Safe and Sustainable

Paediatric Congenital Cardiac Services

NHS

Specialised Services

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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.