Scrutiny Inquiry Report

Review of Children's Congenital Cardiac Services in England

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

2nd Report – November 2012

Appendices

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Appendix 1

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

Safe and Sustainable
Paediatric Congenital Cardiac Services

NHS

Specialised Services

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18 July 2012

Dear Cllr Illingworth

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

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

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

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

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

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

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

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

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

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

Yours sincerely

Sir Neil McKay C.B.

Chair of the Joint Committee of PCTs

1. **Recommendation 1:**

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

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

> *"mediocrity must not be our benchmark for the future*[1]"

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

1.3 The analysis of the consultation responses concluded that:

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

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

[1] Safe and Sustainable, *Review of children's congenital cardiac services in England – Report of the independent expert panel chaired by Professor Sir Ian Kennedy*, 2010

[2] Ipsos Mori, *Safe and Sustainable Review of Children's Congenital Heart Services in England – Report of the public consultation*, 2011, p. 23

[3] Ipsos Mori, *Safe and Sustainable Review of Children's Congenital Heart Services in England – Report of the public consultation*, 2011, p. 7

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

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

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

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

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

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

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

[4] See appendix R of the Decision Making Business Case for detail.

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

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

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

2. Recommendation 2:

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

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

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

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

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

3. Recommendation 3

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

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

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

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

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

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

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

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

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

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

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

4. Recommendation 4:

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

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

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

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

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

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

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

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

5. Recommendation 5:

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

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

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

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

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

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

6. The views of people from Yorkshire and the Humber

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

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

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

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

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

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

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

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

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

Bradford
Doncaster
Huddersfield
Hull
Halifax
Leeds
Sheffield
Wakefield

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

Review process, governance and transparency

7. Governance

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

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

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

8. Our approach to consultation

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

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

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

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

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

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

- Leicester – 16 June 2011, 3pm–5pm
- Leicester – 16 June 2011, 6pm–8pm

- Clinicians from the *Safe and Sustainable* Steering Group were present at the events to answer questions put by the audience. Professor Sir Roger Boyle CBE, former National Director of Heart Disease and Stroke, was present at most events to give the background to the review and to explain the 'need for change'.

- The events were facilitated by an experienced, independent facilitator. In some locations an additional event was held on the same day in response to demand. A free crèche facility was available to facilitate access for parents. Interpreters were made available.

- Birmingham – 9 March 2011
- London – 19 March 2011
- York – 14 May 2011

- In an attempt to obtain even more qualitative information Ipsos Mori was asked to run focus groups targeted at specific groups: The aim was to conduct qualitative research to explore the issues raised throughout the consultation in depth. Parents of children with congenital heart disease and young people who currently use children's congenital heart services were asked about their views on the proposals. They were identified by the centres hospitals and parent groups.

- Ipsos MORI also conducted qualitative research with the general public from Black and Minority Ethnic groups, focusing on parents from a South Asian origin given the available research evidence that suggests that there is a higher relative incidence of congenital heart disease for some conditions amongst South Asian populations. Participants in the BAME groups were of Bangladeshi or Pakistani origin and from a range of socio-economic backgrounds.

- Focus groups with parents of children with congenital heart disease

- London – 17 May 2011
- Leeds – 31 May 2011
- Leicester – 1 June 2011
- Newcastle – 7 June 2011
- Oxford – 8 June 2011
- Southampton – 14 June
- Taunton – 15 June 2011
- Manchester – 21 June 2011
- London – 21 June 2011
- Birmingham – 22 June 2011
- Cardiff family interviews – 29th June 2011

- Focus groups with children with congenital heart disease

- Leicester – 1 June 2011
- Southampton – 14 June 2011

- Focus groups with people from BAME groups

- Oxford – 8 June 2011
- Southampton – 14 June 2011
- Manchester – 21 June 2011
- London–- 22 June 2011
- London – 22 June 2011
- Birmingham – 22 June 2011
- Leicester – 28 June 2011
- Leeds – 28 June 2011
- Cardiff – 29 June 2011
- Newcastle – 29 June 2011
- Cambridge – 30 June 2011

- In addition interviews were offered either on the phone or in the home with people who could not attend the groups.

9. The impact on children, family and friends

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

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

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

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

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

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

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

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

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

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

10. Nationally Commissioned Services

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

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

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

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

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

11. Yorkhill Hospital, Glasgow

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

Appendix 2

Letter from the Secretary of State for Health and the initial advice from the Independent Reconfiguration Panel (IRP) (February 2012)

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

Department of Health

POC1_682589

Richmond House
79 Whitehall
London
SW1A 2NS

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

Councillor Lisa Mulherin
Chair
Joint Health Overview and Scrutiny Committee
Leeds City Council
3rd Floor (East)
Civic Hall
Leeds
LS1 1UR

23 FEB 2012

Dear Councillor Mulherin,

REFERRAL FROM YORKSHIRE AND THE HUMBER JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE "SAFE AND SUSTAINABLE REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES" AND INITIAL IRP ADVICE

Further to your referral letter of 14 October 2011 concerning the above I asked the Independent Reconfiguration Panel (IRP) for its initial advice.

The Panel has now completed its initial assessment and shared its advice with me.

A copy of that advice is appended to this letter.

The advice will be published today on the Panel's website at www.irpanel.org.uk

In order to make my decision on this matter, I have considered the concerns raised by your Committee and have taken into account the IRP's advice.

IRP advice

Essentially, the IRP believes this referral is not suitable for full review. Referral was made on the grounds of inadequate consultation between the JHOSC and the JCPCT. The IRP has considered the four specific pieces

of information not supplied to the JHOSC as set out in your letter of 14 October 2011 and has advised me that:

The detailed breakdown of assessment scores for surgical centres produced by the independent Expert Panel (chaired by Sir Ian Kennedy)

Since the detailed breakdown of assessment scores has not been seen by the JCPCT, it was not material to the production of the consultation document, nor will it be material to the decision-making process. The JCPCT's commitment to release this information once it has made its final decisions is, in our view, reasonable.

I support the Panel's advice on this point.

A finalised Health Impact Assessment report

Emerging findings were published in February, June and August 2011. The JCPCT states that the final version of the HIA report can only be published, once the authors have themselves considered the extent to which responses to the public consultation will influence the HIA's emerging findings. The Panel agrees with this position on the basis that the final HIA is published sufficiently in advance of the JCPCT final decision-making meeting to allow its contents to inform fully that decision.

I support the Panel's approach on the above point concerning the health impact assessment report.

A detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber referred to in the Health Impact Assessment (interim report)

The information requested was not held and, having considered the Joint HOSC's request, the JCPCT concluded that the HIA process would not benefit from this additional analysis, nor would it be equitable to commission it for one area only. The Panel agrees with this position on the basis that the final HIA report is suitably comprehensive.

I support this approach.

The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation

I understand this information was not available prior to the 5 October 2011 deadline for HOSCs to submit responses to the consultation. The Panel believes that it should have been available at a much earlier stage so that it could be communicated to all interested parties. PwC's report was published on the NSCT website in October 2011. The Panel considers that (subject to the forthcoming legal judgement), any comments the Joint HOSC (or any other interested party) may wish to make with regard to this report should be accepted by the JCPCT and considered alongside the report itself as part of its decision-making process.

I support the Panel's approach on this particular point.

I agree with the Panel that the commitment and passion with which your Committee has scrutinised this subject is admirable. I also note the considerable efforts made to improve communications and information exchange in the latter stages of the process.

I like the Panel, hope that this will form the basis for effective working relationships in the future.

I appreciate the next steps in this process are dependent on the outcome of the forthcoming appeal against the Court judgement of the consultation process. The Panel's sound advice will be equally relevant, whatever the outcome of that appeal.

Conclusion

I support in full these recommendations.

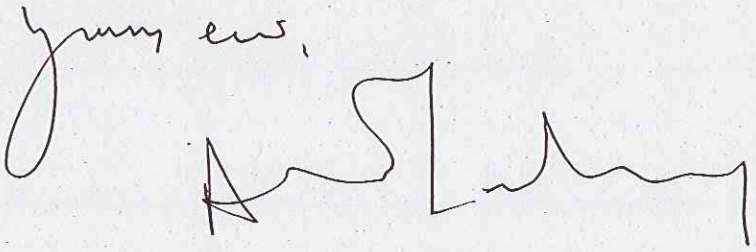
I expect the JCPCT to continue to engage with your Committee about the potential impact of these changes, not least in order to ensure that any further concerns the Committee may have can be considered.

Based on the IRP's initial assessment of the documentation provided by both your Committee and the JCPCT and Safe and Sustainable Review Team, I support in full the IRP's initial advice.

I am satisfied the IRP's advice is in the interests of the local health service and I hope that your Committee will continue to work with local NHS partners in the best interests of patients.

I am copying this letter to:

Ian Dalton, Chief Executive, NHS North of England
Dr Peter Barrett, Chair, IRP
Sir Neil McKay, Chair, Joint Committee of Primary Care Trusts
Teresa Moss, NHS Specialised Commissioning Team



ANDREW LANSLEY CBE

IRP

6th Floor
157 – 197 Buckingham Palace Road
London
SW1W 9SP

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

13 January 2012

Dear Secretary of State

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Basis for referral

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

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

The letter further states:

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

IRP view

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

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

Conclusion

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

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

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

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

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

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

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

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

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

Yours sincerely

Peter Barrett

Dr Peter Barrett CBE DL
Chair, IRP

Independent Reconfiguration Panel
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APPENDIX ONE

LIST OF DOCUMENTS RECEIVED

Yorkshire and Humber Joint Health Overview and Scrutiny Committee

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

Attachments:

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

National Specialised Commissioning Team

1 IRP template for providing initial assessment information

Attachments:

2 Circular: NHS Review of Paediatric Cardiac Surgical Services in England, The Centre for Public Scrutiny, 15 April 2010

3 Circular: Safe and Sustainable Children's Heart Surgery: A Briefing, August 2010

4 Circular: Review of Children's Heart Surgery services in England: An Update, November 2010

5 Circular: Review of Children's Heart Surgery services in England: Briefing 3, Spring 2011

6 Leeds Teaching Hospitals NHS Trust: Staffing – numbers as at 30 November 2009

7 National Clinical Advisory Team – NCAT: Safe and Sustainable Paediatric Cardiac Surgery Services, Desktop Review – Chris Clough

8 Health Gateway Review: Safe and Sustainable Paediatric Cardiac Surgery Service – Review 0: Strategic assessment, Department of Health/OGC Gateway, 9 September 2010

9 Letter to Teresa Moss, chief executive, National Specialised Commissioning Group, from Alastair Finney, Deputy Director – Strategy and Commissioning Development, NHS London, 8 February 2011 and Assurance of the consultation on the proposed reconfiguration of children's congenital cardiac services in England: 8 February 2011

10 Various correspondence (emails and letters) between representatives of NSCT and Yorkshire and Humber Joint HOSC – 9 and 18 November 2010, 8 April 2011, 8 and 14 April 2011, 9 May 2011, 24 May to 9 June 2011, 22 August 2011, 26 August 2011 (x2), 26 and 31 August 2011, 7 September 2011, 12 September 2011, 14 September 2011, 16 September 2011, 23 September 2011, 27 September 2011, 18 November 2011, 5 December 2011, 9 December 2011.

11 JCPCT's response to the Yorkshire and the Humber Joint HOSC's request for information

12 Additional information provided by NSCT regarding consultation

13 URL links to other relevant documentation:

- Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol, July 2001

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

Appendix 3

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

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

Review of Children's Congenital Cardiac Services

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

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

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

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

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

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

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

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

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

Review of Children's Congenital Cardiac Services

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

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

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

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

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

April 2012

Appendix 4

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

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

TUESDAY, 24TH JULY, 2012

PRESENT: Councillor J Illingworth in the Chair

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

55 Late Items

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

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

It was noted that the replacement Appendix 2 had been received very late, with insufficient time for members of the Joint HOSC to give detailed consideration. It was highlighted that after considering the information presented at the meeting – including the detailed breakdown of the assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy) – other information may be identified and subsequently requested by the Joint HOSC.

56 Declarations of Interest

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

There were no other declarations of interest.

57 Apologies for Absence and Notification of Substitutes

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

Attendance of the following substitute members was confirmed:

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

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

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

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

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

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

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

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

Thanks were expressed to Councillors Wilson and Saunders for their contributions to the work of the Joint Health Overview and Scrutiny Committee

(Yorkshire and the Humber). There was particular thanks reserved for Councillor Mulherin, the former Chair of the Joint Committee.

RESOLVED –

(a) That the information presented in the report and revised Terms of Reference be noted.

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

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

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

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

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

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

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

- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust

- University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St. Thomas' NHS Foundation Trust

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

A range of interested parties / stakeholders were identified in the report as having been invited to attend the meeting and assist the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in its consideration of the JCPCT's decision.
The Chair advised the meeting that contributions would be received and considered in the following order:

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

Elected representatives:

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

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

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

- Issues associated with the general population around Leeds (14 million people with 2 hours drive of the City) and transport links had not been sufficiently considered as part of the review.
- Concerns around Newcastle's ability to reach the minimum level of 400 surgical procedures per year, and the assumptions used to support this aspect of the review.
- It was clear from the PwC work that patients across Yorkshire and the Humber would not travel to Newcastle and, in the absence of a surgical centre at Leeds, would access services at other centres, including Liverpool, Birmingham and London.
- The JCPCT had assumed that a minimum of 25% of patients from Yorkshire and the Humber would travel to Newcastle. This assumption suggested that Newcastle would just meet the requirement to undertake the minimum level of 400 surgical procedures per year. However, it was

unclear what evidence there was to suggest 25% was an accurate assumption and/or how this had been derived.

- The co-location of services was an important factor to take into account, as this would have a direct impact on the level and quality of care accessible at surgical centres. There was concern that the decision to close the surgical centre at Leeds would not result in an improved service and would in fact deliver a worse service for the population of Yorkshire and the Humber.
- Concerns that impacts on specific BME communities had not been adequately reflected in the JCPCTs decision.

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

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

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

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

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

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

- Kevin Watterson[1] (Chair and Trustee) – Children's Heart Surgery Fund
- Lois Brown – parent
- Jon Arnold – parent and Trustee of Children's Heart Surgery Fund
- Steph Ward – parent
- Gaynor Bearder – parent
- Kimberley Botham – adult congenital heart patient

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

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

- There was general support for the basis of the review – i.e. fewer, larger surgical centres.
- The concerns around the JCPCT's decision raised by parents and patients across Yorkshire and the Humber had not been raised as a result of unquestionable loyalty to the surgical centre at Leeds. Concerns raised were as a result of wanting the best outcome for children and securing improvements to the services already available across Yorkshire and the Humber.
- The JCPCT's decision would lead to a lesser service for children and families across Yorkshire and the Humber – but with increased travel distances.
- Concern that Newcastle would not reach the minimum number of 400 surgical procedures per annum – thus making the surgical centre unsustainable and potentially leaving the whole north eastern part of England without a surgical centre.
- Concern that the PwC report on patient flows and clinical networks refers to the 'management' of patients and it was unclear how this reflected the right of patient choice (as detailed in the NHS Constitution).
- Concerns over the openness and transparency of the decision-making processes and engagement with children and families across Yorkshire and the Humber.
- The importance of co-location of services with the increasing complexity of needs and co-morbidities of children. It was highlighted that following the JCPCT's decision, Newcastle remained the only 'stand alone' congenital heart surgical unit in England.

[1] Paediatric Cardiac Surgeon at Leeds Teaching Hospitals NHS Trust

- Concern regarding the long-term impacts on children with a congenital cardiac condition, particularly in terms of accessing specialist services where general anaesthesia would be needed.
- Consideration of 'the patient experience' appeared to be lacking within the review process and there was a lack of evidence to confirm the JCPCT's decision would deliver enhanced services for Yorkshire and the Humber.
- It was unclear what would be gained by reviewing the services for adults with congenital heart disease separately from review services for children. The outcome of the children's review was likely to predetermine any review of services for adults with congenital heart disease.
- The impact on capacity should there be an increased number of adults with congenital heart disease referred to Birmingham.

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

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

Mr. Watterson also reflected on his personal experience (in his professional capacity as a Paediatric Cardiac Surgeon at Leeds Teaching Hospitals NHS Trust) of working in a 'stand-alone' surgical centre (at the former Killingbeck Hospital site in Leeds) with that of working in a dedicated Children's Hospital

setting – where all the necessary services (including obstetrics and maternity services) on a single site. Mr. Watterson stressed the benefits for patients under a co-location of services model.

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

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

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

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

Leeds Teaching Hospitals NHS Trust representatives:

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

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

The following issues were highlighted and discussed:

- The fragmentation of the existing Yorkshire and Humber clinical network and how the proposed clinical networks would work in practice, with respective cardiology centres.

[2] Council Member of the British Congenital Cardiac Association (BCCA)
[3] Honorary Secretary to the British Congenital Cardiac Association (BCCA)

- Queries around whether the proposed cardiology centre in Leeds would be required to work across three different networks (Newcastle, Birmingham and Liverpool).
- Realities of the proposed patient flows and the respective roles of clinicians (in terms of referrals) and parents (in terms of patient choice).
- The considerable local impact on Leeds Teaching Hospitals NHS Trust (LTHT) associated with the loss of surgical services, including clinical governance risks for cardiologists.
- The use of the Kennedy scores as a 'proxy' for service quality and the apparent arbitrary and irrational nature of the scoring process.
- Concerns around inconsistencies and apparent arithmetical errors in some of the published data.
- One of the impacts of the JCPCT's decision being that Newcastle would remain the only stand alone unit in England (i.e. not a Children's Hospital providing the full range of services available elsewhere).
- Concerns that some of the comments about the review that had been provided by the British Congenital Cardiac Association (BCCA) had not been fully reflected by the JCPCT.
- Significant impacts (operationally and financially) of the JCPCT's decision for the Paediatric Transport Service offered by Embrace.
- The impact of the JCPCT decision on the operation of the Paediatric Intensive Care Unit PICU) in Leeds – including issues around capacity and flexibility during peak (winter) periods. It was highlighted that this may lead to greater use/ access of PICU beds outside Yorkshire and the Humber. This in turn may have a significant impact on the Paediatric Transport Service offered by Embrace.
- The loss of surgical services was likely to have an impact on the cardiology services provided by LTHT and the training programme offered by the Trust.
- The importance of the co-location of services – in particular for children and families from BME communities.
- The impact of additional travelling on children and their families.
- Improved survival rates of neonates leading to increased and greater complexities of needs in children. The co-location of services in this respect being vitally important.
- The well established network arrangements across Yorkshire and the Humber covering cardiac, PICU and neonatal services.
- Issues associated with 'blue' babies and children with complex needs. Without full co-location of services, it was unclear how children with complex needs would be treated/ cared for.
- Concerns around the 'quality' scores and it was felt that these were not representative of the services offered by LTHT.
- Concerns around the relative overall expertise of the Kennedy assessment panel. No expertise from the perspective of adults with congenital heart disease and no practicing UK paediatric cardiologist.
- Concern over the lack of complete information provided by the JCPCT in terms of the assessment process and associated scoring mechanism.
- Consideration of training within the assessment scores. Concern that without the provision and access to surgical services, it was unclear how

cardiology trainees in Leeds (and potentially other de-designated centres) would complete their training.

- The BCCA view that cardiac services for children and adults should have been considered jointly.
- The increasing number of adult congenital heart disease patients. Concern that the longer-term impact of increasing numbers in this area had not been fully considered.
- Concerns around the sensitivity testing undertaken by the JCPCT (particular reference to Sensitivity F in the Decision-Making Business Case) in terms of:
    - The accuracy of information provided (no increase in the projected activity at the Birmingham Surgical Centre).
    - The assumed 25% level of patients from Sheffield, Doncaster, Leeds and Wakefield travelling to Newcastle did not appear to be in line with the outcome of the PwC work around patient flows.
- Concern that some significant issues arising from the review remained unresolved and had been 'parked' for the implementation phase of the review.

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

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

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

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

<u>The Joint Committee of Primary Care Trusts (JCPCT) representatives:</u>

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

The following representatives were in attendance.

- Sir Neil McKay – Chair of the Joint Committee of Primary Care Trusts (JCPCT)
- Andy Buck (Chief Executive) – NHS South Yorkshire & Bassetlaw[4]

[4] Also Chair of the Specialised Commissioning Group (Yorkshire and the Humber) and the regional (Yorkshire and the Humber) representative on the Joint Committee of Primary Care Trusts (JCPCT).

- Dr. Leslie Hamilton (Deputy Chair) – Safe and Sustainable Cardiac Surgery Steering Group
- Jeremy Glyde (Programme Director) – Safe and Sustainable Programme

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

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

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

- Development of the standards of care to be delivered by surgical centres and the supporting networks had been supported by a plethora of evidence.
- The network model of care proposed envisaged a system of local services (excluding surgical procedures) delivered closer to patients' homes.
- Interpretation of the NHS definition of Critical Interdependencies and the implications for co-location of services.
- Confirmation that Sir Ian Kennedy's Expert panel had considered the best available evidence around Critical Interdependencies and re-affirmed previous advice, including that Foetal Medicine and Maternity Services were not critical interdependencies.
- The review of services for adults with congenital cardiac disease was outside the scope/ terms of reference for the JCPCT and could not be considered. The review of Children's Services could not be delayed until 2014 to become part of the adults review process/ timetable.

- The JCPCT had taken advice from a number of bodies regarding issues around with retrieval times.
- Consideration of applications to deliver Nationally Commissioned Services (Transplantation, Extra Corporeal Membrane Oxygenation (ECMO) and Complex Tracheal Surgery) had been considered by a national committee – which had discounted Leeds' application. It was reported that the view of the Advisory Group for National Specialised Services (AGNSS) was that it would take 8/10 years to successfully move transplant services from those centres currently delivering such services (including Newcastle).
- It was highlighted that three from the four options included as part of the public consultation process and that eight from twelve options considered by the JCPCT on 4 July 2012 would have resulted in moving one or more nationally commissioned services.
- Confirmed that the Kennedy scores/ rankings had been important when assessing quality and undertaking the sensitivity tests.
- NHS London had assessed the proposals against the four tests for reconfiguration of services identified by the Secretary of State for Health – that is, reconfiguration proposals need to demonstrate:
    - Support from GP commissioners
    - Strengthened public and patient engagement
    - Clarity on the clinical evidence base
    - Consistency with current and prospective patient choice
- Issues around access and journey times had been taken into account by the JCPCT.

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

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

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

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

RESOLVED –

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

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

60 Date and Time of Next Meeting

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

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

Appendix 5

Summary analysis of the Kennedy Panel assessment scores

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

Overview

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

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

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

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

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

Table A: Criterion and associated weightings

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

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

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

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

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

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

Service Standards

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

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

Table B: Designation standards

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

Re-weighted Criterion

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

Table C1: Re-weighted criterion

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

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

Table C2: Criterion and associated re-weightings

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

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

Comparison of the original and re-weighted criterion

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

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

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

Comparison and analysis of the original and re-weighted criterion

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

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

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

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

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

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

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

Kennedy assessment scores: centres' current performance against the standards			**Re-weighted Kennedy assessment scores: centres' current performance against the standards)**		
Ranking	***Centre***	***Score***	***Ranking***	***Centre***	***Score***
1	Southampton	78 (78%)	1	Southampton	81 (79%)
2	GOSH	76 (76%)	2	GOSH	80 (78%)
3	Evelina	75 (75%)	3	Evelina	79 (77%)
4	Birmingham	70 (70%)	4	Birmingham	74 (72%)
5	Brompton	69 (69%)	5=	Brompton	72 (70%)
6	Leeds	68 (68%)	5=	Leeds	72 (70%)
7	Liverpool	66 (66%)	7	Liverpool	70 (68%)
8	Bristol	65 (65%)	8	Bristol	67 (65%)
9	Newcastle	63 (63%)	9	Newcastle	65 (63%)
10	Leicester	54 (54%)	10	Leicester	53 (51%)
11	Oxford	45 (45%)	11	Oxford	46 (45%)
Maximum score		**100**	**Maximum score**		**103**

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

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

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

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

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

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

Appendix 6

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

Central Cardiac Audit Database (CCAD) – activity data

Surgical Procedures

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

Central Cardiac Audit Database (CCAD) – activity data

Interventional Procedures

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

Appendix 7

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

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

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

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

Sent via email only

Dear Sir David,

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

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

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

Relevant agendas, reports and minutes

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

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

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

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

Cont./

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

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

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

Sir Ian Kennedy's expert panel scores

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

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

Nationally commissioned Services

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

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

Cont./

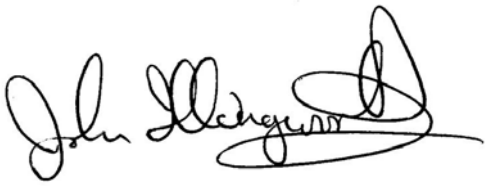
I have enclosed a copy of the Excel spreadsheet that summarises the current position as far as I am able to determine. I do not know all of the meeting dates for NCG, but am aware that AGNSS started work in September 2010. Nonetheless, please could I be provided with a full set of agendas and minutes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

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

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

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

Yours sincerely



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

Enc.

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

Appendix 8

Correspondence to the Secretary of State for Health

Councillor John Illingworth
Chair, Scrutiny Board
(Health and Wellbeing and Adult Social Care)
3rd Floor (East)
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E-Mail address john.illingworth@leeds.gov.uk
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Your ref
Our ref JI/SMC
Date 15 August 2012

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

Dear Secretary of State,

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

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

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

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

Cont./

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

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

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

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

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

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

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

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

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

Cont./

[1] The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulation 2002
[2] Overview and Scrutiny of Health – Guidance (Department of Health (July 2003))

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

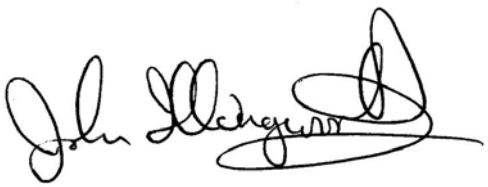
As you will be aware, the scrutiny referral process is a recognised process within any substantial NHS reconfiguration plans that I believe should at the very least be recognised as having a potential impact on any subsequent implementation. I believe this further demonstrates a lack of awareness (or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

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

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

Yours sincerely

Yours sincerely



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

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

Councillor John Illingworth
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Civic Fax 0113 24 78889
Your ref
Our ref JI/SMC
Date 7 September 2012

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

Sent by post and e-mail

Dear Secretary of State,

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

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

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

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

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

Cont./

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

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

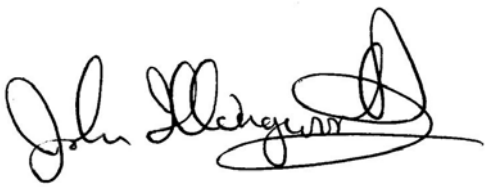
As part of the national consultation on proposals in 2011, the Joint HOSC submitted a detailed and comprehensive report to the JCPCT. This report supported the retention of Leeds as a designated surgical centre for the benefit of the 5.5 million population of Yorkshire and the Humber. The Joint HOSC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

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

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

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

Yours sincerely



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

Enc.

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

Councillor John Illingworth
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Your ref
Our ref JI/SMC
Date 31 October 2012

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

Sent by post and e-mail

Dear Secretary of State,

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

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

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

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

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

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

Cont./

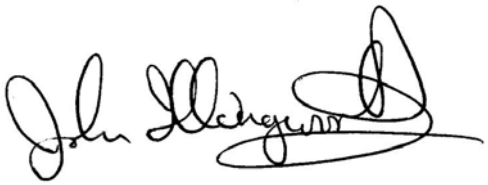
Subject to the completion of the Joint HOSC's referral report and an initial assessment by the IRP, I trust the issues raised will be given full consideration as part of the IRP's review and be reflected in any revised Terms of Reference that may be issued.

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

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

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

Yours sincerely



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

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

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

Subject: Second complaint about the NHS Specialised Commissioning Team NSCT

Dear Secretary of State

Reconfiguration of Children's Heart Surgery

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Appendices

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