

Scrutiny Inquiry Report

Review of Children's Congenital Cardiac Services in England

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

2nd Report – November 2012





Foreword

I am pleased to present a second report from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC). This report is addressed to the Secretary of State for Health and has been produced in response to the decision made on 4 July 2012 by the Joint Committee of Primary Care Trusts (JCPCT) to close the Paediatric Cardiac Surgery Unit in Leeds.

It is the unanimous view of the Joint HOSC that the JCPCT's decision is not in the best interests of children and families across Yorkshire and the Humber. The existing provision in Leeds already meets all relevant standards for patient safety and quality of care. It offers genuine co-location of essential services and is already on target to deliver the required 400 cases per year. The cardiac network in Yorkshire and the Humber is widely acknowledged to be one of the best in the country. The current Leeds unit is fully staffed, properly equipped, very close to the majority of patients, and is readily accessible by public or private transport and emergency vehicles from the whole of the Yorkshire and Humber region.

In contrast, most of the proposed alternative provision for children and families across Yorkshire and the Humber would be remote, inaccessible and markedly inferior in terms of co-location of services and network arrangements. It would seemingly deny patient choice and require the majority of mothers to deliver by caesarean section. It would require the dismantling and fragmentation of one of the best cardiac networks in the country. The JCPCT's decision is extremely unpopular across Yorkshire and the Humber and, in our view, can only be achieved by compulsion. However, if patients exercise their choice of provider then some of the replacement units are likely to become overloaded, with others likely to fail to achieve the stated minimum volume of cases – which could lead to the entire north eastern part of England without any provision. In turn, this could jeopardise the sustainability of the same transplant services in Newcastle that the JCPCT's decision is seemingly trying to protect.

Decision making by the JCPCT apparently failed to achieve basic standards of transparency, objectivity and professional competence that the public legitimately expect. The JCPCT and its secretariat have attempted to frustrate the Scrutiny process, by refusing to (1) properly consider an earlier Joint HOSC report in October 2011, and (2) release non-confidential information and reports requested by the Joint HOSC that every citizen should be entitled to see.

I believe this report sends some clear and powerful messages to the Secretary of State and the Independent Reconfiguration Panel, and concludes that the JCPCT and its secretariat failed to achieve the basic minimum standards of accountability expected of a public body acting in the Public Interest – with the resulting decisions, at best, being questionable and, at worst, being neither safe nor sustainable.



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However, while focusing on the needs of children and families across Yorkshire and the Humber and the retention of services in our region, the Joint HOSC has been mindful of the potential negative impacts of alternative proposals in other parts of the country. We do not wish to inflict on other areas the disproportionate disadvantages we have identified in the present decision.

As outlined in our first report, we therefore propose that in addition to the retention of the Leeds unit (which is already viable and in our view requires no special dispensation) that the requirement for 400 cases annually be relaxed in sparsely populated areas such as the far North East – thus also retaining the existing surgical centre in Newcastle. This would reflect the current practice in Scotland, and we suggest this approach is retained for the North of England.

This report reflects the considerable time and effort of all the members of the Yorkshire and Humber Joint Committee – both past and present. I am particularly grateful to the previous Chairs of the Joint HOSC and my predecessors – Councillor Mark Dobson and Councillor Lisa Mulherin, I am extremely grateful for the enthusiasm and commitment of all my colleagues on the Joint HOSC and feel this report demonstrates the considered approach we have taken.

In formulating this report the Joint HOSC considered a wide range of evidence – and wanted to consider additional relevant information that was not made available. The Joint HOSC heard from a variety of witnesses – most of whom willingly accepted the invitation to meet and share their knowledge and experience of the issues under consideration. While the Joint HOSC is extremely grateful to all those who provided evidence and contributed to this inquiry, I would like to specifically recognise the input of the following:

- The numerous parents and families who:
 - (a) shared their experience of the excellent treatment and facilities provided at the current surgical centre at Leeds Children's Hospital; and,
 - (b) outlined their fears for other families in similar situations in the future, should the Leeds unit be closed.
- Sharon Cheng from the Children's Heart Surgery Fund;
- Mr Kevin Watterson, Dr John Thomson and other clinicians at LTHT; and
- Stacey Hunter and her staff at Leeds Teaching Hospitals NHS Trust (LTHT).

Details of the information we have considered and the people we have consulted are outlined in the report. It would not have been possible to complete our inquiry and produce this report without the support and dedication of all involved. On behalf of the Joint HOSC, I would like to thank the scrutiny support officers from all the participating authorities who have provided assistance throughout this inquiry, but I would like to reserve special thanks to Steven Courtney at Leeds City Council for his tireless efforts over the course of this scrutiny inquiry.



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Finally, I must emphasise that the Joint HOSC has undertaken a statutory function, having drawn its membership from the democratically elected councillors representing the 15 top-tier local authorities across Yorkshire and the Humber, with a population in excess of 5 million people. We are unanimous in our view that the JCPCT's decision is not in the best interests of children and families across Yorkshire and the Humber and they will be severely and disproportionately disadvantaged if the children's cardiac surgery unit in Leeds closes, as proposed by the JCPCT. We trust that our findings and recommendations will be respected and given full and proper consideration by the Secretary of State and the Independent Reconfiguration Panel.

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 represent the 5.2million¹ residents from across Yorkshire and the Humber.
4. This is our 2nd 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 our 1st [October 2011] report 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.

¹ Based on the 2010-based sub-national population projections available from the Office for National Statistics





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 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 constituted. The minutes from the JCPCT meetings were eventually made



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available to us (after a number of requests), however we are concerned that we have been denied access to the associated agendas and reports from these meetings, despite our repeated requests – the first of which was outlined in a letter to the Chair of the JCPCT, dated 5 July 2012.

9. At its first public 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 on the number and location of surgical centres

Option A: Seven surgical centres: <ul style="list-style-type: none">• Freeman Hospital, Newcastle• Alder Hey Children's Hospital, Liverpool• Glenfield Hospital, Leicester• Birmingham Children's Hospital• Bristol Royal Hospital for Children• 2 centres in London²	Option B: Seven surgical centres: <ul style="list-style-type: none">• Freeman Hospital, Newcastle• Alder Hey Children's Hospital, Liverpool• Birmingham Children's Hospital• Bristol Royal Hospital for Children• Southampton General Hospital• 2 centres in London¹
Option C: Six surgical centres: <ul style="list-style-type: none">• Freeman Hospital, Newcastle• Alder Hey Children's Hospital, Liverpool• Birmingham Children's Hospital• Bristol Royal Hospital for Children• 2 centres in London¹	Option D: Six surgical centres: <ul style="list-style-type: none">• Leeds General Infirmary• Alder Hey Children's Hospital, Liverpool• Birmingham Children's Hospital• Bristol Royal Hospital for Children• 2 centres in London¹

² The preferred two London centres in the four options are Evelina Children's Hospital and Great Ormond Street Hospital for Children



Background

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.

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 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. In our first report, we 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 October 2011 report identified a number of recommendations – including an alternative model of designated surgical centres. A summary of our previous recommendations is presented below in Table 2.



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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 first 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 wish to register our general dissatisfaction with the overall approach adopted by the JCPCT and its supporting secretariat in relation to the legitimate scrutiny function**, primarily established to facilitate open and transparent decision-making and hold decision-makers to account.

Additional information previously identified

18. Prior to completing 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. Our comments on the additional information available to us are detailed 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 advice from the IRP was provided to the Secretary of State for Health in January 2012, and subsequently accepted in full. Details of the IRP's assessment and advice, together with the letter from the Secretary of State for Health, are attached at **Appendix 2**.



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21. While the overall consultation arrangements were assessed as satisfactory, the IRP agreed that 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.'

22. 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**.
23. However, despite the 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 first 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)

24. As outlined previously, the JCPCT was formally established in the early part of 2011 – although the precise date is unclear – for the purposes of public consultation and decision making about the future provision and delivery of children's cardiac surgical services in England.
25. 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



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- Guy's and St. Thomas' NHS Foundation Trust
26. At our meeting held on 24 July 2012, we considered the JCPCT's decision and the associated Decision-Making Business Case.
27. At that meeting we heard from a range of interested parties that all contributed to 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.
28. 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.





Conclusions and Recommendations

Overview

29. As the Joint Health Overview and Scrutiny Committee for Yorkshire and the Humber, **we represent the 15 top-tier authorities and the 5.2³ million residents from across our region.**
30. 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 our understanding of the proposals and the likely implications across Yorkshire and the Humber.
31. We maintain that the Leeds Children's Hospital provides the most comprehensive range of clinical services for children suffering from congenital heart conditions – delivering the 'gold standard' in terms of co-location of services. As such, **we believe the JCPCT's decision will result in a worse level of service offered and available 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 children and families having restricted access to the full range of services at some of the alternative surgical centres identified for future designation.
32. 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;**
 - **The dismantling of the already well established and very strong cardiac network across Yorkshire and the Humber – and the implications for patients with the proposed Cardiology Centre at Leeds essentially working across multiple networks;**
 - **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 stressful and difficult time;**

³ Based on the 2010-based sub-national population projections available from the Office for National Statistics



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- **The implications of patient choice and the subsequent patient flows – resulting in too onerous caseloads (i.e. overloading) in some surgical centres, with other centres unable to achieve the stated minimum number of 400 surgical procedures.**

33. However, from our first 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.**
34. Nonetheless, given the JCPCT’s decision and some of the assumptions set out in the decision-making business case, a number of our arguments make reference to the 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.
35. We would like to make it explicitly clear that our view of the JCPCT’s decision is evidence-based and not founded on any particular ‘loyalty’ towards the surgical centre at Leeds Children’s Hospital – which unfortunately has been an assertion repeatedly 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 principle of our work.
36. 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.**
37. At the time of publishing our first 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 unreasonably 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.



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38. **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 some of the behaviour 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.**
39. **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 (see paragraphs 176– 187).
40. **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.** Nonetheless, this report has been compiled based on the evidence and information available to us at the time of its writing and the following 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.
41. However, it should be acknowledged that once again **we reserve the right to add further comment and/or recommendations as and when any additional information we have requested or any other relevant details become available.**



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Quality Scores

Quality in the NHS

42. 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.
43. 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 (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.
44. 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.
45. 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



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the review process, and in particular the assessment process adopted by the Kennedy Panel.

46. 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.
47. 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, which essentially dates back to 2008, and that the NQB advise us have '*...been embraced by staff throughout the NHS and subsequently by the Coalition Government.*'**
48. Specifically, with particular reference to 'patient experience', we question a quality assessment methodology that takes no account of the significant additional travel times and associated costs likely to affect children and families under the various reconfiguration options. We fail to see how such impacts will not affect the overall quality of service (at least from a patient experience perspective) and therefore believe this should have formed an integral part of the quality assessment.

Kennedy Panel's detailed scoring

49. 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.
50. Our repeated requests for the detailed breakdown of the Kennedy Panel scores are well known and have been well documented. Concerns around being denied access to the detailed breakdown of this information were initially highlighted in our original report and previous referral to the Secretary of State for Health (October 2011). Our serious concerns in this regard remain and cannot be over-stated.



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51. 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.'***
52. 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, not only has our view in this regard been strengthened since the JCPCT's decision on 4 July 2012, **we believe it is impossible to properly and fully assess the reliability of the Kennedy Panel's assessments without seeing a detailed breakdown of the individual panel members' scores.**
53. 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 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 overall responsibility, which should have been discharged prior to using such details to significantly determine the options presented for public consultation, and subsequently determine the future provision of services to children and families across England.

Post the JCPCT's 4 July 2012 decision

54. 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 sought. However, we should point out that this in itself was not straightforward and we were presented with a number of mislabelled versions of the information. Indeed, on the morning of our meeting on 24 July 2012, we received a 'replacement' of the data we had already received – which itself turned out to be incorrect/ mislabelled. Such repeated errors initially caused some significant difficulties as we tried to understand and reconcile the original and re-weighted scoring methodologies – particularly in terms of providing a clear and effective response at our meeting in July 2012. Clearly,



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providing the information when it was originally requested, at least 12-months earlier, would have allowed more detailed scrutiny at the appropriate time and enabled the JCPCT to have reviewed the information taken and relied upon on trust in a more open and transparent manner.

55. 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 both the public and non-public meetings held by the JCPCT since its establishment.
56. 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...'

57. 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.
58. 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.**
59. 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 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 – attempted to make the JCPCT less susceptible to legal challenge regarding the 'quality scores'.

'Sir Ian Kennedy highlighted the risk of judicial review; the process was undermined if data was provided when experts had been appointed to make a judgement.'

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-



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making. Consequently, **we do not believe the JCPCT has conducted all its business in a manner we would expect from a publicly funded body, established to work in the interests of the public.**

60. 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). 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

61. 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**.
62. By its very nature the term 'quality' can be 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 roots 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.
63. 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 references throughout the decision-making business case that state the Kennedy Panel scores provide an assessment of surgical centres' compliance with the Safe and Sustainable designation service standards. However, the analysis provided at **Appendix 5** demonstrates that the Kennedy Panel 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 only 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**)



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- 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.**

64. 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 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.
65. 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 concerning that each of the following criterion represent significantly less of the overall 'quality scores' than the 'Leadership and Strategic Vision' criterion:



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- Strength of network
- Facilities and capacity
- Ensuring excellent care
- Age appropriate care
- Information and choices

66. Given the significance attached to the 'quality scores' within the decision-making processes, we question a scoring methodology that attaches significantly greater weighting to 'Leadership and Strategic Vision' than is attached to other 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 question whether these proportions reflect a definition of 'quality' recognisable to children and families currently accessing the service, or the public in general.**
67. Furthermore, it is not clear where the Kennedy Panel weightings were agreed and whether these were tested with any other stakeholders: The rationale is unclear and **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.** Nonetheless, if deviating from the definition of NHS quality suggested by Darzi and the NOB, we believe that given the endorsements from relevant professional bodies, the agreed clinical standards provide the best alternative definition of quality. As such, we do not understand why current performance against the clinical standards did 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.
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 Trusts and some are not – which, given the additional freedoms and flexibilities afforded to Foundation Trusts, we believe should have been 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. That said, we believe it is interesting to highlight the assessment of 'Leadership and Strategic Vision' at the current Leeds Surgical Centre, in the context of some of the other areas assessed – such as 'Interdependent Services' and 'Strength of Network'. In both these areas the Leeds Surgical Centre was awarded the 2nd and 3rd highest score, respectively; scoring more highly than the Newcastle centre in both areas. We believe these areas of assessment, in



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particular, are a function of 'Leadership and Strategic Vision' which do not appear to be reflected in the assessment scores for that criterion.

70. We also note with interest the details and comments made in Section 14 (Financial Analysis and Review of Capacity) of the decision-making business case, when considering potential set-up costs of various options. In options where the surgical centre in Leeds is retained, the details estimate the potential set-up cost for Leeds at £0.56m. This should be considered in the context of the average typical spend per centre of £3m–£6m across the twelve options and the £4.6m per centre under Option B. It is also interesting to note the set-up costs associated with the Newcastle centre of £5.7m, under Option B. Details in the decision-making business case explain the underlying reason as follows:

'Other centres have made space for the expansion within a hospital reconfiguration and this is why options containing Leeds Teaching Hospitals NHS Trust are relatively low.'

We believe this demonstrates that Leeds Teaching Hospitals NHS Trust had planned to continue to provide this service and provides further evidence of the Trust's 'Leadership and Strategic Vision' qualities. We believe it is unclear if/ how such factors were taken into account within the assessment process.

71. 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 implementation phase of the review – as has been the case for other important matters.
72. Once again, had we not been denied access to the detailed scores until after the JCPCT's decision, it would clearly 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 2010)

73. 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**. We wish to highlight that **service quality has been assessed using less than 35% of the total number of service standards**.



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74. 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 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 unclear whether or not the Kennedy 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 feel 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 Kennedy 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 Kennedy Panel’s December 2010 report have been translated into the detailed assessment scores. We believe these details warrant further and more detailed scrutiny – something we have been seeking to undertake for over 18 months.

Validity of Kennedy Panel ‘Quality Scores’

75. While not included within the scope of our initial inquiry, 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 necessary.
 - **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.



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- **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.

76. 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.
77. 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'.
78. 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' and the fundamental purpose of the review was to deliver 'safe and 'sustainable' children's congenital cardiac services for the future, we believe the findings of the CQC are significant and warrant further and more detailed scrutiny of the Kennedy Panel scores and assessment process.

The Health Impact Assessment (June (2012))

79. 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 in the JCPCT's decision-making business case (8 from 12), where the health impacts have been assessed, have not been tested through public consultation.**
80. 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



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extremely useful to those seeking to compare the impacts of alternative models, relative to the current provision.

81. 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 principles of planning health services – i.e. services should be located within major population centres.
82. We recognise a summary of impacts by vulnerable group is presented in Table 17.4 of the HIA. Comments in this regard are detailed elsewhere in this report (paragraphs 88–95 and 139), however we are disappointed to see there is no comparison of the impacts across different regions/ areas highlighted in the table, as highlighted and requested in our first (October 2011) report.
83. **We strongly 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. More detailed comments regarding the consideration and impact on retrieval services are detailed in our first report and in this report at paragraphs 139–146.
84. We believe there is evidence of conflicting information and at least one anomaly within 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 unsatisfactory and misleading to those outside of the decision-making processes and, at worst, could call into question the validity of other data presented and relied upon in both documents.
85. 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 – while the total number of procedures remains constant. As such, the sum of the various increases and decreases within each option should total ‘zero’. However, 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 unsatisfactory and potentially misleading to those outside of the decision-making processes.**



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86. 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

87. 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.

88. We maintain our position as previously stated and set out in our first report (October 2011).

89. 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 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.'

90. 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.

91. 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*



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- *Appendix C. Service demand and 'at risk' patient groups*
- **Appendix D. Postcode districts and vulnerable groups**
- *Appendix E. Carbon Assessment*

92. Table 3 (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 versions 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

93. 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 effects in different regions. **Severe impacts on particular localised areas are effectively masked by averaging them into a national picture where there was little overall change.** 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.
94. As such **we believe the JCPCT's decision will have a disproportionately negative impact on the vulnerable groups across Yorkshire and the Humber and their ability to access surgical services.**

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

95. 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.



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96. **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.**
97. The outcome of our consideration of the PwC report was issued to the JCPCT in April 2012 and is attached at **Appendix 3**. However, despite clear advice from the IRP that any additional comments we provided relating to the PwC report should be taken into account within the JCPCT's decision-making processes, there is little suggestion of this being the case. Specifically, within the JCPCT's response to our first report (presented at **Appendix 1**) there is no reference to our comments in this regard. **We can only conclude that the comments we provided have not been considered by the JCPCT**, and it is unclear to what extent the JCPCT took account of the IRP's previous advice, endorsed by the Secretary of State for Health.

Patient flows

98. 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.
99. 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.
100. We recognise that, given the feedback it received during the public consultation and the outcome of the PwC report, the JCPCT has sought 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



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Doncaster (DN), Leeds (LS), Sheffield (S) and Wakefield (WF) will flow to Newcastle. **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. **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 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.**

101. **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



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of the comment made by the Chair of the JCPCT at its meeting on 1 September 2010, 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)

102. 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-determining the outcome of the other.
103. This is also supported by the BCCA⁴, 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.’
104. 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.
105. 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.

⁴ Statement issued by the British Congenital Cardiac Association (BCCA) in February 2011.



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106. 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**. Furthermore, it is clear that by combining the number of paediatric and adult surgical procedures undertaken in Leeds, the existing surgical centre in Leeds would meet the standard around the minimum number of 400 procedures per annum and would be sustainable in its own right.

Manageable networks

107. 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 dismantle and fragment the existing strong cardiac network arrangements across Yorkshire and the Humber.
108. 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.
109. 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 essentially 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.
110. 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**.



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111. Again, it is unclear what impact this might have had on the JCPCT's final decision, however **we believe this raises a crucial issue and 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.**

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

112. 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

113. As outlined in our previous report, the huge benefits brought about by the co-location of services for children and adults with interdependent conditions / co-morbidities are widely acknowledged.
114. 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). However, we have serious concerns that the JCPCT has been selective in both its use of the views from others and general interpretation of co-location, as agreed at the JCPCT's decision-making meeting on 4 July 2012. We are extremely concerned by the comments provided by Dr Sheila Shribman⁵ at the JCPCT's decision-making

⁵ The National Clinical Director for Children, Young People and Maternity



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meeting and wish to emphasise that **we are not content with the JCPCT's general interpretation of co-location**. We would still argue that the public would generally consider co-location to mean just that – services co-located on a single hospital site. We believe that including centres where such services may be located over multiple sites within the definition of co-location is misleading and disingenuous.

115. In our previous report we outlined that the review of Children's Congenital Cardiac Services has its roots in the findings and recommendations arising from the Bristol Royal Infirmary Inquiry report (often referred to as the Kennedy Report (2001)). Within that report, Sir Ian Kennedy presented the following recommendation (recommendation 178):

'Children's acute hospital services should ideally be located in a children's hospital, which should be as close as possible to an acute general hospital. This should be the preferred model for the future.

116. Through the following February 2011 statement, we were previously advised by the British Congenital Cardiac Association (BCCA) that its view of the 'gold standard' of co-location (insofar as it relates to children's congenital cardiac services) equates to the co-location of foetal, maternity, neonatal services, Paediatric Intensive Care (PICU), children's inpatient services and Adult Congenital Cardiac services, on a single hospital site. We strongly support the BCCA's statement, which is presented below:

'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.'

117. We previously reported that, after a significant amount of reconfiguration work and at considerable public expense, the gold standard of service provision (as detailed above) is currently provided at Leeds Children's Hospital. Furthermore, in our October 2011 report we also highlighted the following comment from the Yorkshire and Humber Congenital Cardiac Network, in its response to the public consultation:

'As a network, our view is that the gold standard for care would be delivery in a maternity unit with tertiary neonatal care on the



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same site as the cardiac unit, to avoid any unnecessary delay in treatment. The parents in our region currently have this choice, so Options A, B and C would be viewed by parents in our region as a retrograde step.'

118. Children and families across Yorkshire and the Humber currently access surgical and interdependent services at the Leeds Children's Hospital – which is located within an acute general hospital (Leeds General Infirmary) on one hospital site. These services are also co-located alongside maternity and neonatal services, which are essential for the wellbeing of mother and baby if cardiac interventions are required at birth.
119. Based on the evidence we have considered, it is clear that all children's acute services are *genuinely co-located* in Leeds and therefore **we believe that the Leeds Children's Hospital achieves the 'gold standard' for children's congenital cardiac care and co-location of inter-dependent services.**
120. We understand the level of services currently offered at Leeds Children's Hospital would not be available to children and families from Yorkshire and the Humber at the alternative centres proposed by the JCPCT. We were previously advised by the Yorkshire and Humber Congenital Cardiac Board (the regional network body) that 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 and experience for patients compared to the current service in Leeds. As such, **we believe the JCPCT's decision – if implemented – will result in a worse level of service offered and available to children and families across Yorkshire and the Humber.**
121. We are advised that, with maternity services located on a different hospital site to paediatric cardiac surgery services at Newcastle, an increased number of planned caesarean sections could result. We would again question whether this would lead to improved outcomes for children and families across Yorkshire and the Humber. Furthermore, we were also advised that as a result of the configuration of maternity services and paediatric cardiac surgery services at Newcastle, there are serious doubts over the level of obstetric referrals to Newcastle as a result – which may further reduce the Newcastle centre's ability to achieve the minimum standard of 400 paediatric cardiac surgical procedures per year. **We believe this may be a key consideration around sustainability that has not been considered by the JCPCT that the IRP should take account of within its review of the JCPCT's decision.**
122. 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



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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.**

Caseloads

123. 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.
124. 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.
125. 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.
126. 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.
127. In terms of adults, the Leeds surgical centre delivered 13% more cardiac procedures and 106% more interventional cardiology procedures.
128. We believe that, compared to the surgical centre at Newcastle, the surgical centre at Leeds is larger in every way. Notwithstanding the issues and principles 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.



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Population density

129. We have already stated on numerous occasions that the population of Yorkshire and the Humber is in the region of 5.2 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.’

130. 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 – at paragraphs 42 – 78), **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 – and would again refer to the comment made by the Chair of the JCPCT at its meeting on 1 September 2010, where it was stated ‘...it would [be] pointless to devise a network of centres that people would not use...’.
131. 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...’.
132. We would be extremely interested to know at what point within the decision-making process, more detailed population growth figures start to become necessary – particularly 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...’. In our view, in deciding the future configuration of surgical centres across



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England, the JCPCT should have taken account of more detailed predictions of population growth, to reflect any regional variations when compared to the *All-England* average. 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. For comparative purposes, we have also included the overall *All-England* projections.

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 Statistics⁶

AREA NAME	AGE GROUP	2010	2025	Variation
All England	<i>All ages</i>	52,213	58,607	6394 (12%)
	0 to 4	3,267	3,485	218 (7%)
	5 to 9	2,903	3,561	658 (23%)
	10 to 14	2,981	3,564	583 (20%)
	Sub-total 0 to 14	9151	10610	1459 (16%)
North East	<i>All ages</i>	2,587	2,717	130 (5%)
	0 to 4	148	148	0 (0%)
	5 to 9	135	157	22 (16%)
	10 to 14	144	160	16 (11%)
	Sub-total 0 to 14	427	465	38 (9%)
Yorkshire and The Humber	<i>All ages</i>	5,247	5,729	482 (9%)
	0 to 4	321	336	15 (5%)
	5 to 9	287	347	60 (17%)
	10 to 14	300	348	48 (16%)
	Sub-total 0 to 14	908	1031	123 (14%)
NB Population figures presented in thousands (to one decimal place). Percentages rounded to full percentage points.				

133. We are very concerned that in reaching its decision on the future configuration of surgical centres, the JCPCT not only failed to take account of any regional differences around population growth, but we believe the JCPCT may not have used the most up-to-date population projections/ estimates – detailed within the decision-making business case, as 2006-based National Population Projections. Given that one of the fundamental aims of the review is to ensure the sustainability of services into the future, we believe it is vital that the most

⁶ The projections were published on 21 March 2012 and are based on the indicative 2010 mid-year population estimates published on 17 November 2011.



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up-to-date information is used and considered. **We would urge the IRP to specifically consider this aspect within its review of the JCPCT's decision.**

134. The details in Table 4 suggest a potentially larger increase in the volume of paediatric cardiac surgery activity than that identified in the JCPCT's decision-making business case – 16% as opposed to 14% (approx.). However, more significantly, **we believe this demonstrates very important 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.
135. We have also considered the Health 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.
136. 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.
137. However, as previously reported, we would not wish to see similar pressures 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

138. Our comments in this regard are detailed elsewhere in this report, at paragraphs 87 – 94. However, in Appendix 3 and Appendix 6 of our October 2011 report we highlighted some issues relevant to specific local authority areas that we believe are pertinent and worthy of repeating.

Kirklees Council

- The Index of Deprivation 2007 Kirklees identified as one of the 50 most deprived local authorities in England for both the income and employment domains – Kirklees is ranked 12th worst in England.



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- More than 70,000 people (about 1 in 6) were classed as income deprived and 27% of the Kirklees population live in the top 20% of most deprived areas, nationally.
- Over 1 in 8 people are of south Asian origin – Pakistani and Indian primarily. Over 1 in 3 young people in the north of Kirklees are of south Asian origin, especially in Dewsbury and Batley.
- 19% of white women smoke during pregnancy (17% national average) – with variations from 33% in Dewsbury to 7% in Denby Dale & Kirkburton.
- 49% of 130 teenage mothers enrolled in the Kirklees Family Nurse Partnership programmes smoked at enrolment with 38% continuing to smoke in their 36th week of pregnancy.
- 48% of mothers were at least overweight, especially Pakistani origin mothers (60%). Obesity was worse in north Kirklees with 23% of mothers obese.

Leeds City Council

- An analysis of the Index of Multiple Deprivation (IMD) 2010 showed that Leeds has:
 - 25 Super Output Areas (SOAs) (5.3%) in the most deprived 3% on the national scale (covering an approximate population of 40,600);
 - 92 SOAs (19.3%) in the most deprived 10% on the national scale (covering an approximate population of 150,000);
 - 136 SOAs (28.6%) in the most deprived 20% on the national scale (covering an approximate population of 225,600);
 - The most deprived SOA in the city is ranked 114 on the national scale (Spencer Place, Bankside Street, Shepherds Lane);
 - The least deprived is ranked 32,105 (Cookridge, Moseley Woods)
 - Gipton & Harehills is the only ward with 100% of its SOAs ranked in the most deprived 20%;
 - 9 wards have 50% or more of their SOAs ranked in the most deprived 20%.
- Between 2007 and 2010, of the 476 SOAs in Leeds, 322 (68%) have seen their overall ranking fall.
- The BME population increased from 77,900 in 2001 to 137,200 in 2009 (representing a 76% increase).
- BME communities account for 17.4% of the resident population (from 10.9% in 2001).
- The largest BME groups in the city are the Pakistani and Indian communities with 22,500 people (49% increase from 2001) and 20,700 people (67% increase from 2001), respectively.



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Yorkshire and the Humber

- Over 30% of all households with no cars or vans – with Hull (44%), Sheffield (36%) and Leeds (35%) showing the highest levels.

Travel and access to services

139. In our October 2011 report we highlighted the modelling and analysis undertaken by Embrace⁷. Based on the 2010/11 transfer activity (comprising 224 transfers with a cardiac condition), the analysis highlighted that, under the configuration model now agreed by the JCPCT, **73% of transfers from Yorkshire and the Humber would be in excess of the additional 1½ hours highlighted in the review – compared to the national figure of 6.2%**. Under the agreed reconfiguration model, we believe this will be an issue for all children and families across Yorkshire and the Humber, particularly those areas to the east (the East Coast, Hull, North and North East Lincolnshire) and south (Doncaster, Rotherham and Sheffield) of our region.
140. Therefore, 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 health services currently available to children and families across Yorkshire and the Humber**.
141. Overall, we reaffirm our belief that the JCPCT's decision will result in children and families from across Yorkshire and the Humber being 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 significant additional strain and result in significant additional costs for 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.
142. We reinforce our previous points about the excellent transport links to and from Leeds, and would highlight the significant impact recent flooding had on access to Newcastle via the A1. However, 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**.

⁷ 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.



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143. We note that in its response to our first 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***
144. 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.
145. As set out earlier in this report, 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.
146. 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.**



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Costs to NHS

147. 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.**
148. 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 the proposed model of care. We were advised that the view was not about generating savings and was more likely to need additional investment.
149. 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.**
150. The financial analysis section of the decision-making business case also summarises 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.**
151. Furthermore, within the Kennedy Panel's report and associated quality scores, it is clear that it was an original intention for the Panel to consider (and presumably score) criterion associated with deliverability and achievability. While it is clear that it transpired that the Kennedy Panel did not consider such aspects, it is not clear what criterion would have been used to make such assessments. However, we believe it is not unreasonable to assume this would



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have included some consideration of costs. Therefore, we believe 'costs' should have been a material consideration within the JCPCT's decision-making processes and scored alongside other criteria and sub-criteria outlined in the decision-making business case.

The impact on children, families and friends

152. 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.
153. 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.**
154. 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

155. Our comments in this regard are detailed elsewhere in this report (see paragraphs 107–111).

Adults with congenital cardiac disease

156. Our main comments in this regard are detailed elsewhere in this report (see paragraphs 102–106). 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.** This was reinforced at our meeting held on 24 July 2012.

The views of the people of the Yorkshire and Humber region

157. We maintain our previous comments set out in our first report 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.**



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Nationally Commissioned Services (NCS) – Heart transplantation, ECMO and Complex Tracheal Surgery

158. 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.
159. It is interesting that in the decision-making business case, 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 the most significant consideration within the JCPCT's decision-making processes.
160. 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, presented in the decision-making business case and relied upon by the JCPCT, 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. We also note the reference to Figure 2 (although presented as Figure 1) in Appendix DD of the decision-making business case, which is used to support the notion that an 8-10 year period is needed before a transplant service is sufficiently mature to produce excellent clinical outcomes. We would contest that the information presented demonstrates such a relationship and we would argue that the information provided supports a contrary view with any findings and conclusions about the relationship between time and successful outcomes being inconclusive.
161. Issues around the potential transfer of NCS and in particular paediatric cardiothoracic transplant services seem to have shifted over time. There are a number of issues that concern us in this regard, including:
- The risks of transfer two or more NCS to a single site were never considered by the appropriate independent expert panel – or indeed those that commissioned the work of the expert panel.
 - The assumption made by Birmingham Children's Hospital that its application was for an additional (i.e. third) transplant centre, rather than a potential



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replacement. It is unclear how Birmingham had drawn this conclusion during the time of its application and whether Birmingham's applications for other NCS were made on the same basis – particularly given the details contained in the pro-forma supplied to each aspiring NCS provider, which stated:

'The NSCT is not looking to increase the number of centres providing these services in the future. However it does need to be assured that whatever the future configuration of paediatric cardiac surgery provision, the nationally commissioned services can continue to be provided to a good standard of care with good geographical access across England.'

- It is unclear whether the timescales set by the JCPCT for establishing alternative NCS provision (particularly paediatric cardiothoracic transplant services) were ever truly realistic and achievable.

162. 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 principle should not be applied to the NCS for children's heart transplants – or at least considered in more detail.
163. We 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.**
164. In our previous report, we also highlighted concerns around the assessment process associated with testing 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.
165. 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.**



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Services to Scotland and at Yorkhill Hospital, Glasgow

166. 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.
167. 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.
168. 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.
169. 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.'***
170. It is not clear how the concerns identified by Independent Expert Panel are being addressed.
171. Nonetheless, it should be noted that in our first 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
172. 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



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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.

173. As such, we maintain there should have been more effort to include all UK surgical centres within the scope of the review – including those services accessed by patients from Northern Ireland. 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

174. 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 issues around staff recruitment, staff retention and staff training and development have not been considered in detail. We believe



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these aspects are fundamental issues that will affect both the sustainability and deliverability of any future reconfiguration and model of care. As such, **we believe the implications for changes to the workforce should have formed part of the JCPCT's decision-making process and not simply deferred to the implementation stage of the review.**

175. 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.

Governance, transparency and public accountability

176. 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.
177. 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 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 affected by this decision across Yorkshire and the Humber.
178. 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.
179. 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.



Conclusions and Recommendations

180. We believe it is important that, as a legitimate democratically elected body, we are afforded the opportunity to question, scrutinise and interrogate the available evidence and appropriately hold decision-makers to account. However, having been denied access to much of the relevant information we have identified, 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.
181. 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.'*
182. 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 can comment effectively on important aspects of the proposed reorganisation when we have been needlessly and, in our view, unlawfully denied access to important evidence we have identified and believe is necessary to reach an informed conclusion.
183. 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 why our reasonable requests for additional information have repeatedly been refused.
184. 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**.
185. Similar concerns have also been raised with the Secretary of State for Health and attached at **Appendix 8**. Details include letters dated 15 August 2012, 7 September 2012 and 31 October 2012. The content of an email sent on 6 November 2012 is also included.



Conclusions and Recommendations

186. Nonetheless, we want to reinforce the point that **we challenge the JCPCT's assertion that it has been completely open and transparent in its decision-making processes** – not least 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 Professor Sir Ian Kennedy's assessment panel members. In our view, such information should not be deemed 'confidential' and therefore should be readily available to any individual who may wish to access such information. A complaint has been lodged with the Information Commissioner's Office in this regard and we look forward to the independent assessment of the case we have put forward.
187. 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.

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) has already agreed to maintain an overview of the implementation phase of the review and will determine any further actions and/or monitoring arrangements as required.

Reports and Publications Submitted / Considered

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*: Review of Children's Congenital Cardiac Services in England – Decision Making Business Case (July 2012)
- Detailed breakdown of assessment scores for surgical centres produced by Professor Sir Ian Kennedy's Independent Expert Panel
- Detailed breakdown of assessment scores for surgical centres produced by Professor Sir Ian Kennedy's Independent Expert Panel (replacement information)
- Formal JCPCT response to the report of the Joint Health Overview and Scrutiny Committee (October 2011) – dated 18 July 2012
- Submission from Leeds Teaching Hospitals NHS Trust (LTHT)
- 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)
- City of Bradford MDC – Council resolution – 10 July 2012
- Letter from Sheffield City Council
- Details of additional Council motions



Evidence

Reports and Publications Submitted / Considered (continued)

In preparing this report consideration has also been given to the finalised Health Impact Assessment (June 2012) and its multiple iterations. Reference has also been made to other information, including minutes and agendas (where made available) from the meetings of the following:

- Advisory Group for National Specialised Services (AGNSS)
- Joint Committee of Primary Care Trusts (JCPCT)¹
- National Commissioning Group (NCG)
- National Specialised Commissioning Group (NSCG)
- Review of Children's Congenital Cardiac Services – Steering Group
- Review of Children's Congenital Cardiac Services – Standards Working Group

¹ **NB** Despite numerous requests, no agendas or reports have been made available from the non-public meetings of the JCPCT.

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 a range of additional information, including the PwC report on patient flows and manageable networks. |
| 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 draft 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.*





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