the draft report to support the referral to the Secretary of State for Health detailed above.

### **4.0 Corporate Considerations**

#### **4.1 Consultation and Engagement**

4.1.1 There are no specific considerations relevant to this report.

#### **4.2 Equality and Diversity / Cohesion and Integration**

4.2.1 When initially considering the potential impact of the proposed changes during the consultation period, the Joint HOSC considered a regional Health Impact Assessment (HIA) produced by the Yorkshire and Humber Specialised Commissioning Group (SCG) and a nationally commissioned Interim HIA report, produced by Mott McDonald.

4.2.2 Both reports identified potential negative impacts associated with three of the proposed options put forward for consultation. In particular, the HIA interim report produced by Mott McDonald identified the following as vulnerable groups:

- Children (under 16s)\* who are the primary recipient of the services under review and, therefore, most sensitive to service changes;
- People who experience socio-economic deprivation;
- People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;
- Mothers who smoke during pregnancy; and
- Mothers who are obese during pregnancy;

These are defined as vulnerable groups because they are more likely to need the services under review and, are most likely to experience disproportionate impacts.

4.2.3 A finalised Health Impact Assessment report has been completed (dated June 2012) and was referenced as an appendix to the Decision-Making Business Case. A summary analysis of the impacts of the different configurations of surgical centres considered by the JCPCT was included within the Decision-Making Business Case document itself. This provided high level analysis (i.e. on a national level) of the total number of patients, including those living within vulnerable postcode districts, who would experience significant travel impacts under the various configuration models considered. A regional breakdown of the overall numbers was not provided in the Decision-Making Business Case, however maps of the country identifying the vulnerable postcode districts experiencing significant travel time impacts are included in the final HIA report (June 2012) produced by Mott MacDonald.

4.2.4 Prior to finalising its initial report in October 2011, the Joint HOSC requested a detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber (as referred to in the Health Impact Assessment (interim report)). This information has not been provided.

### **4.3 Council Policies and City Priorities**

4.3.1 There are no specific considerations relevant to this report.

### **4.4 Resources and Value for Money**

4.4.1 Prior to completing its report in October 2011, the Joint HOSC was advised that the proposed model of care for the delivery of children's congenital cardiac services was likely to result in an increased level of expenditure. The Joint HOSC was also specifically advised of a likely significant increase in costs associated with the transport and retrieval service in Yorkshire and the Humber.

4.4.2 Financial analysis details considered by the JCPCT were presented in Chapter 14 of the Decision-Making Business Case.

### **4.5 Legal Implications, Access to Information and Call In**

4.5.1 This report does not contain any exempt or confidential information.

## **4.6 Risk Management**

4.6.1 There are no specific considerations relevant to this report.

## **5.0 Conclusions**

5.1 At its meeting on 4 July 2012 , the JCPCT agreed consultation Option B for implementation and the designation of congenital heart networks led by the following surgical centres:

- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St. Thomas' NHS Foundation Trust

5.2 At its meeting on 24 July 2012, the Joint HOSC considered the JCPCT's decision and the associated Decision-Making Business Case. The Joint HOSC also heard from a range of interested parties / stakeholders, including:

- The JCPCT and supporting secretariat;
- Parent representatives;
- The Children's Heart Surgery Fund;
- Leeds Teaching Hospitals NHS Trust
- Executive Member for Health and Wellbeing (Leeds City Council)
- Stuart Andrew (MP)

5.3 At that meeting, the Joint HOSC made the following resolutions:

- (c) *That the 4 July 2012 decision of the Joint Committee of Primary Care Trusts, regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres, and associated network configuration, be referred to the Secretary of State for Health for consideration, on the basis of the decision not being in the interest of the local NHS.*
- (d) *That, reflecting the evidence considered and the issues raised by members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), a draft report be prepared to support the referral to the Secretary of State for Health*

5.4 The purpose of this report is to present the draft report to support the referral to the Secretary of State for Health detailed above

## **6.0 Recommendations**

6.1 That the Joint HOSC:

- (a) Considers the details presented in draft report and identifies any necessary amendments; and,
- (b) Subject to any amendments, agree the report for submission to the Secretary of State for Health



## **7.0 Background documents<sup>1</sup>**

None used

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<sup>1</sup> 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.

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# **Review of Children's Congenital Heart Services in England:**

## **2nd report of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – draft**

**DRAFT**



# Foreword

TO BE INSERTED

**Councillor John Illingworth**  
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber



# Introduction

1. The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – subsequently referred to as the Joint HOSC – is a committee specifically formed to consider the proposals for the future delivery of children’s congenital cardiac services across England, with specific reference to the implications for local health services, and the children and families served by such services across Yorkshire and the Humber.
2. The Joint HOSC was first established in March 2011 and, while our membership has changed over time, we have always included a single representative from each of the 15 local authorities with health scrutiny powers across Yorkshire and the Humber, namely:
  - Barnsley MBC
  - Bradford MDC
  - Calderdale Council
  - City of York Council
  - Doncaster MBC
  - East Riding of Yorkshire Council
  - Hull City Council
  - Kirklees Council
  - Leeds City Council
  - North East Lincolnshire Council
  - North Lincolnshire Council
  - North Yorkshire County Council
  - Rotherham MBC
  - Sheffield City Council
  - Wakefield MDC
3. As such, the Joint HOSC is made up of democratically elected local councillors that representative the 5.5 million residents from across Yorkshire and the Humber.
4. This is our 2<sup>nd</sup> formal report regarding proposals for the future delivery of children’s congenital cardiac services across England. Our first report was formulated during the period of public consultation over the summer of 2011 and was subsequently published in October 2011. This report covers many of the issues highlighted in our original report and should, therefore, be read in conjunction with the October 2011 report. A copy of the October 2011 is provided for ease of reference.
5. Reflecting on the interests of the children and families across Yorkshire and the Humber we have been elected to represent, the views expressed in both reports are based on the evidence we have received and considered.



# Background

## Overview

6. In 2008 the NHS Medical Director requested a review of Children's Congenital Heart Services in England. The aim of the review was to develop and bring forward recommendations for a Safe and Sustainable national service that has:
  - Better results in surgical centres with fewer deaths and complications following surgery.
  - Better, more accessible assessment services and follow up treatment delivered within regional and local networks.
  - Reduced waiting times and fewer cancelled operations.
  - Improved communication between parents/ guardians and all of the services in the network that see their child.
  - Better training for surgeons and their teams to ensure the service is sustainable for the future.
  - A trained workforce of experts in the care and treatment of children and young people with congenital heart disease.
  - Surgical centres at the forefront of modern working practices and new technologies that are leaders in research and development.
  - A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network.
7. On behalf of the ten Specialised Commissioning Groups in England, and their constituent local Primary Care Trusts, the Safe and Sustainable review team (at NHS Specialised Services) has managed the review process. This has involved:
  - Engaging with partners across the country to understand what works well at the moment and what needs to be changed
  - Developing standards – in partnership with the public, NHS staff and their associations – that surgical centres must meet in the future
  - Developing a network model of care to help strengthen local cardiology services
  - An independent expert panel assessment of each of the current surgical centres against the standards
  - The consideration of a number of potential configuration options against other criteria including access, travel times and population.
8. For the purposes of formal public consultation and decision making about the future provision and delivery of children's cardiac surgical services in England, a Joint Committee of Primary Care Trusts (the JCPCT) was formally established in the early part of 2011 – although the precise date is unclear. As such, the JCPCT has acted as the single decision-making body on behalf of all the Primary Care Trusts across England. We are aware that the JCPCT met on at least 5 occasions – between July 2010 and January 2011 – before it was fully and formally constituted.



# Background

9. At its meeting held on 16 February 2011, the JCPCT was presented with and agreed the following recommendations and options for consultation:
- Development of Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services.
  - Implementation of new clinical standards that must be met by all NHS hospitals designated to provide heart surgery for children
  - Implementation of new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with Congenital Heart Disease.
  - A reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence.
  - The options for the number and location of hospitals that provide children's heart surgical services in the future are:

**Table 1:** Consultation options for the number and location of hospitals

<b>Option A: Seven surgical centres:</b> <ul style="list-style-type: none"><li>• Freeman Hospital, Newcastle</li><li>• Alder Hey Children's Hospital, Liverpool</li><li>• Glenfield Hospital, Leicester</li><li>• Birmingham Children's Hospital</li><li>• Bristol Royal Hospital for Children</li><li>• 2 centres in London<sup>1</sup></li></ul>	<b>Option B: Seven surgical centres:</b> <ul style="list-style-type: none"><li>• Freeman Hospital, Newcastle</li><li>• Alder Hey Children's Hospital, Liverpool</li><li>• Birmingham Children's Hospital</li><li>• Bristol Royal Hospital for Children</li><li>• Southampton General Hospital</li><li>• 2 centres in London<sup>1</sup></li></ul>
<b>Option C: Six surgical centres:</b> <ul style="list-style-type: none"><li>• Freeman Hospital, Newcastle</li><li>• Alder Hey Children's Hospital, Liverpool</li><li>• Birmingham Children's Hospital</li><li>• Bristol Royal Hospital for Children</li><li>• 2 centres in London<sup>1</sup></li></ul>	<b>Option D: Six surgical centres:</b> <ul style="list-style-type: none"><li>• Leeds General Infirmary</li><li>• Alder Hey Children's Hospital, Liverpool</li><li>• Birmingham Children's Hospital</li><li>• Bristol Royal Hospital for Children</li><li>• 2 centres in London<sup>1</sup></li></ul>

10. Proposals around the future of Children's Congenital Heart Services in England were launched for public consultation on 1 March 2011, running until 1 July 2011.

<sup>1</sup> The preferred two London centres in the four options are Evelina Children's Hospital and Great Ormond Street Hospital for Children



# Background

## **The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the Joint HOSC**

11. We formed the Joint HOSC in March 2011 – to act as a statutory overview and scrutiny body considering the future proposals of Children’s Congenital Heart Services in England. This included the proposed reconfiguration of designated surgical centres and, in particular, consideration of the potential impact of any proposals on children and families across Yorkshire and the Humber.
12. As part of this public consultation, Health Overview and Scrutiny Committees were subsequently given until 5 October 2011 to respond to the proposals. We submitted our formal response to the consultation in line with the stated deadline and subsequently issued a formal report to JCPCT – as the appropriate decision-making body – on 10 October 2011.
13. As detailed in our previous report, during the initial public consultation we received and considered a wide range of evidence and heard from a number of witnesses, and highlighted a number of areas we believed required further and more detailed consideration.
14. We previously stated that any future service model that did not include a designated children’s cardiac surgical centre at Leeds – as the current centre serving the whole of Yorkshire and the Humber – would have a disproportionately negative impact on the children and families across Yorkshire and the Humber. This was specifically based on the evidence considered in relation to:
  - Co-location of services;
  - Caseloads;
  - Population density;
  - Vulnerable groups;
  - Travel and access to services;
  - Costs to the NHS
  - The impact on children, families and friends;
  - Established congenital cardiac networks;
  - Adults with congenital cardiac disease;
  - Views of the people across Yorkshire and the Humber
15. Our initial report identified a number of recommendations – including an alternative model of designated surgical centres. A summary of our initial recommendations is presented below in Table 2.





# Background

**Table 2:** Summary of previous recommendations

**Principal Recommendation 1:**

In order to meet the needs and growing demand of the 5.5 million people living in the Yorkshire and Humber region, the surgical congenital cardiac unit currently provided by Leeds Teaching Hospitals NHS Trust must be retained and included in any future configuration of paediatric congenital cardiac surgical centres.

**Principal Recommendation 2:**

Based on the matters outlined in this report we recommend the following 8-centre configuration model:

- Leeds General Infirmary
- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- Freeman Hospital, Newcastle
- Southampton General Hospital
- 2 centres in London

**Recommendation 3:**

Given the significant benefits to the patient and their families of genuinely co-locating relevant services, we believe genuine co-location should receive greater recognition and weighting when determining future service provision.

**Recommendation 4:**

Given one element of the review is to ensure more care is delivered closer to home, population density should be a key consideration in the configuration of future provision.

**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.



# Background

16. It should be noted that despite several requests, a formal response to our report and recommendations was not provided until 18 July 2012 – some 9 months after our initial report was submitted to the JCPCT. The response provided on behalf of the JCPCT is attached at **Appendix 1** to this report.
17. Notwithstanding the legitimate delays brought about by various legal proceedings, this is far beyond the 28-day response time set out in the current Health Scrutiny regulations and supporting guidance. At this juncture, based on our experience **we believe it is worthwhile registering our general dissatisfaction with the overall approach adopted by the JCPCT and its supporting secretariat in relation to the legitimate scrutiny function** established to facilitate open and transparent decision-making and hold decision-makers to account.

## Additional information previously identified

18. Prior to finalising our October 2011 report, we requested the following additional information on a number of occasions:
- The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Professor Sir Ian Kennedy).
  - A finalised Health Impact Assessment report.
  - A detailed breakdown of the likely impacts on identified vulnerable groups across Yorkshire and the Humber highlighted in the Health Impact Assessment (interim report).
  - The Price Waterhouse Coopers (PwC) report that tested the assumed patient travel flows under each of the four options presented for public consultation.
19. In our October 2011 report, we reserved the right to pass further comment on these points once further information was made available. As such, more details are provided elsewhere in this report.

## Previous referral to the Secretary of State for Health

20. It should be noted that in October 2011 we initially referred this matter to the Secretary of State for Health on the basis of inadequate consultation. Our referral was issued to the Independent Reconfiguration Panel (IRP) for initial assessment, the details of which are attached at **Appendix 2**.
21. The advice from the IRP was accepted in full by the Secretary of State for Health.



# Background

22. While the overall consultation arrangements were assessed as satisfactory, the IRP agreed that at some of the information we had requested (namely the PwC report that tested the assumed patient travel flows under each of the four options presented for public consultation) should have been made available during the consultation period. This is demonstrated by the following extract from the IRP's advice:

*'The Panel believes that it should have been available at a much earlier stage so that it could be communicated to all interested parties. PwC's report was published on the NSCT website in October 2011. The Panel considers that (subject to forthcoming legal judgement) any comments the Joint HOSC (or any other interested party) may wish to make with regard to this report should be accepted by the JCPCT and considered alongside the report itself as part of its decision-making process.'*

23. We considered the PwC report that tested the assumed patient travel flows and manageable clinical networks at our meeting on 19 December 2012. The outcome of our deliberations was issued to the JCPCT in April 2012 and is attached at **Appendix 3**.
24. However, despite the clear advice from the IRP that any additional comments we provide regarding the PwC report should be taken into account, within the JCPCT's response to our initial report there is no reference to our comments on the PwC report. **We can only conclude that the comments we provided have not been considered by the JCPCT.**

## The Joint Committee of Primary Care Trusts (JCPCT)

25. As outlined previously, the JCPCT was established in **xxxx** for the purposes of formal public consultation and decision making about the future provision and delivery of children's cardiac surgical services in England.
26. Following the public consultation (March 2011 – July 2011) and subsequent delays in the decision-making process – primarily caused by various legal proceedings – at its meeting on 4 July 2012, the JCPCT agreed consultation Option B for implementation and the designation of congenital heart networks led by the following surgical centres:
- Newcastle upon Tyne Hospitals NHS Foundation Trust
  - Alder Hey Children's Hospital NHS Foundation Trust
  - Birmingham Children's Hospital NHS Foundation Trust
  - University Hospitals of Bristol NHS Foundation Trust
  - Southampton University Hospitals NHS Foundation Trust
  - Great Ormond Street Hospital for Children NHS Foundation Trust
  - Guy's and St. Thomas' NHS Foundation Trust



# Background

27. At our meeting held on 24 July 2012, we considered the JCPCTs decision and the associated Decision-Making Business Case.
28. At that meeting we heard from a range of interested parties that all contributed to the our consideration of the JCPCT's decision, including:
- Representatives from the JCPCT and supporting secretariat;
  - Parent representatives;
  - The Children's Heart Surgery Fund (CHSF);
  - Clinical representatives from Leeds Teaching Hospitals NHS Trust;
  - Other elected representatives.
29. The minutes from that meeting are attached as **Appendix 4**. The outcome from our July 2012 meeting and consideration of the available evidence is presented in the following sections of this report.

DRAFT



# Conclusions and Recommendations

## Overview

30. As the Joint Health Overview and Scrutiny Committee for Yorkshire and the Humber, **we represent the 15 top-tier authorities and the 5.5 million residents from across our region.**
31. Throughout our consideration of the proposals to reconfigure Children's Congenital Cardiac Services, we have sought to take account of a wide range of evidence and engage with a number of key stakeholders – to help in our understanding of the proposals and the likely implications across Yorkshire and the Humber.
32. At the time of publishing our initial report in October 2011, we reported that we had not been able to consider all the information we identified as being necessary to conclude our review ahead of the 5 October 2011 consultation deadline. Regrettably – even though the JCPCT's decision was made in July 2012 – **we still feel we have been denied access to information we believe to be relevant to the review and the associated decision-making processes.** We feel very strongly that such information should have been made available for general public scrutiny and certainly once it had been identified by a legitimate statutory body established to review decisions and decision-making within the NHS.
33. **We believe the approach adopted by the JCPCT and its supporting secretariat has, at times, been unhelpful and obstructive** – and well below the standards of openness and transparency we would expect from a publicly funded body, established to work in the interests of the public. As such, we are again stunned by the contempt displayed towards the legitimate public scrutiny of the review and its decision-making processes. **We believe that such behaviour should not be tolerated and a significant shift in organisational culture is required.**
34. **We challenge the JCPCT's assertion that it has been completely open and transparent in its decision-making** – not least of all due to the complete lack of any publicly available reports from the numerous meetings held in private, and the refusal to release the individual scores from Sir Professor Ian Kennedy's assessment panel members. A complaint has been lodged with the Information Commissioner's Office in this regard and our detailed views are outlined elsewhere in this report.
35. Nonetheless, this report has been compiled based on the evidence and information available to us at the time of its writing. Once again, **we reserve the right to add further comment and/or recommendations as and**



# Conclusions and Recommendations

**when any additional information we have requested or any other relevant details become available.**

36. We maintain that the Leeds Children's Hospital provides the most comprehensive range of clinical services for children suffering from congenital heart conditions. As such, **we believe the JCPCT's decision will result in a worsening in the level of service offered to children and families across Yorkshire and the Humber.** This is not necessarily as a result of the proposed model of care, but largely due to the range of services available at some of the alternative surgical centres identified for future designation.
37. We believe that without the retention of the surgical centre at Leeds Children's Hospital, **the overall patient experience for children and families across Yorkshire and the Humber will be significantly worse.** This belief is based on the following reasons:
- The range of interdependent surgical services, maternity and neonatal services are not co-located at proposed alternative surgical centres available to Yorkshire and the Humber children and their families;
  - Fragmentation of the already well established and very strong cardiac network across Yorkshire and the Humber;
  - The current seamless transition between cardiac services for children and adults across Yorkshire and the Humber;
  - Considerable additional journey times and travel costs – alongside associated increased accommodation, childcare and living expense costs and increased stress and strain on family life at an already difficult time.
38. As outlined in our previous report, we maintain that the decision of the JCPCT – insofar as it relates to the designation of children's congenital cardiac surgical centres and the establishment of associated clinical networks – will have a disproportionately negative impact on the children and families across Yorkshire and the Humber. Therefore, **we dispute the JCPCT's claim that its decision will lead to improved outcomes and services for all children across England.**
39. We would like to make it explicitly clear that our view of the JCPCT's decision is not based on any misguided loyalty towards the surgical centre at Leeds Children's Hospital – which has been an assertion made by members of the JCPCT and others. **Our view of the JCPCT's decision is primarily based on the best interests of children and families across Yorkshire and the Humber.** We believe that the JCPCT and its supporting secretariat has not grasped this fundamental and underlying principal to our work.
40. Given the JCPCT's decision and some of the assumptions set out in the decision-making business case, some of our arguments make reference to the





# Conclusions and Recommendations

surgical centre and facilities available at Newcastle. The purpose of any comparisons is to help demonstrate the likely impacts of the decision on children and families across Yorkshire and the Humber.

41. However, from our initial report and one of its principal recommendations, it is clear that we never saw this as a 'Leeds versus Newcastle' issue. We believe such a stance is too simplistic and therefore maintain and reinforce our original position detailed in our principal recommendations (Table 2). **We firmly believe that a North of England solution is needed, that recognises and reflects the demographics and geography of this part of the country.**
42. The structure of this report is based on the additional information we previously requested, namely:
- The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Professor Sir Ian Kennedy) – referred to as the 'Quality Scores'.
  - A finalised Health Impact Assessment report.
  - A detailed breakdown of the likely impacts on identified vulnerable groups across Yorkshire and the Humber highlighted in the Health Impact Assessment (interim report).
  - The Price Waterhouse Coopers (PwC) report that tested the assumed patient travel flows under each of the four options presented for public consultation.
43. **We also believe there are some significant flaws and anomalies in the JCPCT's decision-making processes, in addition to the issues around openness and transparency in decision-making referred to above.**

## Quality Scores

### Quality in the NHS

44. The emphasis on 'quality' has been a constant throughout the review process, with the overall assessment scores produced by the Independent Expert Panel (chaired by Professor Sir Ian Kennedy) – the Kennedy Panel, often and routinely been referred to as the 'quality scores' by the JCPCT and its supporting secretariat. However, we believe the JCPCT and its supporting secretariat have been somewhat disingenuous in this regard.
45. We recognise that service quality is an important consideration in all service reconfigurations. However, in considering quality we would like to refer to the National Quality Board's (NQB) recently published draft report – Quality in the new health system: Maintaining and improving quality from April 2013



# Conclusions and Recommendations

(published in August 2012) – which sets out the following three dimensions used to assess quality across the NHS:

- **clinical effectiveness** – quality care is care which is delivered according to the best evidence as to what is clinically effective in improving an individual's health outcomes;
- **safety** – quality care is care which is delivered so as to avoid all avoidable harm and risks to the individual's safety; and
- **patient experience** – quality care is care which looks to give the individual as positive an experience of receiving and recovering from the care as possible, including being treated according to what that individual wants or needs, and with compassion, dignity and respect.

46. The NQB's report makes reference to these dimensions forming a single definition of quality for the NHS – first set out in Lord Darzi's report – High quality care for all: NHS Next Stage Review final report (June 2008). The report goes on to state that the definition and dimensions of quality have since been embraced by staff throughout the NHS and subsequently by the Coalition Government.
47. We recognise that on the advice of the Safe and Sustainable Steering Group – i.e. that a meaningful analysis of outcome data was not possible due to the low volume of surgical procedures nationally and within centres, and because it would not adjust for risk factors that can have a bearing on outcomes such as the severity of the clinical condition of individual children – outcome data was not generally taken into account as part of the review. We also recognise that the NQB's report has only recently been published. Nonetheless, we believe the reference to a definition for quality that dates back to 2008 is very striking – as there appears to have been little reference to this definition of quality within the review process, and in particular the assessment process adopted by the Kennedy Panel.
48. We note the report from the panel of experts chaired by Mr James Pollock – that undertook a limited review of three centres following an analysis of mortality data provided by an independent third party – and acknowledge this work did not result in any changes to the assessment scores.
49. Nonetheless, given the JCPCT's continued and, in our opinion, over reliance on the Kennedy Panel's scores to define 'quality' at existing surgical centres, we do not believe there has been sufficient assessment of the definition and other dimensions of quality adopted across the NHS within the review in general and in particular within the methodology adopted by the Kennedy Panel. As such, **we would question whether the Kennedy Panel assessed quality in a way that is consistent with the definition and dimensions of quality**





# Conclusions and Recommendations

that the NQB advise us have '*...been embraced by staff throughout the NHS and subsequently by the Coalition Government.*', which essentially dates back to 2008.

## Kennedy Panel's detailed scoring

50. It has been clear to us from an early stage of our deliberations that **the overall assessment scores produced by the Kennedy Panel have been a material consideration for a significant proportion of the review process**. The Kennedy Panel scores were included in the original consultation document in the form of a 'league table' (page 82) and we believe these not only influenced the assessment of the configuration options determined as 'viable' by the JCPCT (as detailed on page 83 of the original consultation document), but they were presented in such a way (i.e. in the form of a league table) designed to influence public opinion regarding the reconfiguration options put forward.
51. Our repeated requests for the detailed breakdown of the Kennedy Panel scores are well known and have been well documented. Our concerns around being denied access to the detailed breakdown of this information was highlighted in our original report and previous referral to the Secretary of State for Health (October 2011).
52. In considering this aspect of our referral, we were disappointed with the initial advice provided by the Independent Reconfiguration Panel (IRP), which stated:
- 'Since the detailed breakdown of assessment scores has not been seen by the JCPCT, it was not material to the production of the consultation document, nor will it be material to the decision-making process. The JCPCT's commitment to release this information once it has made its final decisions is, in our view, reasonable.'***
53. While we accept the IRP's comments – insofar as the breakdown of the scores may not have been directly material to the production of the consultation document – it is clear that the overall scores were material and were presented in such a way as to influence public opinion. Given the significance that the JCPCT has attached to the Kennedy Panel scores – as evidenced in the decision-making business case – **we maintain that the detailed breakdown of the Kennedy Panel scores should have been made available to us at the time of our original request**. Indeed, since the JCPCT's decision on 4 July 2012, our view in this regard has strengthened significantly.
54. During the period of public consultation, we questioned the JCPCT's rationale for not considering the detailed Kennedy Panel scores before agreeing the options for consultation. Not only do we believe this to have been a poor error of judgement, but **we also believe the JCPCT failed to sufficiently assure**



# Conclusions and Recommendations

**itself of the robustness of the Kennedy Panel scores and ensure they were fit for purpose.** We believe these to be fundamental aspects of the JCPCT's before using such details to significantly determine the options presented for public consultation.

Post the JCPCT's 4 July 2012 decision

55. Since the JCPCT's decision-making meeting, we have been able to gain access to more information – including the detailed breakdown of the Kennedy Panel scores we originally sort. However, we should point out that this in itself was not straightforward, as we were presented with different versions where the sub-scores simply did not add up. We assume this was human error rather than anything more deliberate or cynical. However, we believe providing the information originally requested at least 12-months earlier, should have been handled in a much better and less confusing way.
56. We believe we have now had access to the 'original' and 're-weighted' Kennedy Panel scores. The 're-weighted' scores were produced as part of the sensitivity testing work undertaken by the JCPCT and its supporting secretariat. It should be noted that we have also gained access to copies of the minutes from formal meetings held by the JCPCT since its establishment.
57. However, we have not gained access to all the reports we have requested – nor have we been given access to the detailed scoring of individual members of the Kennedy Panel, as requested. In this regard, we wish to highlight the following comments from the Safe and Sustainable Programme Director, in his letter to the Chair of the Joint HOSC, dated 17 August 2012:  
  
***'I have considered whether the request for disclosure of the individual scores by panel members is reasonable for the purpose of scrutinising the JCPCT's decision. I have decided not to disclose the individual scores as the panel members were not asked to submit individual scores to the secretariat or to the JCPCT...'***
58. Once again, we believe this demonstrates a level of disregard to open and transparent decision-making that is wholly unacceptable, and we would question the rationale of the Programme Director's decision.
59. Nonetheless, we have gained access to some additional information and our original **concerns regarding 'the quality scores' and the JCPCT's reliance on such information within its decision-making processes have been exacerbated.**
60. As previously outlined, during the period of public consultation, we questioned the JCPCT's rationale for not considering the detailed Kennedy Panel scores before agreeing the options for consultation. However having considered the



# Conclusions and Recommendations

details of the minutes from the JCPCT meeting on 28 September 2010, we now believe that the JCPCT's actions – based on the advice of Professor Sir Ian Kennedy – were an attempt to make the JCPCT less susceptible to legal challenge regarding the 'quality scores'. Given the significance placed on the Kennedy Panel scores by the JCPCT, **we believe such behaviour is not in the spirit of open and transparent decision-making and feel the JCPCT has been somewhat Machiavellian in its approach to this part of the review and decision-making processes.** Consequently, we believe the JCPCT has not conducted all its business in a manner we would expect from a publicly funded body, established to work in the interests of the public.

61. We also believe that the JCPCT's decision to deny itself access to the detailed Kennedy Panel scores – and subsequent use of this decision to deny us (and others) access to the information – effectively prevented public scrutiny of such information at a more appropriate time (i.e. during the period of public consultation). We recognise that at the time of the IRP's initial assessment of our previous referral, the significance of the detailed Kennedy Panel scores and the JCPCT's rationale for denying itself access to such information, may not have been apparent. **Therefore we would ask that the IRP reconsiders the advice previously provided to the Secretary of State for Health in this regard.**

## Consideration of the Kennedy Panel scores within the decision-making business case

62. It is clear to us that the overall Kennedy Panel scores have been a significant and material consideration throughout the review and decision-making processes. Having finally received the 'original' and 're-weighted' Kennedy Panel scores, we have now been able to consider these in detail. A summary analysis of the Kennedy Panel scores is presented at **Appendix 5**.
63. By its very nature the term 'quality' can be a very subjective. It follows, therefore, that the assessment of 'quality' is also likely to be subjective without a clear definition of what constitutes 'quality'. Nonetheless, as outlined previously, the National Quality Board (NQB) has recently published three domains used to assess quality across the NHS – which have their routes in report published by Lord Darzi back in 2008. We believe the quality of surgical centres should have been assessed against the criteria embraced and used more generally across the NHS.
64. However, there appears to have been little reference to the generally accepted definition and dimensions within the assessment process adopted by the Kennedy Panel. Nevertheless, there are numerous referrals within the decision-making business case that states the Kennedy Panel scores provide an assessment of surgical centres' compliance with the Safe and Sustainable



# Conclusions and Recommendations

designation service standards. However, the analysis provided at **Appendix 5** demonstrates that the Kennedy Panel scores did not just assess centre's compliance with the service standards. We wish to specifically highlight the following points:

- The assessment of centres' current performance against the service standards represents 16% (100 out of a possible total of 610) of the original assessment score and 17% (103 out of a possible 609) of the re-weighted scores. (see *Appendix 5 – Table D and Table F*)
- The assessment of centres' development plans against the service standards represents 16% of both the original and re-weighted assessment scores – 100 out of a possible total of 610 and 100 out of a possible 609, respectively. (see *Appendix 5 – Table D and Table G*)
- The assessment of the impact of increased activity against the service standards (i.e. ability to meet the minimum of 400 surgical procedures) represents 48% (290 out of a possible total of 610) of the original assessment score and 50% (304 out of a possible 609) of the re-weighted scores. (see *Appendix 5 – Table D and Table H*)
- The 'Leadership and Strategic Vision' criterion (which does not form part of the service standards) has been a significant factor in the assessment scores – representing 20% (120 out of a possible total of 610) of the original assessment scores and 17% (102 out of a possible 609) of the re-weighted scores. (see *Appendix 5 – Table C1 and Table C2*)
- When presenting the outcome of the assessment visits to the JCPCT meeting on 7 July 2010, Sir Ian Kennedy highlighted the following key themes identified during the panel's work:
  - The importance of a seamless transition between antenatal diagnosis through to adult services – meaning the fragmentation of pathways should be avoided;
  - The need for a sustainable workforce (including nursing);
  - The importance of formal network arrangements;
  - The size of centres was important to ensure sufficient experience among surgeons.

However, it was also highlighted that these themes had not affected the quality scores. We question the methodology of an assessment approach that identifies key themes, but then fails to recognise such themes within the final assessment score.

65. We believe it is important that these details – in particular the 'Leadership and Strategic Vision' criterion, which does not form part of the service standards – should be considered in the context of the 'Strength of Network' criterion, which represents 12% and 10% of the original and re-weighted assessment scores, respectively. We believe this is particularly relevant given the comments of the





# Conclusions and Recommendations

Chair of the JCPCT at its decision-making meeting on 4 July 2012, when stressing the 'importance of teams and people' in delivering successful outcomes.

66. Given the Kennedy Panel's role was to assess 'quality' at each of the existing surgical centres and the well used quote from Professor Sir Ian Kennedy, '...[that] mediocrity must not be our benchmark...', we believe it is interesting that each of the following criterion represent significantly less of the overall 'quality scores' than the 'Leadership and Strategic Vision':
- Strength of network
  - Facilities and capacity
  - Ensuring excellent care
  - Age appropriate care
  - Information and choices
67. It is not clear where the Kennedy Panel weightings were agreed and whether these were tested with any other stakeholders – the rationale is unclear. We believe that if deviating from the defined assessment of NHS quality suggested by Darzi and the NQB, the agreed clinical standards provide the best overall definition of quality – particularly given the associated endorsements from relevant professional bodies. As such, we do not understand why the clinical standards – and current performance against those standards – have not featured more highly within the assessment process. Nor do we understand why the 'Leadership and Strategic Vision' criterion – which does not form part of the service standards – has been ranked and weighted so highly. Given the significance attached to the 'quality scores' within the decision-making processes, **we question whether these proportions reflect a definition of 'quality' recognisable to children and families currently accessing the service, or the public in general.**
68. Nonetheless, it is clear that within the Kennedy Panel's (and therefore the JCPCT's) overall assessment of 'quality', the 'Leadership and Strategic Vision' criterion has had a significant impact on the overall 'quality scores'. However, we believe it should be noted that some of the Trusts assessed are NHS Foundation Trust and some are not – which we believe should be a significant consideration in the respective scores for different surgical centres. However, it is unclear if/ how 'Trust status' has been taken into account and reflected in the assessment scores for 'Leadership and Strategic Vision'.
69. It should be noted that we are not suggesting that the Kennedy Panel did not identify any relevant issues around Leadership and Strategic Vision; however, we are questioning the significance and weightings applied as part of the assessment of quality. We believe matters around Leadership and Strategic Vision could have equally been identified and addressed as part of the



# Conclusions and Recommendations

implementation phase of the review – as has been the case for other important matters.

70. Once again, had we not been denied access to the detailed scores until after the JCPCT's decision, we believe it would have been more appropriate for these matters to have been considered during the original consultation period.

## Report of the Independent Expert Panel, Chaired by Professor Sir Ian Kennedy (December 2012)

71. We believe it is worth being explicit that the Kennedy Panel report (and subsequent scores) is based on the assessment of the 'core' service standards for designation. A detailed breakdown of the proportion of 'core' standards – as they related to the (then) total number of service standards – is presented at **Appendix 5**. However, we feel it is worth highlighting that **service quality has been assessed using less than 35% of the total number of service standards**.
72. Having had access to the detailed scores from the Kennedy Panel to consider alongside the December 2010 report, we believe it is also useful to highlight the following general observations.
- The Panel did not seek to compare centres as it made its deliberations – yet the assessments have explicitly been used for that purpose. It is also unclear whether or not the Panel used a 'model answer' or attempted to define what constituted an 'exemplary response'. We believe this is particularly unclear in terms of the assessment of the impact of increased activity against the service standards (i.e. ability to meet the minimum of 400 surgical procedures). We believe this is particularly relevant, given this element of scoring represents 48% (290 out of a possible total of 610) of the original assessment score and 50% (304 out of a possible 609) of the re-weighted scores.
  - The Panel received a briefing on 20 May 2010, which included an outline of the 'importance of ensuring the process is transparent, proportionate and fair.' – our experience suggests the process has been anything other than 'transparent'. Due to the lack of transparency, it is difficult to comment (with any certainty) on whether the process has been 'proportionate and fair'.
  - We believe it is difficult to see how the comments detailed in the December 2010 report have been translated into the detailed assessment scores. We believe the details warrant further and more detailed scrutiny – something we have been attempting to undertake for over 18 months.



# Conclusions and Recommendations

Care Quality Commission – review of compliance at University Hospitals Bristol NHS Foundation Trust (October 2012)

73. We are aware that, in October 2012 – following an inspection at Bristol Royal Children's Hospital, the Care Quality Commission (CQC) issued a formal warning to University Hospitals Bristol NHS Foundation Trust. The formal warning was in relation to staffing levels on the children's cardiac ward (ward 32) at Bristol Royal Children's Hospital and we note that the CQC found the Trust had been failing to meet three essential standards of quality and safety covering:
- **Staffing levels** – with not enough qualified, skilled and experienced staff to meet patients' needs. In addition, the Trust did not have a designated high dependency unit to provide care to children who may require closer observation and monitoring than is usually.
  - **Staff training and support** – it was found that staff were not supported to deliver care and treatment safely and to an appropriate standard. Several members of staff expressed concerns about the lack of specialist training for doctors, registered nurses and health care assistants in children's cardiac care or high dependency care.
  - **The overall care and welfare of patients** – while patients were generally safe, there were inherent risks to health and wellbeing which the Trust had been aware of for some time, but had not effectively addressed.
74. We also note that the Trust has since reduced the number of beds on the ward from 16 to 12 and decided to reduce its programme of cardiac surgery in line with the new bed capacity.
75. Although we have not considered the CQC's report and the Trust's response in detail, we are saddened that children and families accessing children's cardiac services at Bristol Royal Children's Hospital have not received the necessary standards and quality of care. However, in light of the CQC's report, we feel we must question the accuracy and validity of the Kennedy Panel's assessment, which does not appear to have identified any similar issues, and in many cases describes the services on offer as 'good'.
76. We recognise that the Kennedy Panel's assessment (site visit 28 May 2010) and the CQC inspection (site visit 5 September 2012) present information from different points in time, however given the significance placed on the Kennedy Panel scores (by the JCPCT) to define 'quality', we believe the findings of the CQC are significant and warrant further and more detailed scrutiny of the Kennedy Panel scores – something that we have been attempting to undertake for over 18 months.



# Conclusions and Recommendations

## The Health Impact Assessment (June (2012))

77. Prior to finalising our October 2011 report, we requested a finalised Health Impact Assessment (HIA) report. We note that this was published in June 2012, with extracts included in the JCPCT's decision-making business case – including a summary of the impacts on pages 82 and 83. This details 12 different reconfiguration models (7 different 7-site models; 3 different 8-site models; 2 different 6-site models). The public consultation document proposed 4 different reconfiguration models – 2 different 7-site models and 2 different 6-site models. As such, **we believe it is worth highlighting that the majority of options (8 from 12), where the health impacts have been assessed, have not been tested through public consultation.**
78. We are disappointed to note that the 8-centre option recommended in our response to the consultation and detailed in our original report (October 2011) has not been the subject of a detailed HIA. We are also disappointed that a similar HIA – based on the existing configuration of surgical centres – was not presented for comparative purposes. We believe this would have proved extremely useful to those seeking to compare the impacts of alternative models, relative to the current provision.
79. Nonetheless, **we believe that the HIA demonstrates that, in those proposed models where the surgical centre in Leeds is retained, the negative impacts are less when compared to similar models where the surgical centre in Leeds is not retained.** We believe this supports our comments about the fundamental principals of planning health services – i.e. they should be located.
80. We recognise a summary of impacts by vulnerable group is presented in Table 17.4 of the HIA. While our comments in this regard are detailed elsewhere in this report, we are disappointed to see there is no comparison of the impacts across different regions/ areas highlighted in the table.
81. **We also believe there has been insufficient consideration of the impacts of the various options on the capacity of ambulance/ patient transport services.** This is reflected in the minimal comments highlighted on pages 75 and 76 of the HIA.
82. We believe there is evidence of conflicting information and at least one anomaly within then the HIA report, compared to the decision-making business base. This relates to Option G – and the patient flows from the 'NG' and 'LN' postcodes. These areas are highlighted as being in different networks in the HIA (Leeds network) and the decision-making business base (Birmingham network). At best this is sloppy and misleading to the those outside of the





# Conclusions and Recommendations

decision-making processes and, at worst, could call into question the validity of other data presented and relied upon in both documents.

83. Furthermore, we have identified further errors in the HIA – relating to Table 4.2 (Increased volumes of paediatric cardiac procedures by hospital network). The table seeks to present increases and decreases across different surgical centres – however the total number of procedures remains constant. As such, the sum of the various increases and decreases within each option should total 'zero'. This is not the case for any of the options presented, with a maximum error of 93 additional procedures (under Option B). We have been advised that this is an administrative error with no material impact. Once again, **we believe the best case scenario is that this is sloppy and potentially misleading presentation.**
84. Our comments regarding the likely impacts on identified vulnerable groups across Yorkshire and the Humber, and the issues highlighted in the Price Waterhouse Coopers report around patient flows and clinical networks, are detailed elsewhere in the report.

## Likely impacts on identified vulnerable groups across Yorkshire and the Humber

85. Prior to submitting our previous report, we sought additional, and in our view essential, information on the following vulnerable groups highlighted in the Health Impact Assessment (HIA) Interim Report:
- *Children (under 16s) who are the primary recipient of the services under review and, therefore, most sensitive to service changes;*
  - *People who experience socio-economic deprivation;*
  - *People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;*
  - *Mothers who smoke during pregnancy; and*
  - *Mothers who are obese during pregnancy;*
- These groups are defined as vulnerable groups because they are more likely to need the services under review and, are most likely to experience disproportionate impacts.*
86. We maintain our position as previously stated and set out in our initial report (October 2011).
87. However, we have subsequently received the following details outlined in the IRP's referral advice (dated 13 January 2012), which states:

***'The information requested was not held and, having considered the Joint HOSC's request, the JCPCT concluded that the HIA process***



# Conclusions and Recommendations

***would not benefit from this additional analysis, nor would it be equitable to commission it for one area only. The Panel agrees with this position on the basis that the final HIA report is suitably comprehensive.'***

88. We were disappointed with the IRP's advice in this regard and at the time found it hard to believe that the information requested was not available, at least on a regional basis.
89. Subsequently, some information in this regard appears in the published appendices to the final HIA (dated November 2011) – available on the Safe and Sustainable website – which includes the following information:
- *Appendix A. Stakeholder forums invitation lists*
  - *Appendix B. Stakeholder Consultation Findings*
  - *Appendix C. Service demand and 'at risk' patient groups*
  - **Appendix D. Postcode districts and vulnerable groups**
  - *Appendix E. Carbon Assessment*
90. Table 4 (below) summarises the 'issue and revision' information detailed in the appendices document. From the details above, we do not feel it is unreasonable to assume that the information we requested may have been available at the time of request, and almost certainly became available at some point relatively soon after. Given we made a specific request for this information, we believe the JCPCT and its supporting secretariat had a responsibility to ensure we were provided with any associated information as soon as it became available. This was not the case – even once we requested all previous draft version of the HIA. We believe this reflects the, sometimes, less than helpful approach taken when dealing with our legitimate requests.

**Table 3:** HIA appendices issue and revision information

Revision	Date	Originator	Checker	Approver	Description
1	30/11/11	JD	KS	BN	Draft
2	01/06/12	JD	KS	BN	Draft
3	20/06/12	JD	IS	BN	Final version

91. While the HIA concludes that the differences between the options are 'fairly marginal', we believe this is based on the assessment of total numbers affected, rather than an analysis and assessment of the affects in different regions. Nonetheless, we believe the details presented via the various maps outlined in the final HIA report support our previously held view, that Yorkshire and the Humber has a significant concentration of vulnerable groups, including large South Asian populations in Kirklees, Bradford and Leeds who we know are more susceptible to congenital cardiac conditions.



# Conclusions and Recommendations

92. As such **we believe the JCPCT's decision will have a disproportionately negative impact on the vulnerable groups across Yorkshire and the Humber.**

## **The Price Waterhouse Coopers (PwC) report – patient flows and clinical networks**

93. As outlined earlier in this report, we considered the PwC report that tested the assumed patient travel flows and manageable clinical networks at our meeting on 19 December 2011. The outcome of our deliberations was issued to the JCPCT in April 2012 and is attached at **Appendix 3.**
94. **We welcome the findings of PwC, which we believe supports our previously reported view, that children and families from across Yorkshire and the Humber will not travel to the surgical centres assumed by the JCPCT (in particular Newcastle) ahead of the public consultation.** We still believe this to be the case and have significant reservations about the ability of the Newcastle surgical centre to achieve the minimum of 400 surgical procedures set out in the designation standard. Should this standard be upheld and the Newcastle surgical centre fail to achieve it, **we believe the option agreed by the JCPCT is at significant risk of being unsustainable in the future.**
95. As mentioned previously, despite clear advice from the IRP that any additional comments we provided regarding the PwC report should be taken into account, within the JCPCT's response to our initial report there is no reference to our comments in this regard. **We can only conclude that the comments provided have not been considered by the JCPCT.**

### Patient flows

96. The proposed patient flows for the option agreed by the JCPCT are based on the 2010/11 CCAD data. While we have the total number of procedures – broken down by surgical centre, for 2010/11 (detailed in **Appendix 6**) – we have not received the detailed postcode analysis provide for the four proposed options presented in the consultation document. However, based on the 2010/11 CCAD data (and a total of 3740 procedures (approx.) per annum), page 158 of the decision-making business case details the projected number of procedure per surgical centre under each of the 12 options considered.
97. Under the agreed option, the Newcastle network is forecast to undertake 559 procedures – including a significant proportion of the 336 procedures undertaken at the Leeds surgical centre.



# Conclusions and Recommendations

98. We recognise that, given the feedback it received during the public consultation and the outcome of the PwC report, the JCPCT has sort to explore the issue of patient flow and manageable networks in more detail. This is primarily presented by way of a sensitivity test (Sensitivity F) detailed in the decision-making business case. **However, we have some significant concerns regarding the validity of 'Sensitivity F' as follows:**

- Given the outcome of the additional work/ analysis undertaken by PwC, we do not understand the rationale for assuming 25% of patients from Doncaster (DN), Leeds (LS), Sheffield (S) and Wakefield (WF) will flow to Newcastle. In addition, **it would only take a further shift of less than 2% from the DN, LS, S and WF postcode areas to render the Newcastle centre unsustainable against the minimum number of 400 procedures per annum.**
- In addition, the sensitivity test takes no account of patients from the Hull (HU) and Halifax (HX) postcode areas – who, as highlighted in our previous report, are equally as likely to choose an alternative surgical centre to Newcastle. We estimate this could be in the region of between 27 and 36 patients per annum – casting further doubt on the Newcastle centre's ability to achieve the minimum number of 400 procedures per annum. In addition, **given the PwC report highlights that, under options A, B and C, patients from the East Coast in particular would experience an increased risk due to extended travel times, we would question why such risks do not appear to have been reflected in the sensitivity tests undertaken.**
- Combining these issues suggests there could be a net reduction of between 183 and 244 procedures per annum against the projected activity levels at Newcastle – resulting in the surgical centre undertaking between 376 and 315 procedures per year. This does not take into account any other potential reductions arising from elsewhere across Yorkshire and the Humber, yet still **casts significant doubt on the Newcastle centre's ability to achieve the minimum number of 400 procedures per annum.**
- **The impact would result in Option B failing to score against 'sustainability' and reducing the overall score to 211, with Option G becoming the highest scoring option.**
- Notwithstanding the points above, there are also a number of arithmetical errors evident in 'Sensitivity F'. For example, additional patient numbers (arising from a reduced number of patients allocated to the Newcastle network) have been included in the Liverpool projections rather than the Birmingham network. Using the recalculated net reduction of between 183 and 244 procedures for Newcastle could have a significant impact on the Birmingham and/or Liverpool networks, with





# Conclusions and Recommendations

increased activity resulting in the total number of procedures for Birmingham of anywhere between 794 and 855 procedures, or at the Liverpool surgical centre of anywhere between 662 and 723 procedures. Clearly **this could also result in too onerous a caseload for a surgical centre – again rendering Option B unsustainable.**

99. **We believe the above points cast sufficient doubt on this part of the sensitivity testing undertaken by the JCPCT and its supporting secretariat.** It is unclear what impact this might have had on the JCPCT's final decision, but we believe these points are particularly interesting in the context of the comment made by the Chair of the JCPCT at its meeting on 1 September 2012, where it was stated '*...it would [be] pointless to devise a network of centres that people would not use...*'. Therefore we believe this needs further and more detailed consideration by the IRP.

## Services for Adults with Congenital Heart Disease (ACHD)

100. We believe the PwC report also corroborates our previous view that **the adult and children's congenital cardiac services (or at least the outcomes of the separate reviews) should be considered together**, in order to determine a configuration of surgical centres across England that meets the needs of both service areas – without the decisions from one review, pre-determined the outcome of the other.
101. This is also supported by the BCCA, which has consistently called for the services for ACHD to be considered alongside the review of services for children.

***'It has become increasingly clear throughout this review that paediatric cardiac surgery cannot be considered in isolation and that numerous inter-dependencies between key clinical services (from fetus to adult) must be reflected in the final decision. The BCCA welcomes the recognition by the review that the linking of paediatric and adult cardiac services is integral to providing high quality care. It is important that the centres designated to provide paediatric cardiac surgery must be equipped to deal with all of the needs of increasingly complex patients. For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential.'***

102. Given the BCCA's position regarding the respective reviews for children and adults, we believe in its response to our previous report, the JCPCT has adopted an unhelpful 'pick and mix' approach to the comments and views from the BCCA, on which it relies.



# Conclusions and Recommendations

103. While we accept the JCPCT's advice that it was not established with the legal powers to incorporate services for adults within its remit, **we feel very strongly that, once issues had been raised with the JCPCT regarding the obvious links between the two reviews, the JCPCT could (and in our view, should) have been more proactive in seeking to resolve this matter.** We also believe that the delays in the review process – primarily caused by the various legal proceedings – presented a good opportunity for the JCPCT to 'do the right thing' in this regard.
104. Nonetheless, we maintain that, if the suggested minimum number of 400 surgical procedures were continued to be applied, **the current (and increasing) level of adult surgical procedures carried out across England would be enough to justify retaining another two surgical centres.**
- Manageable networks
105. The PwC report highlights that referrers interviewed suggested the most well developed clinical networks are those related to centres (including Leeds) more likely not to continue as specialist surgical centres under the options presented for public consultation. We believe this supports our previously expressed view that it is completely illogical to fragment the existing strong cardiac network arrangements across Yorkshire and the Humber.
106. We believe that, in any service review and reconfiguration, it is important to have a clear view of the strengths of the current arrangements and for these to be retained and built upon as part of the future service model. With regard to clinical networks, we do not believe this is reflected in the JCPCT's decision.
107. We note the JCPCT's sensitivity test (Sensitivity C), which purports to '*assume significant risks to the manageability of the Newcastle network and that the quality sub-criteria are equally weighted*'. However, we believe that if the risks associated with the manageability of the Newcastle network and the quality sub-criteria are equally weighted, this would result in a reduction in the 'total score for quality' for Option B (from 3 to 2). In turn, this would result in a reduction of the overall score from 286 (as presented) to 247 – **with Option G becoming the highest scoring option on 278.**
108. Again, it is unclear what impact this might have had on the JCPCT's final decision, however **we believe this casts sufficient doubt on this part of the sensitivity testing undertaken by the JCPCT and its supporting secretariat** that it warrants further and more detailed consideration by the IRP.



# Conclusions and Recommendations

## Other matters – including those previously considered in the October 2011 report

109. We have considered a range of other issues, including those highlighted in our first report (October 2011). For ease of reference, and in light of the additional information now available, we have attempted to consider these issues in a similar order to our previous report. As such, the issues considered in this section of the report relate to:

- Co-location of services;
- Caseloads;
- Population density;
- Vulnerable groups;
- Travel and access to services;
- Costs to the NHS;
- The impact on children, families and friends;
- Established congenital cardiac networks;
- Adults with congenital cardiac disease;
- Views of the people of the Yorkshire and Humber region;
- Nationally Commissioned Services
- Services to Scotland and at Yorkhill Hospital, Glasgow
- Implementation

### Co-location of services

110. As previously reported, it is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions.

111. We acknowledge the JCPCT's response to our previous comments and concerns regarding the co-location of services – summarised in its response to us, dated 18 July 2012, and detailed in the reconsideration of issues around co-location (Appendix V within the decision-making business case).

112. However, in considering the issue of co-location, we maintain that the JCPCT has been selective in both its use of the views from others and general interpretation of co-location.

113. As outlined in our previous report, we considered some aspects of Bristol Royal Infirmary Inquiry report (often referred to as the Kennedy Report (2001)) and were particularly struck by recommendation 178 within that report, which states:

***'Children's acute hospital services should ideally be located in a children's hospital, which should be as close as possible to***



# Conclusions and Recommendations

***an acute general hospital. This should be the preferred model for the future.'***

114. We would still argue that the public would generally consider co-location to mean just that – services co-located on a single site. We believe that including centres where such services may be located over multiple hospital sites within that definition of co-location is misleading and disingenuous.
115. With regard to the co-location of services, we would make particular reference to the British Congenital Cardiac Association (BCCA) statement, dated 18 February 2011, which states:
- 'It is important that the centres designated to provide paediatric cardiac surgery must be equipped to deal with all of the needs of increasingly complex patients. For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential.'***
116. As outlined in our previous report, currently children from across Yorkshire and the Humber access surgical and interdependent services in a children's hospital within an acute general hospital (Leeds General Infirmary) on one hospital site. All children's acute services are *genuinely co-located* in Leeds alongside maternity services, which is essential for the wellbeing of mother and baby if cardiac interventions are required at birth.
117. As previously advised by the Yorkshire and Humber Congenital Cardiac Board (the regional network body), any option without a surgical centre in Leeds will offer inferior co-location of services for patients and families from Yorkshire and the Humber. This will have a detrimental impact on the access to services and the overall patient experience compared to the current service in Leeds. We understand that the range of interdependent surgical services, maternity and neonatal services are not co-located at proposed alternative surgical centres available to Yorkshire and the Humber children and their families. As such, **we believe the JCPCT's decision – if implemented – represents a worsening of services available to children and families across Yorkshire and the Humber.**
118. We understand that with maternity services located on a different hospital site to paediatric cardiac surgery services at Newcastle. Anecdotal, this could lead to an increased number of planned caesarean sections, with some doubts over obstetric referrals to Newcastle as a result. We would again question whether this would lead to improved outcomes for children and families across Yorkshire and the Humber.





# Conclusions and Recommendations

119. In our previous report, we made reference to the importance of a bond between a mother and new born child. While we would like to reinforce the points made, we do not intend to repeat any of the information previously provided. However, in its response to our previous report, the JCPCT makes reference to the service standards B3, B8, B9 and B10 – which all relate to prenatal diagnosis and associated issues: However, we note that in its assessment of quality, the Kennedy Panel only considered B3 as a core standard for assessment. As such, **we do not believe that the JCPCT has considered the issues associated with the bond between mother and child in sufficient detail within its decision-making processes.**
120. More detailed consideration of the Kennedy Panel assessment of quality is presented elsewhere in this report. Nonetheless, we question a scoring methodology that attaches significantly greater weighting to 'Leadership and Strategic Vision' than is attached to other, and in our opinion, more important factors such as 'Strength of Network', 'Facilities and Capacity' and 'Excellent Care' – with the latter receiving only 50% of the weighting of Leadership and Strategic Vision'. We do not believe that the weightings attached to the various components of the Kennedy Panel's assessment of quality are in line with the public definition of quality. Indeed, **we have not been presented with any evidence to suggest there was any patient and public involvement in determining the weightings applied by the Kennedy Panel.**
- Caseloads
121. From the information available from the Central Cardiac Audit Database (CCAD) – attached at **Appendix 7** – in 2009/10 and 2010/11 the Leeds surgical centre delivered 316 and 336 paediatric cardiac surgical procedures, respectively. This represented approximately 9% of the national caseload. The surgical centre also delivered 179 (2009/10) and 184 (2010/11) interventional cardiology procedures. In terms of services to adults the Leeds surgical centre delivered 78 surgical procedures and 138 interventional cardiology procedures.
122. In contrast the Newcastle surgical centre delivered 255 and 271 surgical procedures in 2009/10 and 2010/11, respectively – representing approximately 7% of the national caseload. The surgical centre also delivered 107 (2009/10) and 93 (2010/11) interventional cardiology procedures. In terms of services to adults the Newcastle surgical centre delivered 69 surgical procedures and 67 interventional cardiology procedures.
123. From this information, it is clear that not only does the surgical centre in Yorkshire and the Humber benefit from a significantly larger population catchment area, it is a larger surgical centre – benefiting from larger caseloads of cardiac surgery and interventional cardiology procedures – for both paediatrics and adults.



# Conclusions and Recommendations

124. Over the two years (2009/10 and 2010/11) the Leeds surgical centre undertook approaching 25% more paediatric cardiac procedures and over 80% more interventional cardiology procedures.
125. In terms of adults, the Leeds surgical centre delivered 13% more cardiac procedures and 106% more interventional cardiology procedures.
126. We believe that, compared to the surgical centre at Newcastle, the surgical centre at Leeds is larger in every way. Notwithstanding the issues and principals associated with sound health planning, **we believe an approach that (effectively) merges a larger surgical centre with a smaller surgical centre – while maintaining the smaller centre as the host – is completely illogical.** Drawing on our experience of other – albeit unrelated – service reconfiguration proposals, we are unable to identify any that have suggested such an approach.

## Population density

127. We have already stated on numerous occasions that the population of Yorkshire and the Humber is in the region of 5.5 million people. As outlined in our previous report, it should also be recognised that a total population of around 14 million people are within a 2-hour drive of the current surgical centre at Leeds. In planning the delivery of NHS services and to help ensure we make best use of public resources, it would seem logical to ensure that specialist surgical centres are located within areas of higher population – and therefore demand. We do not believe that the JCPCT has taken sufficient account of population density within its decision-making processes and, once again, we make reference to the statement and advice from the BCCA, dated 18 February 2011, which has seemingly been ignored:

***'The quality of service is key and where possible, the location of units providing paediatric cardiac surgery should reflect the distribution of the population to minimise disruption and strain on families.'***

128. In its response to our previous report and the concerns raised, the JCPCT makes reference to 'the quality of services' being the most important consideration for the JCPCT – rather than population density or convenience and travel. While we understand the importance of service quality (which is considered elsewhere in this report), we have already outlined our **concerns that children and families from Yorkshire and the Humber will not receive improved services.** Furthermore, we would argue that matters of access and the associated practicalities are equally important to consider: There would seem little point in developing the highest quality service in areas of the country where less of the population can benefit from such quality.



# Conclusions and Recommendations

129. We also note with interest the reference to the analysis of future activity projections and the associated population growth within Appendix Y of the decision-making business case. However, we are concerned that within this section of the decision-making business case, it is stated that 'Future growth has not been projected at postcode level, but nationally' and '...for planning purposes, at this stage in the process this level of detail is not required...'.
130. We would be extremely interested to know at what point within the decision-making process, more detailed population growth figures start to become necessary. In our view, **the JCPCT has not only been misadvised, but it has been negligent by not taking account of more detailed predictions of population growth.** In particular, we would make reference to the following sub-national population projections available from the Office for National Statistics – which compares the projections for Yorkshire and the Humber against those for the North East.

**Table 4:** 2010-based Sub- national Population Projections for All England, Yorkshire and the Humber and the North East taken from the Office for National Statistics

AREA NAME	AGE GROUP	2010	2025	%age change
All England	All ages	52,213	58,607	12%
	0 to 4	3,267	3,485	7%
	5 to 9	2,903	3,561	23%
	10 to 14	2,981	3,564	20%
	<b>Sub-total 0 to 14</b>	<b>9061</b>	<b>10610</b>	<b>17%</b>
North East	All ages	2,587	2,717	5%
	0 to 4	148	148	0%
	5 to 9	135	157	16%
	10 to 14	144	160	11%
	<b>Sub-total 0 to 14</b>	<b>427</b>	<b>465</b>	<b>9%</b>
Yorkshire and The Humber	All ages	5,247	5,729	9%
	0 to 4	321	336	5%
	5 to 9	287	347	17%
	10 to 14	300	348	16%
	<b>Sub-total 0 to 14</b>	<b>908</b>	<b>1031</b>	<b>14%</b>
NB Population figures presented in thousands (to one decimal place). Percentages rounded to full percentage points.				



# Conclusions and Recommendations

131. The details in Table 3 suggest a potentially larger increase in the volume of paediatric cardiac surgery activity than that identified in the JCPCT's decision-making business case – 17% as opposed to 14% (approx.). **We believe this demonstrates significant and material differences in the population projections for Yorkshire and the Humber compared to the North East of England.** Moreover, we believe that the JCPCT should have considered this level of detail as part of its decision-making processes and included this within the decision-making business case.
132. We have also considered the Heath Impact Assessment report (June 2012) prepared by Mott MacDonald, and summarised with the decision-making business case. From this information, it is clear to us that population density is a determinant on the impact of proposals – both generally and across vulnerable groups. However, it is unclear if/how projected population growth has been taken into account when determining the impacts of the various configurations of designated surgical centres.
133. Furthermore, and as outlined in our previous report, in terms of delivering sustainable networks, it seems logical that it will be more difficult to deliver care closer to home and share expertise, if the surgeons are more remotely located from their patients and the staff in the proposed district children's cardiology centres.
134. However, as previously reported, we would not wish to see issues that would affect children and families across Yorkshire and the Humber simply transferred to other areas of the country. **We believe this further strengthens the case for a North of England solution that recognises and reflects the demographics and geography of this part of the country.**

## Vulnerable Groups

135. Our comments in this regard are detailed elsewhere in this report.

## Travel and access to services

136. Overall, we reaffirm our belief that as a result of the JCPCT's decision, children and families from across Yorkshire and the Humber will be disproportionately and consistently disadvantaged in terms of access and travel times. **We believe that extending travel times and the complexity of journeys is likely to place additional strain on children and families across Yorkshire and the Humber, at what will already be a particularly stressful time.** As previously reported, we believe this is both unreasonable and unnecessary.



# Conclusions and Recommendations

137. We reinforce our previous points about the excellent transport links to and from the Leeds, and would highlight the significant impact recent flooding had on access to Newcastle via the A1.
138. As such, as outlined in our previous report and mentioned elsewhere in this report, we would not wish to see issues that would affect children and families across Yorkshire and the Humber simply transferred to other areas of the country. **We believe this further strengthens the case for a North of England solution that recognises and reflects the demographics and geography of this part of the country.**
139. In our previous report, we made reference to the evidence we had received from Embrace<sup>2</sup> that suggested under Consultation Option B (the option subsequently agreed for implementation by the JCPCT), **73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review – in comparison to the national figure of 6.2%.** We believe this not only represents a disproportionate impact that has not been adequately reflected in the decision-making process, but **further demonstrates that the agreed option represents a worsening of services currently available to children and families across Yorkshire and the Humber.**
140. We note that in its response to our initial report, the JCPCT refers to evidence it considered that was submitted by Embrace and were assured of Embrace's ability to undertake safe and timely retrievals in options where retention of the surgical centre at Leeds was not proposed. However, it is not clear what evidence the JCPCT actually considered in this regard and we believe this does not reflect the evidence we previously considered, which in summary suggested:
- **An 84% increase in the number of transfer/ retrieval journeys**
  - **Over 100,000 additional miles; and,**
  - **Over 2000 additional work hours**
141. We were previously advised that any increase in activity would need further investment in Embrace, with an increase in the number of teams available to the service (driver, nurse and doctor), alongside an increase in the number of ambulances and other essential equipment.
142. Issues around patient flows and cardiac networks are considered elsewhere in this report. However, we would like to raise the following issue in terms of travel and access.

<sup>2</sup> The United Kingdom's first combined infant and children's transport service, which undertakes neonatal transfers, alongside paediatric retrievals for the 23 hospitals across Yorkshire and the Humber.





# Conclusions and Recommendations

143. The proposed configuration model (Option B) assumes the majority of children from Yorkshire and the Humber will flow to the Newcastle surgical centre, while children from some areas of West Yorkshire (Bradford, Halifax and Huddersfield) will flow to the surgical centre at Liverpool. However, it is unclear whether children from Bradford, Halifax and Huddersfield would access cardiology services at Manchester (part of the proposed Liverpool cardiac network) or at Leeds (part of the proposed Newcastle cardiac network). If accessing services at Manchester, this may not align with one of the review's aims of delivering care (other than surgery) closer to patients' homes. Equally, if accessing cardiology services at Leeds, this would essential result in the proposed Leeds Cardiology Centre operating across more than one network – potentially working to different policies and procedures. Either way, we do not believe this is in the interest of children and families across Yorkshire and the Humber.
144. However, we recognise that should the surgical centre at Leeds be retained at the expense of the one currently located in Newcastle, children and families from across the North East of England (albeit fewer in number) could be subject to similar issues around travel and access to services. As outlined previously, we would not wish to see issues that would affect children and families across Yorkshire and the Humber simply transferred to other areas of the country. **We believe this further strengthens the case for a North of England solution that recognises and reflects the demographics and geography of this part of the country.**
- Costs to NHS
145. As outlined above and in our previous report, we have been advised that **any option where the current surgical centre at Leeds is not retained, will result in very significant increases in transportation and retrieval costs for the NHS.** However, such considerations are not covered in any detail within the JCPCT's decision-making business case – but is seemingly 'parked' to be dealt with during the implementation phase of the review. Given that concerns have been raised that some retrieval services are at capacity, alongside the significant increase in activity predicted by Embrace across Yorkshire and the Humber alone, **we believe this matter should have been given much greater consideration as part of the JCPCT's decision-making process and not simply left to be dealt with during the implementation phase of the review.**
146. Based on the responses to our questions during the consultation period, we believed that the overall financial implications were likely to be very significant – both in terms of establishing new arrangements and the on-going delivery of



# Conclusions and Recommendations

the proposed model of care. We were advised that the view was not about generating savings and was more likely to need additional investment.

147. However, the decision-making business case sets out the level of increased spending and 'retained spending' under the various models considered by the JCPCT. There is a clear correlation between the number of centres and level of retained financial resource and it states that under Option B, Commissioners will retain an estimated £31M to re-invest. However, elsewhere in the financial analysis section of the decision-making business case it states that reduced spending should filter through into a reduced tariff after three years. **This suggests an overall reduced level of spending in relation to these services and does not reflect the 'increased investment' points made to us during the public consultation.**
148. The financial analysis section of the decision-making business case also summaries the impact of de-designation on providers (described as legacy costs). Under Option B, it is estimated that Leeds Teaching Hospital Trust (LTHT) will have to budget for over £14M of legacy costs – the highest for any de-designated centre and approaching 3 times the average level of legacy costs. **We believe this is a disproportionate burden for both LTHT and Yorkshire and the Humber.**

## The impact on children, families and friends

149. Given that a fundamental aim of the Safe and Sustainable review, and de facto the JCPCT's decision, was to deliver a sustainable model for the future, we cannot state strongly enough that minimising the negative financial impact and emotional strain on children and families should have featured more strongly in the decision-making process.
150. We acknowledge the comments made by the JCPCT in its response dated 18 July 2012, however **as a result of the JCPCT's decision we believe the significant impact on home and family life likely to result from this service reconfiguration will be felt most acutely by children and families across Yorkshire and the Humber.**
151. We do not believe that such impacts have been given sufficient consideration as part of the decision-making processes and **we are disappointed that a number of suggestions to mitigate negative impacts have been 'parked' for the implementation phase of the review.**

## Established congenital cardiac networks

152. Our comments in this regard are detailed elsewhere in this report.

## Adults with congenital cardiac disease



# Conclusions and Recommendations

153. Our main comments in this regard are detailed elsewhere in this report. However, we believe it is worth reiterating our view that **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 review of services for adults with congenital heart disease.**
154. This was reinforced at our meeting held on 24 July 2012.
- The views of the people of the Yorkshire and Humber region
155. We maintain our previous comments, and **we strongly believe there has been insufficient regard to the views expressed by children and families from across Yorkshire and the Humber via the petition signed by over 600,000 people.**
- Nationally Commissioned Services (NCS) – Heart transplantation, ECMO and Complex Tracheal Surgery
156. In our previous report we highlighted concerns around the significance being attached by the JCPCT to the provision of Nationally Commissioned Services (NCS). We believe our concerns in this regard have been borne out by the JCPCT's decision.
157. It is interesting that in the decision-making business, one of the issues around the need for change highlights, '*Congenital heart services for children have developed on an ad hoc basis*'. However, by considering the current location of the three related NCS (i.e. heart transplantation, ECMO and complex tracheal surgery) we believe the statement highlighted in the decision-making business case is at least equally relevant to these NCS. However, due to the apparent risks associated with relocating these services (in particular heart transplantation) – albeit perhaps to a more rational and logical configuration – it appears that such services have been a significant consideration within the JCPCT's decision-making processes.
158. We note the advice provided to the JCPCT by the Advisory Group for National Specialised Services (AGNSS) regarding heart transplant services, particularly in terms of the quality of service currently provided by surgical centre in Newcastle. However, we would question the evidence that suggests it takes between 8-10 years for a new programme to develop full expertise. This does not appear to have been the view of the Cardiothoracic Transplant Advisory Group (CTAG) when it previously advised the JCPCT.





# Conclusions and Recommendations

159. In addition, given the very small number of patients and procedures involved, we do not understand the rationale behind the stated need for two paediatric cardiothoracic transplant services. There does not appear to have been any consideration given to amalgamating the current services onto a single site in London. We find this aspect particularly intriguing – given that one of the aims of the review of Children’s Congenital Cardiac Services is to reduce occasional surgical practice. We cannot understand why the same principal should not be applied to the NCS for children’s heart transplants – or at least considered in more detail.
160. We also note the advice provided by CTAG – that a paediatric cardiothoracic transplant programme should be co-located or closely networked with a similar programme for adults. **We believe this provides further evidence to support the argument that services for children and adults should have been considered jointly.**
161. In our previous report, we also highlighted concerns around the assessment process associated with gauging the readiness of other surgical centres to deliver the three identified NCS. Given the significant change in the position around Birmingham Children’s Hospital and its ability to deliver a paediatric cardiothoracic transplant service, we believe our previous observations and concerns are both justified and relevant.
162. Nonetheless, given the circumstances around the NCS and the paediatric cardiothoracic transplant programme in Newcastle, and other matters relevant to the North of England (highlighted elsewhere in this report), our over-riding view is that this aspect provides further support **that a North of England solution is needed, that recognises and reflects the demographics and geography of this part of the country.**
- Services to Scotland and at Yorkhill Hospital, Glasgow
163. During the period of consultation, we raised concerns regarding the scope of the review and the exclusion of similar services delivered in Scotland. We were advised that the scope of the review was limited to services in England and Wales. We note this advice is repeated by the JCPCT in its response (dated 18 July 2012) to our previous report.
164. Nonetheless, we have become aware of a published report following a review of the children’s congenital cardiac services at Yorkhill Hospital, Glasgow. The report was produced by an Independent Expert Panel, chaired by Professor Sir Ian Kennedy and published in February 2012.



# Conclusions and Recommendations

165. We note that membership of the Independent Expert Panel that reviewed the services at Yorkhill Hospital was largely drawn from the membership of the Safe and Sustainable Independent Expert Panel (6 out of 8 members) and the methodology of the assessment closely followed that used to assess surgical centres in England.
166. We specifically note the summary observations and comments detailed in the report – in particular the opening statement:
- 'The panel had significant concerns about important aspects of the service in the surgical unit and in the broader congenital heart network. Of most concern was a lack of leadership and coherent team working. Also of concern was a sense that the provision of paediatric intensive care may be unsafe if critical staffing problems are not addressed.'*
167. It is not clear how the concerns identified by Independent Expert Panel are being addressed.
168. Nonetheless, it should be noted that in our initial report we clearly recognised that the children's heart surgical unit at Yorkhill Hospital, Glasgow was part of the responsibility of the Scottish devolved administration. The point we raised related to '...more effort being made to include all UK surgical centres within the scope of the review.' As such, we do not believe that the JCPCT's response adequately reflects our concerns – particularly in light of the published findings following the assessment of the unit at Yorkhill Hospital, Glasgow
169. Furthermore, notwithstanding services delivered in Scotland being deemed outside the scope of this review, we note the previous reference (in the consultation document) to the cardiology centre at Edinburgh (not to be confused with the surgical unit at Yorkhill Hospital, Glasgow) and the support this provides to the nearby surgical centre, presumably in Newcastle. We also note the reference to services in Scotland in relation to Nationally Commissioned Services (namely cardiac transplants). As such, we believe some aspects of services (and access to services) have been material considerations within parts of the decision-making process.
170. As such, we maintain there should have been more effort to include all UK surgical centres within the scope of the review. Alternatively, any activity relating to patients from the Scottish devolved administration should have been specifically excluded from any aspects of the review – including Nationally Commissioned Services.

## Implementation



# Conclusions and Recommendations

171. We accept that any decision to reconfigure NHS services will identify issues that need to be addressed as part of the implementation process. However, we are concerned that some of the issues highlighted to be form part of the 'implementation phase' of the review. These include:

- **Development of standards for Children's Cardiology Centres and district level heart services** – which form fundamental elements of the proposed model of care.
- **Impacts for Paediatric Intensive Care Units** – where there are significant concerns regarding the sustainability of PICUs (or other relevant services for that matter) as a result of the agreed option, we believe proposals to mitigate any such affects should have been considered more closely by the JCPCT to avoid any unnecessary consequences as a result of its decision.
- **Development of manageable networks** – this is fundamental to the practical operation of the proposed model of care. It is also unclear how the fragmentation of the Yorkshire and Humber Cardiac Network will be managed.
- **Retrieval services** – we do not believe that the JCPCT has given sufficient consideration to the impact of its decision (or the other options considered) on retrieval services. We believe this represents a significant and specific risk for children and families across Yorkshire and the Humber.
- **Recruitment and retention of appropriately qualified staff** – we previously highlighted our concern that the training and development of staff had received insufficient consideration ahead of public consultation. Having reviewed the JCPCT's decision, we still believe this matter has received insufficient consideration. As stated by the Chair of the JCPCT at its meeting on 4 July 2012, it is 'people and teams that will determine the success of this review' – yet detailed issues around staff recruitment, staff retention and staff training and development have not been considered in detail. We believe these aspects are key issues that will affect both the sustainability and deliverability of any future reconfiguration and model of care.

172. Notwithstanding our comments regarding the designation of surgical centres, we believe these matters are fundamental to the success (or otherwise) of the proposed model of care and delivering the quality improvements the review is seeking to deliver. As such, we believe these aspects (alongside the risks associated with failing to successfully deliver the necessary requirements) should have been considered in much more detail by the JCPCT, as part of its decision-making process.



# Conclusions and Recommendations

## Governance, transparency and public accountability

173. Since forming as a Joint HOSC for the purpose of considering the proposals around the future delivery of Children's Congenital Cardiac Services and despite a number of changes to our membership, we have always taken our responsibility very seriously and endeavoured to undertake our work diligently and to the best of our ability.
174. We believe we have identified a number of significant issues relevant to the JCPCT's decision. We believe many of the issues we have raised particularly highlight why, in our view, the JCPCT's decision will not result in an overall improvement to services for the significant number of children and families across Yorkshire and the Humber.
175. In our previous report we highlighted a number of concerns regarding the review and various processes. While we do not intend to repeat all of the matters raised, we hope the issues we identified will be considered in full and taken into account as part of any review of the JCPCT's decision and associated decision-making processes. Nonetheless, following the JCPCT's decision on 4 July 2012, we believe there are some relevant matters that need repeating and reiterating.
176. As a Joint HOSC, we form part of the current statutory arrangements for public accountability across the NHS. In this role, we have been particularly concerned with considering the implications of the review and the subsequent decisions on the children and families we represent Yorkshire and the Humber. However, as demonstrated by the reports we have produced, we do not believe that the JCPCT and its supporting secretariat have always appreciated our legitimate and unique role.
177. Furthermore, as democratically elected representatives for communities across Yorkshire and the Humber, we believe it is important that we are afforded the opportunity to question, scrutinise and interrogate the available evidence and appropriately hold decision-makers to account. There have been some significant instances where we have not been able to discharge our scrutiny function as fully as we would have liked. In many cases, this has been the result of action (often in terms of attendance) or decisions (often in response to legitimate requests for information) of those representing the JCPCT and/or its supporting secretariat.
178. We previously raised a 'lack of transparency' as a particular issue during the public consultation in 2011. We were assured that this would improve and all the relevant information would be available after the JCPCT's decision. Regrettably, this does not reflect our experience. It is difficult to see how we



# Conclusions and Recommendations

can comment effectively on important aspects of the proposed reorganisation when we have been needlessly and unlawfully denied access to important evidence we have identified and believe is necessary to reach an informed conclusion.

179. The current Health Scrutiny Regulations are very clear in this regard, and make it plain that Health Overview and Scrutiny Committee's can legitimately decide what information is required to discharge their function, as demonstrated by the following extract from the regulations:

*'...it shall be the duty of a local NHS body to provide an overview and scrutiny committee with such information about the planning, provision and operation of health services in the area of that committee's local authority as the committee may reasonably require in order to discharge its functions.'*

180. Given the role of the JCPCT and the arrangements in place to allow the JCPCT to discharge the statutory role of Primary Care Trusts (i.e. local NHS bodies), we fail to see how our reasonable requests have repeatedly been refused.
181. We believe our experiences highlight some significant organisational development issues for parts of the NHS – particularly around governance, transparency and accountability. We have raised our concerns with the Chief Executive of the NHS, but at the time of writing this report we had not received a response to the concerns raised. A copy of the letter, dated 2 October 2012, is attached at **Appendix 7**.
182. Similar concerns have also been raised with the Secretary of State for Health and attached at **Appendix 8**. Details include letter dated 15 August 2012, 7 September 2012 and 31 October 2012. The content of an email sent on 6 November 2012 is also included.
183. Despite our continued frustration in this regard, **we remain hopeful that our concerns have been logged by those concerned and that the Department of Health will reflect on such matters when drafting the forthcoming revised health scrutiny regulations and supporting guidance.**





# Evidence

## Monitoring arrangements

As this report forms the basis of a referral to the Secretary of State for Health, standard arrangements for monitoring the report and the outcome of any recommendations will not apply.

Nonetheless, the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) will determine any further actions and/or monitoring arrangements as required.

## Reports and Publications Submitted

### 19 December 2011

- Letter from the Secretary of State for Health – dated 8 December 2012
- PwC Report: Testing assumptions for future patient flows and manageable clinical networks – Reports and Executive Summary
- Report of Sir Ian Kennedy's Panel in Response to Questions made by the Joint Committee of Primary Care Trusts (and associated letter) - 17 October 2011
- Report to the Joint Committee of PCTs by Dr Patricia Hamilton CBE, Chair of the Safe and Sustainable Steering Group, on behalf of Steering Group members – 17 October 2011
- Submission from Children's Heart Surgery Fund
- Submission from Leeds Teaching Hospitals NHS Trust

### 24 July 2012

- Safe and Sustainable - A new vision for Children's Congenital Heart Services in England: Consultation Document (March 2011)
- Safe and Sustainable - Congenital Heart Services in England: Briefing 2 (Spring 2011)
- Safe and Sustainable – A New Vision for Children's Congenital Heart Services in England – Presentation Slides prepared by Cathy Edwards, Director of Yorkshire and Humber Specialised Commissioning Group





# Evidence

## Witnesses Heard

- Stuart Andrew – Member of Parliament for Pudsey
- Jon Arnold (Parent) and Trustee of Children's Heart Surgery Fund
- Gaynor Bearder (Parent)
- Kimberley Botham (Adult Congenital Heart Patient)
- Lois Brown (Parent)
- Andy Buck (Chief Executive) – NHS South Yorkshire & Bassetlaw1
- Dr Mark Darowski (PICU Consultant) – Leeds Teaching Hospitals NHS Trust
- Dr Kate English (Consultant in Adult Congenital Heart Disease) – Leeds Teaching Hospitals NHS Trust and
- Dr. Leslie Hamilton (Deputy Chair) – Safe and Sustainable Cardiac Surgery Steering Group
- Stacey Hunter (Divisional General Manager, Children's Services) – Leeds Teaching Hospitals NHS Trust
- Jeremy Glyde (Programme Director) – Safe and Sustainable Programme
- Sir Neil McKay – Chair of the Joint Committee of Primary Care Trusts (JCPCT)
- Karl Milner (Director of Communications) – Leeds Teaching Hospitals NHS Trust
- Councillor Lisa Mulherin – Executive Member for Health and Wellbeing (Leeds City Council)
- Dr Simon Newell (Consultant Neonatologist) – Leeds Teaching Hospitals NHS Trust
- Steph Ward (Parent)
- Dr John Thomson (Consultant Cardiologist) – Leeds Teaching Hospitals NHS Trust and
- Kevin Watterson (Chair and Trustee) – Children's Heart Surgery Fund and Paediatric Cardiac Surgeon at Leeds Teaching Hospitals NHS Trust



# Evidence

## Dates of Scrutiny

- |                  |   |  |
|------------------|---|--|
| 19 December 2011 | – | Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – consideration of the JCPCT’s decision and associated Decision-Making Business Case |
| 24 July 2012     | – | Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – consideration of the JCPCT’s decision and associated Decision-Making Business Case |
| 16 November 2012 | – | Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – consideration of the referral report   |

**Please note:** The above details do not reflect any local engagement work undertaken by individual members of the committee, outside of the formal meeting arrangements and organised site visits.

DRAFT



## Appendix 1

# **Response from the Joint Committee of Primary Care Trusts to the report from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) Report (October 2011)**



## Appendix 2

# **Initial advice to the Secretary of State for Health from the Independent Reconfiguration Panel (IRP) – January 2012**

**DRAFT**



## Appendix 3

# **Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) response to PwC report on travel flows and manageable clinical networks (April 2012)**



## Appendix 4

# **Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) minutes of the meeting held on 24 July 2012**

**DRAFT**





## Appendix 5

### Summary analysis of the Kennedy Panel scores

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## Appendix 6

# Activity Data from the Central Cardiac Audit Database (CCAD) for 2009/10 and 2010/11

DRAFT



## Appendix 7

### Letter to the Chief Executive of the NHS – 2 October 2012

DRAFT



## Appendix 8

### Correspondence to the Secretary of State for Health

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**Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)**

**Review of Children's Congenital Cardiac Services  
2nd Report, November 2012**

**Report author: Steven Courtney (Principal Scrutiny Adviser)**

**[www.scrutiny.unit@leeds.gov.uk](http://www.scrutiny.unit@leeds.gov.uk)**



## **Specialised Services**

Cllr John Illingworth  
Chair, Scrutiny Board  
(Health and Wellbeing and Adult Social Care)  
3<sup>rd</sup> Floor (East)  
Civic Hall  
Leeds LS1 1UR

2<sup>nd</sup> Floor Southside  
105 Victoria Street  
London  
SW1E 6QT  
Tel: 020 7932 3951

18 July 2012

Dear Cllr Illingworth

Please find below the response from the Joint Committee of Primary Care Trusts (JCPCT) to the consultation submission by the Yorkshire and Humber Joint Health Overview and Scrutiny Committee (JHOSC).

The response below represents the summary of the JCPCT's deliberations at its meeting in public on 4 July. I am conscious that the JHOSC has previously expressed concern that our response has not been submitted to you earlier, and I have explained that it would not have been appropriate to do so before the JCPCT met on 4 July to formally consider the evidence submitted during consultation and to agree a final decision.

The option agreed by the JCPCT for implementation presents a rare opportunity to improve the quality of care for all children in England and Wales, including the children of Yorkshire and the Humber. The case for change has strong clinical support and I am heartened that on 6 July a number of Royal Colleges of medicine and professional associations welcomed the JCPCT's decision as one that would improve outcomes for the children of this country.

It is fully acknowledged by the JCPCT, and fully understandable that this is an emotional time for many parents and the NHS staff in the centres that will not provide surgery for children with congenital heart disease. The decision taken by the JCPCT was a difficult one. It is remarkable that it took as long as 12 years since the tragic events in Bristol.

The JHOSC has raised an issue of transparency of the review process. We have strived to be transparent throughout this process. All of the evidence on which we have relied has been published; the process that we have followed has been set out in considerable detail;

public events and workshops have been held across the country; and we have commissioned additional work from independent experts to test our own assumptions.

We also sought independent advice on how best to consult with various stakeholders; for example we sought advice from the Centre for Public Scrutiny before consultation started on how to best engage and consult with scrutiny committees. We also listened to advice given to us during consultation, for example, we extended the period of consultation to over seven months for HOSCs in response to representations put to us by Yorkshire and Humber JHOSC.

The process of consultation and for the development of options has already been scrutinised in depth by two courts and by the Independent Reconfiguration Panel. The final judgment was clear – the JCPCT had conducted a consultation that was proper, lawful and fair. It will be important for the NHS to continue this engagement with the NHS staff, patients and their families during implementation, to monitor the impacts of the reconfiguration and seek solutions together to any issues that may emerge.

There is a strong support for the review's principles, although not everyone who supports change is equally enthusiastic to see it happen locally. This is the right decision to ensure services are safe and sustainable for the future.

I look forward to meeting you and your colleagues on 24 July.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Neil McKay', with a large, stylized loop at the end.

Sir Neil McKay C.B.

Chair of the Joint Committee of PCTs

## 1. Recommendation 1:

**In order to meet the needs and growing demand of the 5.5 million people living in the Yorkshire and Humber region, the surgical congenital cardiac unit currently provided by Leeds Teaching Hospital NHS Trust must be retained and included in any future configuration of paediatric congenital cardiac surgical centres.**

1.1 This recommendation touches upon issues of convenience and travel. But ‘quality’ has been paramount to this review. We were told during consultation that quality was considered to be the most important consideration by patients, parents and clinicians. Ipsos Mori reported that the JCPCT received many submissions that ‘quality’ should be the JCPCT’s main consideration. Many respondents expressed support for Professor Kennedy’s recommendation that

*“mediocrity must not be our benchmark for the future”<sup>1</sup>*

1.2 The importance of high-quality care is also evident in respondents’ views on one of the key principles underpinning the proposals that “all children in England and Wales who need heart surgery must receive the very highest standards of NHS care”. Ipsos Mori reported that *“Almost all respondents answering the question agreed with the principle – 98% of personal respondents and 99% of organisations”<sup>2</sup>*.

1.3 The analysis of the consultation responses concluded that:

*“the quality of care provided was the most frequently mentioned issue for respondents discussing either specific hospitals or the options more generally. In fact, quality of care featured heavily throughout the consultation responses, at each of the questions posed in the response form and in the letters and emails that were submitted. There was a strong belief amongst many that quality should be the deciding factor in service planning”<sup>3</sup>*.

1.4 The views submitted during consultation reflect those of stakeholders with whom we engaged in 2010 around the proposed criteria for the evaluation of potential options (including clinicians working in the Yorkshire and Humber cardiac

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<sup>1</sup> Safe and Sustainable, *Review of children’s congenital cardiac services in England – Report of the independent expert panel chaired by Professor Sir Ian Kennedy*, 2010

<sup>2</sup> Ipsos Mori, *Safe and Sustainable Review of Children’s Congenital Heart Services in England – Report of the public consultation*, 2011, p. 23

<sup>3</sup> Ipsos Mori, *Safe and Sustainable Review of Children’s Congenital Heart Services in England – Report of the public consultation*, 2011, p. 7

network and parents from Yorkshire and Humber who attended the engagement event in Leeds in 2010). The various groups agreed that 'quality' should be the most important consideration and that 'travel times' should be the least important consideration.

1.5 The clinical case for fewer surgical units is compelling and has garnered strong support from professional associations and national charities even though it is recognised that reconfiguration would result in longer travelling times for some children requiring surgery or interventional cardiology services.

1.6 The JCPCT has considered the issues put forward in Yorkshire and Humber, where respondents gave significant emphasis to issues around travel and population density.

1.7 The analysis set out in the Decision-Making Business Case has considered the impact of longer elective journey times for surgery. Under the current configuration of services 35% of families are over an hour away from their closest surgical centre; this would rise to 47% in option B. The evidence available to the JCPCT suggests that this equates to 92 more families in or around Yorkshire and Humber who would experience an increased journey time of over 1 hour in option B compared to option G, the next highest scored option<sup>4</sup>.

1.8 The JCPCT therefore concluded that the significant quality potential offered by option B outweighs the relatively limited impact to elective travel times.

1.9 However, the impact to family life of increased travel times is clearly important to those individuals affected, particularly to those families whose children have multiple surgical procedures. The consultation process has highlighted particular concerns from parents in Yorkshire and Humber. The implementation plan will consider the extent to which potential mitigations suggested by respondents are achievable.

1.10 The JCPCT has sought to minimise inconvenience to families by proposals to develop non-interventional care locally so that children only have to travel to a surgical unit for a very small number of times over the course of their childhood. The

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<sup>4</sup> See appendix R of the Decision Making Business Case for detail.

JCPCT has proposed that this will be achieved through the development of Children's Cardiology Centres and District Children's Cardiology Services.

1.11 The JCPCT's model of care therefore envisages that under option B children, including those in Yorkshire and Humber will have greater access to Children's Specialist Cardiac Nurses and Paediatricians with Expertise in Cardiology working across the local networks.

1.12 In summary, we did not agree that the determining factor for the designation of children's congenital cardiac surgical services should be population levels or population density. It was taken into consideration with all of the other evidence in the round, but the most important consideration was that of 'quality' and the ability of the centres to meet the *Safe and Sustainable* standards in the future. This approach has the support of the professional associations and the majority of respondents to consultation.

## **2. Recommendation 2:**

**Based on the matters outlined in this report we recommend the following 8-centre configuration model:**

- **Leeds General Infirmary**
- **Alder Hey Children's Hospital, Liverpool**
- **Birmingham children's Hospital**
- **Bristol Royal Hospital for Children**
- **Freeman Hospital, Newcastle**
- **Southampton General Hospital**
- **2 centres in London**

2.1 For the purpose of consultation we had proposed that 8-site options would not be viable. However, the strengths of the option suggested by the JHOSC were considered by the JCPCT. In fact, in response to submissions put to us during consultation we tested all of the assumptions that we had previously relied upon for the purpose of identifying potential configuration options, which resulted in six new

options for consideration (including three new options that included Leeds Teaching Hospital and three 8-site options).

2.2 We concluded that the option proposed by the JHOSC is unviable. The reasons are set out in the Decision-Making Business Case on pages 78, 84-85 and in Appendix Y on pages 189-193. In summary, we concluded that the relatively small caseload in the North of England would not support the retention of three surgical units in the North given the requirement for each centre to perform at least 400 paediatric cardiac surgical procedures each year.

### 3. Recommendation 3

**Given the significant benefits to the patient and their families of genuinely co-locating relevant services, we believe genuine co-location should receive greater recognition and weighting when determining future service provision.**

3.1 The *Safe and Sustainable* standards are based on the definition of co-location in the *Framework of Critical Interdependencies*, (*‘the Framework’*), drafted by a team of clinical experts and supported by the relevant Royal Colleges and professional associations. The Specialist Surgical Centres have to be co-located with four specialised children’s services defined by the Framework:

- ENT (airways)
- Paediatric surgery
- Paediatric critical care
- Paediatric anaesthesia

3.2 Leeds Teaching Hospital NHS Trust has all of these services co-located on the same site with paediatric cardiac surgery. Newcastle upon Tyne Hospitals NHS Foundation Trust has three of these services co-located at the Freeman Hospital with paediatric cardiac surgery; paediatric surgeons (non-cardiac) are based at the Great North Children’s Hospital, less than ten minutes from the Freeman Hospital, and are transported to the Freeman Hospital when needed by the cardiac team.

3.3 During consultation, a number of respondents including the British Congenital Cardiac Association disagreed with the JCPCT’s approach to the requirement for the co-location of services. We have set this evidence out in

some detail on pages 39 to 42 of the Decision-Making Business Case. The JCPCT's reading of the *Framework* was that the document did not stipulate an absolute requirement for the co-location of services on the same site. That the *Framework* demands a subjective approach in interpretation was acknowledged during consultation by Professor Edward Baker, the chair of the working group that developed the *Framework*.

3.4 The co-location of core paediatric services was an important consideration for the JCPCT. During the assessment process, surgical units were allowed to demonstrate the extent to which they met the 'gold standard' of co-location of all services on one site. This was then reflected in the score awarded by the Professor Kennedy's panel. In this regard, Leeds Teaching Hospital received a high score by Kennedy panel.

3.5 We listened carefully to the many voices from Yorkshire and the Humber who suggested that the review had given insufficient weighting to the issue of 'co-location'. We asked Professor Kennedy's panel to consider the evidence put to us during consultation and to re-consider its advice in this regard. The panel advised us that it was content that its application of the definition of 'co-location' was correct and it re-iterated that the Freeman Hospital / Great North Children's Hospital meet the requirements for the co-location of services. Before we accepted this advice on 4 July Dr Sheila Shribman CBE, National Clinical Director for Children, Young People and Maternity (and Department of Health sponsor of the *Framework*) confirmed with the JCPCT that she was content with this approach.

3.6 We also tested our own process by re-calculating the Kennedy panel scores for each centre by giving greater weighting to the requirement for co-location (see Appendix V of the Decision-Making Business Case). This test assumed that the requirement for co-location of services should be the most heavily weighted criterion. As Leeds Teaching Hospital received a high score against this criterion by the Kennedy panel, we were interested to see what impact this would have on the overall weighted scores awarded by the panel. In the event, there was only limited movement in the scores and Leeds Teaching Hospital remained at a lower score to the Freeman Hospital. This is because the less optimal elements of the service in Leeds, as reported by the Kennedy panel, were sufficiently significant that even a greater emphasis to the requirement of



co-location did not place Leeds Teaching Hospital higher than the Freeman Hospital.

3.7 The importance of a bond between a mother and a new born child, as described in your submission by Dr Sara Matley is recognised in the future model of care. The standards specify that services within the congenital heart network would plan and deliver services in close collaboration with each other and with the parents (see standards B3, B8, B9, and B10).

#### **4. Recommendation 4:**

**Given the element of the review is to ensure more care is delivered closer to home, population density should be a key consideration in the configuration of future provision.**

4.1 As I have set out earlier, the quality of services was the most important consideration for the JCPCT rather than population levels (or population density) or convenience and travel. Our analysis of population growth is set out in Appendix Y of the Decision-Making Business Case; over the next 15 years the growth in the number of children with congenital heart disease will be relatively small in terms of absolute numbers, including those from South Asian communities.

4.2 However, we have acknowledged that travel times are an issue for individual families and have proposed ways of reducing unnecessary long journeys for non-interventional care. Most children have surgery only once and the follow up appointments represent the majority of their care. At present, these usually take place in surgical centres, which means that patients and their families travel unnecessarily to the centres which are often far from where they live. This is disruptive on family life.

4.3 The JCPCT's decision means that this unnecessary travel should no longer be the case due to our decision to expand and develop specialist paediatric cardiac care locally. This includes the decision to expand the numbers of Consultant Paediatricians with Expertise in Cardiology and Children's Specialist Cardiac Nurses.

4.4 We have also tested in some detail the potential impacts to vulnerable groups and we have investigated how the NHS would discharge its

responsibilities under the public sector equality duty in regard to the implementation of our decision. The summary findings of the Health Impact Assessment are set out in detail on pages 79-84 of the Decision-Making Business Case and the full Health Impact Assessment report has been published on our website. As you know, the process for developing the Health Impact Assessment was extensive involving eleven public workshops across the country (including four in your region: in Bradford and Kirklees and two in Leeds).

4.5 Overall, the HIA concludes that the differences between the options are “fairly marginal”. In terms of the impacts on vulnerable groups, it reports that:

*“vulnerable groups are expected to benefit disproportionately from the positive impacts of improved health outcomes and care delivered closer to home”.*

## **5. 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.**

5.1 The Decision Making Business Case addresses the relationship between *Safe and Sustainable* and the separate review of adult congenital cardiac services on pages 45 – 47 and 48 - 51.

5.2 In summary, the JCPCT does not have the legal authority to incorporate adult services within its remit. The powers of decision making delegated to the JCPCT by the Board of each PCT in England are confined to services for children with congenital heart disease.

5.3 The JCPCT was advised on 4 July that it could delay a decision on the review of paediatric congenital services until a decision could be made jointly with the separate review of adult congenital services. This would have meant a delay until 2014. In view of the calls upon the JCPCT to “urgently” conclude *Safe and Sustainable* in the interests of children, including from the British Congenital Cardiac Association, the JCPCT concluded that this would not be appropriate.

5.4 Neither did we agree that the threshold of '400 surgical procedures' in each centre should be measured with reference to both paediatric and adult congenital surgical procedures. The need for each surgical centre to perform at least 400 paediatric surgical procedures (and ideally a minimum of 500 paediatric surgical procedures) has been the bedrock of the *Safe and Sustainable* review in the interests of securing a sustainable service and good quality outcomes, and we did not agree that this standard should be relaxed. There was very strong support for this position amongst respondents to consultation.

The JHOSC has also raised a number of additional issues in its response. These issues have been previously addressed in correspondence between the JHOSC and the *Safe and Sustainable* secretariat and the JCPCT, and also via the Secretary of State for Health's response to the referral by Yorkshire and Humber JHOSC.

## **6. The views of people from Yorkshire and the Humber**

6.1 I would be disappointed if the view prevailed that the views of respondents in Yorkshire and Humber had been ignored by the JCPCT. They were most certainly considered, and they influenced our process and our deliberations. The Decision Making Business Case outlines in considerable detail how these responses were taken into account and how they have shaped the final decision. The Decision Making Business Case has dealt explicitly with comments and suggestions made by the JHOSC and it specifically refers to the significant support for the retention of surgery at Leeds Teaching Hospital.

6.2 However, it is necessary to bear in mind that as invaluable as these views have been, the JCPCT has consistently advised the respondents that the consultation is not a vote. The Court of Appeal said of the *Safe and Sustainable* consultation that:

*"True consultation is not a matter of simply "counting heads": it is not a matter of how many people object to proposals but how soundly based their objections are"*

6.3 The views of the people of Yorkshire and the Humber have influenced the process and the outcome of the JCPCT's deliberations in a number of ways:

a. For the purpose of consultation we offered one option that proposed the retention of surgery at Leeds Teaching Hospital NHS Trust. In response to the view put to us during consultation we re-tested our assumptions in this regard and identified three new options that proposed the retention of surgery in Leeds. These options were considered in detail by us. Option G, which proposed the retention of surgery in Leeds, was scored highly by the JCPCT against the agreed criteria for the evaluation of options.

b. In view of the relative strength of Option G, the Decision Making Business Case provides a detailed analysis of the potential merits of Option G compared to Option B (section 12).

c. In direct response to views submitted by people in Yorkshire and Humber around the JCPCT's application of the co-location requirements, we re-tested the significance that we had attached to the issue of co-location and we asked Professor Kennedy's panel to consider the consultation submissions and advise us on the extent to which those submissions changed the panel's advice.

d. We also considered very carefully the potential impact to emergency retrieval times in response to concerns put to us from respondents in Yorkshire and Humber (pages 89 – 92) and we carefully considered evidence from a number of expert sources. We agreed to accept the professional advice that the proposals *"do not present increased risk to the child provided the options comply with the maximum journey time thresholds as set out in the Paediatric Intensive Care Society standards for the care of critically ill children"*. We specifically considered evidence submitted by *Embrace*, the dedicated paediatric retrieval team based in Barnsley, and we were reassured by *Embrace's* assessment of its continued ability to undertake emergency safe and timely retrievals of cardiac children in Yorkshire and Humber were paediatric cardiac surgery to cease at Leeds Teaching Hospitals NHS Trust.

e. In response to concerns put to us about assumed patient flows in the North we commissioned an independent third party, (PWC) to test these assumptions. This involved interviews with NHS staff, parents and the public in your region in:

Bradford  
Doncaster  
Huddersfield  
Hull  
Halifax  
Leeds  
Sheffield  
Wakefield

f. A key issue for JCPCT members was to consider the extent to which the Newcastle network envisaged by option B can be considered viable in view of some respondents in Yorkshire and Humber expressing alternative preferences for centres in Liverpool, Birmingham and London. The Decision-Making Business Case acknowledges that the viability of the Newcastle centre in option B partly depends upon patient flows from Yorkshire and the Humber, including from the Doncaster, Sheffield, Hull, Wakefield and Leeds postcodes. The Decision-Making Business Case sets out the advice that we received from PwC and how this was applied to our deliberations. The document also sets out how we tested the impact of the exercise of patient choice to the viability of the Newcastle centre (and we concluded that the Newcastle centre would remain viable even if a significant number of people in Yorkshire and Humber exercised their right to be seen at other centres in Liverpool, Birmingham or London).

## **Review process, governance and transparency**

### **7. Governance**

7.1 The 2003 Direction from the Secretary of State requires scrutiny committees to convene a joint HOSC when two or more HOSCs consider proposals affecting a population larger than a single HOSC to be 'substantial'. However, despite this statutory requirement, a single, national JHOSC was not formed. Instead, the JCPCT was obliged to consult with hundreds of HOSCs across the country.

7.2 I have explained before that the invitations to the meetings of the Yorkshire and Humber JHOSC on 2 September 2011 and 19 September 2011 were issued to me with 6 working days notice. Regrettably, I was unable to attend at such short notice. I explored the availability of other JCPCT members to attend; however, this was not possible due to the short notice. A meeting on 22 September was attended by Ailsa Claire, the JCPCT member at the time, and Andy Buck, the designated member of the JCPCT, as well as Cathy Edwards, the Yorkshire and the Humber SCG Director.

7.3 The JCPCT comprises the 10 Specialised Commissioning Groups in England. The Directors of the 10 Specialised Commissioning Groups agreed in 2010 that for the purpose the consultation, in the absence of a national JHOSC, the local SCGs would lead on engagement with HOSCs as it would be impractical for the JCPCT members, including the Chairman, to attend all OSC meetings across the country. You will be aware that the Yorkshire and the Humber SCG representatives have consistently attended the JHOSC meeting and their attendance is acknowledged in the JHOSC's response.

## **8. Our approach to consultation**

8.1 I am of course pleased that the Independent Reconfiguration Panel advised the Secretary of State for Health that our approach to consultation was reasonable and proper. This was a huge public consultation which presented obvious challenges. But we strived to reach the largest possible audience. We publicised the review through a number of channels with the aim of reaching the widest possible audience. The main message encouraged people to take part as "your views count".

8.2 The Decision Making Business Case summarises our approach, which I set out below for convenience:

- The consultation was publicised by advertisements in a number of Black and Minority Ethnic newspapers. The consultation was also publicised on the *Safe and Sustainable* website and of those of third parties within the NHS and the voluntary sector. A seven-minute video that explained the background to the review, including real-life stories, and which encouraged people to take part was professionally produced and was placed on the *Safe and Sustainable* website.

- Communications briefings were issued to local authorities, MPs, Health Overview and Scrutiny Committees, LINKs and London Assembly members. Copies of the consultation document, together with response forms that were developed with input from Ipsos Mori were available from the *Safe and Sustainable* website, and were posted in large bundles to NHS Trusts, national and local parent groups, professional associations and SCGs. Respondents were also told that other forms of submission such as letters and emails were acceptable. Respondents were told in the consultation document that it could be translated into other languages upon request. Requests for different languages were acted upon as soon as they were received. In the event documents and response forms were translated into the following languages with 6 weeks of the consultation remaining: Arabic, Urdu, Farsi, Gujarati, Punjabi, Cantonese, Polish, Somali, Hindi and Bengali. Ipsos Mori reported that 20% of respondents to consultation were from Black and Minority Ethnic backgrounds, which is higher than the total percentage of BAME people in England.

- A facility for consultees to “text” responses by mobile phone was introduced by Ipsos Mori. This was aimed primarily at children and young people. Over 2000 people attended 16 consultation events in England and Wales:

- Birmingham – 4 April 2011
- Cardiff – 5 April 2011
- Newcastle – 7 April 2011
- Oxford – 4 May 2011
- London – 7 May 2011, 11am–1pm
- London – 7 May 2011, 2pm–4pm
- Warrington – 9 May 2011
- Leeds – 10 May 2011, 3pm–5pm
- Leeds – 10 May 2011, 6pm–8pm
- Gatwick – 19 May 2011
- Cambridge – 23 May 2011
- Southampton – 24 May 2011, 3pm–5pm
- Southampton – 24 May 2011, 6pm–8pm
- Taunton – 7 June 2011



- Leicester – 16 June 2011, 3pm–5pm
  - Leicester – 16 June 2011, 6pm–8pm
- Clinicians from the *Safe and Sustainable* Steering Group were present at the events to answer questions put by the audience. Professor Sir Roger Boyle CBE, former National Director of Heart Disease and Stroke, was present at most events to give the background to the review and to explain the 'need for change'.
- The events were facilitated by an experienced, independent facilitator. In some locations an additional event was held on the same day in response to demand. A free crèche facility was available to facilitate access for parents. Interpreters were made available.
- Birmingham – 9 March 2011
  - London – 19 March 2011
  - York – 14 May 2011
- In an attempt to obtain even more qualitative information Ipsos Mori was asked to run focus groups targeted at specific groups: The aim was to conduct qualitative research to explore the issues raised throughout the consultation in depth. Parents of children with congenital heart disease and young people who currently use children's congenital heart services were asked about their views on the proposals. They were identified by the centres hospitals and parent groups.
- Ipsos MORI also conducted qualitative research with the general public from Black and Minority Ethnic groups, focusing on parents from a South Asian origin given the available research evidence that suggests that there is a higher relative incidence of congenital heart disease for some conditions amongst South Asian populations. Participants in the BAME groups were of Bangladeshi or Pakistani origin and from a range of socio-economic backgrounds.
- Focus groups with parents of children with congenital heart disease

- London – 17 May 2011
  - Leeds – 31 May 2011
  - Leicester – 1 June 2011
  - Newcastle – 7 June 2011
  - Oxford – 8 June 2011
  - Southampton – 14 June
  - Taunton – 15 June 2011
  - Manchester – 21 June 2011
  - London – 21 June 2011
  - Birmingham – 22 June 2011
  - Cardiff family interviews – 29th June 2011
- Focus groups with children with congenital heart disease
- Leicester – 1 June 2011
  - Southampton – 14 June 2011
- Focus groups with people from BAME groups
- Oxford – 8 June 2011
  - Southampton – 14 June 2011
  - Manchester – 21 June 2011
  - London— 22 June 2011
  - London – 22 June 2011
  - Birmingham – 22 June 2011
  - Leicester – 28 June 2011
  - Leeds – 28 June 2011
  - Cardiff – 29 June 2011
  - Newcastle – 29 June 2011
  - Cambridge – 30 June 2011
- In addition interviews were offered either on the phone or in the home with people who could not attend the groups.

## **9. The impact on children, family and friends**

9.1 The impact on family life was an important consideration for the JCPCT and the JCPCT members were very conscious of how emotive and difficult it is for the families of children with congenital heart disease.

9.2 The JCPCT members understood that very long journey time impacts will be experienced by a small number of patients and their families, and that for these families this would be felt as significant. At the same time, the JCPCT recognised that these impacts are not specific to the patients of the Yorkshire and Humber. When the impacts on families were explored, for example by the independent expert third party, they have concluded that the differences between the options are marginal. Therefore, it does not appear that patients from a particular region would be disproportionately disadvantaged.

9.3 The well-being of children and their families was an important part of the JCPCT's deliberations. A substantive impact assessment was undertaken by an independent third party, Mott MacDonald, to explore these impacts. The research was considerable in scope and length – it took place between October 2010 and June 2012, including targeted workshops with affected families in England and Wales, as well as interviews with those who are considered to be most vulnerable. The findings were considered by the JCPCT on 4 July and can be found at appendices X1 and X2.

9.4 The JCPCT recognised there would be potential negative and positive impacts on patients and their families. It has also recognised that these negative impacts can be significantly mitigated or completely removed, and the positive ones should be enhanced. The Decision-Making Business Case sets out many measures that can help patients and their families who will be, to differing degrees, affected by the changes. Some of these measures are included on pages 77 and 217. Many measures were also suggested in the independent Health Impact Assessment and by PCTs as part of their compliance with the Equality Act 2010. The JCPCT have discussed these issues at their meeting in depth and committed to monitor the impacts and efficiency of the measures designed to deal with them during implementation.

9.5 The new model of care will address many concerns that patients had about the impacts. The agreed quality standards already include many measures that will help patients and their families.

9.6 Clinical and support facilities would be designed around the need of children and their families. Communication with families and children will be improved through provision of Children's Specialist Nurses and a Clinical Psychologist during decision-making processes to explain the diagnosis/treatment to help ease stress and provide a good family experience.

9.7 More care will be brought closer to patients' homes. At present, many patients from Yorkshire and the Humber have to travel to Leeds for these appointments, with consequences to the families' well-being. Instead, Consultant Paediatricians with Expertise in Cardiology will be based at most large hospitals. Children will be able to have echocardiograms in their local hospitals. Babies and children with suspected congenital heart disease may be referred to their local hospital for diagnosis and treatment.

9.8 The new congenital heart networks will result in better "joined up" care across the various NHS services that see children with congenital heart disease. Children will only need to travel for surgery and interventional care, which for most of them takes place once in their lifetimes. It is only this element of their care that will take place in the seven Specialist Surgical Centres.

9.9 However, these centres will also provide the non-interventional care for children who live nearby or wish to receive this care there. All this means that the non-interventional services will be significantly extended - they will be provided in more hospitals than in present.

9.10 Finally, as accommodation was a concern often raised by respondents in your area, it is important to bear in mind that the standards also include the provision of accommodation. The standards F1-F15 address specifically the family experience.

## **10. Nationally Commissioned Services**

10.1 In your report you set out a number of concerns about the JCPCT's approach to the future location of the three nationally commissioned services (paediatric cardiothoracic transplantation, extra-corporeal membrane oxygenation

(ECMO) service for children with severe respiratory failure and complex tracheal surgery).

10.2 I want to emphasise that all centres were treated equally in this process. All centres were given the same information and asked to submit their applications by the same deadline.

10.3 Our approach to this issue was tested during consultation with a number of expert respondents and a detailed analysis is provided on pages 94 - 101 of the Decision-Making Business Case. For example, we sought advice on the possible re-location of paediatric cardiothoracic transplant service with the Cardiothoracic Transplant Advisory Group who advised us that Leeds Teaching Hospital could not be considered a viable provider of paediatric transplant services in the absence of an adult cardiothoracic transplant service in the same city (the nearest adult cardiothoracic transplant service to Leeds is in Manchester). Similarly the Advisory Group for National Specialised Services (comprising Royal Colleges of medicine and professional associations) advised us on the significant risks of moving paediatric cardiothoracic transplant services from the Freeman Hospital given its excellent outcomes and particular expertise in this field (including in the insertion of ventricular assist devices as a 'bridge' to transplantation).

10.4 However, that is not to say that this issue determined the JCPCT's decision. It did not. The strength of Option B – compared to Option G - was apparent based on a consideration of all of the evidence. Even if Leeds Teaching Hospital had been found to be a viable provider of transplant and ECMO services – and if the 'score' for each option had been adjusted accordingly - Option B would remain higher scored than option G based on a consideration of all of the evidence against all of the agreed criteria for the evaluation of options.

## **11. Yorkhill Hospital, Glasgow**

11.1 A number of respondents from Yorkshire and Humber proposed that the paediatric congenital cardiac service in Glasgow be included in the scope of the *Safe and Sustainable* review. The service at Yorkhill Hospital is subject to the devolved administration in Scotland and, as such, the JCPCT has no authority over this service.



6<sup>th</sup> Floor  
157 – 197 Buckingham Palace Road  
London  
SW1W 9SP

The Rt Hon Andrew Lansley CBE MP  
Secretary of State for Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

13 January 2012

Dear Secretary of State

**REFERRAL TO SECRETARY OF STATE FOR HEALTH**  
**Review of Children's Congenital Cardiac Services**  
**Yorkshire and Humber Joint Health Overview and Scrutiny Committee**

Thank you for forwarding copies of the referral letter and supporting documentation from Cllr Lisa Mulherin, Chair Yorkshire and Humber Joint Health and Overview Scrutiny Committee (Joint HOSC). The National Specialised Commissioning Team (NSCT) provided initial assessment information. A list of all the documents received is at Appendix One.

The IRP has undertaken an initial assessment, in accordance with our agreed protocol for handling contested proposals for the reconfiguration of NHS services. The IRP considers each referral on its merits and its advice in this case is set out below. **The Panel concludes that this referral is not suitable for full review.**

**Background**

Following a higher than expected number of deaths of children receiving heart surgery between 1984 and 1995, the Bristol Royal Infirmary Inquiry report (the Kennedy report) was published in 2001 recommending that specialist expertise be concentrated in fewer surgical units in England. Further consideration by the Department of Health (DH) and relevant medical bodies followed until, in May 2008, the NSCT was asked to undertake a review with a view to reconfiguring surgical services for children with congenital heart disease. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated on fewer sites than the current eleven sites in England.

The *Safe and Sustainable* team was established to manage the review process on behalf of the ten Specialised Commissioning Groups (SCG) and their local primary care trusts (PCT). In December 2008, an expert clinical Steering Group was formed to direct the process of developing a report to the NHS Management Board and DH Ministers.

Draft quality standards, against which surgical centres would be assessed, were published in September 2009 and sent directly to all HOSCs and other organisations for comment. The

*Independent Reconfiguration Panel*  
Tel: 020 7389 8045/6  
E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk) Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)



final version of the standards was published in March 2010 and a process of self-assessment by surgical centres commenced in April 2010. In the same month, the *Safe and Sustainable* team published *Children's Heart Surgery – the Need for Change*. Also in April 2010, the NHS Operations Board recommended to DH Ministers that PCTs delegate their consultation responsibilities and decision-making powers to a joint committee of PCTs (JCPCT). The Secretary of State for Health approved the establishment of the JCPCT in June 2010. The revised NHS Operating Framework confirmed that the *Safe and Sustainable* review was expected to deliver recommendations for consultation in the autumn of 2010.

Between May and June 2010, an expert panel, chaired by Professor Sir Ian Kennedy, visited each surgical centre to meet staff and families and to assess each centre's ability to comply with the standards. Pre-consultation engagement events commenced in June 2010. In September 2010, the case for change was supported by the National Clinical Advisory Team and proposed processes for consultation were endorsed by OGC Gateway review. The JCPCT met for the first time as a formally constituted body in October 2010. Briefings for HOSCs by SCG representatives began the following month. The report of the Kennedy panel was published in December 2010.

Options for consultation were agreed by the JCPCT in February 2011 and a four-month public consultation began in March 2011. The consultation proposed concentrating clinical expertise on fewer sites by reducing the number of surgical centres from eleven to either six or seven. A judicial review of the proposal to reduce the number of surgical centres in London from three to two centres was initiated by the Royal Brompton & Harefield NHS Foundation Trust.

A briefing for HOSCs, informing them of the forthcoming launch of the consultation, had been issued in February 2011. Earlier communications to HOSCs, notably a Centre for Public Scrutiny briefing in April 2010, had alerted them to the intention to conduct a formal consultation and encouraged them to consider the need for a joint committee. In recognition of changes to membership resulting from local elections in May 2011, the deadline for receipt of responses from HOSCs was extended to 5 October 2011. In the event, no national joint committee was formed and arrangements for scrutiny varied around the country with a mixture of individual and area and regional joint committees ultimately responding to the consultation.

Key emerging findings from a Health Impact Assessment (HIA) were sent to HOSCs and Local Involvement Networks (LINK) and published on the review website in June 2011. The formal public consultation closed on 1 July 2011. An independent analysis of the consultation and a report from focus groups involving parents, young people and black and minority ethnic (BAME) communities, commissioned from Ipsos MORI, was published in August 2011.

In September 2011, the *Safe and Sustainable* Steering Group considered clinical issues raised during the consultation and advised the JCPCT to agree the quality standards and

Independent Reconfiguration Panel  
Tel: 020 7389 8045/6

E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk) Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)

model of care as set out in the consultation document. A supplementary report in response to issues raised during the consultation was published by the Kennedy panel in October 2011.

On 14 October 2011, the Yorkshire and Humber Joint HOSC wrote to the Secretary of State for Health to refer the proposals. Referral was made on the basis of inadequate consultation with the Joint HOSC. Documentation provided with the referral letter evidences numerous exchanges of correspondence between the Joint HOSC and representatives of the JCPCT, *Safe and Sustainable* team and SCGs regarding invitations to attend meetings and requests for information. The referral letter specifies four pieces of information requested by the Joint HOSC, which were not received prior to the 5 October 2011 deadline for submission of HOSC responses to the consultation. These were:

- *The detailed breakdown of assessment scores for surgical centres produced by the independent Expert Panel (chaired by Sir Ian Kennedy)*
- *A finalised Health Impact Assessment report*
- *A detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber referred to in the Health Impact Assessment (interim report)*
- *The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation*

On 7 November 2011, the judgement was delivered in a judicial review brought by the Royal Brompton & Harefield NHS Foundation Trust. The judge, whilst rejecting a number of the arguments put forward, found against the JCPCT on a matter of process. An appeal against the judgement has been lodged. Depending on the outcome of that appeal, it is anticipated either that a final decision on the future location of surgical centres will be made by the JCPCT in spring 2012 or that a further public consultation will be necessary.

## **Basis for referral**

The referral letter of 14 October 2011 from Cllr Mulherin, Chair, Yorkshire and Humber Joint HOSC states that:

*“...on behalf of the Joint HOSC and in accordance with the provisions set out in the Health and Social Care Act (2001) (as amended) and the associated regulations [The Local Authority (OSCHSF) Regulations 2002] and guidance [Overview and Scrutiny of Health – Guidance, DH July 2003], I am writing to formally refer this matter for your consideration. This referral is on the basis of inadequate consultation with the Joint HOSC by the Joint Committee of Primary Care Trusts (JCPCT), as the appropriate NHS body.”*

The letter further states:

*“As such, subject to any additional information that becomes available and any future decision of the JCPCT, the Joint HOSC reserves the right to refer this matter on the grounds that the proposal would not be in the interests of local health services or the population served by such services.”*

Independent Reconfiguration Panel

Tel: 020 7389 8045/6

E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk)

Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)

## IRP view

With regard to the referral by the Yorkshire and Humber Joint HOSC, the Panel notes that:

- The referral by the Yorkshire and Humber Joint HOSC is solely on the grounds of inadequate consultation with that HOSC – it is not on the grounds that the proposals are not in the interests of local health services
- The referral does not, therefore, require the Secretary of State (or by extension the IRP) to consider the relative merits of the options identified in the formal consultation or the rigour of either the pre-consultation public involvement work undertaken or the wider formal *public* consultation
- The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 enable the Secretary of State to direct local authorities to appoint a joint committee where appropriate – this power was not exercised in this case
- Although the proposals in question, and the consultation exercise held in relation to them, relate to services covering the whole of England, a national joint HOSC was not appointed to carry out scrutiny duties – joint HOSCs were formed in some areas of the country while individual HOSCs responded to the consultation elsewhere
- The absence of a national joint HOSC led to the delegation of responsibility for the supply of information and liaison with interested HOSCs to local representatives of the ten SCGs covering England
- The Joint HOSC acknowledges a “recent shift” in the willingness of those concerned to engage with the scrutiny process in Yorkshire and the Humber
- The crux of the matter now appears to relate to information sought by the Joint HOSC, summarised in its referral letter of 14 October 2011, which was not provided before 5 October 2011 – some of which the JCPCT has declined either to procure or to release at this stage

## Conclusion

The IRP offers its advice on a case-by-case basis taking account of the specific circumstances and issues of each referral. **The Panel does not consider that a full review would add any value in this instance.**

The Panel understands that the *Safe and Sustainable* consultation was the first national consultation to have been conducted since the introduction of health scrutiny by local authorities. The *Safe and Sustainable* team appears to have made efforts to inform HOSCs in advance of the intention to conduct a national consultation and to encourage the establishment of a national joint HOSC. But, for whatever reason, this did not happen and, in the absence of a national joint HOSC to scrutinise the proposals and respond to the consultation, engagement with all interested HOSCs inevitably became a complex matter. In the circumstances, the Panel considers that the decision of HOSCs across Yorkshire and the Humber to form a joint HOSC for that area was a helpful one and that, equally, the delegation of responsibility for liaising with HOSCs from the JCPCT to the ten SCGs was probably the only practical solution.

*Independent Reconfiguration Panel*

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E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk)

Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)

The obstacles that prevented the establishment of a national joint HOSC for the *Safe and Sustainable* consultation are unlikely to be peculiar to this review alone. The Panel understands that regional joint HOSCs were established in the north east, east midlands and the south east of England and this may be a more appropriate option for scrutiny of future national exercises. The Department of Health may wish to give further consideration to this issue and also to whether its guidance on overview and scrutiny of health – published in 2003 – would benefit from some updating.

The main issue outstanding now with regard to this referral relates to the information requested by the Yorkshire and Humber Joint HOSC and summarised in its letter of 14 October 2011. Regulation 5 (1) of the Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 requires NHS bodies to provide an overview and scrutiny committee with “*such information.....as the committee may reasonably require in order to discharge its function*”. Clearly, what constitutes “reasonable” is open to some interpretation. In the Panel’s view:

- *The detailed breakdown of assessment scores for surgical centres produced by the independent Expert Panel (chaired by Sir Ian Kennedy)*  
Since the detailed breakdown of assessment scores has not been seen by the JCPCT, it was not material to the production of the consultation document, nor will it be material to the decision-making process. The JCPCT’s commitment to release this information once it has made its final decisions is, in our view, reasonable.
- *A finalised Health Impact Assessment report*  
Emerging findings were published in February, June and August 2011. The JCPCT states that the final version of the HIA report can only be published once the authors have themselves considered the extent to which responses to the public consultation will influence the HIA’s emerging findings. The Panel agrees with this position on the basis that the final HIA is published sufficiently in advance of the JCPCT final decision-making meeting to allow its contents to inform fully that decision.
- *A detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber referred to in the Health Impact Assessment (interim report)*  
The information requested was not held and, having considered the Joint HOSC’s request, the JCPCT concluded that the HIA process would not benefit from this additional analysis, nor would it be equitable to commission it for one area only. The Panel agrees with this position on the basis that the final HIA report is suitably comprehensive.
- *The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation*  
This information was not available prior to the 5 October 2011 deadline for HOSCs to submit responses to the consultation. The Panel believes that it should have been available at a much earlier stage so that it could be communicated to all interested parties. PwC’s report was published on the NSCT website in October 2011. The Panel considers that (subject to forthcoming legal judgement) any comments the Joint HOSC (or any other interested party) may wish to make with regard to this report should be

accepted by the JCPCT and considered alongside the report itself as part of its decision-making process.

The Yorkshire and Humber Joint HOSC has scrutinised this subject with considerable commitment and passion. That there appear, on occasion, to have been breakdowns in communications and relationships between the Joint HOSC and the JCPCT is disappointing, the difficult circumstances notwithstanding. While the pre-consultation engagement work undertaken by the *Safe and Sustainable* team was extensive, the suspicion remains that, in the absence of a national joint HOSC, the communications strategy for handling a large number of individual HOSCs could have been more effective. It is interesting to note that, in spite of the comprehensive and detailed content of the formal consultation document, there still appears to be some misunderstanding about how the future model of care will work. This only serves to underline the importance of face-to-face communications in such circumstances.

The Panel recognises, however, the considerable efforts of individuals to improve communications and information exchange in the latter stages of the process. The Joint HOSC has also acknowledged this and we hope this will form the basis for effective working relationships in the future.

The next steps in this process are entirely dependent on the outcome of the forthcoming appeal against the Court judgement of the consultation process. If the judgement is overturned, effective relationships and lines of communication with the Joint HOSC must be maintained and reinforced to aid their understanding and involvement in the run-up to the JCPCT's final decision-making. If the judgement is upheld, and the consultation is to be repeated in its entirety, the opportunity will arise to consider the lessons learnt that will be equally relevant on a national scale.

Yours sincerely



Dr Peter Barrett CBE DL  
Chair, IRP

*Independent Reconfiguration Panel*  
Tel: 020 7389 8045/6

E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk) Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)

## APPENDIX ONE

### LIST OF DOCUMENTS RECEIVED

#### **Yorkshire and Humber Joint Health Overview and Scrutiny Committee**

- 1 Letter of referral from Cllr Mulherin, Chair, Yorkshire and Humber Joint HOSC to Secretary of State for Health, 14 October 2011

Attachments:

- 2 Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services, Joint Health Overview and Scrutiny Committee (Yorkshire and Humber), October 2011

#### **National Specialised Commissioning Team**

- 1 IRP template for providing initial assessment information

Attachments:

- 2 Circular: NHS Review of Paediatric Cardiac Surgical Services in England, The Centre for Public Scrutiny, 15 April 2010
- 3 Circular: Safe and Sustainable Children's Heart Surgery: A Briefing, August 2010
- 4 Circular: Review of Children's Heart Surgery services in England: An Update, November 2010
- 5 Circular: Review of Children's Heart Surgery services in England: Briefing 3, Spring 2011
- 6 Leeds Teaching Hospitals NHS Trust: Staffing – numbers as at 30 November 2009
- 7 National Clinical Advisory Team – NCAT: Safe and Sustainable Paediatric Cardiac Surgery Services, Desktop Review – Chris Clough
- 8 Health Gateway Review: Safe and Sustainable Paediatric Cardiac Surgery Service – Review 0: Strategic assessment, Department of Health/OGC Gateway, 9 September 2010
- 9 Letter to Teresa Moss, chief executive, National Specialised Commissioning Group, from Alastair Finney, Deputy Director – Strategy and Commissioning Development, NHS London, 8 February 2011 and Assurance of the consultation on the proposed reconfiguration of children's congenital cardiac services in England: 8 February 2011
- 10 Various correspondence (emails and letters) between representatives of NSCT and Yorkshire and Humber Joint HOSC – 9 and 18 November 2010, 8 April 2011, 8 and 14 April 2011, 9 May 2011, 24 May to 9 June 2011, 22 August 2011, 26 August 2011 (x2), 26 and 31 August 2011, 7 September 2011, 12 September 2011, 14 September 2011, 16 September 2011, 23 September 2011, 27 September 2011, 18 November 2011, 5 December 2011, 9 December 2011.
- 11 JCPCT's response to the Yorkshire and the Humber Joint HOSC's request for information
- 12 Additional information provided by NSCT regarding consultation
- 13 URL links to other relevant documentation:
  - Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol, July 2001

*Independent Reconfiguration Panel*

*Tel: 020 7389 8045/6*

*E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk)*

*Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)*



- Children's Heart Surgery in England – the need for change, April 2011
- Papers from PCPCT meeting, 16 February 2011
- Pre-consultation Business Case, February 2011
- Consultation document, February 2011
- Better care for your heart – a summary, March-July 2011
- Consultation document and questionnaire in Welsh, March-July 2011
- Consultation document and questionnaire in minority languages, March-July 2011
- Consultation document – improving children's congenital heart services in London, March-July 2011
- National Clinical Advisory Team (NCAT) report, September 2010
- Health Impact Assessment – Key Emerging Findings, 21 June 2011
- Health Impact Assessment – Interim Report, 5 August 2011
- Testing assumptions for future patient flows and manageable clinical networks for Safe and Sustainable (PWC), October 2011
- Report of the Independent Panel on the relationship of interdependencies at the Royal Brompton Hospital ("Pollit Report"), 15 September 2011
- Report from Sir Ian Kennedy's independent expert panel to JCPCT, 17 October 2011
- Report to the OCPCT by Dr Patricia Hamilton CBE, Chair of the Safe and Sustainable steering Group, on behalf of Steering group members, 17 October 2011
- The relation Between Volume and Outcome in Paediatric Cardiac Surgery. A Literature Review for the National Specialised Commissioning Group. Henrietta Ewart, Consultant in Public Health Medicine, PHRU, Oxford, September 2009
- Children's Heart Surgery Centres in England: Comments on Draft Service Specification, 17 February 2010

*Independent Reconfiguration Panel*  
*Tel: 020 7389 8045/6*

*E Mail: [info@irpanel.org.uk](mailto:info@irpanel.org.uk) Website: [www.irpanel.org.uk](http://www.irpanel.org.uk)*



# **JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE AND THE HUMBER)**

## **Review of Children's Congenital Cardiac Services**

### **Testing assumptions for future patient flows and manageable clinical networks (PwC final report – October 2011)**

#### **Statement issued on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)**

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (JHOSC) met in December 2011 to consider the findings of the PwC work testing the review assumptions around future patient flows and manageable clinical networks.

The JHOSC welcomed the findings of PwC, which supported its view that patients across Yorkshire and the Humber would not travel to the centres assumed in the options presented in the consultation document. This view being derived from members' local knowledge and experience and from the engagement with the public across our region during the course of the Inquiry.

The JHOSC believes the PwC report also corroborates its view that the adult and children's congenital cardiac services should be considered together – not separately – because of the absolute patient numbers and to avoid any possibility of the adult's review being pre-determined by the outcome of the children's review.

The finding that extending travel times and the complexity of journeys for patients across Yorkshire and the Humber would place additional strain on families, as highlighted in the October 2011 report, is also supported. The PwC report highlights that patients from the East Coast in particular would experience an increased risk under options A, B and C. It remains the view of the JHOSC that such increased risks are both unreasonable and unnecessary.

The JHOSC's initial report highlighted the modelling of transfer activity undertaken by Embrace (the Yorkshire and Humber paediatric and neonatal dedicated transport service). This suggested that between 53% and 73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review documentation. This was in comparison to the national figures of between 3.6% and 6.2%. While the PwC report makes reference to some concerns about retrieval services in future network models, there is little evidence to suggest the work undertaken by Embrace has been given further consideration. However, the JHOSC maintains that the outcome of the work undertaken by Embrace is very striking and once again highlights the disproportionate impact that Options A, B and C would have on children and families across Yorkshire and the Humber.

The PwC report highlights that referrers suggested the most well developed clinical networks are those related to centres (including Leeds) more likely not to continue as specialist surgical centres under the current options. The JHOSC believes this supports its previously expressed view that it is completely illogical that three of the four proposed options would see the break-up and fragmentation of the existing very strong network arrangements across Yorkshire and the Humber.

# **JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE AND THE HUMBER)**

## **Review of Children's Congenital Cardiac Services**

### **Testing assumptions for future patient flows and manageable clinical networks (PwC final report – October 2011)**

The JHOSC believes that in any service review and reconfiguration it is important to have a clear view of the strengths of the current arrangements and for these to be retained and built upon within the future service model. With regard to clinical networks, members of the JHOSC do not believe this to have been the case within the review of children's congenital cardiac services.

Furthermore, the JHOSC maintains that the strength of networks has not been given an appropriate level of consideration within the review process to date, and believes that unless efforts are made at this stage to take the strength of the existing clinical networks into account this will severely disadvantage the children and families of Yorkshire and the Humber.

**To conclude, the view of the JHOSC representing 5.5 million people in the Yorkshire and Humber region remains that any future configuration of Congenital Cardiac Surgical Centres must include the surgical centre in Leeds if the people of this region are not to be disproportionately disadvantaged.**



**Councillor Lisa Mulherin  
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and  
the Humber**

**April 2012**

## **JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE & THE HUMBER)**

**TUESDAY, 24TH JULY, 2012**

**PRESENT:** Councillor J Illingworth in the Chair

Councillors D Brown, J Clark, P Elliott, C Funnell, A Naylor, A McAllister, B Hall, T Revill, Y Crewe and L Smaje.

### **55 Late Items**

It was agreed to admit the following additional information for consideration at the meeting (Minute 59 refers):

- Submission from Leeds Teaching Hospitals NHS Trust (LTHT)
- Formal JCPCT response to the report of the Joint Health Overview and Scrutiny Committee (October 2011)
- City of Bradford MDC – Council resolution – 10 July 2012
- Letter from Sheffield City Council
- Review of Children’s Congenital Cardiac Services at Royal Hospital for Sick Children (Yorkhill), Glasgow – Report of the Independent Expert Panel Chaired by Professor Sir Ian Kennedy (February 2012)
- Details of additional Council motions
- Replacement Appendix 2 showing the detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy)

### **56 Declarations of Interest**

Cllr. Naylor declared a personal interest due to ownership of a company that undertook work on behalf of the NHS from time to time. As this was a non-pecuniary interest, Cllr. Naylor remained in the meeting.

There were no other declarations of interest.

### **57 Apologies for Absence and Notification of Substitutes**

Apologies for absence were submitted on behalf of Councillors J Bromby, M Gibbons, R Goldthorpe, B Rhodes, M Rooney and J Worton.

Attendance of the following substitute members was confirmed:

- Bradford MDC – Cllr. Adrian Naylor attending as a substitute for Cllr. Mike Gibbons
- Calderdale Council – Cllr. Ann McAllister attending as a substitute for Cllr. Ruth Goldthorpe
- Wakefield Council – Cllr. Yvonne Crewe attending as a substitute for Cllr. Betty Rhodes

## 58 Review of Children's Congenital Heart Services in England: Revised Terms of Reference

The Head of Scrutiny and Member Development informed the Board that, due to the local elections held in May 2012 and the subsequent changes in appointments within Council's across the region, it was necessary to consider and formally agree changes to the membership of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

The following proposed changes to the membership of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) were reported:

- Leeds City Council – Cllr. John Illingworth replacing Cllr. Lisa Mulherin (with Cllr. Illingworth to act as Chair of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)).
- North East Lincolnshire Council – Cllr. Peggy Elliott replacing Cllr. Karl Wilson
- Sheffield City Council – Cllr. Mick Rooney replacing Cllr. Ian Saunders

It was also reported that when first established, the Terms of Reference for the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) had focused on the proposed changes to Children's Congenital Heart Services in England (including the reconfiguration options and future location of surgical centres) and responding to the formal consultation. However, as the review and consultation processes had progressed, it had become increasingly apparent that potentially there were significant implementation issues that the Joint HOSC may wish to consider on an ongoing basis.

Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) were presented with revised Terms of Reference that reflected the proposed changes in membership and included consideration of issues associated with the implementation stage of the review.

Members considered the revised Terms of Reference and agreed the proposed changes without any additional amendments.

Thanks were expressed to Councillors Wilson and Saunders for their contributions to the work of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber). There was particular thanks reserved for Councillor Mulherin, the former Chair of the Joint Committee.

### **RESOLVED –**

- (a) That the information presented in the report and revised Terms of Reference be noted.
- (b) That the proposed changes to the membership of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) and the scope of the Joint Committee's work, as set out in the revised Terms of Reference be agreed.

Draft minutes to be approved at the meeting  
to be held on Date Not Specified

## **59 Review of Children's Congenital Heart Services in England: Final Decision**

The report of the Head of Scrutiny and Member Development introduced a range of information related to the decision by the Joint Committee of Primary Care Trusts (JCPCT) regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres and associated network configuration.

The report reminded members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) of the previous report prepared by the Joint Committee that highlighted a number of areas members believed needed further and more detailed consideration, including:

- Co-location of services;
- Caseloads;
- Population density;
- Vulnerable groups;
- Travel and access to services;
- Costs to the NHS
- The impact on children, families and friends;
- Established congenital cardiac networks;
- Adults with congenital cardiac disease;
- Views of the people across Yorkshire and the Humber

The report highlighted the overall view previously expressed by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) that any future service model that did not include a designated children's cardiac surgical centre at Leeds would have a disproportionately negative impact on the children and families across Yorkshire and the Humber.

The report also highlighted that, at its meeting on 4 July 2012, the JCPCT had agreed consultation Option B for implementation and the designation of congenital heart networks led by the following surgical centres:

- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St. Thomas' NHS Foundation Trust

The associated Decision-Making Business Case was appended to the report for consideration by members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

A range of interested parties / stakeholders were identified in the report as having been invited to attend the meeting and assist the Joint Health

Draft minutes to be approved at the meeting  
to be held on Date Not Specified

Overview and Scrutiny Committee (Yorkshire and the Humber) in its consideration of the JCPCT's decision.

The Chair advised the meeting that contributions would be received and considered in the following order:

- Elected representatives;
- Children's Heart Surgery Fund and patient and parent representatives;
- Leeds Teaching Hospitals NHS Trust representatives; and,
- Joint Committee of Primary Care Trusts (JCPCT) representatives.

#### Elected representatives:

The following representatives were in attendance and addressed the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

- Stuart Andrew – Member of Parliament for Pudsey
- Councillor Lisa Mulherin – Executive Member for Health and Wellbeing (Leeds City Council)

Stuart Andrew MP addressed the meeting, stating he was representing a large number of Members of Parliament from across different political parties. It was emphasised that MPs were not against the principles of the review but questioned the outcome and some of the assumptions made to support the JCPCT's decision. A number of specific issues, including the following matters, were highlighted:

- Issues associated with the general population around Leeds (14 million people with 2 hours drive of the City) and transport links had not been sufficiently considered as part of the review.
- Concerns around Newcastle's ability to reach the minimum level of 400 surgical procedures per year, and the assumptions used to support this aspect of the review.
- It was clear from the PwC work that patients across Yorkshire and the Humber would not travel to Newcastle and, in the absence of a surgical centre at Leeds, would access services at other centres, including Liverpool, Birmingham and London.
- The JCPCT had assumed that a minimum of 25% of patients from Yorkshire and the Humber would travel to Newcastle. This assumption suggested that Newcastle would just meet the requirement to undertake the minimum level of 400 surgical procedures per year. However, it was unclear what evidence there was to suggest 25% was an accurate assumption and/or how this had been derived.
- The co-location of services was an important factor to take into account, as this would have a direct impact on the level and quality of care accessible at surgical centres. There was concern that the decision to close the surgical centre at Leeds would not result in an improved service and would in fact deliver a worse service for the population of Yorkshire and the Humber.
- Concerns that impacts on specific BME communities had not been adequately reflected in the JCPCT's decision.

On behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), the Chair thanked Mr Andrew for his contribution to the meeting.

Councillor Lisa Mulherin, Leeds City Council's Executive Member for Health and Wellbeing addressed the meeting. It was clarified that until recently, Councillor Mulherin had previously been Chair of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) and therefore had a detailed knowledge and understanding the Committee's work to date.

A number of specific issues, including the following matters, were highlighted:

- Concerns that the JCPCT had failed to adequately engage with the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) sufficiently early in the review process, and that the work of the Joint Committee was not viewed as a valuable and constructive part of the process.
- The length of time between the submission of the report from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) and the response now presented, demonstrated the dismissive nature of the JCPCT's approach to much of the Joint Committee's work.
- Issues around travel and access highlighted by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) were not issues of convenience, but related to the real life impacts on children and families.
- Some issues and comments related to 'quality' had been misleading and used disingenuously, however there was no doubt about the quality of services available at Leeds Teaching Hospitals NHS Trust (LTHT).
- The ability of LTHT to meet the minimum standard of 400 procedures per annum under a 4 surgeon model.
- Issues around transparency of decision-making and specifically information repeatedly requested by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) that had not been provided by the JCPCT.
- General concern that the decision to close the surgical centre at Leeds would not result in an improved service. Rather, it would deliver a worse service for the population of Yorkshire and the Humber.

On behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), the Chair thanked Councillor Mulherin for her input into the meeting and continued contribution to the work of the Joint Committee.

#### Children's Heart Surgery Fund and patient and parent representatives:

The following representatives were in attendance and addressed the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

- Kevin Watterson<sup>1</sup> (Chair and Trustee) – Children's Heart Surgery Fund
- Lois Brown – parent
- Jon Arnold – parent and Trustee of Children's Heart Surgery Fund

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<sup>1</sup> Paediatric Cardiac Surgeon at Leeds Teaching Hospitals NHS Trust



- Steph Ward – parent
- Gaynor Bearder – parent
- Kimberley Botham – adult congenital heart patient

The parent / patient representatives thanked the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) for the opportunity to highlight their concerns regarding the JCPCT's decision and addressed the meeting.

A summary of the issues highlighted and discussed at the meeting is as follows:

- There was general support for the basis of the review – i.e. fewer, larger surgical centres.
- The concerns around the JCPCT's decision raised by parents and patients across Yorkshire and the Humber had not been raised as a result of unquestionable loyalty to the surgical centre at Leeds. Concerns raised were as a result of wanting the best outcome for children and securing improvements to the services already available across Yorkshire and the Humber.
- The JCPCT's decision would lead to a lesser service for children and families across Yorkshire and the Humber – but with increased travel distances.
- Concern that Newcastle would not reach the minimum number of 400 surgical procedures per annum – thus making the surgical centre unsustainable and potentially leaving the whole north eastern part of England without a surgical centre.
- Concern that the PwC report on patient flows and clinical networks refers to the 'management' of patients and it was unclear how this reflected the right of patient choice (as detailed in the NHS Constitution).
- Concerns over the openness and transparency of the decision-making processes and engagement with children and families across Yorkshire and the Humber.
- The importance of co-location of services with the increasing complexity of needs and co-morbidities of children. It was highlighted that following the JCPCT's decision, Newcastle remained the only 'stand alone' congenital heart surgical unit in England.
- Concern regarding the long-term impacts on children with a congenital cardiac condition, particularly in terms of accessing specialist services where general anaesthesia would be needed.
- Consideration of 'the patient experience' appeared to be lacking within the review process and there was a lack of evidence to confirm the JCPCT's decision would deliver enhanced services for Yorkshire and the Humber.
- It was unclear what would be gained by reviewing the services for adults with congenital heart disease separately from review services for children. The outcome of the children's review was likely to predetermine any review of services for adults with congenital heart disease.
- The impact on capacity should there be an increased number of adults with congenital heart disease referred to Birmingham.

Mr. Watterson addressed the meeting in his capacity as Chair of the Children's Heart Surgery Fund and outlined the following issues:

- As Chair of the Children's Heart Surgery Fund, Mr Watterson had spoken at and received feedback from 17 public events across the region during the period of public consultation (March 2011 – July 2011). As such, Mr. Watterson was well aware of many of the issues and concerns raised by parents and families across the region.
- As far as the North Eastern side of England was concerned, the JCPCT's decision appeared to be illogical and did not reflect the basic health planning principles – i.e. services are placed as close as possible to the general population – thus limiting both the number of individuals needing to travel excessive distance and also limiting the overall impact on those accessing services.
- The JCPCT's decision did not appear to reflect the population projections for Yorkshire and the Humber and the North East.
- Expertise does not reside in bricks and mortar (i.e. hospital buildings), but in the teams and individuals delivering services. This is particularly important when considering the issues of co-location of services and work between different medical specialisms.
- Clinical outcomes were regarded as a key measure of quality across the NHS generally. However, the Kennedy scores (often referred to as the 'quality' scores) did not measure and therefore did not reflect issues associated with current clinical outcome.
- The JCPCT's decision did not appear to take sufficient account on the impact of emergency work undertaken on critically ill children and the associated impact.
- Concern that the petition from Yorkshire and Humber against any closure of Leeds' surgical unit, which included 600,000 signatures had not been given sufficient weighting or consideration as part of the JCPCT's decision-making process.

Mr. Watterson also reflected on his personal experience (in his professional capacity as a Paediatric Cardiac Surgeon at Leeds Teaching Hospitals NHS Trust) of working in a 'stand-alone' surgical centre (at the former Killingbeck Hospital site in Leeds) with that of working in a dedicated Children's Hospital setting – where all the necessary services (including obstetrics and maternity services) on a single site. Mr. Watterson stressed the benefits for patients under a co-location of services model.

Members of the Joint Committee highlighted and discussed a number of issues at this point in the meeting, including:

- Services available at the Freeman Hospital, Newcastle and the location of maternity services;
- The role of referring clinicians in the service model agreed by the JCPCT;
- The role of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) to comment on the standards of care likely to

be experienced as a result of the JCPCTs decision, and the evidence to support the decision.

Members also briefly discussed the content of the report of the Independent Expert Panel Chaired by Professor Sir Ian Kennedy regarding Children's Congenital Cardiac Services at Royal Hospital for Sick Children (Yorkhill), Glasgow (February 2012).

On behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), the Chair thanked those in attendance for their contributions to the meeting and work of the Joint Committee.

#### Leeds Teaching Hospitals NHS Trust representatives:

The following representatives were in attendance and addressed the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

- Stacey Hunter (Divisional General Manager, Children's Services) – Leeds Teaching Hospitals NHS Trust
- Karl Milner (Director of Communications) – Leeds Teaching Hospitals NHS Trust
- Dr Kate English<sup>2</sup> (Consultant in Adult Congenital Heart Disease) – Leeds Teaching Hospitals NHS Trust
- Dr John Thomson<sup>3</sup> (Consultant Cardiologist) – Leeds Teaching Hospitals NHS Trust
- Dr Mark Darowski (PICU Consultant) – Leeds Teaching Hospitals NHS Trust
- Dr Simon Newell (Consultant Neonatologist) – Leeds Teaching Hospitals NHS Trust

The following issues were highlighted and discussed:

- The fragmentation of the existing Yorkshire and Humber clinical network and how the proposed clinical networks will work in practice, with respective cardiology centres.
- Queries around whether the proposed cardiology centre in Leeds would be required to work across three different networks (Newcastle, Birmingham and Liverpool).
- Realities of the proposed patient flows and the respective roles of clinicians (in terms of referrals) and parents (in terms of patient choice).
- The considerable local impact on Leeds Teaching Hospitals NHS Trust (LTHT) associated with the loss of surgical services, including clinical governance risks for cardiologists.
- The use of the Kennedy scores as a 'proxy' for service quality and the apparent arbitrary and irrational nature of the scoring process.
- Concerns around inconsistencies and apparent arithmetical errors in some of the published data.

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<sup>2</sup> Council Member of the British Congenital Cardiac Association (BCCA)

<sup>3</sup> Honorary Secretary to the British Congenital Cardiac Association (BCCA)

- One of the impacts of the JCPCT's decision being that Newcastle would remain the only stand alone unit in England (i.e. not a Children's Hospital providing the full range of services available elsewhere).
- Concerns that some of the comments about the review that had been provided by the British Congenital Cardiac Association (BCCA) had not been fully reflected by the JCPCT.
- Significant impacts (operationally and financially) of the JCPCT's decision for the Paediatric Transport Service offered by Embrace.
- The impact of the JCPCT decision on the operation of the Paediatric Intensive Care Unit (PICU) in Leeds – including issues around capacity and flexibility during peak (winter) periods. It was highlighted that this may lead to greater use/ access of PICU beds outside Yorkshire and the Humber. This in turn may have a significant impact on the Paediatric Transport Service offered by Embrace.
- The loss of surgical services was likely to have an impact on the cardiology services provided by LTHT and the training programme offered by the Trust.
- The importance of the co-location of services – in particular for children and families from BME communities.
- The impact of additional travelling on children and their families.
- Improved survival rates of neonates leading to increased and greater complexities of needs in children. The co-location of services in this respect being vitally important.
- The well established network arrangements across Yorkshire and the Humber covering cardiac, PICU and neonatal services.
- Issues associated with 'blue' babies and children with complex needs. Without full co-location of services, it was unclear how children with complex needs would be treated/ cared for.
- Concerns around the 'quality' scores and it was felt that these were not representative of the services offered by LTHT.
- Concerns around the relative overall expertise of the Kennedy assessment panel. No expertise from the perspective of adults with congenital heart disease and no practicing UK paediatric cardiologist.
- Concern over the lack of complete information provided by the JCPCT in terms of the assessment process and associated scoring mechanism.
- Consideration of training within the assessment scores. Concern that without the provision and access to surgical services, it was unclear how cardiology trainees in Leeds (and potentially other de-designated centres) would complete their training.
- The BCCA view that cardiac services for children and adults should have been considered jointly.
- The increasing number of adult congenital heart disease patients. Concern that the longer-term impact of increasing numbers in this area had not been fully considered.
- Concerns around the sensitivity testing undertaken by the JCPCT (particular reference to Sensitivity F in the Decision-Making Business Case) in terms of:
  - The accuracy of information provided (no increase in the projected activity at the Birmingham Surgical Centre).

- The assumed 25% level of patients from Sheffield, Doncaster, Leeds and Wakefield travelling to Newcastle did not appear to be in line with the outcome of the PwC work around patient flows.
- Concern that some significant issues arising from the review remained unresolved and had been 'parked' for the implementation phase of the review.

Members discussed the details presented and statements made at the meeting. Members overall assessment being that while the overall service was likely to result in additional costs and investments, the JCPCT's decision would not result in an improved service across Yorkshire and Humber, rather the contrary being the case.

On behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), the Chair thanked those in attendance for their contributions to the meeting and work of the Joint Committee.

The Chair adjourned the meeting for lunch at approximately 1:30pm

The meeting was reconvened at approximately 2:00pm. Members were advised that Councillors D Brown (Hull City Council) and B Hall (East Riding of Yorkshire Council) had left the meeting due to other engagements, and Councillor Shaukat Ali (Rotherham Council) had joined the meeting.

#### The Joint Committee of Primary Care Trusts (JCPCT) representatives:

The Chair welcomed everyone to the second part of the meeting and advised that the meeting would now focus on the work of the JCPCT and the decision made on 4 July 2012.

The following representatives were in attendance.

- Sir Neil McKay – Chair of the Joint Committee of Primary Care Trusts (JCPCT)
- Andy Buck (Chief Executive) – NHS South Yorkshire & Bassetlaw<sup>4</sup>
- Dr. Leslie Hamilton (Deputy Chair) – Safe and Sustainable Cardiac Surgery Steering Group
- Jeremy Glyde (Programme Director) – Safe and Sustainable Programme

Sir Neil McKay initially addressed the meeting and acknowledged the emotive issue under discussion, stating it would be difficult not to be moved by the statements provided to the Joint Committee earlier in the meeting. Sir Neil went on to make a series of comments, including:

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<sup>4</sup> Also Chair of the Specialised Commissioning Group (Yorkshire and the Humber) and the regional (Yorkshire and the Humber) representative on the Joint Committee of Primary Care Trusts (JCPCT).

- There appeared to be a view that the comments and concerns from Yorkshire and the Humber had been ignored by the JCPCT.
- The JCPCT had attempted to manage the process in good faith and had tried to do what's right. Confirmation that the JCPCT had made the decision and that any advisers had only provided advice.
- Some of the arguments already put forward could be made / equally applied elsewhere in England.
- Confirmation that there was no evidence that current centres were unsafe (with the possible exception of Oxford that had been regarded as an outlier in terms of performance).
- Confirmation that the case for change was generally accepted – which supported the need for fewer, larger surgical centres.
- An outline that the JCPCT's work and decision had not been scientifically precise – but a product of processes involving analysis of a large number of different sources of information and advice, coupled with professional judgement.
- The outcome of the recent Court of Appeal process had found the public consultation process to be sound.

Further representatives addressed the meeting and the points highlighted and discussed included:

- Development of the standards of care to be delivered by surgical centres and the supporting networks had been supported by a plethora of evidence.
- The network model of care proposed envisaged a system of local services (excluding surgical procedures) delivered closer to patients' homes.
- Interpretation of the NHS definition of Critical Interdependencies and the implications for co-location of services.
- Confirmation that Sir Ian Kennedy's Expert panel had considered the best available evidence around Critical Interdependencies and re-affirmed previous advice, including that Foetal Medicine and Maternity Services were not critical interdependencies.
- The review of services for adults with congenital cardiac disease was outside the scope/ terms of reference for the JCPCT and could not be considered. The review of Children's Services could not be delayed until 2014 to become part of the adults review process/ timetable.
- The JCPCT had taken advice from a number of bodies regarding issues around with retrieval times.
- Consideration of applications to deliver Nationally Commissioned Services (Transplantation, Extra Corporeal Membrane Oxygenation (ECMO) and Complex Tracheal Surgery) had been considered by a national committee – which had discounted Leeds' application. It was reported that the view of the Advisory Group for National Specialised Services (AGNSS) was that it would take 8/10 years to successfully move transplant services from those centres currently delivering such services (including Newcastle).
- It was highlighted that three from the four options included as part of the public consultation process and that eight from twelve options



considered by the JCPCT on 4 July 2012 would have resulted in moving one or more nationally commissioned services.

- Confirmed that the Kennedy scores/ rankings had been important when assessing quality and undertaking the sensitivity tests.
- NHS London had assessed the proposals against the four tests for reconfiguration of services identified by the Secretary of State for Health – that is, reconfiguration proposals need to demonstrate:
  - Support from GP commissioners
  - Strengthened public and patient engagement
  - Clarity on the clinical evidence base
  - Consistency with current and prospective patient choice
- Issues around access and journey times had been taken into account by the JCPCT.

Members of the Joint Committee went on to highlight and discuss a number of issues, including:

- Travel and access issues to Newcastle.
- Consultation with BME communities and the lack of engagement in this regard. It was highlighted that children from BME backgrounds represented 24% of the surgical cases in Yorkshire and the Humber – often presenting more complex needs. The issues around co-location of services was particularly important in this regard.
- The long-term sustainability of the Newcastle surgical centre.
- Clarity around the Kennedy scores (used as a proxy for quality).
- The significant challenges around implementation.
- Clarity around the improvements to services for the children and families of Yorkshire and the Humber.
- Queries around the 8/10 years timescale quoted to successfully move transplant services from those centres currently delivering such services.
- The availability and provision of services in Leeds covering antenatal care through to adulthood.

The Chair addressed the meeting and in summing up the Joint Committee's deliberations, proposed that the 4 July 2012 decision of the Joint Committee of Primary Care Trusts, regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres, and associated network configuration, be referred to the Secretary of State for Health for consideration, on the basis of the decision not being in the interest of the local NHS.

For the purpose of the issues under consideration, the local NHS was interpreted as being the NHS across Yorkshire and the Humber.

#### **RESOLVED –**

- (a) That the 4 July 2012 decision of the Joint Committee of Primary Care Trusts, regarding the future reconfiguration of Children's Congenital Cardiac Surgical Centres, and associated network configuration, be referred to the Secretary of State for Health for consideration, on the basis of the decision not being in the interest of the local NHS.



- (b) That, reflecting the evidence considered and the issues raised by members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), a draft report be prepared to support the referral to the Secretary of State for Health.

## **60 Date and Time of Next Meeting**

In order to agree the report to accompany the Joint Committee's referral to the Secretary of State for Health and to continue with any other aspects of work, as appropriate, it was agreed to convene future meetings of the Joint Committee as and when appropriate.

The Chair of the Joint Committee thanked all those present for their attendance and contribution to the meeting.

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## **Analysis of the assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Professor Sir Ian Kennedy)**

### **Overview**

The evaluation process undertaken by Professor Sir Ian Kennedy's Panel, and the scores produced were based on the following broad areas of assessment:

- Leadership and Strategic Vision
- Strength of network
- Staffing and activity
- Inter-dependent services
- Facilities and capacity
- Age appropriate care
- Information and choices
- Ensuring excellent care
- Deliverability and achievability

The pre-decision business case states that *'the criteria for designation were taken from the proposed clinical standards – endorsed by the relevant professional associations and developed in partnership with stakeholders across the country' and '...other criteria were applied to this phase of the assessment process around 'leadership and strategic vision' and 'deliverability and achievability...'*.

It should be noted that criterion 'deliverability and achievability' was never considered by the assessment panel, as the panel did not consider it had the necessary expertise to score this section. The assessment therefore considered 'core' elements of the proposed clinical standards along with details associated with 'leadership and strategic vision'.

The weightings/ maximum scores achievable in the assessment process are detailed in the Table A.

Table A: Criterion and associated weightings

<b>Rank</b>	<b>Criterion</b>	<b>Maximum score / weighting</b>	<b>Percentage of maximum score</b>
1	Staffing and activity	130	21.3%
2	Leadership and Strategic Vision	120	19.7%
3=	Strength of network	70	11.5%
3=	Interdependent services	70	11.5%
3=	Facilities and capacity	70	11.5%
6	Ensuring excellent care	60	9.8%
7=	Age appropriate care	45	7.4%
7=	Information and choices	45	7.4%
	<b>Total</b>	<b>610</b>	<b>100.1%</b>

*Please note: As the criteria around deliverability and achievability were never considered by the Kennedy Panel, the criterion is not included in the above table.*

Within the 'Strategic Vision and Leadership' criterion, the Kennedy panel assessed the following elements:

- Organisation's main aims etc
- IT and estates strategy
- How proposals contribute to key objectives
- Current service delivery arrangements
- Stakeholder groups and contribution
- Critical success factors
- Internal/ external factors
- Constraints and risks
- Benefits
- Opportunities for innovative working
- How the team learns, develops and grows

Within the core standards considered, the Kennedy Panel assessed centres' across three areas:

- current performance against the standards;
- development plans; and,
- the impact of increased activity (i.e ability to meet the minimum of 400 surgical procedures).

### Service Standards

It is clear from the available documentation that in its assessment of quality, the Kennedy Panel took account of 'core standards' within the Service Standards produced by Children's Congenital Cardiac Services in England. While additional standards have subsequently been agreed by the JCPCT, it is understood that the Kennedy Panel assessments reflected the March 2010, Service Standards document.

Based on the March 2010, Service Standards document, the analysis in Table B may be useful:

Table B: Designation standards

<b>Designation Standard</b>	<b>Number of Standards</b>	<b>Number of Core Standards</b>	<b>Percentage of 'Core standards'</b>
A Congenital Heart Network for the Child and Family	28	8	29%
Prenatal Diagnosis	10	1	10%
The Specialist Surgical Centre	68	18	26%
Age Appropriate Care	8	8	100%
Information and Making Decision	13	13	100%
The Family Experience	15	2	13%
Excellent Care	14	3	21%
<b>Total</b>	<b>156</b>	<b>53</b>	<b>34%</b>

## Re-weighted Criterion

As a result of feedback provided during the consultation period regarding the importance of 'co-location of services', the JCPCT undertook a sensitivity test using re-weighted assessment criteria. The re-weightings used are presented on page 170 of the decision-making business case and have been used to produce Table C, below.

Table C1: Re-weighted criterion

Revised Rank	Criterion	Maximum score		Variance
		Original	Re-weighted	
1	Staffing and activity	130	130	0
1=	Interdependent services	70	130	+60
3	Leadership and Strategic Vision	120	102	-18
4=	Strength of network	70	60	-10
4=	Facilities and capacity	70	60	-10
6	Ensuring excellent care	60	51	-9
7=	Age appropriate care	45	38	-7
7=	Information and choices	45	38	-7
<b>Totals</b>		<b>610</b>	<b>609</b>	<b>-1</b>

*Please note: As the criteria around deliverability and achievability were never considered by the Kennedy Panel, the criterion is not included in the above table.*

Table C2: Criterion and associated re-weightings

Rank	Criterion	Maximum score / weighting	Percentage of maximum score
1	Staffing and activity	130	21.3%
1=	Interdependent services	130	21.3%
3	Leadership and Strategic Vision	102	16.7%
4=	Strength of network	60	9.9%
4=	Facilities and capacity	60	9.9%
6	Ensuring excellent care	51	8.4 %
7=	Age appropriate care	38	6.2 %
7=	Information and choices	38	6.2 %
<b>Totals</b>		<b>609</b>	<b>99.9%</b>

*Please note: As the criteria around deliverability and achievability were never considered by the Kennedy Panel, the criterion is not included in the above table.*

## Comparison of the original and re-weighted criterion

Table D details the differences between the overall Kennedy Panel scores detailed in the original public consultation document and the re-weighted Kennedy Panel scores following feedback around the importance of co-location of services provided during the consultation period.

Table D: Analysis of the application of the original and re-weighted criterion

Original Kennedy Panel scores			Re-weighted Kennedy Panel scores		
<i>Ranking</i>	<i>Centre</i>	<i>Score</i>	<i>Ranking</i>	<i>Centre</i>	<i>Score</i>
1	Evelina	535 (88%)	1	Evelina	544 (89%)
2	Southampton	513 (84%)	2	Southampton	513 (84%)
3	Birmingham	495 (81%)	3	Birmingham	507 (83%)
4=	GOSH	464 (76%)	4	GOSH	478 (78%)
4=	Brompton	464 (76%)	5	Brompton	467 (77%)
6	Bristol	449 (74%)	6	Bristol	454 (75%)
7	Newcastle	425 (70%)	7	Liverpool	430 (71%)
8	Liverpool	420 (69%)	8	Newcastle	420 (69%)
9	Leicester	402 (66%)	9	Leeds	414 (68%)
10	Leeds	401 (66%)	10	Leicester	382 (63%)
11	Oxford	237 (39%)	11	Oxford	235 (39%)
Maximum score		610	Maximum score		609

## Comparison and analysis of the original and re-weighted criterion

The following tables provide analysis of the original and re-weighted scores.

Table E: Analysis of the scores against the designation standards using the original and re-weighted criterion

Kennedy assessment scores using the 7 designation standards areas (excluding Leadership & Vision)			Re-weighted Kennedy assessment scores using the 7 designation standards areas (excluding Leadership & Vision)		
<i>Ranking</i>	<i>Centre</i>	<i>Score</i>	<i>Ranking</i>	<i>Centre</i>	<i>Score</i>
1	Evelina	424 (87%)	1	Evelina	447 (88%)
2	Southampton	417 (85%)	2	Southampton	431 (85%)
3	Birmingham	393 (80%)	3	Birmingham	419 (83%)
4	Brompton	370 (76%)	4	GOSH	395 (78%)
5	GOSH	367 (75%)	5	Brompton	387 (76%)
6	Bristol	359 (73%)	6	Bristol	376 (74%)
7	Liverpool	339 (69%)	7	Liverpool	360 (71%)
8	Newcastle	326 (67%)	8	Leeds	347 (68%)
9	Leeds	323 (66%)	9	Newcastle	335 (66%)
10	Leicester	312 (64%)	10	Leicester	306 (60%)
11	Oxford	184 (38%)	11	Oxford	192 (38%)
Maximum score		490	Maximum score		507

Considering quality as the assessment against the 7 [core] designation standards is likely to have an impact on the overall 'total score for quality'.

Using the original and re-weighted criterion, the following tables analyse the Kennedy Panel scores against the 7 core designation standards and:

- (a) centres' current performance against the standards;
- (b) centres' development plans; and,
- (c) the impact of increased activity (i.e. ability to meet the minimum of 400 surgical procedures).

Table F: Analysis of 'centres' current performance against the standards' scores using the original and re-weighted criterion

Kennedy assessment scores: centres' current performance against the standards			Re-weighted Kennedy assessment scores: centres' current performance against the standards)		
Ranking	Centre	Score	Ranking	Centre	Score
1	Southampton	78 (78%)	1	Southampton	81 (88%)
2	GOSH	76 (76%)	2	GOSH	80 (88%)
3	Evelina	75 (75%)	3	Evelina	79 (88%)
4	Birmingham	70 (70%)	4	Birmingham	74 (88%)
5	Brompton	69 (69%)	5=	Brompton	72 (88%)
6	Leeds	68 (68%)	5=	Leeds	72 (88%)
7	Liverpool	66 (66%)	7	Liverpool	70 (88%)
8	Bristol	65 (65%)	8	Bristol	67 (88%)
9	Newcastle	63 (63%)	9	Newcastle	65 (88%)
10	Leicester	54 (54%)	10	Leicester	53 (88%)
11	Oxford	45 (45%)	11	Oxford	46 (88%)
Maximum score		100	Maximum score		103

Table G: Analysis of 'centres' development plans' scores using the original and re-weighted criterion

Kennedy assessment scores: centres' development plans			Re-weighted Kennedy assessment scores: centres' development plans		
Ranking	Centre	Score	Ranking	Centre	Score
1	Evelina	88 (88%)	1	Evelina	91 (91%)
2	Southampton	86 (86%)	2	Southampton	89 (89%)
3	Birmingham	83 (83%)	3	Birmingham	86 (86%)
4	Brompton	77 (77%)	4=	Brompton	79 (79%)
5=	Bristol	75 (75%)	4=	GOSH	79 (79%)
5=	GOSH	75 (75%)	6=	Bristol	77 (77%)
7=	Leeds	73 (73%)	6=	Leeds	77 (77%)
7=	Liverpool	73 (73%)	6=	Liverpool	77 (77%)
7=	Newcastle	73 (73%)	9	Newcastle	74 (74%)
10	Leicester	63 (63%)	10	Leicester	62 (62%)
11	Oxford	39 (39%)	11	Oxford	38 (38%)
Maximum score		100	Maximum score		100



Table H: Analysis of 'centres' ability to meet the minimum of 400 surgical procedures' scores using the original and re-weighted criterion

Kennedy assessment scores: ability to meet the minimum of 400 surgical procedures			Re-weighted Kennedy assessment scores: ability to meet the minimum of 400 surgical procedures		
<i>Ranking</i>	<i>Centre</i>	<i>Score</i>	<i>Ranking</i>	<i>Centre</i>	<i>Score</i>
1	Evelina	261 (90%)	1	Evelina	277 (91%)
2	Southampton	253 (87%)	2	Southampton	261 (86%)
3	Birmingham	240 (83%)	3	Birmingham	259 (85%)
4	Brompton	224 (77%)	4=	Brompton	236 (78%)
5	Bristol	219 (76%)	4=	GOSH	236 (78%)
6	GOSH	216 (74%)	6	Bristol	232 (76%)
7	Liverpool	200 (69%)	7	Liverpool	213 (70%)
8	Leicester	195 (67%)	8	Leeds	198 (65%)
9	Newcastle	190 (66%)	9	Newcastle	196 (64%)
10	Leeds	182 (63%)	10	Leicester	191 (63%)
11	Oxford	100 (34%)	11	Oxford	108 (36%)
Maximum score		290	Maximum score		304

Table I: Analysis of 'centres' Leadership and strategic vision' scores using the original and re-weighted criterion

Kennedy assessment scores: Leadership and strategic vision			Re-weighted Kennedy assessment scores: Leadership and strategic vision		
<i>Ranking</i>	<i>Centre</i>	<i>Score</i>	<i>Ranking</i>	<i>Centre</i>	<i>Score</i>
1	Evelina	111 (93%)	1	Evelina	97 (95%)
2	Birmingham	102 (85%)	2	Birmingham	88 (86%)
3	Newcastle	99 (83%)	3	Newcastle	85 (83%)
4	GOSH	97 (81%)	4	GOSH	83 (81%)
5	Southampton	96 (80%)	5	Southampton	82 (80%)
6	Brompton	94 (78%)	6	Brompton	80 (78%)
7	Bristol	90 (75%)	7	Bristol	78 (76%)
7=	Leicester	90 (75%)	8	Leicester	76 (75%)
9	Liverpool	81 (68%)	9	Liverpool	70 (68%)
10	Leeds	78 (85%)	10	Leeds	67 (66%)
11	Oxford	53 (44%)	11	Oxford	43 (42%)
Maximum score		120	Maximum score		102

## **Central Cardiac Audit Database (CCAD) – activity data**

### ***Surgical Procedures***

Type	Code	Centre	2010/11	2009/10	Reason for Exclusion				
			Include		Adult Congenital	No procedure required	Not a relevant procedure	Not a UK patient	Not an English centre
Surgery	GOS	The Hospital for Sick Children	566	541	15		11	57	
Surgery	BCH	Birmingham Childrens Hospital	487	555	7			9	
Surgery	ACH	Alder Hey Hospital	431	400	5	3	1		
Surgery	NHB	Royal Brompton Hospital	389	353	135		1	39	
Surgery	GUY	Guy's Hospital	372	337	48		2	13	
Surgery	LGI	Leeds General Infirmary	336	316	78	1	31		
Surgery	SGH	Southampton General Hospital	330	231	67		2	3	
Surgery	BRC	Bristol Children's Hospital	326	277	87		12		
Surgery	FRE	Freeman Hospital	271	255	69		11	4	
Surgery	GRL	Glenfield Hospital	221	225	63		14		
Surgery	RAD	John Radcliffe Hospital	12	108	36		1		
			3741	3598					

## **Central Cardiac Audit Database (CCAD) – activity data**

### ***Interventional Procedures***

			2010/11	2009/10	Reason for Exclusion				
Type	Code	Centre	Include		Adult Congenital	No procedure required	Not a relevant procedure	Not a UK patient	Not an English centre
Catheter	BCH	Birmingham Childrens Hospital	361	358	18	1	7	5	
Catheter	GOS	The Hospital for Sick Children	293	262	16		11	8	
Catheter	NHB	Royal Brompton Hospital	236	178	87		7	20	
Catheter	BRC	Bristol Children's Hospital	214	113	184		7		
Catheter	LGI	Leeds General Infirmary	184	179	138	1	6		
Catheter	GUY	Guy's Hospital	171	181	69		4	1	
Catheter	ACH	Alder Hey Hospital	169	207	12	1	6		
Catheter	SGH	Southampton General Hospital	146	105	92			1	
Catheter	GRL	Glenfield Hospital	113	139	58		22		
Catheter	FRE	Freeman Hospital	93	107	67				
Catheter	RAD	John Radcliffe Hospital	38	90	120		2	1	
			2018	1919					

**Councillor John Illingworth**

Chair, Scrutiny Board  
(Health and Wellbeing and Adult Social Care)  
3<sup>rd</sup> Floor (East)  
Civic Hall  
LEEDS LS1 1UR

Sir David Nicholson KCB CBE  
Chief Executive of the NHS  
Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

E-Mail address	john.illingworth@leeds.gov.uk
Civic Hall Tel.	0113 39 50456
Civic Fax	0113 24 78889
Your ref	
Our ref	JI/SMC
Date	2 October 2012

**Sent via email only**

Dear Sir David,

I Chair the Joint Health Overview and Scrutiny Committee for Yorkshire and the Humber (JHOSC). On behalf of the constituent local authorities, the JHOSC was formed by the 15 top-tier local authorities across Yorkshire and the Humber to act as the statutory body to scrutinise the proposals for Children's Congenital Cardiac Services and the associated decisions of the Joint Committee of the Primary Care Trusts (JCPCT).

It should be noted that the primary purpose of the JHOSC is to consider the implications of any proposals and/or decisions in terms of local health services and the people they serve, i.e. the population and local health services across Yorkshire and the Humber.

However, I feel that the work of the JHOSC is being severely hampered by the JCPCT and its Secretariat failure to respond to reasonable and legitimate requests for additional information, as detailed below:

**Relevant agendas, reports and minutes**

In my capacity as Chair of the JHOSC, I wrote to the Chair of the JCPCT (Sir Neil McKay) on 5 July 2012:

*"As Chair of the Joint HOSC I would also ask you provide the agendas, reports and minutes of any (formal or informal) meeting of the JCPCT and its secretariat, associated with the drafting and agreement of the Decision-Making Business Case document. In my view, such information may form a key part of the Joint HOSC's consideration of yesterday's formal decision and the processes leading up to it."*

To date, and as we approach the 3-month anniversary of my initial request, the full details requested have still not been provided. Moreover, there appears to be a significant reluctance within the JCPCT and its Secretariat to do so.

Nonetheless, it is now apparent that the full decision-making process was spread over several years from 2007 to the present day. The interaction spread considerably wider than the JCPCT and its Secretariat, with several other NHS committees receiving reports and contributing to these decisions.

The enclosed Excel spreadsheet lists meetings that have been compiled using details I have been able to discover and cross reference. The details may be incomplete, but in the absence of comprehensive disclosure by the JCPCT it is the best that I can achieve. As such, I reserve the right to make further requests once all the, yet to be released, material has been provided and analysed in a similar way.

There has been a particular problem over the release of detailed reports, in addition to the agendas and minutes of meetings. Throughout local government disclosure of reports is normally automatic, seven days **before** each meeting takes place, with draft minutes available to the public on council websites within a couple of days of the decision. Please can you ensure that I receive all the reports that were considered by the JCPCT and its various advisory / steering committees without further delay? Electronic copies would be ideal. So far I have received only those reports that were considered in public on 4 July 2012, and I have not received any papers whatsoever from the JCPCT meeting held on 14 December 2011.

In order to fully understand what has taken place, I am confident that you will recognise the importance of members of the JHOSC having access to the agendas and minutes from all these various NHS bodies, as well as seeing relevant reports. I perhaps need hardly remind you of the commitments in the NHS Constitution in relation to transparency and patient choice. Sadly, I have to report that JCPCT are presently falling far short of these central objectives. Disclosure has been slow, reluctant and incomplete, yet hardly any of this information is even slightly confidential, and I can see no good reason why it could not be immediately released under the Freedom of Information Act.

### **Sir Ian Kennedy's expert panel scores**

You will be aware that various hospitals with an interest in Children's Cardiac Surgery Services were visited by an expert panel led by Sir Ian Kennedy in Spring / Summer 2010. This Panel produced a report in December 2010, which included weighted average scores derived from 35 separate assessment criteria in nine groups.

To help have a better understanding of how the Panel arrived at a consensus score for each surgical centre, I would like to see the individual assessments and scores from each member of Sir Ian Kennedy's expert panel, under each assessment criterion, for each institution that this team visited. Again, repeated requests for this information have been made to the JCPCT and its Secretariat. To date, such requests have been refused.

### **Nationally commissioned Services**

It appears that the reorganisation of children's cardiac surgery was also discussed by the National Commissioning Group (NCG), the National Specialised Commissioning Group (NSCG) and the Advisory Group for National Specialised Services (AGNSS) in addition to the work of JCPCT. Please could we see all the agendas and minutes from NCG, NSCG and AGNSS since 2007, plus any reports relating to paediatric transplants, ECMO or children's congenital cardiac surgery?

Some limited material from this category has already been published on the Specialised Services website, and other material been released by London NHS following a request under the Freedom of Information Act. A block of agendas and minutes from NCG meetings held between February 2008 and April 2009 was posted onto the Specialised Services website on 11 September 2009. This part of the site has not been subsequently updated. Similar partial disclosures, but covering different time periods, have also been published for NSCG and AGNSS.

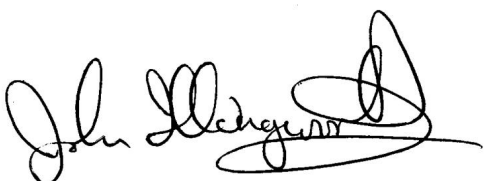
I have enclosed a copy of the Excel spreadsheet that summarises the current position as far as I am able to determine. I do not know all of the meeting dates for NCG, but am aware that AGNSS started work in September 2010. Nonetheless, please could I be provided with a full set of agendas and minutes for all these various committees, plus any relevant reports?

In summary, I believe the work of the JHOSC is being severely impeded by the excessive and wholly unnecessary secrecy surrounding the work of Specialised Services and the JCPCT, and by their inordinate delays in responding to legitimate inquiries and requests for information.

Please be aware that I am preparing a formal complaint to the Information Commissioner about the conduct of these organisations. In addition, patients or carers from across Yorkshire and the Humber who have been adversely affected by the needless secrecy and delay may alternatively choose to complain about the lack of transparency to the Parliamentary and / or the Health Service Ombudsmen.

I sincerely hope that none of this will be necessary, and that I will receive a comprehensive response to our various inquiries and requests without further delay.

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Illingworth', with a stylized flourish at the end.

**Councillor John Illingworth**  
**Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber**

Enc.

cc Secretary of State for Health, Jeremy Hunt  
Professor Sir Bruce Keogh, NHS Medical Director  
All Members of Parliament (Yorkshire and the Humber)  
All Yorkshire and Humber Local Authority Leaders  
All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)  
Cllr. Lisa Mulherin, Executive Board Member for Health and Wellbeing, Leeds City Council  
The Editor, Yorkshire Evening Post  
Jamie Coulson, British Broadcasting Corporation

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**Councillor John Illingworth**

Chair, Scrutiny Board  
(Health and Wellbeing and Adult Social Care)  
3<sup>rd</sup> Floor (East)  
Civic Hall  
LEEDS LS1 1UR

Rt Hon Andrew Lansley MP  
Secretary of State for Health  
Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

E-Mail address john.illingworth@leeds.gov.uk  
Civic Hall Tel. 0113 39 50456  
Civic Fax 0113 24 78889  
Your ref  
Our ref JI/SMC  
Date 15 August 2012

Dear Secretary of State,

**Re: Review of Children's Congenital Cardiac Services in England**

As you will be aware, on 4 July 2012 the Joint Committee of Primary Care Trusts (JCPCT) established following configuration for Congenital Heart Networks:

Area	Specialist Surgical Centre	Potential / existing Children's Cardiology Centre
The North	Freeman Hospital, Newcastle	Leeds General Infirmary (potential)
The North West and North Wales	Alder Hey Children's Hospital, Liverpool	Royal Manchester Children's Hospital (existing)
The Midlands	Birmingham Children's Hospital	Glenfield Hospital, Leicester (potential)
London, East Anglia and the South East	Great Ormond Street Hospital for Children and Evelina Children's Hospital	Royal Brompton Hospital (potential)
The South West	Bristol Royal Hospital for Children	University Hospital of Wales, Cardiff (existing)
South Central	Southampton General Hospital	John Radcliffe Hospital, Oxford (potential)

Following the JCPCT's decision, the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) considered this decision and the associated Decision-Making Business Case at a meeting held on in Leeds on 24 July 2012.

I am writing to advise you that the outcome from that meeting was a unanimous agreement (in principal) to refer the JCPCT's decision for your consideration on the basis that the proposals are not in the interest of local health services across Yorkshire and the Humber.

Furthermore, on 25 July 2012 Leeds City Council's Health Overview and Scrutiny Committee met and considered the outcome of the Joint HOSC's meeting and subsequently agreed (in principal) to refer the JCPCT's decision for your consideration on the basis that the proposals are not in the interest of local health services in Leeds.

Each referral is in accordance with the provisions set out in the Health and Social Care Act (2001) (as amended) and the associated regulations<sup>1</sup> and guidance<sup>2</sup>.

You will appreciate the review of Children's Congenital Cardiac Services has taken over 3 years to conclude and follows national public consultation undertaken in 2011. As such, there is a large volume of information (within the Decision-Making Business Case, the Pre-Decision Business Case and associated information) that requires detailed consideration and careful analysis to support each of the referrals detailed above. Work in this area is currently underway and a range of additional information has been requested from the Safe and Sustainable review team and further information is also likely to be identified in the near future.

Please be aware that at the time of writing this letter, I am yet to receive a range of additional information I believe is both relevant and necessary for the work of scrutiny – some of which relates to details requested by my predecessor, Cllr. Lisa Mulherin, that was withheld by the Safe and Sustainable Team during the consultation period.

You will recall that as part of the national consultation in 2011, the Joint HOSC submitted a detailed and comprehensive report to the JCPCT. This report supported the retention of Leeds as a designated surgical centre for the benefit of the 5.5 million population of Yorkshire and the Humber. The Joint HOSC believes that many of the issues identified in that initial report remain valid and have not been satisfactorily addressed by the JCPCT and its decision on 4 July 2012. A copy of the Joint HOSC's initial report was previously provided to you in October 2011, and is available using the following link:

<http://democracy.leeds.gov.uk/documents/s60806/1%20Review%20of%20Childrens%20Congenital%20Cardiac%20Services%20-%20Joint%20HOSC%20final%20report.pdf>

Nonetheless, subject to the timely provision of additional information and following agreement with the respective Overview and Scrutiny Committees, I hope to provide further supporting information for each referral during September 2012. I will write to you again on this matter in due course.

Notwithstanding the details above, I would also like to take this opportunity to highlight my disappointment and deep concern that, in full knowledge of the Joint HOSC's decision to refer the JCPCT's decision for your consideration, on 6 August 2012 the Safe and Sustainable Team published an outline implementation plan with a series of key dates – some as early as August 2012.

Cont./

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<sup>1</sup> The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002

<sup>2</sup> Overview and Scrutiny of Health – Guidance (Department of Health (July 2003))

While I understand it is important to plan ahead, I think it is equally as important to reflect on and recognise other legitimate processes that might impact on such forward plans. However, the Joint HOSCs decision to refer the JCPCTs decision for your consideration is nowhere to be seen within the implementation plan itself, or indeed the supporting release statement published on the Safe and Sustainable website.

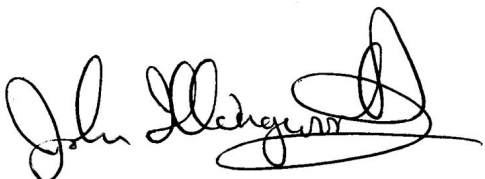
As you will be aware, the scrutiny referral process is a recognised process within any substantial NHS reconfiguration plans that I believe should at the very least be recognised as having a potential impact on any subsequent implementation. I believe this further demonstrates a lack of awareness (or possibly a high degree of indifference within parts of the NHS) to the legitimate scrutiny process, and I would welcome your comments in this regard.

I would also seek your personal assurance that any activity associated with the implementation of the JCPCTs decision is strictly limited to those areas which would not be affected by any recommendations to alter or amend the JCPCTs decision as a result of any scrutiny referral and any subsequent review undertaken by the Independent Reconfiguration Panel.

I forward to hearing from you in this regard as soon as possible. Meanwhile, should you need any clarification and/or additional information, please do not hesitate to contact me.

Yours sincerely

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Illingworth', with a large, stylized flourish at the end.

**Councillor John Illingworth**  
**Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber**

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)  
All Members of Parliament (Yorkshire and the Humber)  
All Yorkshire & Humber Local Authority Leaders  
Cllr. Lisa Mulherin, Leeds City Council

**Councillor John Illingworth**

Chair, Scrutiny Board  
(Health and Wellbeing and Adult Social Care)  
3<sup>rd</sup> Floor (East)  
Civic Hall  
LEEDS LS1 1UR

Rt Hon Jeremy Hunt MP  
Secretary of State for Health  
Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

E-Mail address	john.illingworth@leeds.gov.uk
Civic Hall Tel.	0113 39 50456
Civic Fax	0113 24 78889
Your ref	
Our ref	JI/SMC
Date	7 September 2012

Sent by post and e-mail

Dear Secretary of State,

**Re: Review of Children's Congenital Cardiac Services in England**

Following your very recent appointment as Secretary of State for Health, I wanted to take this early opportunity to write to you and draw the above matter to your attention.

As context, please find attached a copy of the letter sent to your predecessor on 15 August 2012 – which sets out the intention of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) to refer, for your consideration and assessment, the decision of the Joint Committee of Primary Care Trusts (JCPCT) concerning the future configuration and delivery of children's congenital cardiac services in England.

As outlined in the attached letter, I have been carefully studying the voluminous information provided by the Secretariat in support of the JCPCT decision. I believe there are some arithmetical issues around the scoring system used to support the JCPCT's decision and it also appears that some key papers have not been readily available. As such, I have been pressing the Secretariat to make a more complete disclosure of information related to the review and associated decision-making processes. I should remind you that the current regulations around scrutiny referrals require the Joint HOSC to provide details to support its case. However, the continuing delays in obtaining information from the JCPCT and its Secretariat are having an impact on the ability of the Joint HOSC to prepare and agree its final report.

Unfortunately I fear that the Joint HOSC is being so hampered in its attempts to gather all the information necessary to complete its report that it may no longer be possible to achieve the September target originally outlined in the attached letter. I feel obliged to draw this problem to your attention.

Cont./

Nonetheless, from some of the information provided to date, it is clear that most of the JCPCT meetings and the deliberations of the Steering Group / numerous working groups have taken place in private. As such, they have not been subject to effective public scrutiny. Furthermore, I believe the unwillingness of the the JCPCT and its Secretariat to release the information requested is contrary to the *Code of Practice on Openness in the NHS (August 2003)* and the basic principle of responding positively to requests for information – regardless of the statutory role of the Joint HOSC.

My concerns about a published implementation plan remain and I am still awaiting assurance that any activity associated with the implementation of the JCPCTs decision is strictly limited to those areas that will not be affected by outcome of any subsequent review undertaken by the Independent Reconfiguration Panel and any subsequent recommendations to alter or amend the JCPCTs decision.

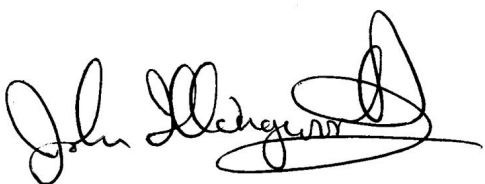
As part of the national consultation on proposals in 2011, the Joint HOSC submitted a detailed and comprehensive report to the JCPCT. This report supported the retention of Leeds as a designated surgical centre for the benefit of the 5.5 million population of Yorkshire and the Humber. The Joint HOSC believes that many of the issues identified in that initial report remain valid and have not been satisfactorily addressed by the JCPCT and its decision on 4 July 2012. A copy of the Joint HOSC's initial report was previous provided to you in October 2011, and is available using the following link:

<http://democracy.leeds.gov.uk/documents/s60806/1%20Review%20of%20Childrens%20Congenital%20Cardiac%20Services%20-%20Joint%20HOSC%20final%20report.pdf>

While I appreciate these are very early days in your new role, and there will be many issues for you to consider, I believe the issues raised by this review and the JCPCT's decision warrant your close attention.

Should you need any clarification and/or additional information, please do not hesitate to contact me, otherwise I look forward to your response in due course.

Yours sincerely



**Councillor John Illingworth**  
**Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber**

Enc.

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)  
All Members of Parliament (Yorkshire and the Humber)  
All Yorkshire & Humber Local Authority Leaders  
Cllr. Lisa Mulherin, Leeds City Council

**Councillor John Illingworth**

Chair, Scrutiny Board  
(Health and Wellbeing and Adult Social Care)  
3<sup>rd</sup> Floor (East)  
Civic Hall  
LEEDS LS1 1UR

Rt Hon Jeremy Hunt MP  
Secretary of State for Health  
Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

E-Mail address	john.illingworth@leeds.gov.uk
Civic Hall Tel.	0113 39 50456
Civic Fax	0113 24 78889
Your ref	
Our ref	Jl/SMC
Date	31 October 2012

Sent by post and e-mail

Dear Secretary of State,

**Re: Review of Children's Congenital Cardiac Services in England**

Further to my previous letters dated 15 August 2012, 7 September 2012 and copy of the letter to the Chief Executive of the NHS (dated 2 October 2012), I wanted to take this opportunity to write again in light of the recent announcement that the Independent Reconfiguration Panel (IRP) has been invited to undertake a full review of the decisions of the Joint Committee of Primary Care Trusts (JCPCT) concerning the future configuration and delivery of children's congenital cardiac services in England.

As previously advised, on 5 July 2012 – immediately after the JCPCT's decision the previous day – in my capacity as Chair of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC), I initially wrote to the Chair of the JCPCT (Sir Neil McKay) requesting:

*“... the agendas, reports and minutes of any (formal or informal) meeting of the JCPCT and its secretariat, associated with the drafting and agreement of the Decision-Making Business Case document. In my view, such information may form a key part of the Joint HOSC's consideration of yesterday's formal decision and the processes leading up to it.”*

Despite meeting some considerable reluctance, I have made some significant progress in this regard – albeit over a protracted period of time. However, I have not secured the full level of disclosure that I had hoped – something which was also experienced by my predecessors. It is highly likely that such matter will be emphasised in the Joint HOSC's report.

However, given the recent announcement that the IRP will be undertaking a full review of the JCPCTs decisions, I recognise the growing urgency to complete and agree the report to support the Joint HOSC's referral. Please be advised that I intend to convene a meeting of the Joint HOSC on 16 November 2012 in this regard.

Cont./

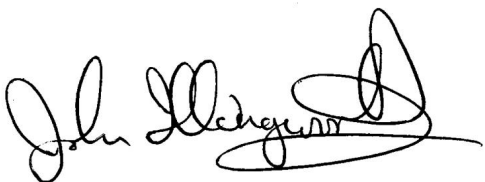
Subject to the completion of the Joint HOSC's referral report and an initial assessment by the IRP, I trust the issues raised will be given full consideration as part of the IRP's review and be reflected in any revised Terms of Reference that may be issued.

Please also be aware that I am currently drafting a complaint to the Information Commissioner's Office regarding the JCPCT's non-disclosure of information requested.

I trust this information is useful and hope to contact you again in the very near future with the Joint HOSC's finalised referral report.

Meanwhile, should you have any queries and/or need any additional information, please do not hesitate to contact me.

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Illingworth', with a large, stylized flourish at the end.

**Councillor John Illingworth**  
**Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber**

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)  
All Members of Parliament (Yorkshire and the Humber)  
All Yorkshire & Humber Local Authority Leaders  
Cllr. Lisa Mulherin, Leeds City Council



**From:** Illingworth, Cllr John  
**Sent:** 06 November 2012 15:03  
**To:** [REDACTED]  
**Cc:** [REDACTED]  
[REDACTED]

**Subject:** Second complaint about the NHS Specialised Commissioning Team NSCT

Dear Secretary of State

### **Reconfiguration of Children's Heart Surgery**

In referring my complaint [attached again below] to the Information Commissioner under the Freedom of Information Act, I also drew attention to the simultaneous breach of Statutory Instrument 2002 No. 3048, which is the **Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002**. I anticipate that this aspect might be of particular concern to you as the appropriate Secretary of State. If these regulations are not observed correctly, I believe much of the regulatory framework that Parliament has put in place for the Health Service will fail to operate as intended.

It is over a month since I raised these issues with the Chief Executive of the NHS, Sir David Nicholson. Although I am assured that his response is in the pipeline, at the time of writing this note, it has yet to appear. Meanwhile, the Joint Health Overview & Scrutiny Committee for Yorkshire & the Humber (JHOSC Y&H) is under pressure to submit its comments on the reorganisation of paediatric cardiac services to the Independent Reconfiguration Panel as rapidly as possible. This will allow the JHOSC Y&H to contribute to the review of the proposals that you have already commissioned. It is, however, difficult to see how the JHOSC can comment effectively on important aspects of the proposed reorganisation when its members have been needlessly and unlawfully denied access to vital evidence necessary to reach an informed conclusion.

It is now four months since I first requested more information from Sir Neil McKay and the NHS Specialist Commissioning Team. My request was initially couched in general terms, because so much of the NSCT business had previously been conducted in secret. When part of this information was released it became possible to frame my requests with greater clarity. Unfortunately this has not been matched by any corresponding openness from NSCT. Lack of transparency has previously been an issue during the public consultation in 2011. The public were assured that things would be better in the future. Sadly, such improvement has yet to take place.

The NSCT seems to have little comprehension of the scrutiny process, and has tried to impose artificial restrictions on the issues that the JHOSC can consider. Despite the volumes of information that have been released, we have been selectively denied precisely that information that is required for effective scrutiny. Nevertheless, the Statutory Instrument is admirably clear, and makes it plain at section 2 (1) that *"An overview and scrutiny committee may review and scrutinise any matter relating to the planning, provision and operation of health services in the area of its local authority."* When will your Department intervene to uphold the law?

We all agree that “quality” is very important, but people in Yorkshire and the Humber are concerned that some NSCT advisors and speakers very publicly expressed their views on quality long before the assessments were complete. JHOSC members wish to examine the adequacy of the assessments conducted by NSCT on the quality of care provided in Leeds, compared with other areas of the country. Concerns have been expressed about the transparency of the Kennedy Panel and whether the process adopted really measured quality at all. This issue has recently been brought into sharper focus by the tragic events in Bristol, where the Care Quality Commission has published adverse comments about a unit that was highly rated by Sir Ian Kennedy and NSCT.

The JHOSC therefore asked to see a breakdown of the quality scores awarded by the Independent Expert Panel chaired by Sir Ian Kennedy. This request was initially and appropriately made during the public consultation in 2011, when it was refused by NSCT. This refusal appears to have no basis in logic and it is questionable whether it ever had any basis in law. It seriously undermined the public consultation, and made it very difficult for anybody to challenge the assessment process at the most sensible time. Part of the scoring was released after the “final” decision had been taken on 4 July 2012, but these were merely “consensus” scores, easily influenced by a single strong-minded member of the group. We want to see the individual scores, independently awarded by each assessor for each aspect of the assessment process. Given the enormous emphasis continually placed on so-called “quality” at every stage of the review, it is really difficult to understand on what legal, moral or practical basis our request can be refused.

The Health Scrutiny Regulations make it plain that the Scrutiny Committee decides what information it requires in order to do its job. Section 5 (1) states: *“Subject to paragraph (3), it shall be the duty of a local NHS body to provide an overview and scrutiny committee with such information about the planning, provision and operation of health services in the area of that committee’s local authority as the committee may reasonably require in order to discharge its functions.”* Not only do JHOSC members reasonably require sight of the individual Kennedy scores, they also reasonably require access to the various reports considered by JCPCT and its numerous advisory committees. Access to detailed reports is an important feature of local government legislation, because Parliament has recognised that the minutes alone do not provide sufficient information. Thus far the only reports released by JCPCT are those considered in public on the two occasions when the public were admitted to the proceedings. Fourteen other JCPCT meetings took place in secret, and for these meetings not one single report has so far been released.

It is increasingly clear that the JCPCT did not operate in isolation, but was advised and, in my view controlled by a plethora of shadowy advisory committees, appointed in secret and accountable to nobody. I have received some of the minutes (but no reports) from a few of these bodies, but for others absolutely nothing has been released. The extent of my knowledge is that they met in secret and apparently decided something important. Perhaps the most extreme example is the Health Impact Assessment Steering Group, for which we have neither the agendas, nor the minutes, nor the reports. We do, of course, have the Health Impact Assessment itself, but this was produced by another organisation, Mott MacDonald, subject to the secret instructions that the Steering Group allegedly provided. How ludicrous is this? The Health Impact Assessment is absolutely central to the Scrutiny process. It defines the detailed service impacts on the people we represent. It is known to contain serious arithmetical mistakes. How can the Secretary of State possibly justify a situation where the public body, whose primary function is to safeguard the Public Interest against the overweening power of the Executive, is selectively denied access to the very papers which are central to its work?

The completely indefensible situation in relation to the Health Impact Assessment is at odds with the assurances provided by the JCPCT during the public consultation in 2011. Here the creation of the Health Impact Assessment steering group was announced with considerable fanfare in the Pre-Consultation Business Case. Terms of Reference for the HIA Steering Group were defined around page 212 of this principal consultation document. These included at section 2.5 Secretariat, the duties of the **Project Coordinator**:

- *Ensure the provision of a secretariat function that supports the HIA Steering Group in:*
  - *distributing the papers for each meeting, at least five working days in advance.*
  - ***preparing the minutes and distributing them within 10 working days of the meeting and disseminating them on the project website. All relevant papers, including minutes, once ratified, may be circulated by members and will be published on the NHS Specialised Services website unless they are clearly marked confidential.***
  - *submitting the minutes and reports to the JCPCT as appropriate and when relevant.*

It appears that the original intention was to publish these records from the HIA Steering Group, and that the public were misled by the JCPCT consultation documents. Please could the Secretary of State explain why these HIA Steering Group records have not been published as originally envisaged?

These problems result entirely from an excessive, inappropriate and wholly unnecessary level of secrecy surrounding the work of the NHS Specialised Commissioning Team. It is difficult for me (and no doubt others) to have confidence that this organisation is working properly and delivering good value for money for the benefit of all patients across the country.

I urge you to use your powers as Secretary of State to ensure that NSCT operates with greater openness and transparency, and that senior NHS administrative staff actually carry out the policies that Parliament has agreed.

**Cllr. John Illingworth**

**Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber**