

## ROTHERHAM BOROUGH COUNCIL – REPORT

1.	<b>Meeting:</b>	<b>Children and Young People's Scrutiny Panel</b>
2.	<b>Date:</b>	<b>14 July 2011</b>
3.	<b>Title:</b>	<b>Update: specialist children's heart surgery; consultation</b>
4.	<b>Directorate:</b>	<b>Chief Executive's All wards</b>

### 5. Summary

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

### 6. Recommendations

#### **That the Health Select Commission:**

- a. **agrees that the nominated members from the former Children and Young People's Scrutiny Panel continue in their role for the duration of this review;**
- b. **comments on the report and refers any concerns/issues regarding the review of children's cardiac services to the Rotherham Council representative on the Regional Health Overview and Scrutiny Committee;**
- c. **notes the Cabinet response to the consultation;**
- d. **receives further updates of progress.**

### 7. Proposals and Details

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

In summary, it is proposed that the reconfigured Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal

screening through to the transition to adult services. However, in doing this there will be a reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence.

Safe and Sustainable consulted on the following areas:

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

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

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

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

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

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

## **7.2 Health Overview and Scrutiny Committee Involvement**

**7.2.1** Health Overview and Scrutiny Committees<sup>2</sup> are being consulted as part of the statutory consultation process and because it affects more than one Local Authority area, this is being coordinated in Yorkshire and Humber through a Joint Committee (chaired by a Member from Leeds City Council). There has been two meetings of the Joint Committee to date (minutes and papers are available on-line). Further meetings are planned with various representatives from health bodies and patients/parents groups from across the region to gather evidence to inform the Committee's formal response to the consultation. Information is also being sought by the Committee in respect of patient flow and a health impact assessment of the proposals on the region's population. This information is expected shortly.

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

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

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

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

## **7.3 Local Discussions**

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

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

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

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<sup>2</sup> Under Rotherham's previous overview and scrutiny arrangements, health scrutiny responsibilities were delegated to the former Children and Young People's Scrutiny Panel if they relate to children's health matters

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

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

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

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

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

## **7.4 Cabinet Response**

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

## **8. Finance**

There are no financial implications directly related to this report.

## **9. Background Papers and Consultation**

Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England: Consultation Document

<http://www.specialisedservices.nhs.uk/document/safe-sustainable-a-new-vision-children-s-congenital-heart-services-in-england-consultation-document>

Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)  
14th March, 2011:

<http://democracy.leeds.gov.uk/ielistDocuments.aspx?MId=5146&x=1>

29<sup>th</sup> March, 2011:

<http://democracy.leeds.gov.uk/ielistDocuments.aspx?CId=793&MId=5149&Ver=4>

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## ROTHERHAM BOROUGH COUNCIL – CONSULTATION RESPONSE

Thank you for the opportunity to respond to the “Safe and Sustainable Review of Children’s Cardiac Services”.

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

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

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

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

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

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

We would support the seven key themes

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

see 6

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

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

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

We are pleased that the review calls for the strengthening of local heart networks and includes proposals to increase the roles of paediatricians locally. We already have a foundation for this work. Indeed, both parents and local clinicians value the

access to regular clinics run locally by Leeds Cardiology staff, including transition nurses, in conjunction with the Rotherham based paediatric team. We are aware that Rotherham clinicians have developed greater degrees of specialism as a result of their collaboration with the Leeds centre, leading to better services for some of the most vulnerable children and young people in Rotherham.

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

**7. To what extent do you support or oppose:**

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

We would support the above aims.

**Additional Comments**

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

**Population**

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

**Blue-light transfer**

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

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

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

## **Co-location**

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

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

## **Transition**

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

## **Intensive Care**

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

## **Support Networks**

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

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

We are aware that the impact on parents who do not have access to their own transport is considerable. Currently a journey to Leeds by public transport can involve up to three changes, plus a short walk (often with buggy) to the LTHT. This

can often take over two hours. It is envisaged that the journey to any of the other centres on public transport would add between 2 -3 hours to the trip. On weekends or out of hours this would be more difficult. This is without taking costs into consideration.

### **Financial consideration**

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

### **Impact on ethnic minority communities**

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

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