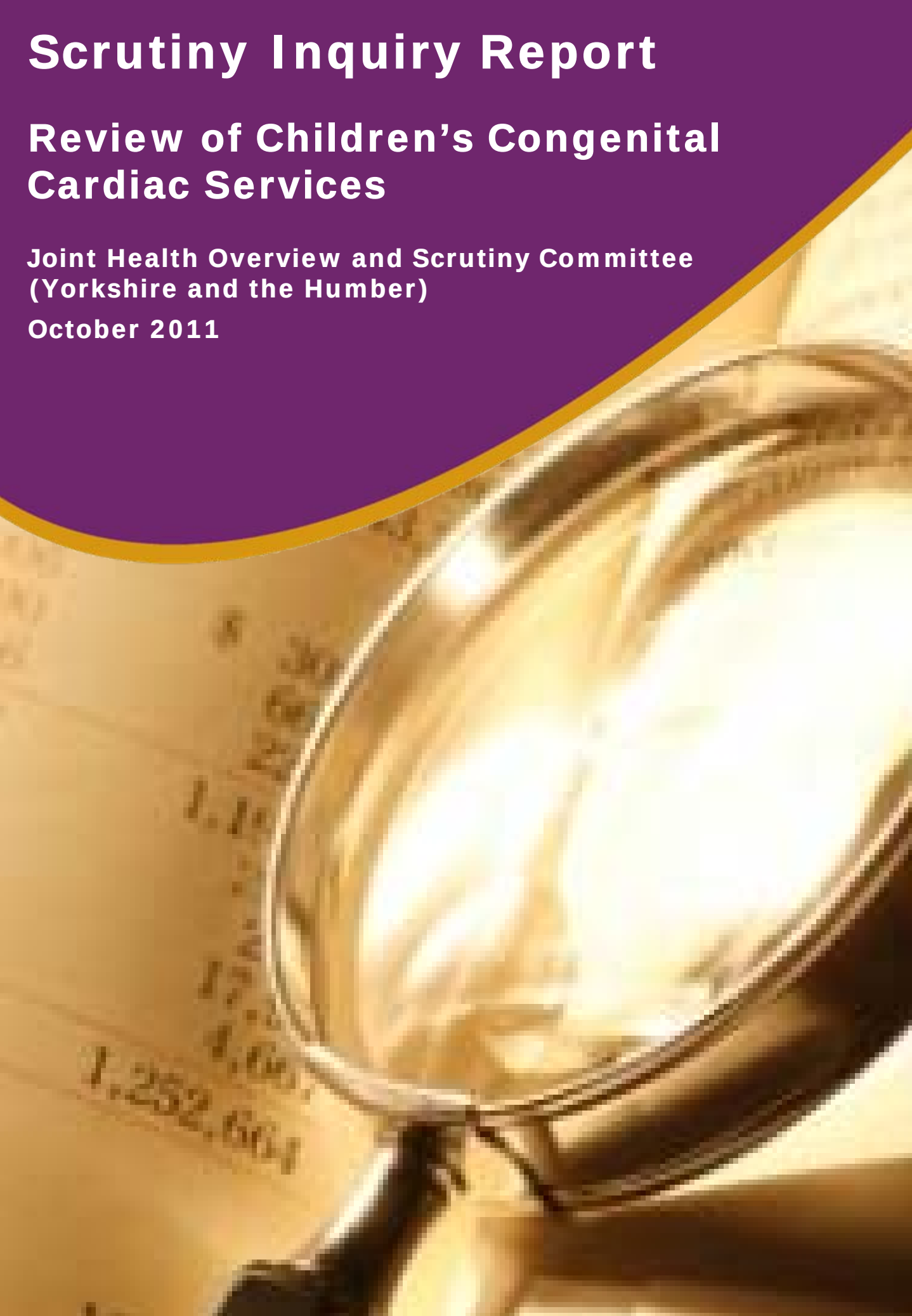
Scrutiny Inquiry Report

Review of Children's Congenital Cardiac Services

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

October 2011



Foreword

I am pleased to present the report of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), following its inquiry into the review of Children's Congenital Cardiac Services in England and the associated proposals.

I believe **this report and its recommendations send a clear and powerful message** to both the national review team and the Joint Committee of Primary Care Trusts (JCPCT) – as the decision-making body. That message is **that children and families across Yorkshire and the Humber will be disproportionately disadvantaged if the current surgical centre in Leeds is not retained in any future service model**.

It is worth emphasising that **over 600,000 people across Yorkshire and the Humber signed a petition – the largest petition of its kind in the United Kingdom** – supporting the retention of the current surgical centre at Leeds Children's Hospital. I and other members of the joint committee firmly believe that the level of support for the petition **demonstrates the strength and depth of feeling across the region** and that this public voice needs to be listened to.

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 committee has been aware of the potential negative impacts of alternative proposals in other parts of the country. As such, and as detailed in the report, we have been mindful not to simply attempt to passport to other parts of the country the disproportionate disadvantages we have identified in three of the four service models presented for public consultation.

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 extremely grateful for the enthusiasm and commitment of my colleagues on the joint committee and feel this report demonstrates the considered approach we have taken.

In formulating this report the joint committee considered a wide range of evidence – and wanted to consider additional information that was not made available. The joint committee 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 committee is extremely grateful to all those who have contributed to this inquiry, I would like to specifically recognise the input of the following:

- Cathy Edwards and Matthew Day from the Specialised Commissioning Group (Yorkshire and the Humber);

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- Stacey Hunter and her staff at Leeds Teaching Hospitals NHS Trust (LTHT);
- Mr Kevin Watterson , Dr. John Thomson and other clinicians at LTHT;
- The families who shared their experience of the excellent treatment and facilities provided at the current surgical centre at Leeds Children's Hospital; and,
- Sharon Cheng from the Children's Heart Surgery Fund

Details of the information we have considered and the people we have spoken and listened to are outlined in the report. However, it is worth highlighting that the joint committee remains disappointed with the JCPCT and its general reluctance to adequately engage with us during our inquiry.

It would not have been possible to complete our inquiry and produce this report without the support and dedication of all those involved. On behalf of the joint committee, 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 and Andy Booth at Leeds City Council for their tireless efforts.

Finally, I must re-emphasise that all of the joint committee's work supports the view that retaining the current surgical centre at Leeds is in the best interests of the children and families of this region. As a joint committee representing the 15 top-tier Yorkshire and the Humber local authorities and a population in excess of 5.5 million, we trust that – alongside the considerable public feeling displayed by children and families across the region – our findings and recommendations will be respected and given full and proper consideration by the Chair and members of the JCPCT.

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

Cardiac patient and nurse on the cardiac surgical unit at Leeds Children's Hospital

Introduction

1. This report is provided on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – a committee specifically formed to consider the outcome and subsequent proposals of the national review of children's congenital cardiac services, alongside the implications for the region. The Committee's membership 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

2. The **background and scope of the inquiry that underpins this report is detailed in Appendix 1**.

Conclusions and Recommendations

Overview

3. As the Joint Health Overview and Scrutiny Committee for Yorkshire and the Humber, we represent the 15 top-tier authorities and the 5.5 million residents from across the region.

4. Throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals set out in the public consultation document 'Safe and Sustainable: A new vision for Children's Congenital Cardiac Service' published in March 2011.

5. Regrettably, we have not been able to consider all the information we identified as being necessary to conclude our review, prior to our 5 October 2011 deadline imposed by the review team. Some of that information was not available due to the timing of some additional work commissioned during the consultation period, while we were also denied access to other information we believe to be relevant. We feel very strongly that such information should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

6. We are stunned by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable. Once again, our detailed views and findings in this regard are outlined elsewhere in this report.

7. Nonetheless, this report has been compiled based on the evidence and information available to us at the time of writing. We reserve the right to add further comment and recommendations as and when the outstanding information we have requested or any other relevant details become available.

8. Fundamentally, **we strongly believe that any future model of designated paediatric congenital cardiac surgical centres that does not include a centre in Leeds will have a disproportionately negative impact on the children and families across Yorkshire and the Humber.** This belief is specifically based on the evidence we have considered in relation to:

   - Co-location of services;
   - Caseloads;
   - Population density;
   - Vulnerable groups;
   - Travel and access to services;

Conclusions and Recommendations

- 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

9. We have serious concerns regarding some aspects of the review process and the subsequent consultation. We will explore all of these issues in more detail elsewhere in the report.

10. We believe that the Leeds Children's Hospital provides the most comprehensive range of clinical services for children with congenital heart problems. These services include foetal cardiology, maternity, neonatal, all inpatient children's specialities and adult congenital services, and are supported by a Paediatric Intensive Care Unit (PICU) with 24/7 Consultant Intensivist support and dedicated psychology and specialist nurse input. There are 41 rooms available for use by families who wish to be resident at the hospital and this includes a purpose built 22 bedded facility which is managed by the Sick Children's Trust.

11. It is clear that the review process to date has determined that the services provided by Leeds Teaching Hospitals NHS Trust (in common with those in the other remaining nine congenital cardiac surgical centres) are 'safe'. We have also been advised that the latest national data which compares outcomes across centres (provided via the national audit database (Central Cardiac Audit Database (CCAD)) has recently been published. This confirms that the outcomes for congenital cardiac patients in Leeds are consistent with the rest of the UK. As such, **as all centres are considered safe we believe that the real focus of this review and our response to it should be around the sustainability of these services for the future**.

12. With a 3-surgeon team, the Leeds surgical centre delivered 316 cardiac surgical procedures for children in 2009/10 – the 3rd highest number of procedures outside of London – which accounts for approximately 8% of the total national caseload. In 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures.

13. As democratically elected representatives of Yorkshire and the Humber, we believe it is imperative to retain a children's congenital cardiac surgical centre in Leeds. Based on what we have heard about the current unit and the operation of the very strong network, we do not believe that de-classifying the current surgical centre at Leeds would be in the interests of local children and families or the local health services, and that **any future configuration that**

does not include a surgical centre in Leeds will disproportionately disadvantage children and families across this region.

14. The argument for retaining the surgical centre in Leeds is, in many ways, underpinned by an extract from an opening statement published in the public consultation document. In summary, the statement (taken from the Guardian newspaper (dated 28 April 2010) and supported by a number of Presidents of various professional medical organisations) relates to the need for NHS changes to be driven by clinical evidence and we believe it is crucial to highlight the following extract:

    'Patients may indeed have to travel further for some specialist care, but if it is significantly better care then we believe that centralisation is justified'.

15. From the evidence we have considered, we believe that without the retention of the Leeds surgical centre, **three of the four proposals (Options A-C) will deliver a significantly worse patient experience for children and families across Yorkshire and the Humber** for the following reasons:

    - The range of interdependent surgical services, maternity and neonatal services are not co-located at any of the alternative surgical centres available to Yorkshire and the Humber patients and their families;
    - Considerable additional journey times and travel costs, and associated increased accommodation, childcare and living expense costs and increasing the stress and strain on family life at an already difficult time;
    - Fragmentation of the already well established, very strong network across the region.

16. Therefore, we believe children and families across Yorkshire and the Humber will not receive significantly better care if the Leeds unit is not retained as part of any future configuration of surgical centres.

17. In considering the best interests of children and families across Yorkshire and the Humber, alongside local health services, we believe it is our duty to highlight this matter publicly. We believe it is also our duty to draw this to the attention of the Joint Committee of Primary Care Trusts (JCPCT), prior to any decision on the future model for children's congenital cardiac services, by making the following recommendation:

Conclusions and 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.

An alternative reconfiguration option

18. It is our view that the interests of children and families across Yorkshire and the Humber are best served by retaining the Leeds centre in any future configuration. However, we fully acknowledge that the proposals put forward in the consultation document are a result of an ongoing *national* review. As such, in considering the proposals and available evidence, we have also tried to reflect on the potential implications in other parts of England. In doing so we put forward our second principal recommendation to the JCPCT, which proposes an alternative model for the configuration of designated 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**

19. In presenting the remainder of our report and further justification for our principal recommendations, we have set out our findings and additional recommendations under the following areas:

- Issues for children and families across Yorkshire and the Humber
- An alternative reconfiguration option
- Concerns and lessons to be learned

Conclusions and Recommendations

Issues for children and families across Yorkshire and the Humber

Co-location of services

20. It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions. The issue of co-location is considered in the consultation document and uses the definition described by the Framework of Critical Inter-Dependencies. In this, a number of service areas are described as having '*an amber relationship*', which is described as a *'…relationship under some circumstances, requiring varying levels of access and contact between specialists, but not necessarily co-location…'*

21. As such, co-location in this context is defined as meaning either:

    - location on the same hospital site; or
    - location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site.

22. We have heard on a number of occasions 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)). Indeed this is included in the NHS Medical Director's opening remarks within the public consultation document. We have considered some aspects of the recommendations made by Sir Ian Kennedy in that report and were particularly struck by recommendation 178, which states:

    '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.'

23. As such, we believe that the definition of 'co-location of services' appears to be loosely interpreted in the options considered in this current review. **We would argue that the public would generally consider co-location to mean just that – services co-located on a single site**. We believe that including centres where such services may be located over multiple hospital sites within that definition of co-location is misleading and disingenuous.

24. Currently in Leeds, children from across Yorkshire and the Humber access surgical and interdependent services in a children's hospital within an acute general hospital (Leeds General Infirmary) on one hospital site.

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25. All children's acute services are *genuinely co-located* in Leeds alongside maternity services, which is essential for the wellbeing of mother and baby if cardiac interventions are required at birth. We believe that co-location of services in this way can significantly reduce the potential negative impacts associated with the separation of the mother and baby immediately after birth.

26. We considered evidence (attached at Appendix 2)presented by Dr. Sara Matley (Consultant Clinical Psychologist at Leeds Teaching Hospitals NHS Trust) on how the bond established between children and parents is crucial to a child's development – which can affect physical growth, as well as emotional and cognitive development and wellbeing. We do not believe this has received any significant consideration during this review, and specifically when defining co-location. **We believe that this review should place greater importance on the life-long wellbeing of children and their families than is currently evident.**

27. Reducing the likelihood of mother and child being separated immediately after birth (where the child could be transferred to another hospital for surgery) would help to minimise the unnecessary stress on the baby, mother and family. Having maternity services and children's congenital cardiac surgery on one site is invaluable to families. As such, we endorse the following comment from the Yorkshire and Humber Congenital Cardiac Network in 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 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."***

28. We understand that of the other surgical centres considered within the review, only one other centre delivers all such services on one site – that being Southampton General Hospital.

29. We are advised that, through its statement issued in February 2011, it is the view of the British Congenital Cardiac Association (BCCA) that the gold standard of co-location in terms of 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. The statement is presented below:

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"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."

30. This standard of provision is currently provided by the service at LTHT. We have been advised that there has been a significant amount of reconfiguration work at LTHT (and at considerable public expense) to be able to deliver the gold standard of care described above.

31. Leeds Children's Hospital provides the most comprehensive range of clinical services for children with congenital heart problems, including foetal cardiology, maternity, neonatal, all inpatient children's specialities and adult congenital services. These are supported by a Paediatric Intensive Care Unit (PICU) with 24/7 Consultant Intensivist support and dedicated psychology and specialist nurse input. There are 41 rooms available for use by families who wish to be resident at the hospital and this includes a purpose built 22 bedded facility which is managed by the Sick Children's Trust.

32. **We believe that through its comprehensive co-location of clinical services, the Leeds Children's Hospital achieves the gold standard in children's congenital cardiac care and co-location of inter-dependent services**.

33. We have been advised by the Yorkshire and Humber Congenital Cardiac Board (the regional network body) that options 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.

34. Furthermore, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. As such, we believe that adult cardiac surgery would be adversely affected by any future model that does not retain the current cardiac surgical centre in Leeds. However, this matter is considered in more detail elsewhere in the report.

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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.

Caseloads

35. The case for a minimum of 400 and an optimum of 500 surgical procedures in a 4-surgeon surgical centre is a cornerstone of the proposals set out in the consultation document. However, based on the 6 or 7 surgical centre models proposed, the current national activity detailed in the consultation document (3,600 surgical procedures) equates to an average of 600 or 514 surgical procedures per surgical centre. We understand that, inevitably, designated surgical centres across the country will not deliver 'an average' number of procedures, we feel this provides a useful proxy measure.

36. On this basis, it seems rather odd that on one hand an optimum number of procedures is presented and then on the other hand the same consultation document outlines two 6-centre options – which will deliver an average number of procedures 20% in excess of the optimum level. As such, **we believe that any current surgical centre that only featured in a 6-centre model, such as Leeds, has been severely disadvantaged during the consultation period**. In addition, the consultation document also sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 and 570 paediatric cardiac surgical procedures per surgical centre under the proposed 6-centre and 7-centre models, respectively.

37. Given one of the main aims of the review is to deliver sustainable arrangements for the provision of children's congenital cardiac services, we would question the methodology that proposes future configuration models that are likely to deliver an average number of procedures in excess of the stated optimum number.

38. The consultation document reports that with a 3-surgeon team, the Leeds surgical centre delivered 316 cardiac surgical procedures for children in 2009/10 – the 3rd highest number of procedures outside of London. This accounts for approximately 8% of the total national caseload. In 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures. Given the level of surgical activity at the Leeds centre, we are intrigued by the comments of the Chair of the JCPCT in

response to one of our requests for additional information, which described the Leeds surgical centre as having '*a relatively low caseload'* – which we believe is clearly not the case.

39. We believe the response from the Chair of the JCPCT is at odds with details contained in the Expert Panel Report, which reported '*Waiting lists at the Trust are long*'. Furthermore, we believe the view of the Expert Panel suggests demand for services at the Leeds surgical centre is outstripping current capacity. We explored this matter further and were advised the Trust had been actively trying to recruit a fourth surgeon for some time but had been hampered in this recruitment by the uncertainties surrounding the future of the surgical centre pending the outcome of this review. We were also advised that the recruitment process was continuing and interviews were due to be held on 7 December 2011.

40. While it is clear that Leeds Teaching Hospitals NHS Trust (LTHT)has reached a level of surgical activity approaching 400 procedures per year (children and adults combined) with only 3 surgeons, we believe surgical activity would have been far in excess of this level if a fourth surgeon were already in post. We can only speculate on the impact this may have had on the options put forward for public consultation and the inclusion of the Leeds surgical centre in more options.

41. We also believe that the impact on other services has not received sufficient consideration in the process to date. For example, we have been advised that were Leeds not to be retained as a designated surgical centre, the Trust would be unable to perform paediatric interventional cardiology procedures without a cardiac surgeon on standby. We were advised that this is a growing area of activity and currently approximately 550 such procedures are performed annually in Leeds. However, we understand that such cardiac interventions are not included as part of the overall surgical activity figures for individual centres, and we do not believe there has been sufficient consideration in this regard to date.

42. Nonetheless, as it is clear that the review process to date has determined that the services provided by LTHT are 'safe', **we believe it would be irrational not to retain a designated surgical centre in Yorkshire and the Humber currently undertaking this level of activity with the associated local demand for services.**

Conclusions and Recommendations

Population density

43. We have already stated that the population of Yorkshire and the Humber is in the region of 5.5 million people. However, it should 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 demand. The British Congenital Cardiac Association's (BCCA) view is that:

> **"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."**

44. In the evidence submitted to our committee, Michael Dugher MP for Barnsley East stated:

> **"Population density must be taken into consideration in health planning and if it is based on this principle, all of the problems due to reconfiguration, such as extra distance and extra cost for individual families, are minimised because you move the doctors to the patients, not the patients to the doctors."**

45. Similar views were expressed during the course of our inquiry and through the Director of Public Health at Kirklees Council, we were advised that Yorkshire and the Humber has double the child population of the North East region, and is growing much faster. Within this, the BME population is growing fastest. As such, **we believe the logic of having designated surgical centres that reflect the distribution of the population cannot be refuted**.

46. We also believe that population density has been a significant consideration in identifying other centres as part of each of the consultation options put forward, including the surgical centres in Liverpool, Bristol, Birmingham and the need for two centres in London.

47. In terms of the sustainability of the networks that this review is hoping to achieve, we were advised 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 district children's cardiology centres.

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.

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Vulnerable Groups

48. We sought additional, and in our view essential, information on the vulnerable groups highlighted in the Health Impact Assessment (HIA) Interim Report. Notwithstanding the interim status of the HIA report, this presented the following information in terms of vulnerable groups:

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

    These 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.

49. The report states that there are currently 2745 patients in vulnerable postcode districts, and sets out the likely travel and access impacts on vulnerable groups / postcode districts (based on current patient activity) under each of the proposed options (A-D).

50. We requested further information about how this analysis related specifically to children and families across Yorkshire and the Humber, but this information was not forthcoming. In his response to our request denying access to this information, the Safe and Sustainable Programme Director, stated:

    "Mott MacDonald have been commissioned to report on the Health Impact Assessment in a way that is transparent and equitable… I would not wish to influence the robust process they have undertaken by requesting the methodology is changed by singling out a particular area for analysis. Similarly, it would not be appropriate for me to ask them to release the data to one interested party, particularly as some stakeholders have already submitted their final response to consultation and would not have had the opportunity to take this data into account when formulating their responses."

51. As with a number of other reasonable requests for information, this unsatisfactory response denies access to information that we believe would support the arguments we are making that children and families across Yorkshire and the Humber will be disproportionately disadvantaged by any future configuration that does not retain the Leeds surgical centre.

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52. We would contend that other Overview and Scrutiny Committees (OSCs) have not sought this information because their populations are not being disadvantaged to the same extent in the proposals put forward. All OSCs have had the opportunity to seek this information should they wish to have done so. **We do not believe there is any legitimate reason why this information was not made available to us. We believe it is not in the best interests of the public to withhold such information as it undermines confidence in the process and potentially the outcome of the review.**

53. We believe that Yorkshire and the Humber has a significant concentration of vulnerable groups, including a large South Asian population in Kirklees, Bradford and Leeds who we know are more susceptible to congenital cardiac conditions. Issues associated with consultation with families from these communities are detailed elsewhere in this report.

54. We are also concerned that the needs of people in areas with high levels of deprivation e.g. Hull (ranked 10th out of 326 local authorities in the Indices of Deprivation in England 2010), Bradford (ranked 26th) and Doncaster (ranked 39th) have not been sufficiently taken into account in drawing up the options that went out to consultation.

55. We have also seen evidence from the 2001 Census that a high proportion of households in our region do not have access to a car or van, including 44% of households in Hull, 36% in Sheffield and 34% in Leeds. Across the region an average of 30% of households do not have access to their own private transport which significantly affects their journey times and travel costs to access hospital services already but which will be significantly exacerbated if the Leeds centre is not retained. A summary of this information is detailed in Appendix 3.

56. As such, and as previously stated we do not believe that children and families from across Yorkshire and the Humber will receive significantly better care should the surgical centre at Leeds not be retained in the future.

57. Our attempts to obtain relevant information on the potential impacts on vulnerable groups across Yorkshire and the Humber will continue. As such, once again we reserve the right to add further comment and recommendations should the information we have requested be forthcoming.

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Travel and access to services

58. The patient flows predicted under options A-C presented in the consultation document, alongside supporting information considered by the JCPCT, suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge. We believe this has also been highlighted by the Yorkshire and the Humber Specialised Commissioning Group (YHSCG), which (in part) resulted in the commissioning of additional work around testing the assumptions of patient flows under each of the proposed reconfiguration options.

59. While we welcomed this additional review work and testing of assumptions, we cannot understand why more detailed analysis was not undertaken prior to the options for consultation being identified and issued for public consultation. We also remain frustrated that such information will not be available for public scrutiny until after our 5 October 2011 deadline, despite previously being advised that the details would be available in August 2011. Here again we must reserve the right to comment as and when the Price-Waterhouse Coopers (PwC) report is published.

60. Notwithstanding the availability of this additional assessment work, we firmly believe this will be highly significant and is likely to be a considerable factor in determining whether or not proposed designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre. Furthermore, such information will also help to identify and determine whether proposed surgical centres are at risk of being destabilised by an increase in patient numbers above and beyond the planned capacity. As such, we believe the importance of such information cannot be over emphasised.

61. We believe it is clear from the information considered that children and families from across Yorkshire and the Humber will be disproportionately and consistently disadvantaged in terms of access and travel times under three (options A-C) of the four options presented. This is reinforced by the details presented in Mott MacDonald's Health Impact Assessment (Interim Report).

62. Patient and family access to the proposed surgical centres should be a key consideration in determining the future configuration model. In this regard, we believe the current surgical centre in Leeds has excellent transport links to and from the city. This includes the motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via Leeds-Bradford. It is unclear how such factors have been factored into the review process to date.

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63. Furthermore, we have been denied access to a more detailed breakdown of the likely affects on vulnerable groups across Yorkshire and the Humber. As such, it is difficult to state the likely impacts with any degree of certainty. Nevertheless, **we believe that extending travel times and the complexity of journeys for patients across Yorkshire and the Humber is likely to place additional strain on children and families at what will already be a particularly stressful time**. In our view this is both unreasonable and unnecessary.

64. In terms of access and journey times, the public consultation document suggests that '…there is a minimal impact on journey times for most families…' for each of the reconfiguration options (Options A-D). The public consultation document seeks to demonstrate this by way of the overall percentage of the population likely to experience an increase in travel time in excess of 1½ hours.

65. However, as part of our inquiry, we received evidence from Embrace – which is 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, including four tertiary neonatal units and two paediatric intensive care units. We were advised that Embrace had sought to assess the potential impact of each of the four options by modelling the transfer activity undertaken by Embrace during 2010/11. We were further advised that this comprised a total of 224 transfers with a cardiac diagnosis, and there were up to 188 children within the current surgical centre at Leeds that may have needed to be transferred out under some of the options proposed.

66. The outcome of this work is very striking and once again highlights the disproportionate impact that three of the four options (Options A-C) would have on children and families across Yorkshire and the Humber. This impact assessment suggests that **between 53% and 73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review – in comparison to the national figures of between 3.6% and 6.2%.**

67. Furthermore, any reconfiguration option that does not include the Leeds surgical centre is likely to see more than a four-fold increase in the mileage covered by the region's transfer and retrieval service – as detailed elsewhere in this report.

68. Additionally, care closer to home is described as one of the five key principals that has driven the review – except where surgery and other interventional procedures are necessary. However, we believe these aspects are crucial and

key elements of service and should not be disassociated from the principle of care closer to home.

69. As such, it is clear that the proposed options A-C would significantly affect the ability of children and families across Yorkshire and the Humber to access surgical and other interventional procedures as close to their home as possible. Indeed, options A-C would require the region's children and families to by-pass their nearest centre (in Leeds) in order to access services outside of the region in Newcastle, Liverpool, Leicester or Birmingham.

70. However, we recognise that should the surgical centre at Leeds be retained at the expense of the one currently located in Newcastle (i.e. Option D), children and families from across the North East of England (albeit potentially fewer in number) could be subject to similar issues around travel and access to services. We also believe that similar issues may arise should the current surgical centre in Southampton not be retained.

Costs to NHS

71. Notwithstanding the potential impacts on children and families, the impact assessment work undertaken by Embrace also highlighted the significant impact of Options A-C on the transfer and retrieval service itself. This summarised in the table below:

Option	Transfers and repatriation	Total mileage	Total time
Option D	336	29,396 miles	681 hrs.
Option A	618	133,267 miles	2,633 hrs.
Option B or C	618	139,271 miles	2,866 hrs.

72. We were advised that while increases in the number of out of region transfers were likely with the retention of the Leeds surgical centre, it is clear from the above details that **the impact of options A-C could be exponential** in terms of the increase in transportation and retrieval activity across Yorkshire and the Humber – **resulting in over 80% increase in the number of transfer or retrieval journeys, over 100,000 additional miles and over 2000 additional work hours**.

73. We were advised that the most realistic model to address this resultant increase in activity would need further investment in Embrace, through an increase in the number of teams (driver, nurse and doctor) available to the service, alongside an increase in the number of ambulances and essential equipment. While there has not been any detailed assessment of the increase in expenditure for these services, it is clear that **any option that does not**

retain the current surgical centre at Leeds, will result in very significant increases in transportation and retrieval costs for the NHS, as well as families of patients, across this region.

74. We believe the overall financial implications associated with the model of care proposed by this review are likely to be very significant – both in terms of establishing new arrangements and the on-going delivery of the proposed model of care. The above details help provide some sense of the scale of likely financial implications (albeit restricted to the transfer and retrieval service provided across Yorkshire and the Humber). However from the responses we have received to the questions we have asked, we believe that to date **there has been insufficient consideration of the financial implications.** We also believe that the level of detail publicly available in this regard has been inadequate.

75. Nevertheless, during our discussion with the Yorkshire and Humber representative of the JCPCT in late September 2011, it was highlighted that, **'…the new configuration would inevitably cost more…**' and may provide **'…a worse service for some patients and their families…'** We queried the likely level of the cost increase and, while we were not provided with any detailed analysis, we understand this is likely to be a significant increase with no additional funding likely to be forthcoming. As such, we believe that under Options A-C, **children and families across Yorkshire and the Humber will not only endure a significantly worse patient experience, but this will also be at considerable greater expense to the population across this region**.

The impact on children, families and friends

76. It seems clear to members of our committee that the significant impact that any future reconfiguration of these services would have on home and family life has been given very little consideration. Indeed in his response to our concerns about the disproportionate impact that removing the Leeds centre would have on children and families in our region, dated 16 September 2011, the Chair of the JCPCT makes no reference at all to the impact on the wellbeing of the families of patients. The response also ignores the benefits to be gained in terms of aiding recovery from ensuring that patients can be visited by friends and family whilst they are in hospital and the need for a parent who is at the bedside to have some respite whilst the other parent, grandparents, friends or other family members are visiting.

77. Furthermore, the same letter goes on to state that the financial impact of the reconfiguration falls outside the scope of this Review. Given that we already know that all of the surgical centres being reviewed are safe and that we are

therefore looking for a sustainable model for the future, we cannot state strongly enough that minimising the negative financial impact and emotional strain on families in this region is of fundamental importance.

78. Extending the journeys families have to make also significantly impacts upon their household budgets. We were advised that a parent of a child having to travel from Grimsby to Newcastle by train would have to pay a £70 return train ticket. This cost would be repeated for every visit and given the distance and journey times involved would also be likely to incur accommodation costs, additional living expenses, additional childcare costs for siblings at home and place additional strain on any parent trying to continue to work and visit their ill child.

79. It should also be noted that we have received evidence from parents and grandparents who have emphasised that they would not have been able to support their child or grandchild in hospital as they have done if they were obliged to travel much further than they already do. They stated that they would not be able to visit after work or bring siblings to visit after school if their child or grandchild was in a hospital much further away.

80. The impact on family life, including the impact on siblings at home, has been a key concern throughout our inquiry. We have heard, first hand, about the delicate balancing that parents must strike between supporting a sick child, providing continuity for a child or children at home and maintaining employment. Such issues are difficult enough, without the additional difficultly associated with having to access a surgical centre outside of the region. Such matters are highlighted in the response we received from Julian Smith, MP for Skipton and Ripon, which includes the following statements:

> ***'…Lois and her husband spent months at her daughter's bedside in Leeds…'***
>
> ***'…without the ward being there he would have had to make some fairly tough choices between family commitments and continuous employment.'***

81. In addition, when we visited the centre in the Leeds Children's Hospital we also saw firsthand the facilities that are available to older children and teenagers who are recovering from surgery, which enable friends to visit and support their recovery. While similar facilities may be available in other centres, should the surgical centre in Leeds not be retained, we believe the reality of the situation would be that **the practicalities and costs associated with visiting friends recovering in surgical centres outside this region would be prohibitive for older children and teenagers across Yorkshire and the Humber**.

Conclusions and Recommendations

Established congenital cardiac networks

82. At our meeting in late September 2011, we were advised by the then Yorkshire and Humber representative on the JCPCT that the importance and strength of network arrangements are crucial to the future success, or otherwise, of the proposed changes and future configuration of designated surgical centres.

83. We had previously heard from the Yorkshire and Humber Congenital Cardiac Network manager, who presented the Congenital Cardiac Services Strategy (2011) developed by the Yorkshire and Humber Congenital Cardiac Network. We heard how the strategy had been developed to describe how services are arranged and delivered to meet the needs of both children (from birth) and adults with congenital cardiac conditions. We were also advised that by considering the needs of both children and adults, the network represented the only one of its type nationally.

84. We have been advised that the network model developed across Yorkshire and the Humber has helped form the blueprint for future network arrangements. We are also aware that as part of the assessment of surgical centres, the Yorkshire and Humber Network was judged as **'very strong'**, while others have described the network as 'exemplary', whilst recognising the need for continuous improvement and refinement.

85. However, in order to better inform our understanding of the relative strengths of all existing networks (as detailed in the Expert Panel report (December 2010)), we requested details of the breakdown in assessment scores. Regrettably, once again we were denied access to this information – on the basis that the JCPCT had not received or considered such detail. Once again, we reserve the right to comment further when and if this detail is eventually made available.

86. However, while the Expert Panel report (December 2010) identifies some areas of non-compliance as far as the Yorkshire and Humber network is concerned, we have also heard some contrary evidence in this regard, as detailed in the table below:

Nature of non-compliance	Alternative evidence
Telemedicine within the network is weak; however this may be due to the geography of the region	It is recognised that telemedicine is a specific area of development for the Yorkshire and Humber network in common with most, if not all the other current surgical centres across the country.

Nature of non-compliance	Alternative evidence
The panel felt that clinical governance needs to improve within the network.	No specific details have been provided. At our meeting in September 2011, the Yorkshire and Humber representative on the JCPCT confirmed that there was 'no case to answer' in this regard.
There is no lead transition nurse within the network	At our meeting in September 2011, we were advised that this is factually incorrect and that, as part of its site visit in Leeds, the expert panel was introduced to the transition nurse.

87. Without access to the detailed breakdown in scores, it is difficult to assess the impact of factual inaccuracies on the overall scoring of individual centres and, therefore, on the range of potential options considered.

88. In addition, we have been advised that Leeds Teaching Hospitals NHS Trust did not receive the detailed scoring of the Expert Panel following the site visit and was given very limited opportunity to comment an the Panel's findings, and correct any factual inaccuracies, prior to publication. We are concerned that, seemingly, the review process did not allow existing surgical centres to comment on such aspects.

89. We have been advised that establishing a robust and fully functioning network can take years to embed. Therefore, given the critical role of all networks in the success or failure of future arrangements, **we believe it is completely illogical that three of the four proposed options would see the break-up and fragmentation of the existing very strong network arrangements across Yorkshire and the Humber.** We believe that in the review process to date, the strength of networks has not been given an appropriate level of consideration, or sufficient importance or weighting attached to existing structures. We believe this severely disadvantages the children and families of Yorkshire and the Humber.

Adults with congenital cardiac disease

90. We are aware that the minimum number of surgical procedures, within designated centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. We note the rationale behind the minimum numbers, but remain to be convinced by the clinical evidence used to support the number of procedures presented in the proposals.

Conclusions and Recommendations

91. We understand that the NHS is reviewing the provision of congenital cardiac services via two separate but related reviews and that the process for the designation of adult congenital services will proceed in 2011. This will include reference to the separate standards that have been developed by a separate expert group which were published in 2009. In preparing this report, it should be noted that we have not sought to consider these service standards.

92. As previously stated, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. We also understand that elsewhere in the country, other surgeons also treat both children and adult congenital cardiac patients.

93. We received evidence that Adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. This is clearly not safe or sustainable.

94. We understand that when reviewing any service, it is necessary to define the scope of the review. We also understand that this can be a complex exercise in itself. Nonetheless, we believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice.

95. We firmly believe that on a similar basis to the sustainability issues put forward in the children's congenital cardiac services consultation document, and **by considering adult congenital services separately, the outcome from the children's congenital cardiac services review will almost certainly pre-determine the outcome of the adult's services review.**

96. Adult congenital heart patients at the Leeds Centre have also made their views clear that they feel disenfranchised by the fact that their service is not being consulted upon jointly with the children's service in this review.

97. Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country. We learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Enough to justify retaining another two centres if the suggested minimum number of 400 surgical procedures is applied.

98. As previously stated, we understand that with three surgeons in post, 392 surgical procedures (adults and children combined) were undertaken last year at the current surgical centre in Leeds.

Conclusions and Recommendations

99. Although we have not been provided with any detailed projections, we are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.

100. As such, simply by continuing to treat patient numbers arising in Yorkshire and the Humber, we would question whether in reality there are indeed any sustainability issues around the surgical centre in Leeds. Similar considerations may also be true for other areas.

101. We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We understand that concerns have been raised both in terms of absolute patient numbers and also around pre-determination. Such concerns appear to remain unaddressed.

Recommendation 5:
Adult cardiac services and the overall number of congenital cardiac surgical procedures carried out should be considered within the scope of this review and used to help determine the future configuration of surgical centres. As a minimum there should be a moratorium on any decision to designate children's cardiac surgical centres until the review of the adult congenital cardiac services is completed and the two can be considered together.

The views of the people of the Yorkshire and Humber region

102. Over 600,000 people in the Yorkshire and Humber region signed a petition supporting the retention of the surgical centre at the Leeds Children's Hospital. We firmly believe their voice needs to be listened to. All of our work on this inquiry supports their view that retaining the Leeds centre is in the best interests of the children and families of this region.

103. We have heard evidence that well motivated parents of children with congenital heart problems struggled with the consultation response form and evidence that the response forms and associated consultation document were not translated into ethnic minority languages, e.g. Urdu, until the final 5 weeks of the 4 month consultation.

104. Given the difficulties that even well motivated and more vulnerable groups experienced with the formal public consultation **we trust that the largest petition of its kind in the United Kingdom will be received with respect and given the proper consideration it's signatories expected when adding their support to the Leeds centre.**

105. As such, we pressed for a response from the JCPCT in terms of how it would weight the petition received. In a response dated 27 September 2011, the Safe and Sustainable Programme Director advised that:

> **'It will be for the JCPCT members to determine the weight that it applies to petitions – and all other types of evidence submitted during public consultation...'**

106. We trust the JCPCT will give significantly greater consideration and weighting to public opinion expressed through the petition from this region than is perhaps otherwise suggested by this response.

An alternative reconfiguration option

107. We have already outlined our proposed alternative reconfiguration option for consideration by the JCPCT. However, we believe it is important to highlight that our rationale for putting forward the 8-surgical centre model, detailed in Principal Recommendation 2, is based on the following matters:

- Co-location of services;
- Travel and access to services; and,
- Caseloads and the number of adults with congenital cardiac disease.

<u>Co-location of services</u>

108. It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions.

109. As detailed earlier in this report, 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)). We have considered some aspects of the recommendations made in that report and were particularly struck by recommendation 178, which states:

> ***'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.'***

110. However, we believe that the definition of 'co-location of services' within this review has been loosely interpreted in drawing up the options put forward for public consultation. The term co-location should be used to describe just that – services co-located on a single site, and we believe greater emphasis should be placed on those surgical centres capable of offering services on that basis.

Travel and access to services

111. As previously highlighted, the patient flows predicted under options A-C presented in the consultation document, alongside supporting information considered by the JCPCT, suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge.

112. While we welcomed the additional review work and testing of assumptions, we cannot understand why more detailed analysis was not undertaken prior to the proposed options being identified and issued for public consultation. Notwithstanding the availability of this additional assessment work, we firmly believe this will be highly significant and is likely to be a considerable factor in determining whether or not proposed designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre.

113. Furthermore, such information will also help to identify and determine whether proposed surgical centres are at risk of being destabilised by an increase in patient numbers above and beyond the planned capacity.

114. In lieu of any evidence to the contrary, we believe that children and families from across Yorkshire and the Humber will be disproportionately and consistently disadvantaged in terms of access and travel times under three (options A-C) of the four options presented. This is reinforced by the details presented in Mott MacDonald's Health Impact Assessment (Interim Report).

115. We believe that extending travel times and the complexity of journeys for patients across Yorkshire and the Humber is likely to place additional strain on children and families at what will already be a particularly stressful time, which we believe to be both unreasonable and unnecessary.

116. We have previously outlined the impact assessment work undertaken by Embrace, which highlighted the disproportionate impact that options A-C would have on children and families across Yorkshire and the Humber. This suggested that between 53% and 73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review – in comparison to the national figures of between 3.6% and 6.2%. It

also highlighted that any reconfiguration option that does not include the Leeds surgical centre is likely to see more than a four-fold increase in the mileage covered by the region's transfer and retrieval service.

117. Nonetheless, we recognise that should the surgical centre at Leeds be retained at the expense of the one currently located in Newcastle (i.e. Option D), children and families from across the North East of England (albeit potentially fewer in number) could be subject to similar issues around travel and access to services. We also believe that similar travel and access to services issues may arise should the current surgical centre in Southampton not be retained. For these reasons, we have proposed the retention of the current surgical centres at Leeds, Newcastle and Southampton as part of an 8-surgical centre model.

Caseloads and the number of adults with congenital cardiac disease

118. The minimum number of surgical procedures, both within designated surgical centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. While we note the rationale behind the minimum number of procedures presented in the proposals, we remain to be convinced by the clinical evidence used to support and justify the minimum number of procedures.

119. Notwithstanding the suggested minimum number of surgical procedures, we are aware that the NHS is also reviewing the provision of adult congenital cardiac services and the process for designating surgical centres will proceed during 2011. However, we understand that in many cases, the same surgeons treat both children and adults and there is often continuity of care for patients from childhood through into adulthood.

120. We are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.

121. We received evidence that adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. While this is clearly not safe or sustainable, we also learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Using the rationale applied in relation to the review of children's congenital cardiac services, the current volume of adult patients would be enough to justify retaining two centres.

122. We believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice. Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country and would support the 8-centre model proposed.

123. The public consultation document sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 paediatric cardiac surgical procedures per surgical centre under a 6-centre model and 570 paediatric cardiac surgical procedures per surgical centre under a 7-centre model. This is far in excess of the optimum 400-500 surgical procedures put forward elsewhere in the same consultation document. We feel this represents further evidence to support the 8-centre model proposed.

Concerns and lessons to be learned

124. Throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals set out in the public consultation document '*Safe and Sustainable: A new vision for Children's Congenital Cardiac Service'* published in March 2011. Elsewhere in the report we have already outlined some of our concerns regarding the proposals and the proposed configuration of designated surgical centres.

125. We have also already outlined some of our concerns on a range of other matters, however for ease of reference we have outlined these below:

Review assumptions

<u>Patient flows</u>

126. Options A-C suggest patient travel patterns from the Yorkshire and Humber region that do not match local knowledge. This has also been highlighted by the Yorkshire and the Humber Specialised Commissioning Group (YHSCG), which (in part) resulted in the commissioning of additional work around testing the assumptions of patient flows under each of the proposed reconfiguration options.

127. As previously stated, while we welcomed this additional review work, we cannot understand why more detailed analysis was not undertaken prior to the options for consultation being identified and issued for public consultation. We understand that the additional assessment work will have a significant focus on

areas across Yorkshire and the Humber, with 8 (out of 18) postcode areas identified for more detailed analysis and testing.

128. Nonetheless, we remain frustrated that such information will not be available for public scrutiny until after our 5 October 2011 deadline, despite previously being advised that the details would be available in August 2011. As previously stated we must reserve the right to comment as and when the Price-Waterhouse Coopers (PwC) report is published.

Presumed capacity

129. We understand that the review has worked on a stated capacity of 600 surgical procedure per annum at Leeds Teaching Hospitals NHS Trust. We have been advised that this is factually incorrect and at no time has the Trust stated this to be the case. We understand that some additional work commissioned by the JCPCT around surgical capacity is currently ongoing and therefore is not available to us for comment. Again, we reserve the right to comment on this aspect once this has been completed and becomes available.

The number of surgical centres and patient numbers

130. Based on the proposed 6 or 7 surgical centre models, the current national activity (3,600 surgical procedures) equates to an average of 600 or 514 surgical procedures per surgical centre.

131. It seems rather odd that on one hand an optimum number of procedures is presented and then on the other hand the same consultation document outlines two 6-centre options – which will deliver an average number of procedures 20% in excess of the optimum level. **We believe that any current surgical centre that only features in a 6-centre model, such as Leeds, has been severely disadvantaged during the consultation period**.

132. The consultation document also sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 and 570 paediatric cardiac surgical procedures per surgical centre under the proposed 6-centre and 7-centre models, respectively. Given one of the main aims of the review is to deliver sustainable arrangements for the provision of children's congenital cardiac services, we would question the methodology that proposes future configuration models that are likely to deliver an average number of procedures far in excess of the stated optimum number.

Adult congenital cardiac surgery would be reviewed separately

133. Throughout our inquiry, there has been significant concern expressed that the review to date has solely focused on congenital cardiac services for children, when in reality it is not uncommon for the same surgeons to treat both children and adults on the same surgical site. As we have already outlined, during 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures.

134. While it is clear that Leeds Teaching Hospitals NHS Trust (LTHT)has reached a level of surgical activity approaching 400 procedures per year (children and adults combined) with only 3 surgeons, we believe surgical activity would have been far in excess of this level if a fourth surgeon were already in post. The impact of similar considerations on other surgical centres is not clear. However, what is clear is that **the 859 adult congenital heart surgical procedures carried out across the country last year would be enough to justify retaining another two surgical centres, if the suggested minimum number of 400 surgical procedures were to be applied**.

135. We believe that considering children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach, representing an artificial separation of existing clinical practice. We also fail to see how the outcome of the review of children's congenital cardiac services can do anything other than pre-determine the outcome of the review of adult's congenital cardiac services.

136. Considering both children's and adult's congenital cardiac services in one review would also have given the adult patients the opportunity to have their views equally heard.

137. We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We believe that, as yet, these concerns have failed to be adequately addressed.

Review process, governance and transparency

138. To date, we believe there have been a number of fundamental flaws within the review process, its governance and transparency, that must be drawn to the attention of the JCPCT.

139. The consultation document outlines the process behind the proposed changes. This includes development of the proposed national quality standards and model of care, which summarises work undertaken by the Children's Heart Federation. When we questioned the review team regarding this work, we were referred to the Children's Heart Federation. As our concerns were unable to be

addressed directly, we would question how robustly the JCPCT has considered the information prior to its inclusion with in the consultation document.

Accountability

140. As a Joint Health Overview and Scrutiny Committee (HOSC), we were established as the statutory scrutiny body for Yorkshire and the Humber to consider and respond to the review proposals – representing the 15 top-tier local authorities and a population in excess of 5.5 million. Therefore, not only do we form a key and legitimate part of the democratic process, we also form part of the current statutory arrangements for public accountability within the NHS.

141. As detailed elsewhere in our report, we have been keen to formally engage with the JCPCT as part of our consideration of the proposals and the associated methodology. The former Chair of the Joint HOSC formally raised this matter in April 2011. This was subsequently pursued by the new Chair in August 2011, in the form of two written requests formally inviting a JCPCT representative at attend our meeting on 2 September 2011. This invitation was declined.

142. Subsequent invitations to attend resulted in the offer of attendance on 22 September 2011. This was accepted, only for the expected decision maker not to arrive on the morning of the meeting. The decision maker did eventually attend the committee on the afternoon of the 22 September 2011 but only when issued with a demand to do so.

143. As democratically elected representatives, all members of the Joint HOSC act in the best interest of the communities we represent and take this responsibility very seriously. Three of the four currently proposed options around the reconfiguration of designated surgical centres are likely to have very significant implications for the children and families across our region. It is important therefore that representatives of those communities are afforded the opportunity to question, scrutinise and interrogate the available evidence and appropriately hold decision-makers to account.

144. To help ensure consideration of a broad base of evidence, at its meeting on 2 September 2011, the Joint HOSC formally considered recently published reports by Ipsos MORI on the outcome of public consultation and a Health Impact Assessment report produced by Mott MacDonald.

145. In line with recognised good practice, and as outlined elsewhere in our report, representatives from both organisations were invited to attend our meeting to present their reports and address any questions of the committee. Unfortunately, following discussions with the Safe and Sustainable review team, both organisations declined the invitation to attend as it was not usual practice

and/or it was felt inappropriate to accept invitations to individual HOSC meetings, as this could lead to an inconsistent approach across different regions.

146. As such, we were left in a position where neither the report commissioners nor the report authors (for the Health Impact Assessment and report on the Public Consultation) were in attendance to present the reports or address any questions from the committee.

147. We took exception to this and made it clear that we believe that a failure to engage with us on the part of the JCPCT demonstrates contempt for local democracy, and has increased cynicism and a lack of confidence in the review process.

Scoring

148. As part of the process for assessing current surgical centres, we have been advised that initially panel members separately assessed each centre in April 2010, based on consideration of a written self-assessment form completed by each centre. The panel then visited each centre between May and June 2010, meeting staff, parents, carers and patients. Panel members took account of what they heard and saw on each centre visit by re-assessing and discussing the initial scores to reach a consensus score for each of the relevant factors.

149. However, while the overall assessment scores are publicly available in the consultation document (page 82) and observations (by way of the Independent Expert Panel Report (December 2010)), the detailed breakdown of those assessment scores have not been made publicly available. We also understand that the assessment scores have not been made available to individual centres – despite requests for that information.

150. We feel very strongly that information such as this should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so

Fair comparisons

151. We do not believe that all existing surgical centres have been considered on the same basis.

152. As outlined elsewhere in this report, we feel that population density in the Yorkshire and the Humber region should have been considered on the same basis as Birmingham, Bristol, Liverpool and the requirement for 2 surgical centres in London, which feature in all four options.

Conclusions and Recommendations

153. Furthermore, there is a range of co-located paediatric services available at the Leeds Children's Hospital, alongside maternity and other co-located services and specialisms based on the same site at Leeds General Infirmary. Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have received sufficient weighting in the case for Leeds.

154. The Yorkshire and Humber region's cardiac network which has operated since 2005 and has been recognised as being "exemplar". The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward for consultation would see the fragmentation of the unique and exemplary cardiac network currently in operation in our region.

Consistency of application of criteria

155. Option B includes centres not predicted to achieve the minimum of 400 procedures. As such, we question the consistency of application of the volume criteria which is supposed to underpin the short-listing process.

156. We also question the emphasis that is being placed on nationally commissioned specialist services currently being carried out in certain hospitals in some parts of the country, which seem to outweigh the consideration being given to centres of population in other parts of the country.

Financial calculations and assumptions

157. During our discussion with the Yorkshire and Humber representative of the JCPCT in late September 2011, it was highlighted that, **'…the new configuration would inevitably cost more…**' and may provide **'…a worse service for some patients and their families…'** We queried the likely level of the cost increase and, while we were not provided with any detailed analysis, we understand this is likely to be a significant increase with no additional funding likely to be forthcoming.

158. We have been advised that in terms of the increase in transportation and retrieval activity across Yorkshire and the Humber, increases in the number of out of region transfers are likely under each of the four proposed options, however **the impact of options A-C could be exponential – resulting in over 80% increase in the number of transfer or retrieval journeys, over 100,000 additional miles and over 2000 additional work hours**.

159. The most realistic model to address this resultant increase in activity would need further investment, through an increase in the number of transport teams (driver, nurse and doctor), alongside an increase in the number of ambulances and other essential equipment. We understand that there has not been any detailed assessment of the increase in expenditure for these services, however it is clear that **any option that does not retain the current surgical centre at Leeds, will result in very significant increases in transportation and retrieval costs for the NHS, as well as families of patients, across this region**.

160. We believe that under Options A-C, **children and families across Yorkshire and the Humber will not only endure a significantly worse patient experience, but this will also be at considerable greater expense to the population across this region**.

161. We believe the overall financial implications associated with the model of care proposed by this review are likely to be very significant – both in terms of establishing new arrangements and the on-going delivery of the proposed model of care. However from the responses we have received to our questions, we believe that to date **there has been insufficient consideration of the financial implications.** We also believe that the level of detail publicly available in this regard has been inadequate.

Scope

162. 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. However it was also highlighted that a small number of cases that flow from Scotland and Northern Ireland to English surgical centres had been taken into account as part of the review.

163. While we recognise that the children's heart surgical unit is Glasgow is part of the Scottish devolved administration's responsibility, we believe that more effort should have been made to include all UK surgical centres within the scope of the review, as this may have had an impact on the potential patient flow, particularly for centres in the North of England.

164. In addition, while services delivered in Scotland have been deemed outside the scope of this review, we note the reference within the consultation document to the existing cardiology centre at Edinburgh and the support this provides to the nearby surgical centre, presumably in Newcastle. Therefore we believe that within the review process, some consideration has been given to some of the services currently delivered in Scotland. Notwithstanding the Scottish devolved administration's responsibility mentioned above, we question the rationale for excluding services delivered in Scotland from the scope of this review.

Conclusions and Recommendations

Availability of information

165. We have not been able to consider all the information we identified as being necessary to conclude our review, prior to the 5 October 2011 deadline imposed by the review team.

166. Some of that information was not available due to the timing of additional work commissioned during the consultation period. We were also denied access to other information we believe to be relevant, and **it remains unclear on what grounds access to that information has been denied**. We feel very strongly that such information should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

167. We have attempted to highlight our concerns throughout the consultation process, and have already raised a number of matters with both the national review team and directly with the Chair of the JCPCT. However we remain seriously concerned that not all relevant information was available to us and other key stakeholders prior to the response deadlines. This information includes:

- The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy);
- A finalised Health Impact Assessment report;
- The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation;
- Additional work undertaken around capacity across surgical centres;
- Detailed financial calculations and assumptions.

168. We are also extremely concerned that **the Joint Committee of Primary Care Trusts (JCPCT) failed to adequately engage with us during the consultation period**. Early in the process we highlighted our desire to engage with the JCPCT (as the decision-making body), to discuss the proposals, highlight our concerns and inform the production of this report. Details of our requests are presented at Appendix 4. However, we did not secure the attendance until very late in the process and less than 10-working days prior to our submission deadline. **We believe this type of approach is not in the spirit of open, transparent and accountable decision-making,** and serves only to undermine public confidence in the planning and delivery of local health services. We trust this approach will not be repeated in any future consultations.

Conclusions and Recommendations

169. We are also concerned that we have been unable to engage with two independent third party organisations, namely Ipsos MORI and Mott MacDonald, that authored key reports. While the reports have been available to us for consideration, we feel it is good practice that the author(s) of any report considered by the committee should be available to present and discuss the reports if invited to do so. We extended an invitation to both Ipsos MORI and Mott MacDonald in this regard, which was subsequently declined.

170. We understand that both organisations declined our invitation based on advice given by the national review team. We believe that such advice is wholly inappropriate and once again is not in the spirit of open, transparent and accountable decision-making.

171. We also sought additional, and in our view essential, information highlighted in the Health Impact Assessment (HIA) Interim Report. Notwithstanding the interim status of the HIA report, this presented the following information in terms of vulnerable groups:

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

These 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.

172. The report states there are currently 2745 patients in vulnerable postcode districts, and sets out the likely travel and access impacts on vulnerable groups / postcode districts (based on current patient activity) under each of the proposed options (A-D).

173. We requested further information about how this analysis related specifically to children and families across Yorkshire and the Humber, but this information was not forthcoming. In the response denying access to this information, the Safe and Sustainable Programme Director, stated:

> *"Mott MacDonald have been commissioned to report on the Health Impact Assessment in a way that is transparent and equitable… I would not wish to influence the robust process they have undertaken by requesting the methodology is changed by singling out a particular area for analysis.*

Similarly, it would not be appropriate for me to ask them to release the data to one interested party, particularly as some stakeholders have already submitted their final response to consultation and would not have had the opportunity to take this data into account when formulating their responses."

174. We believe this is an unsatisfactory response that denies legitimate access to information we believe to be crucial when considering the impact on children and families in this region. All Overview and Scrutiny Committees have had the same opportunity to seek similar information should they wish to have done so, as such **we do not believe there is any legitimate reason why this information was not made available to us.**

175. Overall, we have been astounded by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable.

Nationally Commissioned Services – Heart transplantation, ECMO and Complex Tracheal Surgery.

176. As set out in the consultation documents, an expert panel was appointed to consider the delivery of the three nationally commissioned services and advise the JCPCT accordingly. The consultation document also sets out the conclusions of the expert panel, including the view that 'the optimum is to maintain Nationally Commissioned Services in their current locations if possible.'

177. At our meeting on 22 September 2011 and as set out in the consultation document, we were advised that, in common with all other current providers of children's cardiac surgery in England (who were not currently providers of nationally commissioned services) Leeds Teaching Hospitals NHS Trust (LTHT) were invited to express an interest in providing one or more of the three nationally commissioned services. LTHT expressed an interest in providing all three services and we were provided with details of those submissions.

178. We were advised by LTHT that the Trust was given 16 working days (13 April 2010 to 7 May 2010) to complete and submit the proforma and accompanying evidence, and understand that very limited feedback has been provided by the expert panel.

179. We were also advised that the assessment of the potential to deliver these services was undertaken solely through consideration of the completed proforma and accompanying evidence by an expert panel. This is supported by

the details outlined in Appendix 2 of the consultation document. As such, we understand that assessments did not include any site visits and/or interviewing of potential providers.

180. LTHT acknowledged the likelihood that any centre not currently providing these services would need to expand and develop some of the necessary skills / resource. However, we were also advised that without having any specific feedback regarding its submission, it was difficult for the Trust to explain or convey why the expert panel was not confident that the Trust had demonstrated it had the appropriate skills and infrastructure to deliver such services in the future.

181. We had been previously advised by LTHT that, of the three nationally commissioned services, delivery of ECMO specifically would be the easiest to implement – particularly given that such interventions become necessary when undertaking many cardiac surgical procedures, albeit for a relatively short period of time. However, we were subsequently advised that the Trust already had trained perfusionists, surgeons, nurses in theatres and on Intensive Therapy Unit (ITU) who have the necessary skills to deliver the service. As such, expanding and developing such areas would not be prohibitive to the delivery of the service – particularly given the anticipated implementation phase of the review (approximately 12 months).

182. The consultation document details the scoring of the expert panel (against a maximum of 30) and presents these by way of a 'league table' for each of the nationally commissioned services. These league tables also includes current providers of each service – with each provider being awarded the maximum score of 30. However, the available information does not suggest that current providers were required to provide any details associated with their provision against the six assessment areas and, therefore, seemingly not subject to the same assessment process. In our view, to award any centre a maximum score, without any assessment (or description of such assessment) is not good practice and wholly inappropriate. This suggests there are no areas for improvement within a centre currently delivering a nationally commissioned services.

183. Based on the information available to us, we are concerned that:

- the process for considering the potential delivery of nationally commissioned services across all providers (including current providers) has not been consistent,
- the process for considering the potential delivery of nationally commissioned services has not been sufficiently robust, and has essentially been a paper based assessment.

- potential providers were not given sufficient time to complete and return the necessary documentation.
- the future delivery of nationally commissioned services has seemingly proven to be a fundamental factor in drawing up the consultation options. However, these services do not appear to have been considered sufficiently important to be included in the initial self-assessment.
- LTHT has never been provided with the detail of the expert panel's assessment or been given access to the scores / rationale as to why the expert panel was not confident that such services could be provided by the Trust.

184. As such, we would question the appropriateness of the methodology and approach employed for considering the future delivery of nationally commissioned services, and query the relative significance of delivering such services and the associated timing within the overall review.

Training

185. As part of our inquiry, we questioned the degree to which the impact on training future surgeons, cardiologists and other medical/ nursing staff had been factored into the review. In response the Safe and Sustainable Programme Director advised that *'…the JCPCT recognises that improved training processes will need to be put in place for clinical staff…*' and that the independent expert panel, chaired by Professor Sir Ian Kennedy, concluded that *'…the succession planning for surgeons must be a key consideration for the future delivery of paediatric cardiac service.*' The response concluded *'…this is an issue for the implementation phase of the review rather than the assessment phase.*' We were further advised that ***'The 'track record for training new doctors' has not fed into the assessment of the current centres.'***

186. We were advised by a Leeds Teaching Hospitals NHS Trust clinician that in its 'teaching hospital' role, the Trust provides a range of student placements in a wide range of roles and over a number of different disciplines. While the Trust does not deliver any formal training for cardiothoracic surgeons, it was outlined that 3 trainee cardiologists are in post in the Trust at any one time.

187. We were further advised that the Trust had been instrumental in developing a regional training model for general paediatricians to develop and extend their knowledge around cardiology. It seems likely that this would be lost if the current surgical centre at Leeds was not retained in the future configuration of designated surgical centres.

188. While the full impact of the likely training requirements are not yet known, **we believe a regional training and development programme will be an essential element in the delivery of the proposed network model of care.**

189. We believe this aspect has received insufficient consideration to date, and are concerned that Leeds Teaching Hospitals NHS Trust's role in developing a regional training model does not appear to have been given any weighting in this review.

Public consultation

190. As part of the public consultation process, we understand that it has been stated on numerous occasions that the JCPCT is open-minded in terms of the future reconfiguration of designated surgical centres, and will consider any alternative models put forward that have not already considered.

191. While we welcome this suggestion, the public consultation document clearly states that **'Based on 11 centres there are 2047 possible different ways to configure the service.'** The consultation document then describes the various stages of the options assessment process, including establishing a shortlist of viable options and scoring of the viable reconfiguration options identified – which leads to the formation of the four configuration options identified for public consultation. Assuming the 2047 possible permutations and the options assessment process are robust, we fail to see how the public consultation process will deliver any alternative models that have not already been considered and dismissed.

192. As such, we question how open-minded the JCPCT will be and how the public consultation can be described as being *'…at a time where the policy decision can be influenced*'.

193. During our inquiry our attention was drawn to the accessibility of the consultation questionnaire, which was identified as the primary source to gather public opinion on the proposals. We heard from different sources that the questionnaire was complex and not user friendly – referring to a public consultation document in excess of 230 pages in length. While we appreciate that the subject matter is complex and covers a number of different, albeit related issues, we question the logic behind the approach used. Concern was also expressed that a significant emphasis was placed on completing the questionnaire on-line. **We believe that a public consultation exercise should aim to encourage participation, make information accessible and allow people to contribute in a way which is convenient and meaningful to them – not those responsible for analysing responses**.

Conclusions and Recommendations

194. We would also question the role of the JCPCT in agreeing a communications plan that failed to identify particular BME communities within the plans for public consultation at the outset – particularly when it is already known that members of some of those communities are more likely to need to access congenital cardiac services. It was suggested to us that members of the JCPCT raised concerns in this regard but were advised **'…it was too late…'** to do anything about. The timing of such concerns and the origin of the associated advice are unclear, however this seems a wholly inappropriate manner in which to address concerns raised by the decision-making body.

195. We have already expressed our concern regarding the comments from the Safe and Sustainable Programme Director in relation to the weighting likely to be given to public petition, who advised that:

> **'It will be for the JCPCT members to determine the weight that it applies to petitions – and all other types of evidence submitted during public consultation – when it meets to consider the responses to consultation.'**

196. We trust the JCPCT will give significantly greater consideration and weighting to public opinion expressed through the petition from this region than is suggested by this response.

197. We also considered a number of Council motions from a number of authorities across the region. In the main, these were directed at the Secretary of State for Health and for many authorities we were provided with the response received. What is striking is that while the responses more often than not make reference to the on-going public consultation, the Council motions do not appear to have passed to Ipsos MORI for inclusion within the consultation report. We believe this demonstrates a disconnection between different part of the NHS. As such, the council motion details are presented at Appendix 5 for consideration.

Engagement with Black and Minority Ethnic (BME) communities

198. We understand that children and families from the Indian sub-continent in particular are more likely to require children's congenital heart services. There is a significant population of BME communities of Kashmiri, Pakistani and other Indian sub-continent communities across Yorkshire and the Humber who ought to have been better engaged in this consultation from the outset.

199. Engagement of these communities received insufficient attention across Yorkshire and the Humber. Translated information was not available until the final 5 weeks of the 4 month public consultation process.

200. As local authorities strive to maintain stronger and thriving local communities, it is important that public sector agencies work together to ensure active engagement across all communities. We do not feel that this public consultation sufficiently addressed this aspect of involvement and engagement.

Consultation with the Joint Health Overview and Scrutiny Committee (HOSC)

201. To help the Joint HOSC produce a fully informed report/response, it has been essential to gather and consider a wide range of data/ evidence. This specifically includes consideration of the local data and impacts. The level of detail required was not readily available when the proposals were first published and the detail that was subsequently made available has taken time to gather and analyse. The result of which served to severely limit the timeframe for the Joint HOSC to meet to consider the local data and impacts.

202. Concerns were raised about the timing of public consultation and involvement of HOSCs in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed. Hence, following local elections, the inevitable changes to the membership of the Joint HOSC has had a significant impact on the meaningful involvement of the committee during the whole of the reported '7-month consultation period'. It should be recognised that as a result of the public consultation's proximity to local council elections – which resulted in a significant change in membership (over 50%) – the Joint HOSC was unable to arrange further meetings until after the close of pubic consultation on 1 July 2011.

203. Nonetheless, throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals. The range of evidence considered has included information produced by constituent authorities of the Joint HOSC. These details are presented at Appendix 6.

204. Regrettably, we have not been able to consider all the information we identified as being necessary to conclude our review, prior to our 5 October 2011 deadline imposed by the review team. Some of that information was not available due to the timing of some additional work commissioned by the JCPCT during the consultation period, while we have also been denied access to other information we believe to be relevant. **We feel very strongly that such information should have been made available for public scrutiny prior**

to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

205. We are stunned by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable.

206. Nonetheless, we welcome the suggestion that the Centre for Public Scrutiny (CfPS) will be involved as part of the 'lessons learned' activity associated with this review and we look forward to being actively involved and contributing to this process.

Summary of Evidence

Monitoring arrangements

Standard arrangements for monitoring the outcome of the recommendations will apply.

Decision-makers to whom the recommendations are addressed will be asked to submit a formal response to the report and its recommendations, as required under current legislation.

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) will then determine any further monitoring of the recommendations.

Reports and Publications Submitted

14 March 2011

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

29 March 2011

- Reconfiguration of Children's Congenital Heart Services in England – initial response from Leeds Teaching Hospitals NHS Trust
- Projected/ estimated population flows under each of the 4 consultation options
- Frequently asked questions (FAQs) and the associated responses available from the Safe and Sustainable website
- A letter from the Leader of Leeds City Council

2 September 2011

- JCPCT Update: correspondence
- Health Impact Assessment: Interim Report (Mott MacDonald)
- Report of the public consultation (Ipsos Mori)
- Regional Congenital Cardiac Network Strategy (March 2011)
- Congenital Cardiac Network Board: Response to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England (June 2011)
- Yorkshire and the Humber Regional Impact Assessment (Specialised Commissioning Group)
- Leeds Teaching Hospitals NHS Trust: Formal response to the 'Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England – Consultation Document'

Summary of Evidence

Reports and Publications Submitted (continued)

2 September 2011 (cont.)

- Adult Congenital Heart Disease (ACHD) in Yorkshire and the Humber: A briefing document
- Adult Congenital Heart Disease – a commissioning guide for services (May 2006)
- Neonatal time critical cardiac transfers in the Yorkshire and Humber region: S Oruganti et al
- Bonding and attachment in CHD babies and young children: Leeds Teaching Hospitals NHS Trust
- Regional Infant and Children's Transport Service: Impact assessment
- Written submissions from the following Hospital Trusts:
  - Airedale NHS Foundation Trust
  - Alder Hey Children's NHS Foundation Trust
  - Harrogate and District NHS Foundation Trust
  - Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
  - Sheffield Children's NHS Foundation Trust
- Children's Heart Surgery Fund – report on regional engagement activity
- Feedback from the following local authorities:
  - Kirklees Council
  - Leeds City Council
  - North East Lincolnshire Council
  - North Lincolnshire Council
  - North Yorkshire County Council
  - Rotherham Council,
  - Wakefield Council.

19 September 2011

- JCPCT: correspondence and written response to questions

22 September 2011

- JCPCT: correspondence and written response to questions
- Additional information from Leeds Teaching Hospitals NHS Trust
- Details (and associated correspondence) of Council motions from the following authorities across Yorkshire and the Humber:
  - City of York Council – 7 April 2011
  - East Riding of Yorkshire Council – 27 July 2011
  - Harrogate Borough Council – 13 April 2011
  - Kirklees Council – 23 March 2011
  - Leeds City Council – 6 April 2011 and 14 September 2011
  - Rotherham Council – 27 July 2011
  - Sheffield City Council – 6 July 2011
  - Wakefield Council – 30 March 2011

Summary of Evidence

Reports and Publications Submitted (continued)

22 September 2011 (continued)

- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Julian Smith MP (Skipton and Ripon)*
  - Michael Dugher MP (Barnsley East)*
- Additional information from Leeds Teaching Hospitals NHS Trust

29 September 2011

- Children's Heart Federation – details of survey work undertaken
- Feedback from the following local authorities:
  - City of Bradford MDC
  - East Riding of Yorkshire Council
- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Hilary Benn (Leeds Central)*
  - Rosie Winterton (Doncaster Central)*

4 October 2011

- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Austin Mitchell MP (Great Grimsby)*

Other reports and evidence considered

- Bristol Royal Infirmary Inquiry Final Report: Section Two – Recommendations
- Code of Practice on Consultation (HM Government (July 2008))
- Final Report: The relationship between volume and outcome in Paediatric Cardiac Surgery – a literature review for the National Apecialised Commissioning Group (September 2009)
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Pre-consultation business case
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Report of Independent Expert Panel Chaired by Professor Sir Ian Kennedy (December 2010)
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Response form (March 2011)

** Comments provided are attached at Appendix 8*

Summary of Evidence

Witnesses Heard

- Dr Mike Blackburn (Paediatric Cardiologist), Leeds Teaching Hospitals NHS Trust
- Maggie Boyle (Chief Executive), Leeds Teaching Hospitals NHS Trust
- Elspeth Brown (Consultant Cardiologist), Leeds Teaching Hospitals NHS Trust
- Lois Brown (Parent)
- Andy Buck (Chief Executive), NHS South Yorkshire and Bassetlaw
- Dr Derek Burke (Medical Director), Sheffield Children's NHS Foundation Trust
- Ailsa Claire (Yorkshire and the Humber representative), Joint Committee of Primary Care Trusts
- Sharon Cheng (Charity Director), Children's Heart Surgery Fund (CHSF)
- Alison Conchie (Children's Services Business Manager), Leeds Teaching Hospitals NHS Trust
- Dr Mark Darowski (Paediatric Intensivist), Leeds Teaching Hospitals NHS Trust
- Matthew Day (Specialty Registrar in Public Health), Specialised Commissioning Group (Yorkshire and the Humber)
- Cathy Edwards (Director), Specialised Commissioning Group (Yorkshire and the Humber)
- Dr Steve Hancock (Lead Paediatric Consultant), Embrace, Sheffield Children's NHS Foundation Trust
- Stacey Hunter (Divisional General Manager (Leeds Children's Hospital)), Leeds Teaching Hospitals NHS Trust
- Judith Huntley (Cardiac Nurse), Leeds Teaching Hospitals NHS Trust
- Ruth Lund (Yorkshire and Humber Congenital Cardiac Network Manager), Specialised Commissioning Group (Yorkshire and the Humber)
- Karl Milner (Director of Communications),Leeds Teaching Hospitals NHS Trust
- Liz Murch (Clinical Nurse Manager), Embrace and Paediatric Critical Care, Sheffield Children's NHS Foundation Trust
- Dr Kevin Smith (Medical Adviser), Specialised Commissioning Group (Yorkshire and the Humber)
- Dr John Thomson (Consultant Cardiologist), Leeds Teaching Hospitals NHS Trust
- Kevin Watterson (Paediatric Cardiac Surgeon), Leeds Teaching Hospitals NHS Trust and Children's Heart Surgery Fund (CHSF) Trustee
- Debra Wheeler (Children's Services Directorate Manager), Leeds Teaching Hospitals NHS Trust

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

Summary of Evidence

Dates of Scrutiny

12 January 2011	–	Health Overview and Scrutiny Committees - Yorkshire and the Humber Network meeting: Briefing meeting
14 March 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 1 – outline of proposals
29 March 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 2 – evidence gathering
29 March 2011	–	Site visit, Leeds Children's Hospital: Discussions with staff and parents
18 July 2011	–	Health Overview and Scrutiny Committees - Yorkshire and the Humber Network meeting: Briefing meeting (new members)
22 August 2011	–	Site visit, Leeds Children's Hospital: Discussions with staff, parents and other family members
2 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 3 – evidence gathering
19 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 4 – evidence gathering
22 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 5 – evidence gathering
29 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 6 – evidence gathering. Initial draft report
4 October 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 7 evidence gathering. Final draft report

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

Appendix 1:
Background and Scope

Background

1. In 2008, in response to concerns raised by clinicians and parent groups, 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.

2. Since that time, 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, which 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.

3. In August 2009, the first 'Safe and Sustainable' newsletter was published. This set out the aims and objectives of the review programme, and outlined how the children's cardiac surgery programme would be developed in England. This was the first information about the national review provided to a range of stakeholders, including local authority Health Overview and Scrutiny Committees.

Appendix 1:
Background and Scope

4. Subsequent newsletters were published in November 2009, May 2010, December 2010 and most recently in August 2011.

5. In April 2010, a 'Need for Change' document, endorsed by the relevant professional bodies and patients associations, was published, which highlighted the following issues:

   - Children's heart surgery is becoming increasingly complex.
   - Services have developed on an ad hoc basis; there is a need for a planned approach for England and Wales.
   - Surgical expertise (31 surgeons) is spread too thinly over 11 surgical centres.
   - Some centres are reliant on one or two surgeons and cannot deliver a safe 24 hour emergency service.
   - Smaller centres are vulnerable to sudden and unplanned closure.
   - Current arrangements are inequitable as there is too much variation in the expertise available from centres.
   - Fewer surgical centres are needed to ensure that surgical and medical teams are seeing a sufficient number of children to maintain and develop their specialist skills.
   - Available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes.
   - Having a larger and varied caseload means larger centres are best placed to recruit and retain new surgeons and plan for the future.
   - The delivery of non-surgical cardiology care for children in local hospitals is inconsistent; strong leadership is required from surgical centres to develop expertise through regional and local networks.
   - Increasing the national pool of surgeons is not the answer, as this would result in surgeons performing fewer surgical procedures and increase the risk of occasional surgical practice.

6. In January 2011, the Regional Health Scrutiny Network (Yorkshire and the Humber) received a briefing from the Director of the Specialised Commissioning Group (Yorkshire and the Humber) on the review process and associated timescales. This was provided in the run up to the meeting of the Joint Committee of Primary Care Trusts (JCPCT) in February 2011.

7. The meeting of the JCPCT took place on 16 February 2011, where the following recommendations and options for consultation were presented and agreed:

   - 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.

Appendix 1: Background and Scope

- 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 presented:

Option A: Seven surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option B: Seven surgical centres:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[1]
Option C: Six surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option D: Six surgical centres:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]

8. At the same meeting of the JCPCT, it was agreed that public consultation on the proposals would commence on 28 February 2011, running until 1 July 2011.

[1] *The preferred two London centres in each of the four options are Evelina Children's Hospital and Great Ormond Street Hospital for Children*

Appendix 1:
Background and Scope

Scope of the Inquiry

9. Forming a joint health overview and scrutiny committee, to consider the reconfiguration of health services covering the whole of the Yorkshire and the Humber region, is an extraordinary and previously unprecedented requirement. The coordination of this work should not be underestimated and we are extremely grateful to the network of scrutiny support officers for their continued efforts in this regard.

10. At our first meeting in March 2011[2], we considered and agreed the terms of reference for our work as a formal joint committee. The full terms of reference are presented at Annex 1, however these can be summarised as considering:
    - The review process and formulation of options presented for consultation;
    - The projected improvements in patient outcomes and experience;
    - The likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
    - The views of local service users and/or their representatives;
    - The potential implications and impact on the health economy and the economy in general, on a local and regional basis; and,
    - Any other pertinent matters that arise as part of the our inquiry.

11. At our second meeting in March 2011, we considered how we might gather the necessary evidence to help us form an objective view of the proposals and agreed an outline action plan. We kept our actions under review as our inquiry progressed, therefore the outline action plan was indicative rather than completely definitive of our overall approach.

12. A brief outline of our meetings is provided within the main body of the report. Nevertheless, it should be recognised that due to the timing of the consultation and the close proximity of local elections the Joint HOSC was unable to arrange further meetings until after the close of pubic consultation on 1 July 2011.

13. It should be noted that the outcome of the local elections resulted in a significant change in membership (over 50%) of the Joint HOSC. This, almost inevitable change to the membership of the Joint HOSC, has had a significant impact on the meaningful involvement of the committee during the whole of the reported '7-month consultation period' for Health Overview and Scrutiny Committees. Details in the change in membership are outlined in the Terms of Reference attached at Annex 1.

[2] Revisions to the Terms of Reference were agreed at the meeting held on 2 September 2011.

Appendix 1:
Background and Scope

14. It should also be noted that concerns about the timing of public consultation and involvement of HOSCs were raised in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed.

15. As part of our inquiry, many members of the committee took the opportunity to visit the current surgical centre in Leeds and the additional facilities on offer. In addition, a number of members met with children and families within their own local authority boundary to hear first hand of their experience of the current services and any concerns around the proposed changes. This vital information from service users informed a number of the Joint HOSC's discussions and is reflected in the inquiry report and its recommendations.

Appendix 1:
Background and Scope

Annex 1

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

REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND

TERMS OF REFERENCE[3]

1.0 Introduction and background

1.1 Children's heart surgery is an increasingly complex procedure that demands great technical skill and expertise from surgeons and their teams. In the Yorkshire and the Humber region, Leeds Teaching Hospitals NHS Trust currently offers the only surgical centre that provides children's heart surgery services. Following the local reconfiguration of hospital services, these services are delivered at the Children's Hospital, located within Leeds General Infirmary (LGI).

1.2 In 2008, in response to concerns raised by clinicians and parent groups, the NHS Medical Director requested a review of Children's Congenital Heart Services in England. Concerns had been raised that some centres were not performing enough surgical procedures to maintain and develop their specialist skills, and some centres did not have enough surgeons to guarantee a safe 24/7 service. There was also some concern that the NHS is too reliant on other countries to train the next generation of children's heart surgeons.

1.3 As such, 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

[3] As amended on 2 September 2011

- 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

1.4 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.

1.5 At the Joint Committee of Primary Care Trusts (JCPCT) meeting held on 16 February 2011, the review team reported an overwhelming feeling that the time for change is long overdue. At that meeting the JCPCT was presented with the following recommendations:

- 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:

Appendix 1:
Background and Scope

Option A: Seven surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]	**Option B: Seven surgical centres:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[4]
Option C: Six surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]	**Option D: Six surgical centres:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]

1.6 Having analysed the available information, the JCPCT agreed that the above options should form the basis of public consultation – commencing on 28 February 2011 and running until 1 July 2011.

2.0 Purpose and scope of the inquiry

2.1 The purpose of the joint scrutiny inquiry is to make an assessment of, and where appropriate, make recommendations on the potential options to reconfigure the delivery of Children's Congenital Heart Services in England.

2.2 In receiving the identified options, the Joint Health Overview and Scrutiny Committee (HOSC) will consider the likely implications across the Yorkshire and Humber region. This will include consideration of the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience;
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- Views of local service users and/or their representatives;

[4] *The preferred two London centres in each of the four options are Evelina Children's Hospital and Great Ormond Street Hospital for Children*

- Potential implications and impact on the health economy and the economy in general, on a local and regional basis;
- Any other pertinent matters that arise as part of the Committee's inquiry.

2.3 Consideration will also be given to the arrangements for consulting on the proposals and a view given regarding the adequacy of such arrangements.

2.4 The work of the joint HOSC will, as far as practicable, be undertaken to reflect the general principles set out in the Joint Health Scrutiny Protocol (Yorkshire and the Humber).

2.5 The joint HOSC intends to provide a timely and positive contribution to the public consultation on the proposals.

3.0 Comments from participating Health Overview and Scrutiny Committees

3.1 In the development of these terms of reference, comments from constituent and participating local authority health overview and scrutiny committees (HOSCs) have been taken into account.

4.0 Timetable for the inquiry and submission of evidence

4.1 The joint scrutiny inquiry will commence in March 2010.

4.2 As part of the public consultation on the future of Children's Congenital Heart Services in England, Health Overview and Scrutiny Committees have been given until 5 October 2011 to respond to the proposals.

4.3 As such, the likelihood is that any report/ recommendations will need to be finalised and agreed by the end of September 2011.

5.0 Membership and arrangements for the Joint HOSC

5.1 Membership and arrangements for the joint HOSC shall be in accordance with the Joint Health Scrutiny Protocol (Yorkshire and the Humber).

5.2 Following individual decisions and nominations from constituent local authorities, the membership of the Joint HOSC will be:

- Barnsley MBC – Cllr. Jen Worton replacing Cllr. Janice Hancock
- Bradford MDC – Cllr. Mike Gibbons replacing Cllr. Elaine Byrom
- Calderdale Council – Cllr. Ruth Goldthorpe
- City of York Council – Cllr. Sian Wiseman replacing Cllr. Sandy Fraser
- Doncaster MBC – Cllr. Tony Revill replacing Cllr. Georgina Mullis
- East Riding of Yorkshire Council – Cllr. Barbara Hall
- Hull City Council – Cllr. Danny Brown replacing Cllr. John Hewitt

- Kirklees Council – Cllr. Liz Smaje
- Leeds City Council – Cllr. Lisa Mulherin (Chair) replacing Cllr. Mark Dobson (Chair)
- North East Lincolnshire Council – Cllr. Karl Wilson replacing Cllr. Peggy Elliot
- North Lincolnshire Council – Cllr. Jean Bromby replacing Cllr. Trevor Barker
- North Yorkshire County Council – Cllr. Jim Clark
- Rotherham MBC – Cllr. Shaukat Ali
- Sheffield City Council – Cllr. Ian Saunders
- Wakefield Council – Cllr. Betty Rhodes

5.3 As the administering authority, attendance of substitute/ alternate members will be in accordance with Leeds City Council's Scrutiny Procedural Rules.

6.0 Witnesses

6.1 The following organisations (including appropriate representatives) and witnesses have been identified as possible contributors to this joint inquiry:

- Parents and/or service user representatives
- Specialised Commissioning Group (Yorkshire and the Humber)
- Leeds Teaching Hospitals NHS Trust
- Appropriate professionals and/or professional bodies
- Primary Care Trusts (Yorkshire and the Humber)
- Yorkshire Ambulance Service (YAS) and/or other patient transport organisations
- Local GPs and/or their representative body
- Local Members of Parliament
- Local Authority representatives

6.2 The Joint HOSC will seek to identify and receive all relevant contributions, using a variety of methods to gather information. As such, the Joint HOSC will aim to keep the list of witnesses under review throughout the joint inquiry.

7.0 Monitoring arrangements

7.1 Following completion of the joint scrutiny inquiry and the publication of the consultation response and/or recommendations, a response from the appropriate NHS body (or bodies) receiving the report, will be requested within 28 working days and subsequently considered by the joint HOSC as soon as practicable.

7.2 Any other monitoring arrangements agreed by the joint HOSC will be included in the final report.

8.0 Measures of success

8.1 The Joint HOSC will seek to respond to the consultation proposals in an appropriate manner, and publish realistic and practical recommendations, as appropriate. However, how the joint HOSC will deem whether its work has been successful in making a difference to local people will be identified as the joint inquiry progresses and discussions take place. Such information will be detailed in the joint committee's final report.

Appendix 2:
Bonding and attachment

CHD Bonding & Attachment: Dr Sara Matley, Consultant Clinical Psychologist, LTHT

Bonding and attachment in CHD babies and young children

For babies and young children, care and development are strongly linked, and the bond between baby and parent or carer is crucial to the growth and development of the child – affecting physical growth as well as emotional and cognitive development and wellbeing.

Children's earliest experiences shape how their brains develop, which in turn determines future health and wellbeing. Very young children need secure and consistent relationships with other people in order to thrive, learn and adapt to their surroundings and this may also impact their ability to form good future relationships.

Research indicates that attachment aids children to develop physically, emotionally, socially and morally. Good, secure attachments enable children to cope with change and stress, cope with separation and loss, become independent and develop future relationships.

A care giver's ability to respond to, and stimulate a baby is influenced by the degree of attunement with the baby, and this serves to buffer his or her physiological, as well as emotional and behavioral responses to stress.

Attunement between mother and child is directly affected by the maternal-infant bond, which in turn is shaped by prenatal and perinatal events. Among the complex factors that influence bonding at birth are the mother's attitude toward the pregnancy and her perception of available support systems, her experience of procedures e.g echocardiograms, her perception of stress during pregnancy, and separation (Mead, 2004)

The sensitive period

One of the most important perinatal periods affecting bonding are the interactions in the hours and weeks following birth. Classic work by Klaus & Kennell, 1970 indicated the harm caused to the mother-infant relationship and as a result of research such as this there has been significant changes in practice in neonatal care, from a system which routinely separated mothers from newborn infants to a family centered approach which maximises contact and promotes bonding.

An emerging literature suggests that maternal distress in the prenatal and perinatal period may adversely affect development. Factors such as maternal stress, depression, perceived social support, and parenting stress are identified in the literature as risk factors. There is a growing literature indicating that perinatal maternal adjustment is associated with children's longer term emotional and behavioural functioning. (Anhalt et al, 2007)

Appendix 2:
Bonding and attachment

Disruption to bonding

Separation in early life is associated with a reduction in maternal-infant attunement. The impact of maternal-infant separation during the sensitive period may permanently alter emotional relationships.

Many hospital procedures carried out to decrease perinatal health risks may pose a challenge to bonding. For example, bonding can be jeopardized when a child is separated because of illness, when placed in an intensive care nursery, when placed in an incubator, or when the mother is anesthetised at delivery (Madrid & Pennington, 2000).

Events such as these which affect the ability of the mother to meet the needs of her infant shape the capacity of the newborn to tolerate stress. Events occurring during labour and delivery that may affect the mother or the infant's ability to bond include early separation, pain in the mother or infant, the use of medication such as anesthesia, and anxiety. Maternal-infant separation following cesarean sections is common and appears to have a negative impact upon the quality of maternal-infant interactions. Separation from baby is found to be the most difficult aspect for mothers when their child is hospitalised. Parents can often feel excluded (Wigert et al, 2006).

Feldmen et al (1999) studied of maternal bonding under differing conditions of proximity, separation and potential loss, found that separation of a mother from its newborn baby due to hospitalization initially led to increased anxiety and stress in the mother. However prolonged separation due to hospitalization resulted in a decrease in preoccupation with the child and a poor attachment.

Leeds Early Intervention approach

There is a body of evidence that suggests children with chronic illnesses are at greater risk than other, healthy children of developing emotional and behavioural difficulties (Eiser, 1990). Rautava et al (2003) completed a longitudinal study of the impact of hospitalization of a newborn on families and found those who had been separated from their baby due to medical need reported higher levels of behavioural problems at age 3yrs which indicated long lasting effects of early separation. Locally, our own research looking at the incident of behavioural problems in children with Congenital Heart Defects shows significantly higher rates of behavioral problems than would be found in a healthy comparison group (Matley, 1997). Disruption to bonding and attachment play a major role in the development of longer term difficulties.

In an attempt to ameliorate longer term problems the support offered in Leeds is targeted at early and proactive interventions, which aim to support prospective parents from antenatal diagnosis through to delivery, and longer term care thereafter. This enables good working relationships to be developed and a continuity of care, which fosters trust and communication.

Appendix 2:
Bonding and attachment

The benefits of having all Maternity, Neonatal and Paediatric Cardiac Surgery services upon one site, allows for a continuity of care and effective communication between all the teams involved in the care of both mother and baby.

The risks and length of maternal separation can be avoided or considerably reduced because all care can be provided on one site. Accommodation for newly delivered mothers is available on the ward so attachment and bonding can be fostered. Breast feeding, which can enhance bonding, is also encouraged and facilitated by well trained staff and good provision of facilities and equipment.

Emotional support is provided by all the team, and more specific help can be gained from the Cardiac Nurse Specialist team and the integrated Psychology and Counselling service available on the children's ward. The emotional support offered is aimed at bolstering parents' resilience and encouraging personal coping strategies. This work will often compliment the support of family members who are local enough to visit and perhaps share some of the caring responsibilities, and emotional stress.

As a Psychology team we see a number of families who have experienced the trauma of a very unexpected, and perhaps abrupt separation from their baby due to an undiagnosed problem. Much of this work focuses on helping parents to 'grieve' for the loss of a normal birth experience and early interactions, as well as helping them make sense to the trauma they have experienced.

We have also seen a number of parents who have experienced separation from their child, being left behind in a peripheral hospital, as experiencing extreme anxiety and trauma symptoms. These experiences further hinder their ability to bond with their babies.

With the increasing antenatal CHD detection rate and the expert fetal cardiology service available at Leeds, the opportunities to prepare parents, co-ordinate care with the other relevant onsite services, provide counselling and support from the very earliest of days all aims to reduce the risk of stress, anxiety, depression and separation, which in turn is aimed at fostering bonding and attachment, with the longer term goal of reducing the risks of behavioural and emotional problems for children and families in the future. Co-location of Maternity, Neonatal & Cardiac Surgery is essential to continue this unique proactive, early intervention approach to care.

Case Study

L was a young mother whose baby was diagnosed antenatally with complex congenital heart disease. During sessions with a Psychologist L reported a number of worries about the child's future and how this would impact upon her husband and two small children. L's greatest worry however was about being separated from her baby. This upset the mother a great deal and part of the preparation work we did involved visiting the ward so that she could picture where her daughter would be.

Appendix 2:
Bonding and attachment

L was terrified that her child might die without any family around her; it was very important for her that either she or her husband be there when this happened. As the child was critically ill when she was born, there was a good chance that the child may die without her family around her, if the mother was separated from the child. The father was in a difficult position of wanting to support the mother after the birth, but also wanting to be around the baby when she was born.

Care for mother and baby was co-ordinated and arrangements made for L to deliver in Leeds, and her husband and children to be accommodated in Eckersley House, the family accommodation.

L's baby did die, but surrounded by her family once they had the chance to say goodbye. A move to care provided in a standalone heart unit would mean that maternity services would not be located in the same hospital as the cardiac surgery would have been devastating for this family. It would have increased the mother's fear, risk of future emotional & psychological difficulties and the possibility that her child would die without her being there.

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Appendix 3:
Indices of Deprivation in England (2010)

- Table 1 provides the local authority summary of the indices of deprivation (ranked out of 326). North Yorkshire is broken down into the seven borough/district councils. This shows that Scarborough has a higher level of deprivation, compared to other areas in North Yorkshire.

TABLE 1

Indices of deprivation 2010 - local authority summary

A rank of 326 is least deprived, a rank of 1 is most deprived.

	Average Score	Rank of Average Score
Barnsley	28.55	47
Bradford	32.58	26
Calderdale	23.18	105
Doncaster	29.76	39
East Riding of Yorkshire	14.97	202
Kingston upon Hull, City of	37.53	10
Kirklees	25.23	77
Leeds	25.83	68
North East Lincolnshire	29.3	46
North Lincolnshire	21.75	120
Rotherham	28.12	53
Sheffield	27.39	56
Wakefield	25.87	67
York	12.93	234
Craven	12.13	246
Hambleton	10.97	264
Harrogate	10.28	282
Richmondshire	11.18	261
Ryedale	13.91	213
Scarborough	24.75	85
Selby	12.93	235
Source: Indices of Deprivation 2010, Communities and Local Government 2011		

Appendix 3:
Indices of Deprivation in England (2010)

- Table 2 shows the county summary (ranked out of 149) and has an overall figure for North Yorkshire

TABLE 2

Indices of Deprivation 2010 - County summary

A rank of 149 is least deprived, a rank of 1 is most deprived.

Indice of Deprivation 2010 - County summary		
	Average Score	Rank of Average Score
Barnsley	28.55	40
Bradford	32.58	24
Calderdale	23.18	75
Doncaster	29.76	33
East Riding of Yorkshire	14.97	122
Kingston upon Hull	37.53	10
Kirklees	25.23	62
Leeds	25.83	55
North East Lincolnshire	29.30	39
North Lincolnshire	21.75	83
North Yorkshire	13.97	129
Rotherham	28.12	45
Sheffield	27.39	47
Wakefield	25.87	54
York	12.93	131
Source: Indices of Deprivation 2010, Communities and Local Government 2011		

Appendix 3:
2001 Census details

- Table 3 shows the information on households with no cars or vans. Although the source is the 2001 census, this is the most recent information available.

TABLE 3

2001 Census - Cars and Vans

	All Households	Households with no cars or vans	
	Count	Count	Percentage
Barnsley	92165	29633	32.15
Bradford	180246	58592	32.51
Calderdale	80937	25111	31.03
Doncaster	118699	36391	30.66
East Riding of Yorkshire	131084	26536	20.24
Kingston upon Hull, City of	104288	45720	43.84
Kirklees	159031	47059	29.59
Leeds	301614	103987	34.48
North East Lincolnshire	66054	21895	33.15
North Lincolnshire	64014	15122	23.62
Rotherham	102279	30374	29.7
Sheffield	217622	77605	35.66
Wakefield	132212	40465	30.61
York	76920	21008	27.31
North Yorkshire	237583	46398	19.53
Total	2064748	625896	30.31

Source: 2001 Census, Cars and Vans, Neighbourhood Statistics, Office for National Statistics, © Crown Copyright 2003

Appendix 4:
Letters to the JCPCT and review team

Councillor Mark Dobson
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Your ref
Our ref MD/smc
Date 14 April 2011

Mr. Jeremy Glyde, Programme Director
Safe and Sustainable Programme
NHS Specialised Commissioning Team
2nd floor, Southside
105 Victoria Street
London SW1E 6QT

Dear Mr. Glyde,

Re: Review of Children's Congenital Heart Services in England

Thank you for your recent communication (8 April 2011), highlighting concerns associated with comments attributable to Leeds Teaching Hospitals NHS Trust (LTHT). I have sought a response to these concerns from the Trust's Chief Executive, Ms. Maggie Boyle.

As you are undoubtedly aware, the 15 local authorities (with Health Scrutiny responsibilities) across the Yorkshire and Humber Region have established a Joint Health Overview and Scrutiny Committee (HOSC) to consider the proposals of this national review and provide a consultation response in this regard. As such, I will share your communication with other members of the Joint HOSC, alongside any response from LTHT.

I understand that Steven Courtney (Principle Scrutiny Adviser to Leeds City Council's Scrutiny Board (Health) and the Joint HOSC) has already been in contact with you, advising of the current progress and future work of the Joint HOSC. As such, I will not repeat the content of that communication, other than perhaps to re-emphasis the following points:

Cont./

Appendix 4:
Letters to the JCPCT and review team

Involvement of Safe and Sustainable the JCPCT in the work of the Joint HOSC

Members of the Joint HOSC are keen to meet with appropriate representatives and would therefore wish to formally invite you (as Programme Director), along with the Chair of the JCPCT (Sir Neil McKay) and the Yorkshire and Humber SCG representative on the JCPCT (Ms. Ailsa Claire) to contribute to a future meeting (or meetings) of the Joint HOSC in this region. The main purpose of this attendance being to help the Joint HOSC consider in more detail the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience; and,
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times.

I would appreciate your cooperation in this regard and trust you will provide details of availability as a matter of urgency.

Consultation process and associated timescales

Members of the Joint HOSC were concerned about the general accessibility of the proposals, given:

(a) The length and complexity of the consultation document (which exceeds 230 pages);
(b) That a summary document had not been provided; and
(c) The accessibility of the consultation questions

The Joint HOSC also expressed significant concern regarding the timing of the consultation, its proximity to local elections and the impact of purdah. There was a strongly held view that this demonstrated a lack of appreciation (or regard for) local democracy and the potential impact on the work (and membership) of a Joint HOSC.

As you are already aware, one of the outcomes of the Joint HOSC meeting held on 29 March 2011, was to formally seek a three month extension to the consultation period. In part, this is to allow the Joint HOSC to complete its work and issue its report and any recommendations. A report to this effect is currently being prepared and will be formally directed to the JCPCT in the near future.

I trust you appreciate that, as democratically elected representatives of local communities, the overall health and wellbeing of all citizens across the Yorkshire and Humber region is without question an underlying consideration for all local councillors. Nonetheless, I think it is worth reinforcing that this is not only a cornerstone of the work of the Joint HOSC but its primary purpose when considering the proposals put forward. Furthermore, the consultation document detailing the proposed changes states, '*We would like to hear from anyone with a view on the future of congenital heart services*'. This is precisely one of the aims of the Joint HOSC – in order to help inform its view and any recommendations it may put forward.

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Appendix 4:
Letters to the JCPCT and review team

In addition, as Chair of the Joint HOSC and as an advocate of openness and transparency, I will be working hard to ensure that we seek as wide a range of views as possible and that the vast majority of the committee's work is undertaken in public. Undoubtedly, this is likely to attract local media interest – particularly during a period of a public consultation and engagement. As such, I make no apologies for the range of views that may be expressed as part of the scrutiny process and which may be subsequently reported – even where some of those views may be unpalatable and seen as unhelpful to the review team and/or the JCPCT.

Finally, I hope you take the opportunity to engage with the Health Scrutiny process in this region and look forward to receiving your response in the very near future.

Yours sincerely

Councillor Mark Dobson
Chair, Scrutiny Board (Health)

cc Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Cathy Edwards, Director – Specialised Commissioning Group (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

Councillor Lisa Mulherin
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Date 22 August 2011

Sir Neil McKay (Chair, JCPCT)
NHS Specialised Services
Safe and Sustainable Programme
2nd Floor, Southside
105 Victoria Street
London
SW1E 6QT

Dear Sir Neil,

Re: Children's Congenital Cardiac Services Review – Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

As Chair of the Yorkshire and Humber Joint Health Overview and Scrutiny Committee (HOSC) considering the proposed reconfiguration of Children's Congenital Cardiac Services and the potential impact on children and families across the region, I am writing to express our frustration that the outcome of the additional work to test assumptions around patient flows will not be available for HOSCs to consider prior to the 5 October 2011 consultation deadline: This is a vital source of evidence that warrants detailed consideration to help the Joint HOSC prepare a more fully informed consultation response and it is unacceptable that this will not be available to us.

I also note with some concern that this information will not be publicly available until after the JCPCT has made a decision on the reconfiguration proposals – a situation that is quite astounding and certainly not in the spirit of open and transparent decision-making.

At our next meeting on 2 September 2011, and in the absence of the PwC report, the Joint HOSC will be considering patient flow details provided in the regional impact assessment prepared by the SCG, alongside an impact assessment produced by EMBRACE – the regional body responsible for delivering a dedicated paediatric transport service.

Cont./

Appendix 4:
Letters to the JCPCT and review team

With this in mind, I would like to take this opportunity to invite you and/or Ailsa Claire, in your respective roles within the formal decision-making body, to attend this meeting to provide an update on the work of the JCPCT and to address questions on the role of the JCPCT within the review process to date. This will also provide an opportunity for you to hear first hand the details presented by EMBRACE.

I appreciate that this formal invitation to attend on 2 September 2011 may be relatively short notice; however the former Chair of the Joint HOSC first outlined the committee's intentions to involve appropriate representatives of the JCPCT and the Safe and Sustainable Team in April 2011 (copy enclosed). Despite the apparent lack of a formal response to that letter, I trust the content of this letter will have previously been communicated to you.

I look forward to hearing from you in the very near future. However, please do not hesitate to contact me should you have any queries and/or need any additional information.

Yours sincerely

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

Enc.

cc Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

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Sir Neil McKay (Chair, JCPCT)
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Dear Sir Neil,

Re: Children's Congenital Cardiac Services Review – Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Thank you for your response, dated 26 August 2011.

I note your comments regarding regional SCGs being best placed to represent the NHS at local scrutiny committees to speak to this review and am sorry that you will be unable to attend the meeting on 2 September 2011.

As you may be aware, for some time the Joint HOSC has worked very closely with Cathy Edwards (as Director of Yorkshire and the Humber SCG) at different stages during the review process. Cathy has attended a number of meetings – both formal committee meetings and briefing sessions, and I am sure all members of the Joint HOSC (both past and present) are grateful for Cathy's input into the regional scrutiny process.

That said, I would like to reiterate the desire of the Joint HOSC to formally engage with the JCPCT directly – as the decision-making body – and invite a representative from its membership to attend next week's meeting. As outlined in my previous letter, the purpose being to provide an update on the work of the JCPCT, address any questions raised, and to hear first hand any comments and/or concerns raised by the Joint HOSC.

Cont./

Appendix 4:
Letters to the JCPCT and review team

Despite Cathy already attending for a separate item on next week's agenda, I would respectfully remind you that Cathy is neither part of the JCPCT, nor part of the secretariat supporting the decision-making process.

Finally, I would like to take this opportunity to remind you that, in considering and responding to the review proposals, the Joint HOSC is acting as the statutory scrutiny body for Yorkshire and the Humber – representing the 15 top-tier local authorities and a population of 5.5 million. As such, I hope you will reconsider the invitation previously extended and ensure that the JCPCT is appropriately represented at next week's meeting.

Please contact me should you have any queries and/or need any additional information, otherwise I look forward to hearing from you in due course.

Yours sincerely

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

cc Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

Councillor Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and Adult Social Care)
3rd Floor (East)
Civic Hall
LEEDS LS1 1UR

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Civic Hall Tel. 0113 39 51411
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Your ref
Our ref LM/SMC
Date 7 September 2011

Sir Neil McKay (Chair, JCPCT)
NHS Specialised Services
Safe and Sustainable Programme
2nd Floor, Southside
105 Victoria Street
London
SW1E 6QT

Dear Sir Neil,

Re: Children's Congenital Cardiac Services Review – Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Further to the meeting of the Joint Health Overview and Scrutiny Committee (HOSC) on 2 September 2011 and our related correspondence beforehand, on behalf of the Joint HOSC, I must advise you of the anger and frustration of the Committee members that the JCPCT has yet to formally engage with the Joint HOSC, despite a number of written requests to do so.

Members of the Joint HOSC feel it is imperative for there to be some direct input from the JCPCT (as the appropriate NHS decision-making body), in order to inform our response to the proposals around the future provision and configuration of Children's Congenital Cardiac Services. As previously outlined, in considering and responding to the proposals, the Joint HOSC is acting as the statutory scrutiny body for Yorkshire and the Humber – representing the 15 top-tier local authorities and a population in excess of 5.5 million.

The frustrations expressed by members of the Joint HOSC are by no means any reflection on the input and support provided to date by Cathy Edwards (Director, Yorkshire and the Humber SCG) – which has been extremely helpful and of high quality. There are however some aspects of the Joint HOSC's inquiry and specific questions that need to be addressed by those on the decision-making body.

Cont./

Appendix 4:
Letters to the JCPCT and review team

As all of the units that went out to consultation are recognised as being safe, and there seems to be a reluctance (at best) to engage directly with us, there is a growing cynicism within the Committee about the way in which the four options that went out to consultation were drawn up.

As such, we formally request written responses to the following questions which Committee members had wished to put to you or any other JCPCT member at our meeting last week:

(1) Why was the Leeds unit not included in all four options on the grounds of population density in the Yorkshire and the Humber region, on the same basis that the units at Birmingham, Bristol, Liverpool and the 2 London centres, which feature in all four options?

(2) Why isn't the genuine co-location of paediatric services provided at the Leeds Children's Hospital, alongside maternity services and other co-located services and specialisms on the same site at Leeds General Infirmary given greater weighting? Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have been given sufficient weighting in the case for Leeds.

(3) Why isn't the "exemplar" cardiac network which has operated in the Yorkshire and Humber region since 2005 given greater weighting in the drawing up of the four options? The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward would see the fragmentation of this unique and exemplary cardiac network.

(4) Why doesn't the Leeds unit feature in more of the four options put forward given that all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service?

(5) Why isn't travel and access to the Leeds unit given a higher weighting given the excellent transport links to the city by motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via the Leeds-Bradford airport? Almost 14 million people are within a two hour travelling distance of the Leeds unit.

(6) We are keen to understand in more detail the relative strengths and weaknesses of each surgical centre. We therefore request the detailed breakdown of the assessment scores determined by the Independent Assessment Panel, Chaired by Sir Ian Kennedy (referred to on page 82 of the consultation documents).

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(7) How has the potential impact of the proposed reconfiguration of surgical centres on families, including the additional stress, costs and travelling times, been taken into account within the review process to date?

(8) Why have congenital cardiac services for adults been excluded from the review when, in some cases, the same surgeons undertake the surgical procedures?

(9) We have heard that more children with congenital cardiac conditions are surviving into adulthood, which suggests an overall increase in surgical procedures (for children and adults), which is likely to be beyond the 3600 surgical procedures quoted in the consultation document:

(a) As such, what would be the overall impact of combining the number of adult congenital heart surgery procedures with those performed on children, i.e. how many procedures are currently undertaken by the same surgeons and what are the future projections?

(b) How would this impact on the overall number of designated surgical centres needed to ensure a safe and sustainable service for the future?

(c) What would be the affect on the current and projected level of procedures for each of the existing designated centres?

(10) How has the impact on other interdependent hospital services and their potential future sustainability been taken into account within the review process to date?

(11) The Government's Code of Practice on Consultation (published July 2008) sets out seven consultation criteria: Please outline how the recent public consultation process meets each criterion.

(12) What specific arrangements have been put in place to consult with families in Northern Ireland?

(13) How have ambulance services (relevant to the affected patient populations) been engaged with in the review process – particularly in relation to drawing up the projected patient flows and associated travel times?

(14) How has the impact on training future surgeons, cardiologists and other medical/ nursing staff been factored into the review?

(15) What are the training records of each of the current surgical centres and how have these been taken into account in drawing up the proposals?

Cont./

Appendix 4:
Letters to the JCPCT and review team

(16) Why have services provided in Scotland been excluded from the scope of the review, when the availability and access to such services may have a specific impact for children and families across the North of England and potentially Northern Ireland?

(17) Please confirm whether or not a similar review around the provision of congenital heart services for children, is currently being undertaken in Scotland. Please also confirm any associated timescales and outline how the outcomes from each review will inform service delivery for the future

Bearing in mind the 5 October 2011 deadline for the Joint HOSC to formally submit its response to this review, the Joint HOSC is proposing to hold a further meeting to consider this matter on **19 September 2011**, and we feel it is imperative that detailed responses to the above questions are available for consideration at that meeting. As such, **I would be pleased to receive your written response within 5 working days**.

Furthermore, I would request your attendance and that of any other member of the JCPCT (as you feel appropriate) at the above meeting, which is due to commence at 10:00am in Leeds Civic Hall. Please be aware that I believe previous requests for your attendance at meetings of the Joint HOSC have been legitimate and form part of the accountability framework for the NHS – set out in Section 38 of the Local Government Act 2000 and clarified in the Overview and Scrutiny of Health Guidance (Department of Health, July 2003).

Please contact me should you have any queries and/or need any additional information, otherwise I look forward to hearing from you in the very near future.

Yours sincerely

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

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
Rt Hon Andrew Lansley MP, Secretary of State for Health
All Members of Parliament (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

Councillor Lisa Mulherin
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E-Mail address lisa.mulherin@leeds.gov.uk
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Civic Fax 0113 24 78889
Your ref
Our ref LM/SMC
Date 22nd September 2011
12:00 noon

NHS Yorkshire and the Humber
(Headquarters)
Blenheim House
West One, Duncombe Street
Leeds
LS1 4PL

Dear Ms Claire,

Re Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) 22 September 2011

The Yorkshire and Humber Regional Joint HOSC meeting this morning was convened around your availability to attend as the Yorkshire representative of the JCPCT. The Committee was advised at the start of its meeting that Andy Buck was attending in your place. With every respect to Mr Buck he is not a representative of the JCPCT, he has made it clear to our Committee this morning that he has not been briefed by you on this matter and that he has not attended previous JCPCT meetings. He has no official capacity to represent the JCPCT today.

Mr Buck has offered to listen to what we have to say and to take away any questions he cannot answer and ensure that we will be given those answers in writing. At the eleventh hour in the process this is simply not acceptable.

We have repeatedly asked for a JCPCT member to attend our meetings. We first asked for the availability of a JCPCT member to attend our meeting five months ago. We were finally advised that you would be available to attend a meeting this morning at one week's notice.

Cont./

Appendix 4:
Letters to the JCPCT and review team

We were not given any apology for your failure to attend today and were not given any prior warning that you would not be attending.

The committee demand your attendance on behalf of the JCPCT as agreed today. We require you to attend before 2:00pm today. I need not remind you that the NHS has a statutory duty to comply with the Committee's request for attendance.

We intend to make our views clear about this latest incident and the contempt with which the Joint HOSC for this region and the democratically elected representatives of 5.5 million people have been treated by the JCPCT. This has further undermined our confidence in the process of the Safe and Sustainable Review.

Yours sincerely

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

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Appendix 5:
Council motions across Yorkshire and the Humber

City of York Council – 7 April 2011

'There are 11 children's heart surgery units in England, but the NHS is proposing under its 'Safe and Sustainable' review to reduce this to 6 or 7 specialist hubs undertaking 400 operations per year; and,

The choice facing the NHS review team will be to retain either the Children's Heart Surgery Unit at Leeds General Infirmary or the unit at Newcastle to serve the north; and,

Leeds serves a major population catchments area of 14 million people in Yorkshire and the Humber, Lincolnshire and North Derbyshire, has the capacity to expand and has centralised the whole of its children's services operations on one site; and,

Leeds General Infirmary is at the forefront of work on inherited cardiac conditions and is much valued for providing safe, high quality children's heart surgery;

Council asks Members to join with local MPs and community groups to express all-party support for keeping open the Children's Heart Unit at Leeds General Infirmary and asks the Chief Executive to write to the Department of Health to ask for the retention of the Leeds Children's Heart Unit as the centre best placed to serve as the specialist hub for the needs of young cardiac patients in Yorkshire and the north of England.'

Response attached at Appendix 7.

East Riding of Yorkshire – 27 July 2011

'That this Council supports the retention of the Children's Cardiac Surgery Services at Leeds as the unit serves a region of population of almost 14 million people and Leeds General Infirmary is ideally placed to deliver services as it does now, to people living throughout Yorkshire and the Humber, Lincolnshire and the North Midlands.'

Harrogate Borough Council – 13 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in the NHS proposals for the national reconfiguration of Children's cardiac Surgery.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds.'

Letter and response attached at Appendix 7.

Appendix 5:
Council motions across Yorkshire and the Humber

Kirklees Council – 23 March 2011

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to predetermine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services
from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

Report back to Council (including letter and response) attached at Appendix 7.

Leeds City Council – 6 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect.

Letter and response attached at Appendix 7.

Appendix 5:
Council motions across Yorkshire and the Humber

Leeds City Council – 14 September 2011

'That this Council notes with concern the ongoing discussions regarding the proposed reconfiguration of children's cardiac surgery services and the devastating effect this could have on the Yorkshire Heart Centre at Leeds General Infirmary and the families of this region.

The Council supports the demands of the cross party Joint Health Overview and Scrutiny Committee for Yorkshire and Humber for the Government to re-examine the way in which the decision is being made and ensure that the democratic process is not being ignored.

Council therefore urges the government to confirm that all available information will be examined before a decision is made which could force parents from Yorkshire to travel hundreds of miles should their children need cardiac treatment.'

Rotherham Metropolitan Borough Council – 27 July 2011

'This Council recognises the expertise in Children's Cardiac Services which has been built up by the Leeds Teaching Hospitals NHS Trust (LTHT) based at Leeds General Infirmary (LGI). LTHT also supports outreach clinics at Rotherham Foundation Trust (RFT) which are used by approximately 300 children each year:

The Council wishes to register its opposition and serious concerns at the potential loss of the Children's Cardiac Unit in Leeds which would have a devastating impact on those children requiring the specialist services provided by the facility.

The Council resolves to work with all relevant stakeholders to campaign to retain specialist children's cardiac surgery in the region and to inform the Secretary of State for Health of our views.'

Sheffield City Council – 6 July 2011

That this Council

- *(a) notes the NHS Safe and Sustainable Review into the way that children's congenital heart surgery services should be provided in the future*
- *(b) is concerned by the likely closure of the surgical centre at Leeds General Infirmary (LGI) as the only such unit in the Yorkshire and Humber region*
- *(c) is also concerned by the implications of this likely closure for critically ill children and their families in Sheffield who use this service*
- *(d) resolves to continue to raise the profile of this issue locally to make the people of Sheffield aware of the knock-on effect of this closure*
- *(e) fully supports maintaining the paediatric cardiac surgery unit at the LGI for the continued benefit of sick children and their families in Sheffield*

Appendix 5:
Council motions across Yorkshire and the Humber

Wakefield Metropolitan District Council 30 March 2011

Letter attached (dated 15 April 2011). We were advised that no response had been received.

Appendix 6:
Local authority information

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

FEEDBACK FROM PUBLIC CONSULTATION IN KIRKLEES

Background

Kirklees Council arranged two drop-in sessions for members of the public in May 2011 – one was held in Huddersfield and one held in Dewsbury. These sessions were publicised in the local press, on Kirklees Scrutiny's Twitter account, and on Kirklees Scrutiny's Facebook page. Eight people attended and shared their stories – all expressed concern about the potential loss of the unit in Leeds.

Two letters were also received.

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, also held a meeting with Dr Sara Matley from the Children's Heart Surgery Fund on 20 June 2011.

Key Themes

A number of key themes and messages emerged from the discussions, and these are set out below:

- **Pre-Natal Scans**

  Concern was expressed that congenital cardiac conditions were not always picked up during pre-natal scans. Several of those who attended had been aware of other serious health issues, for example, gastrological, and had therefore given birth at Leeds General Infirmary as they have units for other paediatric specialisms. Cardiac surgery was often then needed very quickly on a seriously ill baby.

- **Co-location of Services**

  The centralisation of children's hospital services at Leeds General Infirmary ensures that a wide range of paediatric services are co-located on the same site. A child can therefore have access to various specialists simultaneously and not need to be moved between sites. Concern was expressed that this would not be available at Liverpool or Newcastle.

  There was also concern that maternity services in both Liverpool and Newcastle are on different hospital sites from the children's heart unit, which could see mother and baby separated shortly after birth. In Leeds, both services are co-located on the same hospital site.

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- **Number of Procedures**

  Concern was expressed that the projected number of procedures that would be carried out by a unit in Leeds did not take into consideration that population growth in the Yorkshire and Humber region is exceeding the national average.

  There was also concern that adult procedures had not been accounted for. There are an increasing number of people with congenital heart conditions surviving into adulthood and they are also operated on by the same surgeons, as they are specialists in congenital heart problems.

- **Travel Distance**

  Concern was expressed that the additional travelling time for Kirklees' residents to Liverpool or Newcastle could have significant adverse consequences. There was concern about rush hour traffic on the M62, M1 and A1 and the impact this would have on travel times. Concern was also expressed about the assumption of which postcode areas would attend which of the alternative hospitals and that a situation could arise where Liverpool was overwhelmed and Newcastle was unable to meet the minimum number of procedures.

- **Ambulance Service**

  Concern was expressed about the ability of Yorkshire Ambulance Service, and Embrace, to manage an increased number of neonatal, perinatal and paediatric transfers of critically ill children. Concern was expressed that the air ambulance did not fly in the dark and that it could also be grounded when foggy.

- **Impact on Paediatric Intensive Care Beds**

  In Yorkshire and Humber, Leeds and Sheffield provide the regional paediatric intensive care units and paediatric cardiac intensive care units. Dr Matley advised that the beds within the units are used flexibly and therefore the loss of 8 paediatric cardiac intensive care beds would impact across the region.

- **Staffing**

  Concern was expressed that there was an assumption consultants from the Leeds unit would take up positions at Newcastle or Liverpool if Leeds were to close. Newcastle currently has 2 consultants and Leeds has 3 and are looking to recruit a fourth. There was concern that consultants may not wish to relocate to Newcastle and that if a unit was located there and Leeds closed, there may be a period of time when there were insufficient surgeons available across the north of England.

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- **Affordability**

  A number of parents were concerned about the costs they would incur if procedures were carried out at Liverpool or Newcastle. Expenses such as: travel, accommodation, and food were raised. It was recognised that the Children's Heart Surgery Fund in Leeds give assistance to families by providing nearby accommodation, helping with expenses, and providing kitchen facilities so parents can prepare their own food rather than incurring the expense of eating out. It was not known if similar facilities were available in Liverpool or Newcastle. There was particular concern about parents on low incomes.

- **Family Life**

  Many of those attending spoke about the impact on their family life of supporting a critically ill child through serious surgery. Several mentioned their other children and their needs, and the conflict they had faced in supporting the child in hospital but also being a parent to other children. Children were often kept in hospital for several weeks following surgery, and parents needed to be able to shuttle back and forward. Parents were often very reliant on assistance from their wider families and friends, which they felt would not be as easy if further distances had to be travelled.

- **Engagement Events**

  Those attending had been unhappy with the quality of engagement events at the Armouries, and did not feel that the correct people were presenting the information. They were also dissatisfied that there appeared to be a 'done deal'.

  It was commented that those in attendance were predominantly white, middle class, and articulate people. A suggestion was made that engagement with mosques, for example, could have helped to reach a wider number of people.

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Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

INFORMATION PROVIDED BY KIRKLEES COUNCIL S DIRECTOR OF PUBLIC HEALTH

Background

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, sought clarification from Dr Judith Hooper, Director of Public Health for Kirklees Council, on the likely impact on infant mortality in Kirklees, if children's cardiac provision was to be moved further away.

The following comments were received:

- The infant mortality rate is unlikely to be affected if children's heart surgical services are further away. Evidence suggests that pooling surgical expertise into fewer larger centres ensures they perform the necessary number of procedures a year to maintain and develop their expertise. This results in better outcomes.

- The child does not need to reach a surgical centre in the shortest possible time but the specialist intensive care retrieval teams should get to these children, and stabilise them correctly so that surgery can then be carried out in the best possible circumstances. A letter by Dr Ian Jenkins (the immediate past president of the Paediatric intensive Care Society) describes this http://www.specialisedservices.nhs.uk/news/view/32

- The distance from home and travel to centres further away could have an impact on the parents and siblings. Newcastle is one of the sites proposed as a centre. Yorkshire & Humber has double the child population of the North East region, and is growing much faster. Within this, the BME population is growing fastest. The Pakistani population has more congenital abnormalities and cardiac abnormalities form a significant proportion of these. (In Kirklees almost a quarter of the infant deaths due to congenital abnormalities (2006-8) had cardiac abnormalities observed at time of birth. In addition a small proportion who died of other causes had cardiac abnormalities observed at time of birth and there may also be those cardiac problems picked up some time after birth). The Pakistani population has large families and is more deprived, so a disproportionately high burden is placed on these families by imposing additional travel. However the number of major heart operations needed by a child should be small and much of the rest of the care can be delivered nearer home by networks built around the specialist centre.

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Some children with congenital heart disease will have other complex service and care needs. There may be issues around cardiac surgery being at a separate centre from where other care needed by the child is provided e.g. in Liverpool cardiac would be at Alder Hey and maternity at Liverpool Women's. Newcastle services are actually spread over 3 sites, whilst Leeds is on a single site. The importance of such co-location is not easy to quantify. More information may be available in the impact assessment.

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Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Cardiac Services

Kirklees Joint Strategic Needs Assessment 2010 Information on Vulnerable Groups identified by Health Impact Assessment: Interim Report

In the Health Impact Assessment: Interim Report, published August 2011, information was outlined on the population groups that will be disproportionately affected by reconfiguration proposals due to their higher susceptibility of experiencing congenital heart disease and, therefore, needing children's heart surgery services.

The population groups identified included:

- 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;
- Mothers who are obese during pregnancy.

The Joint Strategic Needs Assessment for Kirklees 2010, published July 2011, provides the following data relevant to these population groups:

Socio-economic deprivation

The Index of Deprivation 2007 identified Kirklees 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. 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.

Asian ethnic groups

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.

Smoking during pregnancy

19% of white women smoke during pregnancy – with variations from 33% in Dewsbury to 7% in Denby Dale & Kirkburton (17% national average). No south Asian women said they smoked during pregnancy and this led to a figure of 10% of all women who smoked during pregnancy.

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.

Obesity during pregnancy

48% of mothers were at least overweight, especially Pakistani origin mothers (60%). Obesity was worse in north Kirklees with 23% of mothers obese

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Local authority information

Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee
- Children s Congenital Cardiac Services

Assumptions have been made by the Safe and Sustainable Team on the patient flows that would arise from each of the proposed configurations of surgical centres. In the event of Options A, B or C being agreed, it is anticipated that the postcode flows within the Kirklees boundary would be as follows: BD to Liverpool; HD to Liverpool; and WF to Newcastle.

Analysis of each of the postcode areas has been undertaken, and it is acknowledged that for patients with an HD or BD postcode, Liverpool would be the natural destination if Option D was not selected. However, the analysis shows that for patients with a WF postcode, Newcastle would not be the natural destination, with travel times nearly double that of Liverpool. This would therefore affect the assumed numbers of patients that would attend each hospital.

	By Car (source: google maps)			**By Public Transport (source: transportdirect.info)**		
	To Leeds General Infirmary	**To Newcastle Freeman Hospital**	**To Alder Hey Children s Hospital**	**To Leeds General Infirmary**	**To Newcastle Freeman Hospital**	**To Alder Hey Children s Hospital**
HD1 Central Huddersfield	31 mins	2 hrs 21 mins	1 hr 6 mins	41 mins	3 hrs 32 mins	2 hrs 6 mins
HD9 Rural Huddersfield (Holmfirth)	44 mins	2 hrs 33 mins	1 hr 19 mins	1 hr 25 mins	4 hrs 5 mins	2 hrs 46 mins
WF12 Dewsbury	25 mins	2 hrs 8 mins	1 hr 15 mins	34 mins	4 hrs 9 mins	2 hrs 18 mins
WF17 Batley	21 mins	2 hrs 8 mins	1 hr 18 mins	40 mins	4 hrs 10 mins	2 hrs 31 mins
BD11 Birkenshaw	18 mins	2 hrs 10 mins	1 hr 10 mins	37 mins	2 hrs 46 mins	3 hrs 4 mins
BD19 Cleckheaton	19 mins	2 hrs 9 mins	1 hr 8 mins	46 mins	3 hrs 5 mins	2 hrs 55 mins

Appendix 6:
Local authority information

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

VISIT TO LEEDS CHILDREN S HEART SURGERY UNIT, LEEDS GENERAL INFIRMARY

On 22 August 2011, Cllr Smaje (Kirklees representative on the Joint HOSC) visited the Children's Heart Surgery Unit at Leeds General Infirmary. Cllr Mulherin from Leeds Council was also present on the visit. Stacey Hunter, Divisional General Manager for Children's Services, and Karl Milner, Executive Director – External Relations, accompanied the visit.

During the visit, Cllr Smaje and Cllr Mulherin spoke with staff in the Children's Heart Surgery Unit, and they raised a number of issues:

- Travelling time to Newcastle or Liverpool if the Leeds unit were to close.
- Continuity of care – many patients had been attending the unit since they were small babies.
- Siblings at home – parents facing difficult situations if siblings were at school.
- Travel costs – many patients seek assistance with travel expenses already.
- Co-location with other services.

Cllr Smaje and Cllr Mulherin also spoke with the grandmother of a young patient on the Children's Heart Unit. She explained that she travelled by public transport 3 or 4 times a week to Leeds General Infirmary to help provide her daughter with a short break. She had been undertaking this journey for the last 7 weeks. She was concerned that this would not be possible if she had to travel to Liverpool or Newcastle.

Concerns raised by Leeds Teaching Hospitals Trust during the visit:

- The decision not to include the number of adult procedures and cardiac interventions within the figures. Intervention cardiology is a growing area and around 550 paediatric interventions are undertaken a year – 200 pacemaker/defibrillator; 200 structural; 150 a combination of the two. The Trust advised that the cardiologists undertaking intervention procedures had stated that they would not undertake them without a cardiac surgeon on standby, as this would not be safe.

- The lack of an evidence base for the 400 procedures figure – it is argued that some surgeons will not undertake as many procedures due to the complexity of the surgery they undertake, however they will still be undertaking a sufficient number to sustain competency. There is no evidence linking the number of procedures to clinical outcomes.

Appendix 6:
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- 17 outreach clinics are run by Leeds, which are attended by sonographers. Around half of these are surgical clinics, which would not continue if Leeds was to close. Leeds did not believe that surgeons would be able to run outreach clinics from Newcastle or Liverpool into the Yorkshire & Humber region, as they would need to be in theatre or on site, and not considerable distances from the hospital.

- Concern was expressed about the separation of obstetrics and cardiology. The Trust have undertaken work in hospitals around the region to ensure that scans can be undertaken in more local settings so that patients do not have to always travel to Leeds.

- The impact on other services, for example, the kidney service. This is hard to quantify, but cannot be ignored.

- The number of paediatric intensive care cots would be reduced by approximately 6-8, as the funding will not be available.

- Leeds is the biggest teaching hospital in the country but would be unable to train in this speciality.

- Concern was expressed about recruitment of high quality staff. It was felt that the most experienced cardiac consultants and cardiac anaesthetists would be drawn to the hospitals where surgery was being performed.

- Concern was expressed that many patients did not just have to attend the hospital once for the procedure, but attended regular appointments. It was estimated that the majority of patients who are maintaining their condition will attend the hospital once every 3 months; a smaller number whose condition was stable would attend the hospital once every 6 months for a check-up. Following a procedure, monthly check ups would be put in place. Liaison nurses are in regular contact with patients, by phone calls where necessary.

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NORTH LINCOLNSHIRE COUNCIL PEOPLE SCRUTINY PANEL

Response to the Consultation on "Safe and Sustainable: A New Vision for Children's Congenital Heart Services in England".

1. INTRODUCTION

1.1 As democratically elected members and statutory co-optees, North Lincolnshire Council's People Scrutiny Panel welcomes the opportunity to comment on this consultation in our role as representatives of the community.

2. THE PANEL S RESPONSE

2.1 The People Scrutiny Panel agrees with the general principle of reducing the number of specialist surgical units in England. We believe that there is clear clinical evidence that health outcomes will improve as units are staffed by a minimum of 4 consultant cardiac surgeons and the number of procedures rises to the 500 per year benchmark. This will also enable 24/7/365 cover and a full consultant-led clinical response to any emergency.

2.2 The panel has fully considered each of the options and considers that Option D provides the most appropriate model, both for the residents of North Lincolnshire, the wider region and the whole of England and Wales. This is based on a number of considerations that are set out below.

3 DEMOGRAPHICS AND GEOGRAPHY

3.1 Clearly, Leeds is a geographically central city, with excellent transportation links via the M1, A1 and M62 for a vast area of the North of England. Yorkshire and the Humber has a population more than twice as large as the North East (5.5m compared to 2.6m) and Leeds is accessible to a population of 13.8m within a 2-hour drive (2.8m in the North-East).

3.2 There is also a relatively large Asian population across the region; proportionally, these communities are likely to have a greater demand for these services than the wider population. The consultation document (page 204) acknowledges that "projected birth rates may be higher for some ethnic community groups." This is in the context of a projected birth rate in the Yorkshire and Humber region that is double the national average to 2015.

3.3 The Emerging Findings from the Health Impact Assessment also acknowledges that mothers who are obese or who smoke throughout pregnancy are also at increased risk of their children requiring access to cardiac surgery. These are particularly challenging issues within North Lincolnshire, with smoking in pregnancy and obesity in the worst-performing quartile in the country.

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4. CLINICAL OUTCOMES, CLINICAL NETWORKS AND MATERNITY

4.1 Like others, the panel has concerns around the specific scoring and weighting system used by Sir Ian Kennedy and his team. Whilst we would agree that the quality of clinical outcomes is the most important consideration, the methodology used by the team has not been released, despite numerous requests. Despite this, (excluding John Radcliffe Hospital) the review acknowledges that "all options got between 95% and 100% of the maximum score" and the review recommended that all options should be "awarded equal score against the quality criteria on the basis that the assessment panel scored individual centres against the standards and did not produce comparative scores".

4.2 The existing Clinical Network in the Yorkshire and Humber area is, rightly, held in very high regard nationally. The scrutiny panel has significant concerns regarding the viability and effectiveness of non-surgical lifelong support delivered from Leeds for patients and their families in the region, if an option other than D was agreed on. Consultants would naturally gravitate to the specialist centres in Liverpool, Newcastle and/or Leicester. This would either lead to lengthy travelling times for consultants providing outreach or clinics in this area (thus reducing the number of procedures undertaken), an increased need for ill babies and children to travel long distances, or a damaging reduction in local services.

4.3 Finally, a pregnant woman from North Lincolnshire with a foetus with serious cardiac problems could potentially have to deliver in Newcastle, Liverpool, Leicester, before being transferred to the local Cardiac Centre. Clearly, this would be an unhelpful and stressful pathway. Similarly, the loss of a surgical unit at Leeds would require lengthy travelling for many children in need of the existing cardiac catheter intervention service in Leeds. Indeed, families would potentially have to drive past Leeds to travel on to Liverpool or Newcastle.

5. TRAVEL AND ACCESS

5.1 As alluded to in 3.1, a key consideration should be to ask the fewest possible number of patients to travel the least possible distance. The local catchment area is far larger and contains far more people than the other options set out.

5.2 We acknowledge that, if Option D is chosen, other people from outside the area would have to travel. However, the numbers would be fewer, and we have particular concerns about the impact that the requirement to travel for a disproportionate number of families, possibly with more than one child, will have. The panel would also ask why no consideration has been given to liaising with the Scottish Government and colleagues North of the border to allow patients from the North of England to access the specialist centre at Yorkhill in Glasgow.

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6. CO-LOCATION OF FACILITIES

6.1 Leeds is one of only two sites in the country to have co-location of all key specialisms on one site, including maternity (see 4.3) and intensive care (PICU). If an option other than D goes ahead, patients and families from North Lincolnshire would potentially see a more fragmented service than they have done previously. Referral and follow-up arrangements for many procedures are not yet formulated so cannot be supported.

7. THE LANSLEY TESTS

7.1 In May 2010, the Secretary of State set out four key tests that would be central to any proposal in the Health Service going ahead. In response to these, we are assured that the proposals are focussed on improving patient outcomes and are based on sound clinical evidence. As this is not a service commissioned by GPs, the second test is largely irrelevant. The third test states that a proposal must genuinely promote choice for patients. In many ways, this is contrary to the aims of improving clinical outcomes through centralisation, so the test must consider how proportionate the impact is likely to be to local populations. In that context, we cannot say that this test has been met, as any option other than D would have a *disproportionate* effect on local people, because of the larger population base and demographics of this area, as described in Paragraph 3. We find it worrying that a full Health Impact Assessment is yet to be completed, despite the public consultation having ended. As such, we have some concerns around the fullness of the consultation carried out (test 4). Whilst the panel is aware of the numerous events undertaken by the review team, including feeding into the joint regional scrutiny committee, many families remain outside of the consultation process.

8. CONCLUSION

8.1 To conclude, after a full consideration of the evidence, the scrutiny panel recommends that Option D is adopted and implemented. This is based on clinical outcomes and the future viability of follow-up, outreach and support arrangements, demographic considerations, co-locality, and the potentially disproportionate effect on children and their families from North Lincolnshire and the wider region.

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North Yorkshire County Council
Chief Executive's Group

County Councillor Jim Clark
(Harrogate Harlow Division) 74 Green Lane
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North Yorkshire
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16 June 2011

Cathy Edwards
Director - Yorkshire & the Humber Specialised Commissioning Group
Hillder House
Gawber Road
BARNSLEY S75 2PY

Dear Cathy

Children s Congenital Heart Services

At the meeting of the North Yorkshire Scrutiny of Health Committee on 8 April 2011 we considered the consultation document on the proposed changes to Children's Congenital Heart Services. In view of what we feel are the special circumstances facing North Yorkshire in looking towards both Leeds and Newcastle as regional centres for this service we supported Option D but with the inclusion of Newcastle – in effect an "Option E".

On the basis of the information available to the Committee and using Option D as the starting point, patient flows under a new Option E would be:

	Option D	**Option E**
London	1,482	1,482
Birmingham	660	660
Bristol	420	420
Leeds	636	380 *
Liverpool	400	389 **
Newcastle		267 ***

* 636 - Carlisle (27) - Durham (26) - Darlington (31) - Newcastle Upon Tyne (97) - Sunderland (22) - Berwick on Tweed (2) - Middlesbrough (51).
** 400 - Lancaster (11).
*** Carlisle (27) + Durham (26) + Darlington (31) + Newcastle Upon Tyne (97) + Sunderland (22) + Berwick on Tweed (2) + Middlesbrough (51) + Lancaster (11).

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In reaching this view we were mindful of the need for consultants to build up specialist expertise and that putting in place a critical mass in a fewer number of locations will lead nationally to a service which is sustainable in the long term. But we feel these factors must be tempered by the need to take into account geographical considerations and the risks to children being transported large distances. For instance, if Leeds were to close, a child born with a congenital heart defect in Hull faces a journey of 144 miles to the Freeman Hospital in Newcastle, a child from Wakefield faces a journey of 111 miles and a child from Leeds faces a journey of 99 miles. These are also huge distances for the relatives and guardians wanting to visit children.

In terms of building viable units at both Newcastle and Leeds we feel there are a number of other factors that could be explored.

Firstly with regard to Newcastle if the possibility of directing some patients to Newcastle from the Scottish borders is explored and if the fact that Newcastle provides children's heart transplant surgery is fully taken into account, we feel there could sufficient case in favour of that unit being retained. With regard to Leeds we feel it is essential that its regional population is taken into account. For instance, between 2011 and 2033 the number of children up to 9 years of age in the region is planned to increase from 623,500 to 696,100 - an increase of 11.6%. This would bridge the shortfall. We also feel the centre's accessibility, its co-location of children's and adult cardiac surgery on one site and the strength of the clinical network that has been established for paediatric congenital heart disease must be given sufficient weighting so the service is not lost.

Secondly we feel there is still a debate taking place across the NHS about whether or not the 400 threshold figure is actually a robust figure and also whether or not the scoring methodology underpinning the options sufficiently takes into account all relevant factors. Unfortunately because the consultation with overview and scrutiny committees is only taking place at a regional level we have not had the opportunity to examine these issues in detail.

Against this background we feel there are sufficient uncertainties to suggest that in actual fact that case for retaining all 3 centres in the North is more finely balanced than first appears. We strongly urge, therefore, that before any final decision is made on this matter the scoring methodology, the threshold figure of 400 and the inherent risks in transporting seriously ill children across large distances are reviewed to ensure all relevant factors and options for the service are fully explored. We need to be reassured.

On behalf North Yorkshire Scrutiny of Health Committee I would be grateful if you would take these points into consideration when reaching your final decision. As a member of the Yorkshire and Humber Joint Committee I hope to have an opportunity to discuss these issues in more detail at its next meeting.

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Finally for ease of reference for the recipients of this letter the actual consultation document on the review of Children's Congenital Heart Services can be accessed via the link below:

http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours sincerely

County Councillor Jim Clark

Chair: North Yorkshire County Council Scrutiny of Health Committee
Copy to: See attached circulation list
Circulation List:
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County Councillor John Weighell, Leader - North Yorkshire County Council
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The Rt Hon William Hague MP
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Robert Goodwill MP
Nigel Adams MP
Julian Smith MP
Julian Sturdy MP
All Chief Executives of Borough/District Councils in North Yorkshire
Sue Cornick, Associate Director - North East Specialised Commissioning Team
Chair of Yorkshire & Humber Joint Committee (C/o: Steven Courtney, Principal Scrutiny Advisor, Leeds City Council)
Chair of the North East Joint Committee (C/o: Peter Mennear, Scrutiny Officer, Stockton Borough Council)
Jayne Brown, Chief Executive – NHS North Yorkshire and York

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ROTHERHAM BOROUGH COUNCIL – REPORT

Meeting:	**Children and Young People's Scrutiny Panel**
Date:	**14 July 2011**
Title:	**Update: specialist children's heart surgery; consultation**
Directorate:	**Chief Executive's All wards**

Summary

Safe and Sustainable – the NHS review into the future of children's congenital heart services in England proposed to change the current service model. Health Overview and Scrutiny Committees are being consulted as part of the statutory consultation process. This report updates members of the Health Select Commission of developments.

Recommendations

That the Health Select Commission:

a. agrees that the nominated members from the former Children and Young People's Scrutiny Panel continue in their role for the duration of this review;

b. comments on the report and refers any concerns/issues regarding the review of children's cardiac services to the Rotherham Council representative on the Regional Health Overview and Scrutiny Committee;

c. notes the Cabinet response to the consultation;

d. receives further updates of progress.

Proposals and Details

The proposals set out in Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England consultation document, are the outcome of a national review process. The four month public consultation period closed on July 1st 2011.

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In summary, it is proposed that the reconfigured 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. However, in doing this there will be 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.

Safe and Sustainable consulted on the following areas:

- Standards of care: proposed national quality standards of care to be applied consistently across the country
- Congenital heart networks: development of networks to coordinate care and ensure more local provision (e.g. assessment, ongoing care)
- The options: the number and location of hospitals that provide children heart surgical services in the future
- Better Monitoring: improvements for analysis and reporting of mortality and morbidity data

The options for the number and location of hospitals that provide children's heart surgical services in the future are:

Option A: Seven surgical centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[5]	**Option B: Seven surgical centres at:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[1]
Option C: Six surgical centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option D: Six surgical centres at:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]

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

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Currently Rotherham children with serious congenital heart problems are referred to Leeds Teaching Hospital Trust for treatment, based at Leeds General Infirmary. LTHT also supports outreach clinics at Rotherham Foundation Trust (RFT). Colleagues from RFT estimate that approximately 300 children use the clinic in Rotherham per year.

Leeds only features in 1 of the four options for service configuration. If closed, it is proposed that Rotherham children and families will receive services from one of the following: Newcastle, Birmingham or Leicester. Alternative proposals for configuration of services can be put forward.

Health Overview and Scrutiny Committee Involvement

Health Overview and Scrutiny Committees[6] are being consulted as part of the statutory consultation process and because it affects more than one Local Authority area, this is being coordinated in Yorkshire and Humber through a Joint Committee (chaired by a Member from Leeds City Council). There has been two meetings of the Joint Committee to date (minutes and papers are available on-line). Further meetings are planned with various representatives from health bodies and patients parents groups from across the region to gather evidence to inform the Committee s formal response to the consultation. Information is also being sought by the Committee in respect of patient flow and a health impact assessment of the proposals on the region s population. This information is expected shortly.

It should be noted that the period for Joint Health Overview and Scrutiny Committees to respond to the consultation has been extended to October 5, 2011.

The former Children and Young People's Scrutiny Panel (in its health scrutiny role) nominated one member from Rotherham Council (Cllr Shaukat Ali) to be part of this joint committee. The Children and Young People's Scrutiny Panel also formed a small member working group consisting of Cllrs Ali, Falvey and Sims to inform Rotherham s input to the process.

All Council Members have been previously contacted by email for their views on the proposals. These have been used to inform questions to witnesses and lines of inquiry. It is suggested that any further comments concerns from the Health Select Commission are referred to the member working group for Cllr Ali to raise with the regional committee. Further updates of progress will be submitted to this committee in due course.

[6] Under Rotherham's previous overview and scrutiny arrangements, health scrutiny responsibilities were delegated to the former Children and Young People's Scrutiny Panel if they relate to children's health matters

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As the members of the working group are familiar with the issues and have undertaken considerable work meeting with parents, MPs and local clinicians, it is proposed to continue with these arrangements for the duration of the review.

Local Discussions

Given the complexity and sensitivity of the issue, the working group held an initial meeting with colleagues from Rotherham Foundation Trust and NHS Rotherham to discuss how the proposals may impact upon local services.

In particular, concerns have been raised about the following:–

- access to facilities for Rotherham children and families, particularly in emergency or acute situations;
- sustainability of local clinics;
- retention and future development of specialist skills;
- sustainability of intensive care facility at Leeds Teaching Hospital Trust should it no longer be a specialist facility.

A further meeting was held with local parents of children with congenital heart diseases who have accessed services in Leeds. Whilst many of the concerns reflected the views of clinicians, further questions were asked about:

- lengthy 'blue light' journeys across busy road networks;
- support networks for children and their carers and increased disruption and costs, particularly for families on low incomes, if services are re-located;
- collocation of services and whether sufficient emphasis had been placed on the benefits of this in the review;
- transition to adult services.

The working group also met with local MPs to inform them of the health scrutiny process and share information. In addition, the views of Youth Cabinet were sought. Their concerns mirrored many of the issues previously raised.

Considerable media interest has been generated both locally and nationally. The local press has been contacted by Cllr Ali to seek the public's views on the proposals. In addition, a regional charity, the Children's Heart Surgery Fund has held a number of meetings throughout the Yorkshire and Humber region, including Rotherham.

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Discussions have also taken place with other South Yorkshire Health Scrutiny support to ascertain any joint areas of concern to feed into the regional consultation.

Cabinet Response

The Cabinet has responded separately to the consultation, opposing the closure of Leeds as a surgical centre. The response is attached as Appendix A

Finance

There are no financial implications directly related to this report.

Background Papers and Consultation

Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England: Consultation Document
http://www.specialisedservices.nhs.uk/document/safe-sustainable-a-new-vision-children-s-congenital-heart-services-in-england-consultation-document
Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
14th March, 2011: http://democracy.leeds.gov.uk/ieListDocuments.aspx?MId=5146&x=1
29th March, 2011:
http://democracy.leeds.gov.uk/ieListDocuments.aspx?CId=793&MId=5149&Ver=4

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ROTHERHAM BOROUGH COUNCIL – CONSULTATION RESPONSE

Thank you for the opportunity to respond to the "Safe and Sustainable Review of Children's Cardiac Services".

1. **In making a response, we fully endorse the principles outlined in the consultation.**

   - Children - The need of the child comes first in all considerations
   - Quality
   - Equity
   - Personal service
   - Close to families' homes where possible

We have specific comments in respect of proximity to families' home (outlined under the headings of blue light transfers; support networks and financial considerations)

2. **Do you agree or disagree with the statement that 'Without change there is a risk that in the future some children's congenital cardiac services may become neither safe nor sustainable'?**

We would support the above statement. However, we would urge the retention of Leeds Teaching Hospital Trust as a surgical centre as we believe that it meets the above conditions and has the capacity to improve its service.

3. **To what extent do you support or oppose the national standards within each of these seven key themes?**

We would support the seven key themes

4. **To what extent do you support or oppose the proposal to increase the role of paediatricians with expertise in cardiology in District Children's Cardiology Services across England?**

see 6

5. **To what extent do you support or oppose the proposal that current surgical units that are not designated for surgery in the future become Children's Cardiology Centres?**

We would support this aim. However, should Leeds not be chosen as an option, we have concerns whether the proposed Cardiology Centre would be sustainable in the long term, particularly in respect of retaining and developing specialist staff to support this service.

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6. To what extent do you support or oppose the proposal to develop Congenital Heart Networks across England?

We are pleased that the review calls for the strengthening of local heart networks and includes proposals to increase the roles of paediatricians locally. We already have a foundation for this work. Indeed, both parents and local clinicians value the access to regular clinics run locally by Leeds Cardiology staff, including transition nurses, in conjunction with the Rotherham based paediatric team. We are aware that Rotherham clinicians have developed greater degrees of specialism as a result of their collaboration with the Leeds centre, leading to better services for some of the most vulnerable children and young people in Rotherham.

We believe that this is a blue-print that should be rolled out elsewhere. We are not persuaded that this excellent service would be replicated to the same standard should Leeds not be the chosen option.

7. To what extent do you support or oppose:

- The need for 24/7 care in each of the Specialist Surgical Centres?
- The proposal that, in the future, interventional cardiology should be provided only by designated Specialist Surgical Centres

We would support the above aims.

Additional Comments

However, in responding we would also like to make some specific observations that we do not believe have been addressed in the Safe and Sustainable review.

Population

Services should be located in proximity to the population. Currently, Leeds has almost 14 million people within a two hour drive of its hospital. Newcastle has far fewer, with less than three million. Whilst population density appears to be a qualifying factor for hospitals in Liverpool and Birmingham; this standard does not appear to have been applied to the selection of Leeds as an option.

Blue-light transfer

Because of the proximity of the motorway and public transports network, the journey to Leeds is relatively simple for patients in Rotherham. Should services relocate to Newcastle or other centres, babies and children in our area would have much greater transfer times to travel. This would not only be the case for specialist heart procedures but also for related procedures in order to ensure heart specialists are on hand in case of a medical emergency. In addition, Newcastle is not well served by a motorway network.

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Feedback from local parents all stress that transfers time are critical; having experienced the emergency transport of their children to Leeds for life-saving treatment they have articulated their concerns about whether longer blue light journeys to the other proposed centres would lead to the same positive outcomes. We share their concerns that a blue light journey of three hours plus on a busy road network is neither safe nor sustainable.

Local parents have expressed existing concerns about blue light services and the availability of specialist equipment to support very sick children being transferred. With journey times being lengthened, both parents and specialist staff based at our local hospital believe that patient safety will be compromised. Parents were not reassured at recent consultation events that sufficient consideration has been given to these issues. Given the potential of longer journey times, we share the view that safe transfer cannot be assured under these circumstance.

Co-location

We do not believe that sufficient consideration has been given in the scoring to the co-location of services in Leeds. We are aware that local parents attending Leeds consider co-location to be a positive factor in their child's care and as such its provision is a great reassurance to them. Local clinicians also cite the significance of co-location; be it in terms of better access to specialisms; minimising disruption and blue-light transfers; continuity of care and smooth transition to adult services; and minimising disruption and stress of parents and carers. We are aware that some of the other options do not have these benefits.

We are aware that local parents attach great value to the services in Leeds; not only in terms of medical care and expertise but also to the support it gives to children and carers in very difficult circumstances. This applied across the team from surgical staff, cardiac nurses or access to counselling services. Basic accommodation is available on site in Leeds, allowing parents to be close to their child whilst undergoing surgery. It is important that such facilities remain available to support parents or carers.

Transition

With the increasing numbers of children with congenital heart defects surviving into adulthood, it is critical that adult services are also safe and sustainable. Given the services are inter-linked, with often the same surgeons performing both adult and paediatric interventions, if Leeds were to close as a surgical centre would the adult service be viable? We do not believe that this issue has been given consideration.

Intensive Care

We are concerned that the closure of Leeds would lead to significant reductions in children's intensive care capacity. This will mean that some children needing intensive care may have to receive care outside of our region or put additional pressure on intensive care beds provided at the other specialist children's hospital locally.

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Support Networks

The impact on families, including other siblings, should not be underestimated. Local parents and clinicians spoke of the practical support given to parents or carers by their own families whilst their child was awaiting or undergoing treatment. At present Leeds is accessible via car or public transport, however, if the service was relocated, there was a widespread view that it would be difficult for their families to maintain the same level of support because they would have travel much further distances. They were concerned that this would be difficult if a round-trip of several hours was required, potentially adding to an already stressful and distressing situation.

Examples were given of existing difficulties of getting time-off work to attend appointments and having to use leave entitlements. This may be compounded if more time off was needed to travel greater distances.

We are aware that the impact on parents who do not have access to their own transport is considerable. Currently a journey to Leeds by public transport can involve up to three changes, plus a short walk (often with buggy) to the LTHT. This can often take over two hours. It is envisaged that the journey to any of the other centres on public transport would add between 2 -3 hours to the trip. On weekends or out of hours this would be more difficult. This is without taking costs into consideration.

Financial consideration

Yorkshire and Humber has a higher proportion of families on low income families. We envisaged the cost of journeys for Rotherham families would increase if Leeds were no longer the specialist centres. Whilst we are aware that claims can be made for some travel costs, the overall cost of journeys/ overnight stays and other associated costs could be substantial.

Impact on ethnic minority communities

We have serious concerns that the proposed closure of Leeds as a surgical centre would have a disproportionate impact on ethnic minority communities as our region is home to a greater number of these families who are also disproportionately higher users of this unit.

In conclusion, any decision to close Leeds as a surgical centre would not best serve the interests of some of the most sick and vulnerable children in Rotherham.

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Report to Regional Health Overview □ Scrutiny Committee
August 2011

Report of: Councillor Ian Saunders
Sheffield City Council Member representative on the Regional Health Overview & Scrutiny Committee

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Subject: Sheffield City Council response to the *Safe* and *Sustainable* Review of Children's Congenital Cardiac Services in England

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Author of Report: David Molloy, Scrutiny Policy Officer, Sheffield City Council

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Summary:
This report outlines the key concerns of Sheffield City Council in response to the *Safe* and *Sustainable* review's proposals for the reconfiguration of children's congenital cardiac surgery services in England.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	**X**
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Community Assembly request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	
Other	

The Scrutiny Committee is being asked to:
Note the concerns of Sheffield City Council to the *Safe* and *Sustainable* proposals and consider these as part of the regional response to the proposals

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Background Papers:
Safe and Sustainable: Review of Children's Congenital Cardiac Services in England

Category of Report: OPEN

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Report of the Sheffield City Council Member Representative on the Regional Health Overview Scrutiny Committee

Sheffield City Council response to the Safe and Sustainable Review of Children s Congenital Cardiac Services in England

1. Introduction

1.1 This report sets out the key concerns of Sheffield City Council in response to the Safe and Sustainable Review's proposals for the reconfiguration of children's congenital cardiac surgery services in England.

2. The rationale for a national review

2.1 There are currently 11 children's heart surgery centres in England. The Leeds Teaching Hospitals NHS Trust is the only centre based in the Yorkshire & Humber region.

2.2 Experts have become concerned that smaller centres are not sustainable in the future and cannot provide the best possible care. It has also been claimed that services have developed on an ad-hoc basis and, as a result, the current care pathway does not deliver the best possible care for children and their families.

2.3 The intention behind the review is to ensure that national standards are met and that the best service is delivered.

2.4 Of the 11 heart surgery centres in England some have fewer than 4 paediatric surgeons. This means that in some centres there will be times when a surgeon is not available to deal with routine cases or emergencies.

2.5 The review states the need for each centre having enough surgeons to meet the day-to-day demands of each centre. These include:

- Being on call for emergencies
- Undertaking ward rounds
- Running outpatient clinics
- Training
- Annual leave

2.6 Smaller centres may not see the same volume and variety of caseload that colleagues in a larger centre will inevitably see. A significant risk of smaller centres with fewer staff is that there may be times when cardiac surgery teams are not available. This can lead to:

- A lack of 24/7 care
- Small case loads
- Occasional practice
- Cancelled operations
- Low availability of staff in emergencies

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2.7 The new standards require a minimum of 4 surgeons in each centre, each performing a minimum number of surgical procedures each year to maintain their expert skills. Experts agree that surgeons should be performing 100 to 125 procedures per year. This suggests that each centre should be performing 400 to 500 procedures a year.

2.8 The 2001 Kennedy public enquiry into the deaths at the Bristol Royal Infirmary recommended that quality standards be developed for children's heart surgery centres and that there be fewer, larger centres of expertise. The 2003 Munro Review also recommended fewer centres, but this recommendation was not implemented. The Summit of Experts (2006) concluded that the current configuration of child heart surgery services was unsustainable and called for fewer centres. Moreover, the Royal College of Surgeons 2007 report, 'Delivering a First Class Service', also called for fewer, larger cardiac surgery centres. In addition, The National Clinical Advisory Team (2010) reviewed the *Safe* and *Sustainable* case for change and endorsed the need for fewer cardiac surgery centres.

2.9 A range of other professional organisations have expressed support for the rationale for change including: Royal College of Surgeons; Royal College of Nursing; Society of Cardiothoracic Surgery in Great Britain and Ireland; Royal College of Paediatrics & Child Health; British Congenital Cardiac Association; Children's Heart Federation; Specialised Healthcare Alliance; and, the Paediatric Intensive Care Society Council.

2.10 The review will lead to fewer, larger centres of excellence providing children's heart surgery. Each centre will have a minimum of 4 consultant congenital cardiac surgeons. Each centre will also have enough doctors and nurses to provide 24/7 care for children and parents. There will be a minimum of 400 paediatric heart surgeries per centre each year. Tertiary surgical centres will provide clinical leadership throughout their networks. The changes will also mean better training for surgeons and their teams to ensure the long-term sustainability of the service.

2.11 The review has stipulated that the location of children's heart surgery centres cannot be 'local' to all people in England. However, the review does stipulate that services that don't involve surgery or interventional procedures can be provided more locally.

2.12 The vision is a network of linked hospitals working together, pooling expertise and experience to ensure the best results for children and young people. The new model aims to deliver better and more consistent care for children and young people with heart disease. Continual review will ensure the service provides the best care and support for parents and their children. The new service will strengthen the delivery of assessment and follow-up care in local hospitals so that children and families do not have to travel long distances. Current surgical centres that are not recommended for designation under the *Safe* and *Sustainable* review will become specialist paediatric cardiology centres, though not providing interventional services. A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network. Under the new standards, the roles of Paediatrics with an interest in Cardiology and cardiac Liaison Teams will be strengthened to ensure expert care is delivered at a local level.

2.13 The principles of the *Safe* and *Sustainable* review are

- The NHS must provide only the very highest standards of care for children and their families, regardless of where they live or which hospital provides their care
- Centres should provide care that is based around the needs of the child and the family, including transition to adult services
- All relevant treatment other than surgery, including follow-up, should be provided as locally as possible to the family
- Clinical standards should be agreed and met by all centres
- The review is not a cost-cutting or bureaucratic exercise

2.14 The new model of care aims to deliver better and more consistent care for children and young people with congenital heart disease. The key points to be emphasised on the new model of care include:

- The outcome of Safe and Sustainable is NOT to close existing centres. Centres that are not designated for surgery will continue to provide non-interventional specialist paediatric cardiology services
- It is envisaged that there will be a number of managed cardiology networks across England
- The model of care seeks to strengthen the delivery of assessment and follow-up services in local hospitals so that children and families have easy access to local services and do not have to travel long distances to the tertiary surgical centres for non-interventional work.

2.15 The benefits for children and families of the new model of care include:

- Improved clinical outcomes
- Improved access: local diagnostic services and follow-up treatments; 24/7 care; and, surgical centres with expertise in complex procedures
- Stronger communication between services and parents: specialist liaison nurses and network collaboration
- Larger and stronger clinical teams: more sustainable; improved training and learning; a sufficient volume and range of operations; joint operating; and, improved recruitment and retention

3. The Sheffield perspective: key concerns

3.1 Sheffield City Council's Children & Young People Scrutiny Committee nominated Councillor Ian Saunders as Sheffield's representative to the Yorkshire & Humber Regional Health Overview & Scrutiny Committee. This regional committee has been scrutinising the proposals in the *Safe* and *Sustainable* review and will be submitting its own regional written response to the proposals.

3.2 Based on extensive work that has been undertaken in Sheffield on these proposals, there are a number of key concerns about the potential closure of the paediatric cardiology surgery centre at Leeds Teaching Hospitals NHS Trust. These include the manner in which the *Safe* and *Sustainable* review has been carried out, along with the potential impact of the Leeds closure on children, parents and their wider families in Sheffield.

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Key areas of concern

Flaws of the review

3.3 During our investigations, we are concerned about the manner in which the *Safe* and *Sustainable* review has been carried out. In our opinion, there are a number of flaws in the review process. These include:

- The lack of thoroughness throughout the process: we are concerned that the Health Impact Assessment was not completed before the final options for consultation were presented. We would stress how important it is for all information being made available for any serious consultation with service users and professionals to take place. Other areas of concern in this regard relate to the lack of engagement with Black Minority and Ethnic Groups and the fact that no Equality Impact Assessment has been undertaken.

- The lack of consideration given to children moving through to adulthood: in our discussions with senior practitioners in Sheffield, they have referred to the absolute focus of the review on children with congenital heart conditions. What has been lacking in this review, in the eyes of professionals, is the lack of attention paid by the review in the transition to adulthood. In the opinion of these professionals, it is a fatal error of the review to fail to consider this transition from childhood to adulthood.

- The importance attached in the review to surgical centres that have Extracorporeal Membrane Oxygenation (ECMO) facilities, such as The Freeman Hospital, Newcastle-upon-Tyne: there has been a great deal of importance attached in the Safe and Sustainable review to this facility being available in a number of hospitals across the UK. However, from our conversations with health professionals, whilst the importance of having these facilities is acknowledged, there is concern that the ability of hospitals to undertake this technique has been overplayed in the review. It is our understanding that ECMO facilities are generic skills that can be transferred to other hospitals across the country. We are therefore concerned that these skills have been overemphasised in the review which has placed certain hospitals that have such facilities, at an advantage over hospitals that do not. It is also worth noting that the LGI perform mini-ECMO with every operation.

Patient flow assumptions and the issue of choice

3.4 There are a number of concerns about the projected patient flows in the *Safe and Sustainable* review report. The 'Options for Consultation' section of the report (pages 88-91) sets out the 'network' that Sheffield would become part of, and where Sheffield children with serious cardiac defects would be referred on to for surgery as part of this network. For each of the options set out in the report, it is presumed that Sheffield children would be referred on to:

- Option A – Leicester Network
- Option B – Birmingham Network

- Option C – Newcastle Network
- Option D – Leeds Network

3.5 Nonetheless, these 'future potential networks' are based on the assumption that individual hospitals will willingly refer their patients to the surgical centres within their respective networks. Based on our conversations with Sheffield Children's Hospital, the City Council are concerned about these assumptions and believe that they are flawed. It is our understanding that it is (and will continue to be) the decision of individual hospitals where they refer their patients on to for paediatric surgery. In the case of Sheffield Children's Hospital, it is understandable that they will refer their paediatric patients to surgical centres where they believe the best outcomes will be delivered. In the case of Sheffield Children's Hospital, if the Leeds surgical centre were to close they would refer their paediatric patients on to Birmingham as this is where they believe that the best outcomes for their patients would be achieved. **It would not be the intention of Sheffield Children's Hospital to refer their paediatric patients on to Leicester or Newcastle as set out in Options A and C.**

3.6 Sheffield Children's Hospital are more than happy with the service that they receive from Leeds General Infirmary for their paediatric patients. The Children's Hospital have been referring to Leeds for approximately 9 years. Before this, they used to refer their paediatric patients to Leicester for heart surgery. However, Sheffield Children's Hospital were not particularly happy with the outcomes at Leicester and decided to switch their referrals to Leeds. The *Safe* and *Sustainable* review therefore raises wider questions about the issue of hospital 'choice'.

3.7 The choice of individual hospitals to refer their paediatric patients to the surgical centre of their choice is an issue that Sheffield City Council believes has been overlooked in the *Safe* and *Sustainable* review report. What also appears to have been overlooked in the review is the issue of patient 'choice' in the wider NHS constitution. As far as the City Council understands, hospitals would become part of a wider network whereby patients with serious cardiac defects would be referred to the cardiac surgery centre within this network. This raises questions, however, about where the choice of patients and their families lies in having surgery at centres that suit their specific circumstances.

3.8 An additional concern is the accuracy of the patient flow figures used in the review. It is not clear to us which postcodes have been used in assessing the flow of patients from Sheffield into the Leeds Teaching Hospital. We are also not clear which areas of Sheffield this covers as there are a number of areas outside the city which have Sheffield (S) postcodes including North Derbyshire and Chesterfield. We welcome the additional work that Pricewaterhouse Coopers have been commissioned to do into this crucial area of work.

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Impact on children, parents and their families

3.9 It is clear that the closure of the paediatric cardiac surgical centre at Leeds General Infirmary will have a significant impact on sick children, parents and families across Sheffield.

3.10 These 'impact' concerns relate primarily to two key areas. Firstly, there is the significant increase in transport times for families in Sheffield with children that have cardiac defects. During interviews, parents and their wider family members have informed us that they feel reassured that an emergency journey to Leeds General Infirmary for cardiac surgery on their child is approximately 45-60 minutes journey time from Sheffield. Should the Leeds cardiac surgery centre close as part of the *Safe* and *Sustainable* review, there will be a significant increased travel times for families in Sheffield taking their children for cardiac surgery to either Birmingham or Newcastle in particular, as set in Options B and C.

3.11 In addition, there is also an increased financial cost implication for families in Sheffield were the Leeds centre to close. For families with children that have serious cardiac defects that requires surgery, there is the increased cost of food and accommodation when their child is in hospital in another part of the country outside the Yorkshire and Humber region. In their interviews, parents told us that whilst Leeds General Infirmary is a reasonable travel away from Sheffield, the advantage of the current arrangement is that they can be with their children whilst they are awaiting heart surgery (or are recovering from heart surgery) and juggle their family arrangements around so that this works for them. For example, their partner can continue to work and wider family members can look after other children within the family. Furthermore, family life can be juggled around so that parents can take a break from being with their sick child and the stresses that are inevitably involved with this. If the Leeds centre were to close, and parents were required to travel to either Birmingham or Newcastle for their children to have surgical treatment, then the options for maintaining a relatively stable family life during this period will be diminished.

3.12 In short, it is the view of Sheffield City Council that the potential closure of the paediatric cardiac surgery centre at Leeds General Infirmary will have a significant 'knock-on' impact on children with cardiac defects, their parents and wider families. It is the view of health professionals across the city, in our conversation with them, that the Yorkshire and Humber region has a large enough population and successful paediatric surgical service at Leeds General Infirmary to justify keeping the centre open. There appears to be some irrationality in the largest geographical region in England not having its own paediatric cardiac surgical unit. In our conversations with senior health professionals, they have emphasised the central health planning principle of moving health services to the general population. Based on these conversations, it is the opinion of Sheffield City Council that the *Safe* and *Sustainable* review appears to have forgotten this key principle of effective health planning.

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The unique selling point of Leeds Teaching Hospitals NHS Trust

3.13 It is clear that the paediatric cardiac surgery centre at Leeds General Infirmary has a number of 'unique selling points'. These all add to the significant added value of maintaining the centre in the Yorkshire and Humber region. At present, patients enjoy a single site paediatric centre at LGI for in-patient care with feotal and adolescent/congenital heart disease services also on-site and out-patient follow-up delivered locally in district general hospitals around the region. Excellence in modern specialist care demands multidisciplinary care with other paediatric specialities being immediately available on site and not semi-available across a city. The modern provision of cardiac care for children and young people demands a well-developed clinical and managerial network such as the Yorkshire, Humber and North Trent Paediatric Cardiology Network working collaboratively with the team at LGI as it does so presently. It is therefore somewhat ironic that the Safe and Sustainable Review is aiming to replicate the LGI model across the country yet proposes to exclude the LGI as a specialist surgical centre.

3.14 Furthermore, it is evident that the paediatric cardiac surgical centre at LGI meets the essential criteria behind the *Safe* and *Sustainable* Review, including:

- Quality – there is no question about the high quality care that children receive at the LGI paediatric cardiac surgical centre. In our interviews, parents had nothing but praise for the staff and quality of care that their child received
- The NHS must plan and deliver care that is based around the needs of the child – services and facilities must be designed and delivered around a child's basic needs. The unique advantage of the centre at LGI is that services are truly co-located with neonatal and paediatric services. This means that services are designed around the needs of children, being based on a single site centre. Having centres for cardiac surgery co-located to general paediatric services is also advised by the British Congenital Cardiac Association (BCCA).

3.15 The *Safe* and *Sustainable* review refers to LGI currently having 3 cardiac paediatric surgeons and in 2010 the centre performed 316 procedures. This is obviously short of the minimum 400 procedures that the review recommends in terms of sustainability. Nonetheless, in our conversations with the cardiac paediatric team at Leeds General Infirmary have said that based on future population projections and some minor changes to referral patterns this number would be expected to exceed 400 procedures per annum. There also appear to be strong demographic reasons for retaining the surgical centre in Leeds, as the table below indicates.

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	Current population (m)	Population over past decade (□□-)	Projected population for 2028 (m)
Yorkshire & Humber	5.5	+ 5.7%	6.1
North East	2.6	- 3.6%	2.8

The □knock-on□impact

3.16 Sheffield City Council are also concerned to note that the potential closure of the paediatric cardiac surgery centre at Leeds General Infirmary will have a significant 'knock-on' impact on the wider regional network, which has been built up over a number of years. It has been suggested that the closure of the Leeds surgical unit could lead to the loss of the substantial support network that has been built around this such as the network of cardiologists and specialised nurses which has been held up as an exemplar model in modern day practice. In our discussion with Sheffield health professionals, it is their view that it is illusionary to divorce surgery from cardiology.

3.17 Sheffield, and the Yorkshire and Humber region more generally, currently benefits from the 'Embrace Transport Service', located near junction 37 of the M1. The service provides a 24 hours a day, 7 days a week critical care transport service for critically ill neonatal and paediatric patients in the Yorkshire and Humber region. The location of the service means that it can respond quickly to referrals from clinicians throughout the region. Whilst recognising the significance of having this service located in, and serving, the region, it is our view that this has, in some ways, gone against the case for the children's surgical centres at the LGI to remain open in the review. What has without doubt been overlooked in the *Safe* and *Sustainable* review is the huge increase in workload for the Embrace Transportation Service that the closure of the surgical centre at the LGI bring.

4. What does this mean for the people of Sheffield?

4.1 The potential closure of the paediatric cardiology surgery centre at the Leeds Teaching Hospital NHS Trust will have a significant impact on children in Sheffield with cardiac problems. This will also, inevitably, have a significant knock-on impact on their parents and wider families. There is a common misconception that Sheffield Children's Hospital provides all relevant services to children and young people, including those with serious cardiac defects. This, of course, is not the case. Whilst Sheffield Children's Hospital has its own Cardiology Unit, those children in the Sheffield region who require cardiac surgery have this at Leeds Teaching Hospital NHS Trust.

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5. Recommendation

5.1 The Committee are recommended to note the contents of the report along with the key concerns of the potential closure of the Leeds' facility from a Sheffield perspective, and consider these as part of the regional response to the proposals.

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Your ref
Our ref LM/SMC
Date 29 June 2011

Freepost RSLT-SRLZ-JYYY
Safe and Sustainable
Ipsos MORI
Research Services House
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Harrow
HA1 2QG

Dear Sirs,

Review of Children□s Congenital Cardiac Services in England □ initial response

In January 2011, the Regional Health Scrutiny Network (Yorkshire and the Humber) received a briefing from the Director of the Yorkshire and the Humber Specialised Commissioning Group (YHSCG) on the review of Children's Congenital Cardiac Services process and associated timescales. This was provided in the run up to the meeting of the Joint Committee of Primary Care Trusts (JCPCT) on 16 February 2011.

Following the February meeting of the JCPCT and subsequent announcements about proposed reconfiguration of Children's Congenital Cardiac Services in England, the regional network established a formal joint health overview and scrutiny committee (JOSC) to consider those proposals on behalf of the 15 local authority Health Overview and Scrutiny Committees covering the whole of the Yorkshire and the Humber region. It should be noted that this is an extraordinary and unprecedented requirement in terms of NHS service reconfigurations and the coordination of this work should not be underestimated.

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At its first meeting in March 2011, the JOSC agreed its terms of reference: These can be summarised as considering:

- The review process and formulation of options presented for consultation;
- The projected improvements in patient outcomes and experience;
- The likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- The views of local service users and/or their representatives;
- The potential implications and impact on the health economy and the economy in general, on a local and regional basis; and,
- Any other pertinent matters that arise as part of the inquiry, and we are extremely grateful to the network of scrutiny support officers for their continued efforts in this regard.

To date, the JOSC has formally received and considered evidence from YHSCG and Leeds Teaching Hospitals NHS Trust (LTHT). However, as a result of the public consultation's proximity to local council elections – which resulted in a significant change in membership (over 50%) – the JOSC has been unable to arrange any further meetings until after the close of pubic consultation on 1 July 2011. However, we were previously advised that the deadline for HOSCs to respond to the proposals had been extended until October 2011 – which was subsequently confirmed by the national team's statement regarding consultation with HOSCs dated 20 May 2011.

I am reliably informed that concerns were raised about the timing of public consultation and involvement of HOSCs in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed, given the inevitable changes to membership of HOSCs immediately after the local elections and the impact this would have on the meaningful involvement with HOSC's during this time.

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

To help the JOSC produce a fully informed report/response, it is essential that it gathers and considers a wide range of data/ evidence. This specifically includes consideration of the local data and impacts. The level of detail required was not readily available when the proposals were first published and has taken time to gather and analyse. The result of which served to severely limit the timeframe for the JOSC to meet to consider the local data and impacts and then provide an informed and more detailed response by the public consultation deadline.

A response from the JOSC will follow ahead of the October 2011 deadline.

However, I would like to make the following personal observations on the reconfiguration options put forward in the public consultation document:

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Co-location of services

It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions. Currently in Leeds, children from across the region access surgical and interdependent services **on one hospital site**. However, the definition of 'co-location of services' appears to be loosely interpreted in the options being considered under "Safe and Sustainable" to include centres where such services may be located over multiple hospital sites. I would argue that the public would consider co-location to mean a single site.

All children's acute services are *genuinely co-located* in Leeds alongside maternity services (which is essential for the wellbeing of mother and baby if cardiac interventions are required at birth). Reducing the likelihood of mother and child being separated immediately after birth (where the child would be transferred to another hospital for surgery) would help to minimise the unnecessary stress on the mother and family. Having maternity services and children's congenital cardiac surgery on one site is invaluable to families across the region at the start of a child's life.

I would add that adult cardiac surgery would also be adversely affected by any move away from children's congenital hear surgery in Leeds, where the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood.

Patient flows, travel and access

The patient flows predicted under options A-C suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge.

I welcome the additional review work that is now being undertaken around travel patterns, but I find it frustrating that more detailed analysis and testing of assumptions was not undertaken prior to the options for consultation being identified, as the impact will be significant in determining whether or not designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre.

Extending travel times and the complexity of journeys for patients across the Yorkshire Region places an additional strain on patients and their families at what will already be a particularly stressful time.

Engagement with Black and Minority Ethnic (BME) communities

I understand that families from the Indian sub-continent in particular are more likely to require children's congenital heart services. There is a significant population of BME communities of Kashmiri, Pakistani and other Indian sub-continent communities in the Leeds City Region who ought to have been better engaged in this consultation from the outset.

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I believe their engagement received insufficient attention and translated information was not readily available early enough in the process.

As local authorities strive to maintain stronger and thriving local communities, it is important that public sector agencies work together to ensure active engagement across all communities. I do not feel that this public consultation sufficiently addressed this aspect of involvement and engagement.

Level of surgical activity

The case for a minimum of 400 procedures per designated surgical centre is a cornerstone of the case for change and underpins the assessment of options. Having recently received the activity data for 2010/11, it is worthy of note that Leeds Teaching Hospitals Trust undertook 342 surgical procedures with 3 surgeons during this time. This represents the 3rd highest number of procedures outside of London. With the review process already determining that the services provided by LTHT are 'safe', it would appear nonsensical not to retain a designated centre in Yorkshire and the Humber that is currently undertaking this level of activity.

In addition, as Option B includes centres not predicted to achieve the minimum of 400 procedures, I would question the consistency of application of the volume criteria which is supposed to underpin the process, when Option B is presented as a valid option for consultation.

One final note is that I would question the emphasis that is being placed on certain nationally commissioned specialist services currently being carried out in certain hospitals in some parts of the country, which seem to outweigh the consideration being given to centres of population in other parts of the country.

I trust these comments will be helpful and look forward to submitting the report of the JOSC (Yorkshire and the Humber) later in the year.

Yours sincerely

Councillor Lisa Mulherin
Chair, Scrutiny Board (Health and Wellbeing and Adult Social Care), Leeds City Council and Chair, Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

cc All members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Cathy Edwards (Director, Yorkshire and the Humber Specialised Commissioning Group)

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Information provided by Leeds City Council:

An analysis of the **Index of Multiple Deprivation (IMD) 2010** shows that **Leeds now has:**

- 25 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%

Comparison with the 2007 IMD

The initial analysis suggests an overall worsening position when compared to the rest of the country with the majority of SOAs in Leeds seeing their ranking fall. Of the 476 SOAs in Leeds:

- 154 have seen an improvement in their IMD ranking
- 322 have seen their ranking fall

In 2007 Leeds had 22 SOAs that were ranked in the most deprived 3% nationally, this number has risen to 25 on the new IMD.

In 2007 Leeds had 95 SOAs that were ranked in the most deprived 10% on the national scale. On the new 2010 IMD Leeds has 92 SOAs in this bracket. 8 SOAs from the 2007 IMD have now moved out of the 10% bracket but there are 5 SOAs which are now ranked in the most deprived 10% and were not previously in this bracket.

The 5 SOAs which are now in the 10% bracket and were not previously are:

Ref number	Area Includes	Ward	2007 Rank	2010 Rank
E01011389	Woodnook Drive, Silk Mills	Weetwood	3701	2802
E01011723	Langbars, Braytons, Eastwoods	Crossgates & Whinmoor	3497	2810
E01011726	Gamble Lane, Tong Drive, Stonecliffes, Hall Lane	Farnley & Wortley	4383	2869
E01011476	Brooms, Nesfields	Middleton Park	4041	2983
E01011656	Boggart Hill Dr, Barncroft Rd, Ramshead Dr, Monkswood Hill	Killingbeck & Seacroft	3922	3140

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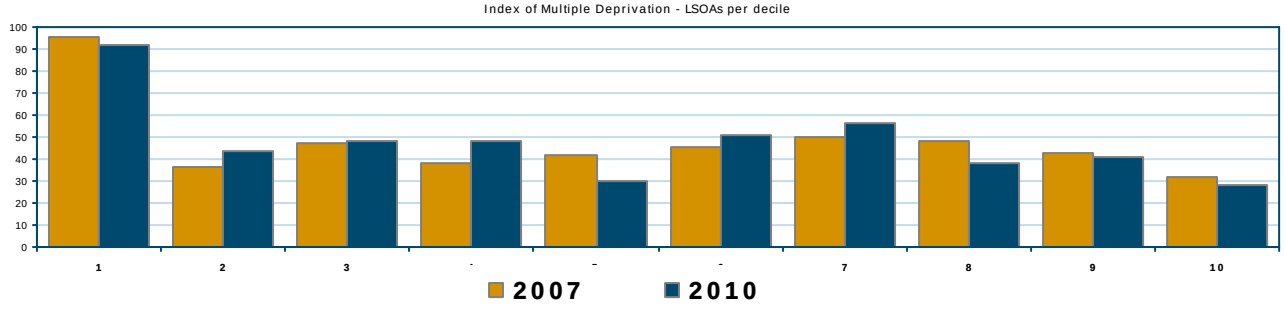
Index of Multiple Deprivation Ward Rankings

Ward	SOA's	Lowest Ranked LSOA	Highest Ranked LSOA	LSOAs ranked in top 10%		LSOA Change in Ward	LSOAs ranked in top 20%		LSOA Change in Ward
				2007	2010		2007	2010	
Adel & Wharfedale	12	**5164**	32105	0	0	◄ 0	0	1	▲ 1
Alwoodley	14	**2034**	30743	2	2	◄ 0	3	3	◄ 0
Ardsley & Robin Hood	12	7085	31122	0	0	◄ 0	0	0	◄ 0
Armley	16	**932**	14118	5	5	◄ 0	10	10	◄ 0
Beeston & Holbeck	14	**1282**	11992	6	5	▼ 1	7	7	◄ 0
Bramley & Stanningley	16	**1568**	21233	4	3	▼ 1	6	6	◄ 0
Burmantofts & Richmond Hill	16	**260**	8773	13	12	▼ 1	14	14	◄ 0
Calverley & Farsley	14	6627	29894	0	0	◄ 0	0	0	◄ 0
Chapel Allerton	13	**122**	27800	6	6	◄ 0	7	7	◄ 0
City & Hunslet	12	**398**	14894	9	9	◄ 0	9	11	▲ 2
Cross Gates & Whinmoor	15	**2810**	24851	1	1	◄ 0	5	5	◄ 0
Farnley & Wortley	16	**1136**	20071	5	5	◄ 0	7	8	▲ 1
Garforth & Swillington	13	13537	29541	0	0	◄ 0	0	0	◄ 0
Gipton & Harehills	16	**114**	**3735**	14	13	▼ 1	16	16	◄ 0
Guiseley & Rawdon	16	7119	31695	0	0	◄ 0	0	0	◄ 0
Harewood	13	17349	30921	0	0	◄ 0	0	0	◄ 0
Headingley	14	7278	21486	0	0	◄ 0	0	0	◄ 0
Horsforth	14	10199	31665	0	0	◄ 0	0	0	◄ 0
Hyde Park & Woodhouse	13	**2619**	17486	2	1	▼ 1	4	4	◄ 0
Killingbeck & Seacroft	17	**120**	17668	10	10	◄ 0	14	14	◄ 0
Kippax & Methley	14	7080	27210	0	0	◄ 0	0	0	◄ 0
Kirkstall	14	**860**	17100	1	1	◄ 0	4	4	◄ 0
Middleton Park	17	**300**	12685	11	12	▲ 1	13	13	◄ 0
Moortown	14	**2727**	28997	1	1	◄ 0	2	2	◄ 0
Morley North	14	8499	29555	0	0	◄ 0	0	0	◄ 0
Morley South	14	**5127**	23361	0	0	◄ 0	0	2	▲ 2
Otley & Yeadon	13	7525	29587	0	0	◄ 0	0	0	◄ 0
Pudsey	15	**3320**	24210	0	0	◄ 0	2	1	▼ 1
Rothwell	15	**4990**	22755	0	0	◄ 0	1	1	◄ 0
Roundhay	17	**2325**	29047	1	1	◄ 0	1	1	◄ 0
Temple Newsam	13	**348**	27927	4	4	◄ 0	4	4	◄ 0
Weetwood	16	**2802**	24366	0	1	▲ 1	2	2	◄ 0
Wetherby	14	12439	32061	0	0	◄ 0	0	0	◄ 0

1-974 = Ranked in worst 3% **975-3248** = Ranked in worst 10% **3248-6496** = Ranked in worst 20%
▼ 1 = decrease of LSOAs in 10/20% margin ▲ 1 = increase of LSOAs in 10/20% margin



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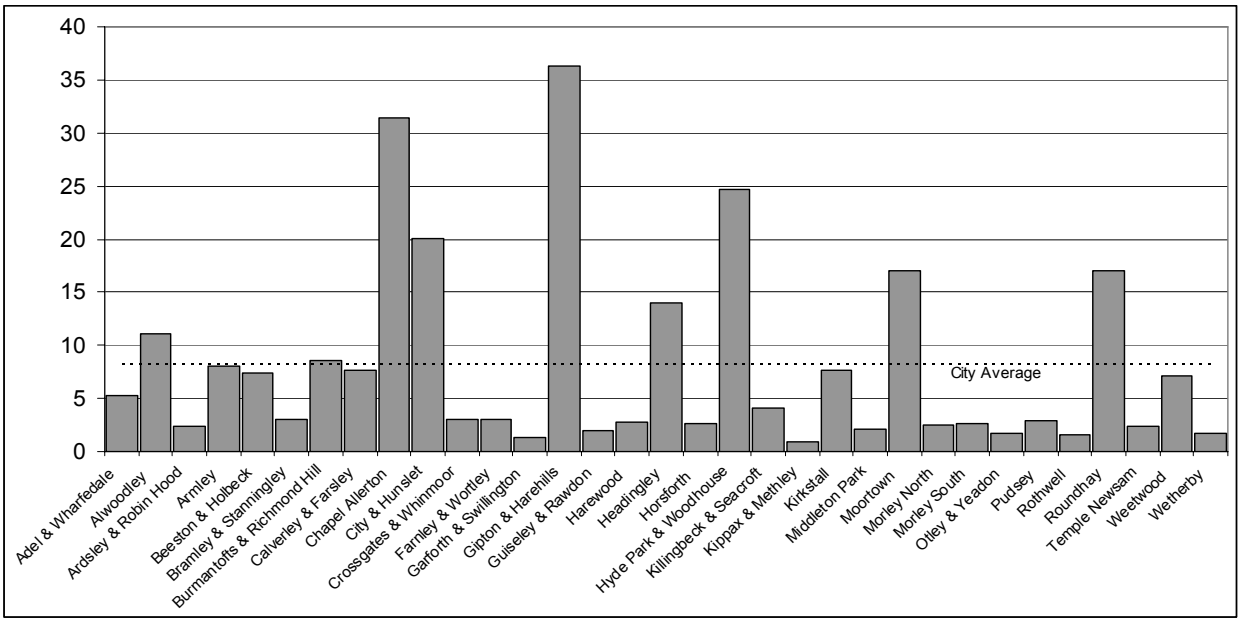
Leeds and its communities

Black and Minority Ethnic (BME) Communities

At the time of the 2001 Census there were almost 78,000 people from BME communities living in Leeds (10.8% of the total resident population). Geographic analysis of the Census data has shown how BME communities are concentrated in particular geographic areas of the city:



- Almost one-third of the city's BME population live in just three wards: Gipton & Harehills, Chapel Allerton and Hyde Park & Woodhouse.
- People from BME communities account for over 40% of the resident population in Gipton & Harehills, in Chapel Allerton 36.5% and in Hyde Park & Woodhouse 31.4%.
- Over a quarter of the Pakistani population lives in Gipton & Harehills.
- The vast majority (85%) of the city's Bangladeshi community is concentrated in three wards: Gipton & Harehills, City & Hunslet and Chapel Allerton.
- Over half (55%) of the city's Black-Caribbean community live in three wards: Gipton & Harehills, Chapel Allerton and Hyde Park & Woodhouse.

In 2009 the Office for National Statistics (ONS) produced some updated information on the numbers of people from BME communities. While this is only available at the city level, it shows that in Leeds:

- The BME population has increased from 77,900 in 2001 to 137,200 in 2009 (representing a 76% increase)

Appendix 6:
Local authority information

- BME communities now 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 (49% increase from 2001) and 20,700 (67% increase from 2001) people respectively
- The "Other White" category has seen the biggest increase in numbers from 10,700 in 2001 to 25,600 in 2009 (139% increase from 2001) many of who will be migrant workers
- Black African, Bangladeshi, Black African / White, Other Asian, and Other Ethnic groups have all seen their numbers more than double

	2001		2009		Change
	Numbers	Rates	Numbers	Rates	
White	*656,900*	*91.8*	*683,400*	*86.8*	*26,500*
White British	637,700	89.1%	650,500	82.6%	12,800
White Irish	8,600	1.2%	7,300	0.9%	-1,300
Other White	10,700	1.5%	25,600	3.2%	14,900
Mixed Heritage	*9.800*	*1.4*	*18,800*	*2.0*	*6,000*
Black Caribbean & White	4,600	0.6%	5,400	0.7%	800
Black African & White	900	0.1%	2,000	0.3%	1,100
Asian & White	2,500	0.3%	5,000	0.6%	2,500
Other Mixed	1,800	0.3%	3,300	0.4%	1,500
Asian or Asian British	*32,400*	*4.5*	*54,500*	*6.9*	*22,100*
Indian	12,400	1.7%	20,700	2.6%	8,300
Pakistani	15,100	2.1%	22,500	2.9%	7,400
Bangladeshi	2,500	0.3%	5,200	0.7%	2,700
Other Asian	2,400	0.3%	6,100	0.8%	3,700
Black or Black British	*10,400*	*1.5*	*19,800*	*2.5*	*9,400*
Black or Black Caribbean	6,700	0.9%	7,700	1.0%	1,000
Black African	2,500	0.3%	10,400	1.3%	7,900
Other Black	1,200	0.2%	1,700	0.2%	500
Other Ethnic Group	*6,000*	*0.8*	*14,200*	*1.8*	*8,200*
Chinese	3,500	0.5%	5,200	0.7%	1,700
Other	2,600	0.4%	9,000	1.1%	6,400
All people	715,600		787,700		72,100

Analysis of the ONS data shows that migration (both internal and international) continues to be a major influence on our population growth. Data on new migrant communities is fragmented – but it is estimated that in 2009 between 6,500 and 10,500 new migrants (who will stay for more than 12 months) arrived in Leeds.

Appendix 6:
Local authority information

Information provided by North East Lincolnshire Council:

> *The Grimsby Telegraph published articles in April and May and asked local residents for their support, by completing coupons published in the newspaper. 117 responses were received in support of retaining the unit at Leeds with 39 responses citing cost of travel/distance to travel as their reason/ concern, and 21 responses identifying increased risk to patients as the primary issue.*

A schedule, providing complete details (i.e. names and addresses) has been provided and was made available to members of the Joint HOSC on request.

Information provided by Wakefield Council:

Wakefield's position:

- Broadly in line with other respondents
- Council debated proposals in March 2011 – supported option D with the retention of Leeds
- Social Care & Health OSC discussed on 21 April 2011-10-06 Member of the public attended Committee to express concerns (supported by written submissions from other members of the public, all supportive of Leeds – concerns expressed in line with other respondents
- Committee's main concerns are:
    a. The review process – concerns that the Health Impact Assessment was not available
    b. Focus on children through to adulthood not given sufficient consideration
    c. Insufficient and flawed consideration of patient flows
    d. Impact on children, parents and families
    e. Level of surgical activity – evidence not conclusive
    f. Affordability – not sufficiently considered
    g. **Disappointment that Joint Health Scrutiny Committee is not seeking common ground with Newcastle on a collaborative response that seeks to promote the vested interests of both whilst upholding the principles of the review. In other words jointly proposing that Leeds <u>and</u> Newcastle are retained in any configuration (as suggested by North Yorkshire).**

Appendix 6:
Local authority information

Information provided by City of Bradford MDC:

On 15 September 2011, the Health Overview and Scrutiny Committee– **resolved:**

1. *That, having given this matter much consideration, from the options proposed within the consultation, the Committee unanimously endorses Option D and recommends this as the option to be taken forward.*

2. *In reaching its decision the Committee are mindful that there has been a severe lack of critical information being presented in a timely manner. Dependant on information yet to be submitted it is possible that a further Children's Heart Surgical Centre may be required to meet demand.*

3. *That the Committee notes with extreme dismay that only a few days will be available to the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) to make its recommendations once it has received information requested from the Joint Committee of Primary Care Trusts*

Information provided by East Riding of Yorkshire Council

On 13 September 2011, the Health, Care and Wellbeing Overview and Scrutiny Committee – **resolved:**

That the Sub-Committee support the retention of children's cardiac surgery services at Leeds General Infirmary to deliver children's cardiac surgery services.

Appendix 7:
Motions of Councils – associated correspondence

Details of the correspondence (sent and received) and reports referred to in Appendix 5.

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_613235

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Kersten England
Chief Executive
City of York Council
The Guildhall
York
YO1 9QN

24 MAY 2011

Dear Kersten,

Thank you for your letter dated 21 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

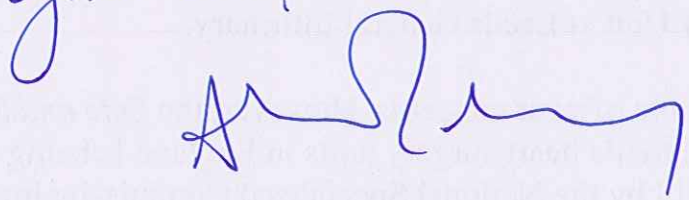
The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for

children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of the City of York Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours ever,



ANDREW LANSLEY CBE

Harrogate BOROUGH COUNCIL

Working for you

Mr T Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
LEEDS LS1 1UR

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Tom

Children's Cardiac Services in Yorkshire And The Humber

Thank you for your letter of 5 May 2011 concerning the national review of Children's Cardiac Services and the options included within that review for consultation purposes.

This matter has already been considered by the Council in the form of the following Notice of Motion presented to its meeting held on 13 April 2011:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of Children's Cardiac Surgery Services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the issue, the Council shared the City's concern over the potential loss of the Children's Cardiac Unit and the impact both locally and regionally of this. Members also discussed the transfer times and network issues to which you refer, were cardiac services to be sited in Newcastle and also the personal consequences of this in terms of children's care and the additional burden for families faced with commuting during a period of already intense pressure and stress.

I am pleased to say that the Council supported the motion unanimously, and I have now written to the Secretary of State for Health calling for the retention of Children's Cardiac Services in Leeds in line with the requirements of the approved motion.

I will of course keep you informed of progress.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

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www.harrogate.gov.uk

Harrogate BOROUGH COUNCIL

Working for you

Mr A Lansley CBE MP
Secretary of State for Health
Richmond House
79 Whitehall
LONDON
SW1A 2NS

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Mr Lansley

Children's Cardiac Services in Yorkshire and the Humber

The extensive national review of Children's Cardiac Services across England has put forward four options for consultation aiming to consolidate Children's Cardiac Services into six or seven locations. As you are aware, Children's Cardiac Services are currently provided in Yorkshire and the Humber by the Leeds Teaching Hospitals NHS Trust. I understand that the National Review Team assessed all Children's Cardiac Services, including Leeds to be "safe". However, retaining the Leeds provision is only one of the four options being put forward in the public consultation. The preferred option places Children's Cardiac Services in Newcastle, Liverpool, Birmingham, Leicester, Bristol and two sites in London.

This region benefits from a comprehensive range of co-located services for adults and children, with Leeds being the only centre in the North of England to fulfil every child and adult inter-dependency. Leeds has pioneered clinical networks in this area and the majority of regional work has been adopted as national guidelines.

In response to the consultation exercise and concerns over the potential loss of Children's Cardiac Services, the Council, at its meeting held on 13 April 2011, considered the following Notice of Motion:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the motion, Members of the Council were conscious of the great number of children and families within the Harrogate District, the region and from other parts of the country benefiting from the expertise held by the Leeds Teaching Hospitals NHS Trust.

Continued ...

Council Offices, Crescent Gardens, HARROGATE HG1 2SG
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www.harrogate.gov.uk

Council also raised concern over the transfer times, were such services to be lost in favour of Newcastle and the additional anxiety and stress that would be faced by families and their children in commuting to Newcastle, a city itself not well served by a motorway network.

Following debate, the motion was unanimously approved by all Members of the Council and in accordance with its wishes I am, therefore, calling for the retention of these vitally important surgical services in Leeds.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

From the Rt Hon Simon Burns MP
Minister of State for Health

Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 4850

Your Ref: CE/LAN

PO00000616648

Mr Wallace Sampson
Chief Executive
Harrogate Borough Council
Council Offices
Crescent Gardens
Harrogate HG1 2SG

06 JUN 2011

Dear Mr Sampson

Thank you for your letter of 13 May to Andrew Lansley on behalf of Harrogate Borough Council about the children's cardiac surgery unit at Leeds General Infirmary. I am replying as the Minister responsible for this policy area.

The *Safe and Sustainable* review of paediatric cardiac surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as paediatric cardiac surgery, across England. The Department of Health has been following its progress.

The *Safe and Sustainable* review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical units. The aim of *Safe and Sustainable* is to ensure that paediatric cardiac surgery services in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease, as have the proposed service standards.

I understand the Council's concern about the provision of continuity of care. Clinicians working in the service and their professional associations have identified the quality benefits of working in larger surgical centres, carrying out a larger numbers of procedures. This is not incompatible with maintaining continuity of care, such as a child continuing to see the same surgeon over their lifetime. A concentration of expertise facilitates research into the different

techniques and thus encourages sharing of best practice. More importantly, though, it ensures better cover in an emergency and less need for transfer of children between centres.

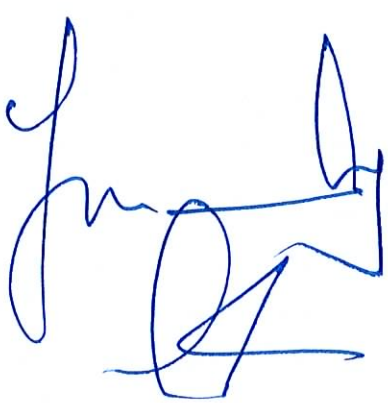
I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. However, many children do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

I would like to highlight that there are no proposals to close any of the units. Surgery may cease at some units in the future but the aim is that these units will continue to provide specialist, non-interventional paediatric cardiac services for their local populations.

No decision has yet been made on the location of paediatric cardiac surgery units. Patients and the public have the opportunity to make their views known during the formal public consultation process, which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. More information about the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.



SIMON BURNS

Name of meeting: **Annual Council**

Date: **25 May 2011**

Title of report: **Leeds Children's Heart Surgery Unit at Leeds General Infirmary and Adopted by Council**

Is it likely to result in spending or saving £250k or more, or to have a significant effect on two or more electoral wards?	**No**
Is it in the Council's Forward Plan?	**No**
Is it eligible for "call in" by Scrutiny?	**Not applicable - item for information only**
Date signed off by Director & name **Is it signed off by the Director of Resources?** **Is it signed off by the Acting Assistant Director - Legal & Governance?**	**16 May 2011, David Smith, Director of Resources** **No financial implications** **No legal implications**
Cabinet member portfolio	**Not applicable**

Electoral wards affected and ward councillors consulted: Not applicable

Public or private: Public

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1. Purpose of report

For Council to note the response from the Department of Health to the Council's Motion on Leeds Children's Heart Surgery Unit.

2. Key points

Council, at its meeting on 23 March 2011, approved and adopted the following Motion:-

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the

Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

A response to the Motion has been received from the Department of Health, as set out below:-

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

3. Implications for the Council

None applicable to this report.

4. Consultees and their opinions

Not applicable.

5. Officer recommendations and reasons

That Council notes the response, which is for information only.

6. Cabinet portfolio holder recommendation

Not applicable.

7. Next steps

None applicable to this report.

8. Contact officer and relevant papers

Adrian Johnson: 01484 221712
Email: adrian.johnson kirklees.gov.uk

Background Papers: Letter dated 14 April 2011 from the Department of Health.

9. Assistant director responsible

Vanessa Redfern, Legal, Governance and Monitoring

DOC871A (160511)

Legal and Governance
Second Floor, Civic Centre 3
Huddersfield HD1 2TG

Tel: 01484 221712
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adrian.johnson@kirklees.gov.uk

www.kirklees.gov.uk

Please ask for: Adrian Johnson

25 March 2011

Our Ref: MAJ/PAW/DOC838A

Andrew Lansey CBE MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Dear Secretary of State

Resolution Passed by Kirklees Council in relation to Leeds Children's Heart Surgery Unit - Leeds General Infirmary (LGI)

At a meeting of the Kirklees Council held on 23 March 2011 the following resolution was passed:-

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

I would welcome your response in due course in order that I may report back to the Council accordingly.

As requested by the Council resolution I am copying this letter to Kirklees Members of Parliament.

Yours faithfully

Adrian Johnson
Governance Officer

c.c. Michael R Wood MP, House of Commons, London SW1A 0AA
Jason McCartney, House of Commons, London SW1A 0AA
Simon Reevell MP, House of Commons, London SW1A 0AA
Barry J Sheerman MP, House of Commons, London SW1A 0AA
Mary Creagh MP, House of Commons, London SW1A 0AA

Your ref: MAJ/PAW/DOC838A

Our ref: TO00000605259

Department of Health
Richmond House
79 Whitehall
London
SW1A 2NS
Tel: 020 7210 4850

Mr Adrian Johnson
Legal and Governance
Kirklees Council
Second Floor
Civic Centre 3
Huddersfield
HD1 2TG

14 April 2011

Dear Mr Johnson,

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

Yours sincerely,

Daniel Nebel
Customer Service Centre

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

Tom Riordan
Chief Executive
3rd Floor
Civic Hall
Leeds LS1 1UR

Tel: 0113 247 4554
Minicom: 0113 247 4000
Fax: 0113 247 4870
tom.riordan leeds.gov.uk

Our reference: **let188/TR/MW**

13 April 2011

RESOLUTION OF LEEDS CITY COUNCIL

I write to inform you that Leeds City Council at a meeting of the Full Council on 6th April 2011 passed the following resolution:

This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit s limited inclusion in NHS proposals for the national reconfiguration of children s cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect.

I would be grateful if you could consider the views of Leeds City Council as expressed in the resolution.

Tom Riordan
Chief Executive

Nigel Richardson/S. Sinclair (TR)

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_611755

Your Ref: let188/TR/MW

MR. T. RIORDAN
25 MAY 2011
CHIEF EXECUTIVE

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Tom Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
Leeds LS1 1UR

Also cc to Andy Koch → Group Leaders.

24 MAY 2011

Dear Tom,

Thank you for your letter dated 13 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary. Councillor Terry Grayshon also wrote to me on 28th April 2011 about this. I have also replied to his letter.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my

knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of Leeds City Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours ever,

ANDREW LANSLEY CBE

Copy of letter from Wakefield Metropolitan District Council

Rt Hon Andrew Lansley, MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London
SW12A 2NL

15 April 2011

Dear Mr Lansley

CHILDREN'S CONGENITAL HEART SERVICES – NHS CONSULTATION

I write in response to the NHS public consultation on the way children's congenital heart services should be provided in the future. The Council of the City of Wakefield at its meeting held on 30 March 2011, debated the issues arising from the consultation document with particular regard to the excellent services currently provided at Leeds General Infirmary.

Members of Council in debating the options for reconfiguring the services noted that the current service provided at Leeds General Infirmary only featured in one option, option D.

Members of Council were unanimously of the view that should any other option be pursued which would result in the closure of the Leeds Specialist Unit, there would be a huge gap in provision from Birmingham or Leicester in the south, Newcastle in the north and Liverpool to the west. The implications of such a decision would mean children from Yorkshire, North Derbyshire and Northern Lincolnshire having to travel long distances for treatment putting additional strain and costs on families. Council was also concerned that as specialisms were lost in the region, there would also be an adverse impact on adult cardiology services.

Members noted that Leeds General Infirmary was at the forefront of work on inherited cardiac conditions holding an excellent record for providing safe, high quality children's heart services. The centralised unit operating from a single site at the Leeds General Infirmary, currently serves a population of some 5.5 million people in the Yorkshire, North Derbyshire and Lincolnshire regions which is one of the highest population coverages of all units in England.

The Council respectfully asks that there concerns and support to retain specialist children's congenital heart services at Leeds General Infirmary are taken into account as part of the consultation and decision making processes and that a favourable outcome will result.

Yours sincerely

Councillor Peter Box, CBE
Executive Leader
Wakefield Metropolitan District Council

Appendix 8:
Comments from Members of Parliament

Comments received from Members of Parliament (Yorkshire and the Humber) referred to in the Summary of Evidence section of the report.

JULIAN SMITH MP
Skipton & Ripon

HOUSE OF COMMONS
LONDON SW1A 0AA

Cllr Lisa Mulherin
Chair
Joint Health Overview and Scrutiny Committee
3rd Floor (East)
Civic Hall
Leeds LS1 1UR

Our ref: SR4596

12 September 2011

Dear Cllr Mulherin,

Please find attached Mr Smith's response to the consultation which sets out his view on the reconfiguration of Children's Congenital Cardiac Services. I hope this is helpful in advance of your meeting on Monday 19 September.

With best wishes.

Yours sincerely,

STEPHEN NAYLOR
Office of Julian Smith MP

Tel: 020 7219 7145 · Email: julian.smith.mp@parliament.uk · Website: www.juliansmithmp.com

Sir Neil McKay CBE
Chair of the Joint Committee of Primary Care Trusts
NHS
2-4 Victoria House
Capital Park, Fulbourn
Cambridge CB21 5XB

Our ref: SR4397

1 June 2011

Dear Sir Neil,

As we are approaching the end of the Safe and Sustainable public consultation on the future of children's congenital heart services, I wanted to set out my views following meetings, discussions and research into the proposals being set out.

I believe strongly that the Children's Heart Surgery Unit at the Leeds General Infirmary should be retained.

There have been many compelling human stories told to me over recent months from constituents across the Skipton and Ripon constituency.

Lois Brown, from Cononley, has been one of the leaders of the campaign. Her three-year-old daughter Amelie was born with a heart defect and Lois and her husband spent months at her daughter's bedside in Leeds. They say Amelie would not have survived without the Leeds unit.

[redacted] eldest daughter had major heart surgery at the Leeds General Infirmary about four years ago. He says that he practically lived there for about six weeks, travelling back and forth to work in Skipton every day. Without the surgery, he says his daughter would not have lived and without the ward being there he would have had to make some fairly tough choices between family commitments and continuous employment.

I have also spoken to parents in Ripon who credit the Leeds unit with saving their child's life, a mum from near Addingham wrote to me to tell me of their experiences and why they think the unit is so valuable and doctors from across North Yorkshire who believe having children's heart surgery in Yorkshire is essential to the care of very sick children.

However, I know that in a review like this those stories, no matter how emotional or compelling, are not enough. The review will be examining facts and figures, medical data and medical views. From all my research, discussions and enquiries I believe the case for keeping the Children's Heart Surgery unit in Leeds is equally compelling.

The Leeds General Infirmary is in the middle of one of the densest population areas of the country. 14 million people are within two hours travel time including the five and a half million people in the Yorkshire and the Humber region. It encompassed both the urban areas of West and South Yorkshire and the more rural parts of North Yorkshire, including my constituency. One of the concerns expressed to me is that getting to another unit – be it Newcastle or Leicester or Liverpool - from somewhere like

the Yorkshire Dales or Nidderdale would mean significantly increased travel times, especially for those parents who have to rely on public transport.

The Leeds unit has the capacity to expand and is also part of the Leeds General Infirmary Leeds General Infirmary. This means it is the only unit to have true co-location - all the specialist services required by the Children's Heart Surgery Unit in one place. This is a huge asset for healthcare, for doctors and nurses, for children and for parents. I believe this important element has been underplayed in the current review process.

Another key element is the multiracial mix of Yorkshire's population. No account has been made of the Asian community of Yorkshire and the fact that doctors have told me that children of Asian parents are more susceptible to heart conditions.

There have also been concerns raised with me about the consultation process itself. Parents and campaigners have not been happy with the public meetings that have been held and some have raised issues regarding the criteria being used to make the decisions.

I have no doubt that there are passionate views around the future of any children's heart surgery unit. However, the case for the facility in Leeds is compelling and overwhelming. It has an excellent record for providing safe, high quality children's heart surgery, a dense population with some parts of that population more predisposed to heart conditions and high quality transport links to the north, south, east and west by road and rail.

The Leeds Children's Heart Surgery Unit is an excellent facility for the whole of Yorkshire and the whole of the North of England. I hope you will ensure it has a strong future.

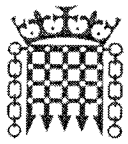
Due to the huge public interest in this consultation, I am releasing this letter to the media.

Yours sincerely,

JULIAN SMITH MP

cc Rt Hon Andrew Lansley MP, Secretary of State for Health
cc Kevin McAleese, North Yorkshire and York Primary Care Trust Chairman
cc Jayne Brown, North Yorkshire and York Primary Care Trust Chief Executive
cc Alisa Claire, Yorkshire and The Humber Specialised Commissioning Group

Michael Dugher MP
Member of Parliament for Barnsley East



HOUSE OF COMMONS
LONDON SW1A 0AA

Jeremy Glyde
Safe and Sustainable Programme Director
NHS Specialised Services
2nd Floor
Southside
105 Victoria Street
London
SW1E 6QT

28th June 2011

Dear Mr Glyde,

Re: Listen to Barnsley – Save Leeds Children's Heart Unit

In response to the 'Safe' and Sustainable' Service Review into the future of children's heart services, on behalf of my constituents I would like to press the case for retaining the service at Leeds General Infirmary.

My constituents and I have been determined to fully participate in this consultation and there has been a lively debate across the local media in Barnsley, plus the issue has been discussed at a range of local meetings, including most recently at a formal round table I held in Hoyland in my constituency. Attending this meeting was Kevin Watterson, Heart Surgeon and Sara Matley, Consultant Clinical Psychologist, both Trustees of the Children's Heart Surgery Fund, as well as a number of former patients whose lives had been saved thanks to the brilliance of the clinicians and the care they received at the Leeds General Infirmary.

So my submission to your consultation is one that is rooted in real peoples' lives and real peoples' experiences. I believe that their evidence makes for a powerful and overwhelming case for retaining a Children's Heart Service in Leeds. Please listen to those Barnsley residents who have made their strong feelings known throughout this submission.

We all want better outcomes for children with congenital heart disease and the highest quality national children's heart service. I am fully aware that the aim of this Review is to drive up the quality of treatment and I understand the principles that lie behind favouring a reduction in the number of units to create hubs of excellence and pool surgical expertise. It is right that decisions are made that improve the service on a clinical basis. However, these decisions must also be made in consultation with patients, their families and staff and on the basis of other relevant facts such as population size, travel times and the need to ensure patients have proper family support during their care in hospital.

Barnsley Office: West Bank House, West Street, Hoyland, Barnsley S74 9EE
Tel: 01226 743483 Email: michael.dugher.mp@parliament.uk
Web: www.michaeldugher.co.uk

A locally delivered service

One of the five principles that guided the Review was the need for a locally delivered service where possible. The significance of this cannot be underestimated and the actual location of the services and the impact on travel times is one of the most important things to get right in this Review.

- Nearly 14 million people are within 2 hours' travel time of the Leeds General Infirmary and its location means it can accommodate patients from outside the current catchment area via some of the UK's major transport links, such as the M1, A1, M62, East Coast, TransPennine and Cross Country rail network.

- The Unit at Leeds covers a population of 5.5 million people in Yorkshire & Humber, Lincolnshire and North Derbyshire regions – covering one of the highest populations of all the Units in England. Newcastle by contrast has a population coverage of 2.6 million. Population density must be taken into consideration in health planning and if it is based on this principle, all of the problems due to reconfiguration, such as extra distance and extra cost for individual families, are minimised because you move the doctors to the patients, not the patients to the doctors.

- The birth rate is growing above the national average in Yorkshire and Humber – in other areas it is falling. Population growth predictions for 2028 put Yorkshire and Humber at 6.1 million and Newcastle at 2.8 million (half the national projection growth rate). With about 1 baby in every 133 births being born with congenital heart disease – it makes sense for services to be based where they will be more babies.

- Heart surgeons and intensive care doctors have said that increased travelling time is not good for children and their families, especially in the case of emergency surgery where it could prove fatal.

"My family has had cause to appreciate first-hand the value of its predecessor, at Killinbeck after our daughter was born with a heart condition 28 years ago. The expertise of the unit and its closeness to our home did much to ensure she is alive today....Whatever the reasons made for closure, there is one fundamental reason why the unit must stay open: IT IS SIMPLY TOO FAR TO TRANSPORT A VERY SICK CHILD FROM OUR REGION TO EITHER NEWCASTLE OR LIVERPOOL"
[redacted] *Barnsley*

"With heart disease in children, one of the more noticeable signs seen is how rapidly and often that child can become very seriously ill. On 4 occasions in his life, Bradley collapsed and had stopped breathing. On one occasion Bradley had to be rushed to LGI from Barnsley (30 minutes by ambulance) after his heart went into SVT (Supra Ventricular Tachycardia). It is a medical fact that if SVT is not reversed within 1 hour of onset then full heart block and death quickly follows. It took a specialist unit like that at LGI to revert Bradley's deformed heart back to a normal rhythm. The new proposed alternative, Newcastle Upon Tyne, is hours further away, and will be way too late to save any child with specialist needs from any such emergency" John and [redacted] *Cudworth*

- A local service means that families are able to rely on external practical and emotional support from family and friends who are close at hand. The length of time a child is in hospital can vary from a couple of days to many months. Therefore, the impact on organising childcare for siblings and continuing to work will be enormous if parents have to travel a significantly greater distance to visit their child. Some patients receive treatment from the time they are born right up until teenage years – the ability for friends to visit the patient on a regular basis has a morale boosting effect and should not be underestimated.

"Having to travel, should the LGI, close will greatly affect siblings and other family members who will then be unable to visit heart children during their stay in hospital. Visits from siblings and family members is proven to help the recovery of the patient and boost moral during very upsetting and scary times"
[redacted], *Cudworth*

"If children have to go to Newcastle for their treatment, an after work commute to see their children would be virtually impossible"
[redacted] *Darfield*

"This is a vital service and serves a very wide area. Families will have long journeys and great inconvenience if this Centre closes. My own son had a heart echo scan when he was only a few days old and this could prove to be a great hardship for families in the future if they have to travel great distances"
[redacted] *Great Houghton*

The service at Leeds General Infirmary also has a strong case in the other five principles that guided the review:

The need of the child comes first in all considerations
The dedicated staff at the Leeds General Infirmary ensure that the necessity to fulfil the needs of all the children attending their Unit is paramount when making decisions about treatment and care. If this Unit closes, sick children will have to get used to a new environment, with new staff. For many children surgery is not a once in lifetime event but something many have to endure many times and the upheaval of travel and new environments is an added burden. Some families may have to think about moving house in order to be nearer a Unit and this would have a huge impact on family life.

"It is a nice hospital where it's a lot like being at home and everyone comes to see me which makes me feel much, much better". [redacted] *aged 9*

Leeds offers a well established lifespan psychological support service with four members of staff. At other Units, the service is less established or not as well provided for. I have been told that Newcastle, for example, only has a part time psychologist limited to transplant patients.

Quality

The Paediatric Cardiac Service at Leeds General Infirmary extends from pre-natal diagnosis to the treatment of congenital heart disease in adults. It has an excellent record of providing safe, high quality surgery. Staff at Leeds have fears that removing surgery will dismantle the rest of the high quality service and lead to a loss in expertise as it becomes harder to retain and attract high quality staff. Leeds General Infirmary is at the forefront of work on inherited cardiac conditions – this expertise should not be lost.

"At the present time we have an excellent service from Leeds General Infirmary that is the hub of the best developed cardiac network in the UK. This network has been adopted as a blueprint of how cardiac services within the country should be run" Child Health Advisory Group for Yorkshire Region

"My Grandson was not expected to survive more than 5 minutes from birth. He spent his first 3 months from birth in LGI and had his first double heart bypass. His second bypass was just over a year ago and now he is aged 9 years, attends Carlton Primary School and is a good swimmer. Many thanks to LGI" [redacted] *Cudworth*

High Standards

Leeds General Infirmary is one of only two centres in the UK (the other is Southampton) which has co-location of children services on one site (cardiac surgery, cardiology and all paediatric services) and as such meets the requirements of the Department of Health's Critical Interdependencies report *Commissioning safe and sustainable specialised paediatric services - a framework" (2008).* The British Congenital Cardiac Association (BCCA), a leading support organisation of the Safe and Sustainable Review, released a statement on 18 February that said: 'For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential.' Other Units are stand-alone sites and as such do not offer the same level of service. This could mean children have to travel to various locations for treatment instead of one.

"If a child is born in a District Hospital, they have a short transfer to Leeds for assessment and if it is felt the problem is not surgical they can continue to be looked after in the tertiary centre. If the future, it would mean a long transfer to either Newcastle, Liverpool or Birmingham for assessment...These hospitals are likely not to be sited at the same place as neonatal and paediatric services and therefore may require a further transfer. These transfers will provide a significant financial burden...and more importantly, pose a significant patient safety issue" Child Health Advisory Group for Yorkshire Region

"I was born with a rare form of heart disease. I was instantly transferred to Killingbeck Children's Heart Hospital – now Killingbeck Ward in the Cardiac Unit of Leeds General Infirmary - there parents felt their children were getting the right specialist treatment and it was closer to their homes to be able to visit their children after work"
[redacted], *Darfield*

A personal service

Feedback from patients and families shows that they receive first class personal service throughout their treatment pathway with support from the Children's Heart Surgery Fund.

Patient Choice is important here too - if patients from Leeds, Yorkshire and the Humber choose to go to Liverpool because it is closer and more convenient to go to there from Yorkshire rather than travel to Newcastle, then it is likely that the Unit at Newcastle will not achieve the minimum 400 cases a year required by the Review.

In addition to all the points above, I have been told that there are significant factual inaccuracies contained in the report by the assessment panel that visited the Unit in Leeds and that there was no opportunity given to address these prior to the publication of the consultation. It appears for example, that Liverpool was given extra scoring due to its high population density, but Leeds was not, despite having a higher population density within a two hour drive.

I am extremely concerned about the impact on my constituents and other families in Yorkshire & the Humber region should the Leeds Unit be closed. It would leave a huge geographical gap in provision and as a result, the nearly 300 families which are currently supported each year would face huge logistical difficulties and increased costs to travel substantial distances at a time of great anxiety about their child's health.

Whichever Units are chosen, there must be steps taken to provide help with additional travel and accommodation costs that will be incurred as a result of this policy to reduce the overall number of Units. I would like to see measures put in place to support families who will have to make increased journey times and who will have no option but to stay overnight as a result. No matter which option is decided upon, families will need additional support, particularly those from areas like Barnsley, who for socio-economic reasons will find it harder to travel longer distances.

We all want better outcomes for children with congenital heart disease and I believe that the children's heart surgery unit at Leeds General Infirmary is ideally placed to act as one of the hubs of excellence. In terms of quality of service, ease of access and the size of population, it is clear that the Unit at Leeds should to be retained as the major centre serving the North Midlands, Yorkshire and the North East. As one person put to me - bring the doctors to the patients, not the other way round.

I am grateful for your consideration and look forward to your response.

Yours sincerely,

Michael Dugher

Michael Dugher MP
Member of Parliament for Barnsley East

Rt Hon Hilary Benn
MP for Leeds Central
House of Commons
London SW1A OAA

Leeds office (tel) 0113 2441097
H of C (tel) 0207 2195770
e-mail:Hilary.benn.mp@parliament.uk
website: www.hilarybennmp.com

20th September 2011

Cllr Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and
Adult Social Care)
3rd Floor East
Civic Hall
Leeds LS1 1UR

Dear Lisa

Many thanks for your letter of the 8th September about the Children's Congenital Cardiac Services Review. As you will be aware, we have as the region's MPs made a number of representations to government and to Sir Neil McKay about the review in support of the LGI unit.

I very much support the points that you made in your letters to Andrew Lansley and Neil Mckay, and I look forward to continuing to work with you as we seek to make sure that the Leeds unit remains open.

Best wishes

Yours sincerely

Rt Hon Hilary Benn
MP for Leeds Central

Cc Rt Hon Andrew Lansley, Secretary of State for Health
Sir Neil McKay, Chair of Joint Committee of Primary Care Trusts

BERWICK, Ann

From: BERWICK, Ann
Sent: 20 September 2011 16:43
To: 'lisa.mulherin@leeds.gov.uk'
Subject: Children's Congenital Cardiac Services Review

Dear Cllr. Mulherin

Thank you for your letter of 8 September regarding the Children's Congenital Cardiac Services Review, enclosing a copy of a letter you have sent to the Secretary of State for Health. I am extremely supportive of the points that you have made in your letter to the Secretary of State. I made a number of representations both individually and together with other Yorkshire and the Humber MPs and will continue to do so, so please do let me know if you feel there is anything further I need to do at this stage with regard to the letter you have sent to the Secretary of State.

Yours sincerely,

Rt Hon Rosie Winterton
MP for Doncaster Central
Tel 01302 326297

Austin Mitchell MP
House of Commons
London
SW1A 0AA
0207 219 4559

Ms Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and Adult Social Care)
3rd Floor (East)
Civic Hall
Leeds LS1 1UR

Monday 3rd October 2011

Dear Lisa,

I write to express the strongest possible support for the case Leeds is putting up for the retention of its Children's Congenital Cardiac Services.

The issue is of vital importance to my area, North East Lincolnshire, our children's unit at Diana Princess of Wales Hospital, and to children and parents in the whole of South Humberside.

The basic reason is the quality and the service children receive from Leeds and the fact that visits there can also be combined with other services at Leeds. I also have to emphasise that we are a somewhat isolated area and that if Leeds were closed and the children and parents forced to travel to Newcastle the increased travel, costs, and extra time involved would be a considerable barrier.

There is a substantial population here on both banks of the Humber who do not seem to have been given sufficient weight in the proposal to look at only four options. This looks to me to have been heavily and unreasonably weighted against Leeds.

If Leeds is closed my constituents would be amongst the worst affected. I am not prepared to see this inflicted on Grimsby and North East Lincolnshire by what looks to be an act of administrative convenience which causes real damage to the people I represent.

I've made my views known to the minister and to the health authorities. I hope that these will not be ignored.

Yours sincerely,

Austin Mitchell MP

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

Review of Children's Congenital Cardiac Services
Final Report, October 2011

Report author: Steven Courtney (Principal Scrutiny Adviser)

www.scrutiny.unit@leeds.gov.uk